

**Returning to Normality: A Grounded Theory  
Study of the Experience of Women with Breast  
Cancer.**

A thesis presented to Dublin City University for the  
Professional Doctorate in Education

By

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## **DECLARATION**

I hereby certify that this material, which I now submit for assessment on the programme of study leading to the award of Doctorate of Education is entirely my own work, that I have exercised reasonable care to ensure that the work is original, and does not to the best of my knowledge breach any law of copyright, and has not been taken from the work of others save and to the extent that such has been cited and acknowledged within the text of my work.

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## ABSTRACT

Breast cancer is the most common type of malignant cancer among women in Ireland.

Women diagnosed with breast cancer undergo breast cancer treatment, and must deal with the stressors while enduring treatments.

The present study drew on Lazarus and Folkman's (1984) transactional model to ensure that the search for meaning of "stress" and "coping" were based on each woman's appraisals. A grounded theory approach was used to explore the experience of 8 women enduring breast cancer treatment aged 47-67 using semi-structured interviews with each participant. This study's purpose was to give a more inclusive picture of the stressors encountered while enduring breast cancer treatments, and the coping strategies used, thus addressing a gap in the literature. The research question that guided each interview was **"Enduring breast cancer treatments what was the most salient stressor, and how did you cope with that stressor?"** Interviews were audio taped and transcribed verbatim.

The data revealed that, for these women, breast cancer treatment presented a number of stressors, and the women responded by mobilizing predominately active strategies. In addition, to a lack of concrete links between stressors and coping strategies, a clear progression in coping strategies of the women enduring treatment was not apparent.

However, the themes indicate that the appraisal processes of the women while enduring treatment was complex and dynamic. The participants in this study were adjusted in a process of "Returning to Normality" from their cancer experience. Furthermore other themes emerged during data analysis and results revealed aspects in relation to 'Making Sense of the Experience'; 'Seeking Support and Loneliness'; 'Reclaiming their Life'; and finally 'Managing the threat of Recurrence' also arose as a direct result of the interview process.

What each woman appraised as a stressor depended on her unique interaction with the environment, and the coping strategies she mobilized on her view of the world, her coping resources, and her context. An understanding that each woman appraisal process (i.e., what are stressors) is unique, and that multiple elements contribute to coping is valuable to healthcare professionals caring for women enduring breast cancer treatment. Overall, these breast cancer women more often looked at the positive aspects of their cancer experience while recognizing the importance of the process of adjustment by “Returning to Normality” and looking to the future.

# **CHAPTER 1: INTRODUCTION AND BACKGROUND**

Breast cancer is a chronic and life-threatening illness. Breast cancer is the most common invasive cancer among women in many European countries including Ireland (Ferlay et al, 2007). Breast cancer is the most common cancer (8%) among women in Ireland (National Cancer Control strategy, DOHC, 2006), It is the most common cancer among women in United States (Wood et al, 2006), yet the psychological health and well-being of women with breast cancer while enduring treatment has not been addressed.

## **1.1 BREAST CANCER AS A HEALTHCARE ISSUE IN IRELAND**

According to the National Cancer Control Strategy Review (DOHC, 2006), cancer is a major cause of morbidity and mortality in Ireland. Each year about 20,000 Irish people develop cancer and 7,500 die of the disease. Although the incidence of cancer appears to be falling, the actual number of people developing cancer is expected to increase because of our population is aging. The number of new cases the system can expect to deal with by 2020 will represent an increase of 107% on the number dealt with in 2000. We now have approximately 120,000 cancer survivors but how are they coping.

According to the National Forum (DOHC, 2006) in 2002 in Ireland, 1921 women were diagnosed with breast cancer and 615 died from the disease. The Central statistics office reported that 731 women died from breast cancer in 2008 making it a significant public health issue (DOHC, 2008). Ireland ranked in the middle of rates observed across Western Europe.

Breast cancer is the second most common cancer in Ireland. Statistically, breast cancer accounts for 30% of all cancers in women in Ireland with approximately 2,500 new breast cancer cases diagnosed each year (HIQA, 2010). It continues to be the most common

malignancy in women. Internationally, breast cancer mortality rates have decreased slightly despite the rise in the incidence of breast cancer in the last two decades (HIQA Report, 2010). However, due to improvements in technology and treatment pathways, the prospects of long-term survival and improved quality of life are increasing. Although not nearly as common, men also develop breast cancer. Breast cancer survival was lower in Ireland than the European average but similar to levels in England and Scotland. The mortality was 33% higher in Ireland than in the USA (National Cancer Registry of Ireland and Women's Health Council in February, 2006).

The stage at which a woman has breast cancer diagnosed greatly influences her survival chances. In general, the earlier the detection, the greater the chance of survival and breast cancer is treatable in most cases (HIQA, 2010). Ireland has one of the highest rates of mortality from breast cancer in the world (Globocan, 2000). Yet there are limited information in the current literature on breast cancer experience of women while enduring breast cancer treatment (Henderson et al, 2003).

The diagnosis of breast cancer confronts women with the fact that daily life is no longer a matter of course. According to Rustoen & Begnum (2000) women with breast cancer are exposed to a double reaction. Firstly, they experience a reaction in the form of uncertainty about possible spreading of the cancer, and uncertainty about suffering and death. Cancer disrupts human beings' basic belief in their existence.

Secondly, problems may arise connected to reactions over appearance and feelings of femininity. The bodily changes that occur following breast cancer diagnosis and treatment can result in loss of patients' faith in their own body. Keller (1998) identified that one year after diagnosis have shown that 20%-30% of patients treated for breast cancer have not adapted to living with cancer.

The current treatments for breast cancer include surgery, chemotherapy and radiotherapy, all which carry their own risks profile in relation to side effects experienced. The psychological impact of a diagnosis can present challenges for both nursing and medical teams, as they aim to provide optimal care for the patient and their family. Patients and their caregivers dealing with breast cancer are presented with a terrifying reality. Patients often present with debilitating physical side effects associated with surgery and psychological complications as they face a life threatening illness. Furthermore these changes may service to affect the patients' role and function within the family unit and socially.

Much of the research in the field of breast cancer and the impact of the diagnosis on different life domains has been descriptive, using standardized questionnaires (Rustoen & Begnum, 2000). This qualitative research study will investigate the experience of women with breast cancer, who have had a programme of chemotherapy and/or radiotherapy. The goals of chemotherapy and radiotherapy treatment include symptom relief; minimize complications and preservation of patient well-being and functioning ensuring a holistic approach to patient care. However, we cannot achieve this without exploring the reality of a breast cancer diagnosis for a woman who has had a program of chemotherapy or radiotherapy. Chemotherapy and radiotherapy focuses on the physical aspects of cancer control; this study will envisage and address the physical and psychological effects of breast cancer treatment and captures the wholeness of their experiences and stressors and how they cope which has not been researched in healthcare. Therefore, a holistic view of a cancer diagnosis will be presented from the experiences and coping strategies of the women under inquiry. Only the women themselves can describe how they experience living with breast cancer after treatment. Few studies have shed a light on living and coping

with breast cancer in a holistic manner while enduring treatment especially in the Irish healthcare setting.

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 when the women are stressful, or with what they are coping (e.g. Cowley, Heyman, Staunton, & Millner, 2000; Heim, Valack, & Schaffner, 1997). There is little research that investigates coping as a process during the course of breast cancer treatment. This study's purpose was to give a more inclusive picture of the stressors encountered during and after breast cancer treatment, and the coping strategies mobilized, thus addressing the gaps in the literature. The question that guided the research was **“Enduring breast cancer treatment, what was the most salient stressor, and how did you cope with that stressor?”**

In order to answer the research question, the concept of “stress” has to be defined. There is a debate in the academic literature as to the definition of “stress”, but the dominant one, and 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 wellbeing” (Lazarus & Folkman's 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 differently over time and also after time when realization occurs.

Consistent with Lazarus & Folkman's (1984) theory, what is stressful for the women treated and after treatment with breast cancer depends on the individual in her unique context. The unpleasant side-effects of treatment, the threats to life, fear of recurrence, and disruption to family are some of the things women may find stressful (Haber et al., 1995; Spiegel, 1990). Cancer presents a variety of different threats over time after treatment, 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 is particular they found stressful, and how they cope with those stressors.

Post breast cancer treatment is a complex process that can span several months or years, and presents an array of stressors that women must cope with. Quantitative research has used standardised 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 and after breast cancer treatment, few studies have investigated the after effects of treatments from women's perspective (Thomas-MacLean, 2004). Moreover, although qualitative studies have begun to emerge in response to critiques of qualitative approaches, researchers have tended to

focus the treatment stage, e.g. breast surgery and radiation therapy (Saares & Suominen, 2005; Thomas-MacLean, 2004; Wengstrom et al., 2001).

In order to access the experience of the participants enduring breast cancer treatment, I conducted semi-structured interviews. During these interviews, I asked 8 women to recall their most salient stressor after their treatment, and how they coped with that stressor. Because after treatment many issues present (e.g. numerous visits to hospital, interacting with healthcare professionals, enduring the realization of treatments, the physical side-effects of treatment, the effects on relationships), I wondered if it might be difficult for women to reflect on the most salient stressor. I anticipated that some women might need space and distance after their treatments in order to be able to reflect upon their experience, and choose the most salient stressor. I assumed that the women would remember stressful events and also the positive situations that were important to them. The findings of the study offer a deeper understanding of stress and coping after breast cancer treatment for those who have not lived it, and it may be useful to healthcare professionals who care for women after breast cancer treatment. Therefore, this study investigated, through grounded theory methodology, the experiences of women with breast cancer enduring treatment, its influence on their lives and how they coped and adjusted also.



## **1.2 OVERALL AIM OF THE STUDY**

The overall aim of this study was twofold:

- To provide an accurate, detailed, and in-depth description of the women's experience while enduring breast cancer treatment and how their lives were adjusted and how they coped to be normal again.
- To develop a theoretical framework for further research.

The study is divided into six chapters. The following section presents an overview of each of these chapters.

## **1.3 SUMMARY OF THE CHAPTERS IN THE STUDY**

In this thesis, the transactional model of stress and coping theory of Lazarus Folkman (1984) is elaborated in considerable detail. The methodological approach is explored, the methods of data collection and analysis are explained, the theory itself is explicated, its significance is considered and its worth is judged.

Chapter Two discusses the existing literature relating to the women's experience while enduring breast cancer treatments. The findings indicate that the research in this area is predominately based on the empirical psychological framework outlining stress and coping theory, which then leads into the discussion of sources of stress and coping strategies for women with breast cancer finally the current literature is explored which places coping strategies in the context of the stressors while enduring breast cancer treatment. There is dearth of research that investigates the entire process of breast cancer treatment, and examined the different stressors endured over time, and the coping strategies that are used at different times.

Chapter Three, gives a detailed account of the research methodology employed in the study. The approaches to data collection and analysis are explored as aspects of ‘doing grounded theory’. Sources of data are identified in terms of interviews with eight participants. How data was collected and analysed is examined in some detail. In addition, ethical aspects of the study are discussed.

Chapter Four provides a discussion on the findings gleaned from the grounded theory analysis in the interview data. The experience of “Returning to Normality” is presented as a constitutive or overarching theme in the study following constant comparative analysis of the interview transcripts. Four sub-categories emerged: - ‘Making Sense of the Experience’; ‘Seeking Support and Loneliness’; ‘Reclaiming their Life’, and finally ‘Managing the threat of Recurrence’.

Chapter Five provides an overall discussion of the findings of the study.

According to Morse et al (2002), in order to recognize and respond to the experience of enduring, healthcare professionals must take time to interact and communicate with cancer patients during treatment. However, as the participants’ accounts reveal to have shown both physical and psychological components, leading to an overriding sense of futility as the women looked for ways of managing their symptoms, while seeking medical advice and appropriate treatment by being Normal again. Healthcare professionals spend very little time communicating with them during their treatment from an emotional perspective. Instead, they concentrated almost entirely on the technical and physiological acts of care.

Chapter Six offers recommendations for healthcare professionals. In particular, it proposes the need to alter the current technologically focused context of care for these patients in order to provide supportive care for these patients. This chapter also provides the limitations and conclusion of the study.

## **Chapter 2: Literature Review**

This chapter reviews the literature concerning women's experience of living with breast cancer and breast cancer treatment. The aims of the review are threefold: (1) to conduct an analysis of the existing research literature related to the person's experience of breast cancer; (2) to identify shortcomings in this research literature and (3) to propose approach that may address the shortcomings identified in the literature.

### **2:1 Introduction**

The existing literature signifies that the onset of a chronic illness creates many losses and disruptions in the person's life. For instance, Chesla (2005) indicated that chronic illness caused the person to lose confidence in their ability to function in work, social life and family relationships. The losses experienced by these individuals represented a breakdown in their everyday life and was a fundamental source of suffering (Chelsa, 2005).

Similarly, Curtin et al (2002) stated that many of the lifestyle alterations caused by chronic cancer illness were irreversible. Hence, the person was required to re-structure their self-identity to adapt to the changed life circumstances. However, the ability to adapt relied primarily on the severity of the cancer illness and the accompanying treatment regime.

This literature review presents an overview of the relevant literature on breast cancer and the issues and stressors that surround living with this disease for women. More specifically, the literature review will present a global picture regarding the level of knowledge in this area. Several studies have been performed to explore aspects of living with breast cancer. Although much of the research has been done in the field of psychological aspects of breast cancer, most of this research has been focused on predefined subissues such as social

support, quality of life, body image, depression and psychological reactions. Few studies have shed light on living with breast cancer in a holistic manner and the psychological health and well-being of women with breast cancer has not been addressed. This study will explore in depth how women with breast cancer experience living with the disease while enduring breast cancer treatment. The study aims to provide a deeper understanding of women's experiences as they face an established diagnosis of breast cancer. Limitations of the current findings are highlighted following discussion of the findings in this study.

## **2: 2 Literature Search**

Cormack, (2000) suggests that a literature search followed by a critical review is a fundamental component of the research process. The purpose of the literature review is to ascertain what is already known about the subject under investigation, provide a broad contextual context into which a research problem will fit, identify disparity in knowledge, avoid unintentional duplication and finally demonstrate how the study will contribute new knowledge in the area of interest, (Holloway and Wheeler, 2002, Polit et al, 2001).

Quantitative researchers carry out the literature review prior to the study to determine all existing knowledge in relation to the topic under investigation. Conversely, in qualitative research in order to maintain objectivity and avoid influences from previous studies, the literature review is carried out once the data has been collected and themes are emerging. Holloway & Wheeler (2002), purport that it is dangerous to start without any prior ideas of what has already been done. Furthermore, the literature review becomes a source of discussion once themes from the data emerge, hence acting as a guide and source of reference.

### **2:3 Literature Review Results**

A comprehensive literature review in relation to the study topic, breast cancer was undertaken using a broad-brush approach and the incremental approach.

The broad approach involved gathering all published literature in relation to the research topic, breast cancer, followed by a process of sieving through the references and identifying those with study relevance. The incremental approach required examining each article reference list, highlighting further references of relevance. This method was found to be time consuming but did uncover a wide birth of knowledge that could be examined and implemented in the current study.

Literature was reviewed intermittently throughout the full course of the study using electronic databases such as CINAHL, MEDLINE, EBSCO, SAGE journals, PsycArticles and BLACKWELL SYNERGY. In addition, the researcher's workplace provided a further source of literature in the form of library access, books, journals, and the Irish Cancer Society. Search titles included breast cancer, chemotherapy for breast cancer and the lived experience of breast cancer, stress, and coping during and after breast cancer treatment. A vast amount of data was uncovered concerning various aspects of breast cancer including psychological and social issues, chemotherapy complications, surgery for breast cancer and the role of the healthcare professional dealing with breast cancer patients. The studies were read in their entirety to obtain an overall understanding of the findings. Interpretive summaries of the relevant studies were written up with a list of the key findings. Using a process of reading, writing and reflecting about the findings in the literature, an extensive list of common themes were developed, which were used to describe the experiences of the women with breast cancer. The primary objective of this interpretive process was to

formulate constitute or overarching patterns from the existing literature. These patterns constituted the research priorities that needed to be addressed in my study and included: The predominately psychological perspective which was embedded within the existing literature related to women's experience of breast cancer and treatments.

The lack of contextual or background information about women's experience of breast cancer, which existed in the quantitative literature of the topic.

These two constitutive patterns were emphasized throughout the literature review. This provided the overarching "interpretive" perspective through which the literature was critiqued and presented.

The existing literature on the lived experience of women with breast cancer predominately evolved from a psychological perspective, which examined the person's experience of breast cancer using a quantitative approach incorporating questionnaires. It is suggested that this research lacked important contextual information about the effects of the illness on the person's life. Therefore the literature review begins with a critical review of this literature, highlighting the potential limitations in its approach. The qualitative literature highlighted that the losses and lifestyle disruptions caused by a chronic illness, such as cancer culminated with stress. Stress was identified as a prominent source of existential suffering and initiated distressing emotional responses in the person, such as anxiety and uncertainty. Based on the findings of these studies, it seemed that people oscillated between the release and suppression of these emotional responses. These features of the women's experience depicted certain characteristics of the model of suffering, formulated by Morse et al (2002). Hence, Morse's work on stress was interwoven through the review of the qualitative literature to ensure an in-depth discussion of this literature was provided.

The literature search uncovered data from European studies, USA, Canada, Sweden and Australia and no study from Ireland was identified. A summary of research issues

identified from the literature will be discussed in this chapter with further reference to published studies taking place in the findings and discussion chapter.

## **2:4 Breast Cancer Aetiology**

Breast cancer is a disease in which certain cells in the breast become abnormal and multiply without control or order to form a tumor. The breast is made up of different types of tissue, including fat, connective tissue and gland tissue. The gland tissue is divided into lobes and ducts, during and after pregnancy milk is produced by the lobes and carried to the nipple by the ducts. The shape of breasts varies and they are seldom the same size, becoming lumpy just before or during the menstrual cycle. It must be noted that breast tissue, known as the tail extends into the armpit known as the axilla. The armpits also contain glands known as lymph nodes that form part of the lymphatic system.

Breast cancer research has shown that there is no single cause of breast cancer. It is a heterogeneous disease, most likely developing as a result of many different factors that are not the same from woman to woman and most of which are yet unknown, (Otto, 2001).

Breast cancer often presents when a woman finds a lump on her breast. Nine out of ten lumps are benign and are not cancerous. These benign lumps can often be fluid filled sacs known as cysts. Another benign presentation of breast lumps is in the form of fibroadenoma, a collection of fibrous glandular tissue.

The most common form of breast cancer begins in cells lining the ducts that carry milk (ductal cancer). Other forms of breast cancer begin in the glands that produce milk (lobular cancer) or in other parts of the breast.



Early breast cancer usually does not cause pain and may exhibit no noticeable symptoms. As the cancer progresses, signs and symptoms can include a lump or thickening in or near the breast; a change in the size or shape of the breast; nipple discharge, tenderness, or retraction (turning inward); and skin irritation, dimpling or scaliness. These changes can occur as part of many different conditions, however having one or more of these symptoms do not mean that a person definitely has breast cancer. Most breast malignancies are ductal accounting for 80%, and lobular accounting for 10% of breast cancers (Otto, 2001). In some cases, cancerous tumors can invade surrounding tissue and spread to other parts of the body. If breast cancer spreads, cancerous cells most often appear in the bones, liver, lungs or brain. Tumors that begin at one site and then spread to other areas of the body are called metastatic cancers. Cancerous tumors in the breast tend to grow very slowly so that by the time one is large enough to be felt as a lump, it may have been growing for as long as ten years (Susan G. Komen Breast Cancer Foundation, 2006).

A small percentage of all breast cancers cluster in families. Hereditary cancers are those associated with inherited gene mutations. Hereditary breast cancers tend to occur earlier in life than noninherited (sporadic) cases and are more likely to involve both breasts.

## **2:5 Breast Cancer Risk Factors**

Several risk factors appear to increase the probability of a woman developing breast cancer. However, it must be noted that many women diagnosed with breast cancer may or may not have any of the risk factors. Identification and discussion of the risk factors highlighted for the development of breast cancer will now be explored.

The first risk factor for the development of breast cancer is gender. This may appear obvious, but it must be noted that breast cancer occurs in 1% of the male population,

(Greenlee et al, 2000). In the United States breast cancer researchers estimate that more than 178,000 new cases of invasive breast cancer will be diagnosed in U.S. women in 2007 and it accounts for 30% of all invasive cancers in women.

Age is the next consideration, as with any cancer the risk of developing breast cancer increases significantly with age. Many breast cancers are diagnosed in women over forty years of age and older with majority of breast cancers diagnosed in women aged over fifty years. In addition, previous history of primary ovarian, endometrial, or colon cancer has been associated with an increased risk of breast cancer development, (relative risk under 1.1 – 2.0), (American Cancer Society, 2006).

Family history of cancer is also a significant risk factor. Women with a first degree relative, (mother, sister, daughter) diagnosed with breast cancer have an increased risk of 2.1-4.0, (American Cancer society, 2006). This risk increases if the cancer diagnosis was pre-menopausal and bilateral. In some families there is a genetic risk for developing breast cancer. Clinical features of this feature include a younger age at diagnosis, bilateral occurrence, multiple family members affected over three or more generations and occurrence of cancers in other sites (ovary, colon, uterus). The presence of these risk factors warrants counseling and consideration for genetic testing. Genetic testing in breast cancer is a subject in its own right and therefore will not be explored in this context.

Early menarche and late menopause are considered to be risk factors. The exact role of hormones in the aetiology of breast cancer has not been precisely determined in breast cancer. Early onset (before the age of twelve), late menopause (at age 55 or above), and greater total duration of years of regular menses are associated with an increased risk of breast cancer development. This is thought to be due to a total lifetime exposure of the breast cancer to estrogens and progesterone, causing fluctuations in cell growth and change

in the breast tissues with each ovulatory cycle. However, surgically induced menopause (bilateral removal of ovaries) reduces the risk of breast cancer development.

Reproductive history can also contribute to breast cancer development. Having no children or having the first child over the age of 30 years places a woman at an increased risk. This risk is higher for delayed pregnancy as opposed to women who do not have children.

Childbirth at an early age may have some protective effect although the exact mechanism is unclear. Some studies have shown that as a number of months of breastfeeding increases, an associated reduction occurs in the risk of developing breast cancer particularly for premenopausal women, (Guinee, 1998).

As with other disease lifestyles factors have implications for development of breast cancer. They include obesity and dietary fats, as excess adipose tissue is rich in the necessary enzyme to convert precursors into circulating estrogen, (Ingram, 1998). Consequently, obese women may have increased levels of circulating estrogens which can affect hormone-dependent breast cancer cells.

The use of the oral contraceptive pill may also be linked with an increased risk for breast cancer development. The majority of studies have shown no increased risk associated with the use of oral contraceptives, (Prichard et al, 1996). However, further analysis of women who have never used oral contraceptives have distinguished subgroups at possible increased risk of age, onset of use and dosing regime. The consumption of excess alcohol in women increases the risk of breast cancer development. This is associated with age at which drinking occurs, amount and type of alcohol consumed and the duration and frequency of consumption of alcohol. The exact implications of alcohol use and its association with breast cancer is unclear, it is proposed that this lifestyle choice can be associated with poor nutrition or other social factors that may affect general health and access to medical care. Further studies are needed to investigate these variables. The

above offers a summary of the risk factors associated with the development of breast cancer, the next section will focus on screening for the disease.

## **2:6 Breast Cancer Screening**

Breast cancer is a heterogeneous disease, in other words, it is a disease of many characteristics, varying from woman to woman in its potential for development, growth and metastasis. The Health Service has a duty of care to detect cancers earlier by raising public awareness in the population. The epidemiology of the disease indicates that it is hormonally influenced with the duration and exposure to estrogens being the primary factor for its development. Early detection is therefore an important means of control of breast cancer and improved the outcomes for patients, (Hermon & Beral, 1995, HIQA, 2010). According to Millar et al, (2000), the five-year survival rate at localized is 84%, with regional spread 71% and with distant metastases only 18%. It is important to know that women interviewed in this study had been diagnosed breast cancer, four of whom had local spread to lymph nodes in the axillary region, none of the females had metastases to any other organ.

Screening for breast cancer is a means of detecting disease before it has developed to the point where it results in symptoms which can encompass breast awareness, clinical breast examination and mammography. Breast awareness begins at the age of 18 years where women are encouraged to become familiar with their breast appearance, shape, size and feeling. The role of the clinical nurse specialist (CNS) is to promote women's self-examination offering both verbal and written information. Interestingly, Eley et al, (2008), found that the efficacy of breast clinical examination undertaken by a qualified expert clinician as a detection measure has not been proved and is not used internationally as a

screening measure. This reiterates the importance of health promotion for these women in relation to breast self-examination.

The work of Patistea, (1992), Bhakta, (1995) and Morrison, (1996), agree that women who are advised about breast awareness by a healthcare professional demonstrate greater knowledge and confidence than when the information comes from other sources. The role of the clinical nurse specialist, therefore, is to empower women by providing information, advice and support. (HIQA, 2010).

Screening is linked to perceptions of risk, benefit and barriers through a reasoning process that includes personal and social influences and attitudes, (Phillips and Wilbur, 1995). It is being argued by some women that their own personal experiences contradict scientific data and insist that breast self-examination has saved several lives and therefore in terms of healthcare resources, it also suggesting that the personal cost to women is never too great, (Phillips and Wilbur, 1995; Lerner, 2002). Some authors argue that women would willingly undergo a needle biopsy for the reassurance that they do not have breast cancer, while others argue that empowered women might decline performing breast examination if they were fully informed, (Gasalberti, 2002; Lerner, 2002). One could argue that the ability of women to make their own healthcare decisions is being undermined because of the lack of clarity in the breast self-examination debate. It must be noted that for some women sound research evidence causes conflict with hopes and expectations, as in the case of breast self-examination. Many women do not always want the evidence of large population-based studies providing the efficacy or otherwise of medical interventions, (Lerner, 2002). This raises the question does the proof / rationale for interventions such as breast self examination always need to be scientifically based. Some find it more powerful to have stories of women who have been saved as a result of breast self examination. This debate is still continuing but gradually being developed as a national issue. The Dept of Health

launched the Quality Assurance Standards for Symptomatic Breast Disease Services in Ireland which was subsequently mandated by Health Information and Quality Authority (HIQA) in May, 2007.

## **2:7 Treatments for Breast Cancer**

Breast surgery is considered primary treatment for breast cancer, while chemotherapy, radiation therapy, and hormone therapy are considered adjuvant conventional therapies (Canadian Cancer Society website, 2006). The Canadian Cancer Society website (2000) provides a description of the different treatments for breast cancer which are being adopted by the Irish National Control Programme (NCCP DOHC, 2009) currently. 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. 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 flushes, gynecological discomfort, depression, and blood clots (Love, 2000).

In summary, conventional treatments for breast cancer can include surgery, chemotherapy, radiation therapy, and hormone therapy. Which treatments the consultant 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 the time breast treatments is, therefore, a process that presents different side effects over time.

### **2:8 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 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. Breasts become a focal point of femininity and self-esteem. This focus on breasts is assumed to carry from young girls to adulthood, when breasts are often linked

to femininity and sexuality, and are most visible and tangible signifier of womanhood in western culture (Landmark & Wahl, 2002; Langellier & Sullivan, 1998).

There is evident that society prefers that women maintain the “normal” look of two breasts – Haber et al. (1995) points out that discussion of breast surgery between surgeon and patient may include the option of reconstruction, and Thorne & Murray (2000) noted that women “barely recovered from anesthetic” are often encouraged to use prosthetics. There is also evidence provided by Landmark & Wahl (2002) that women with breast cancer want to look like they still have two breasts and the findings revealed that the female breast is linked to femininity and sexuality. It also highlighted that the desire to hide the loss of a breast was very evident and even chose to hide themselves. These findings support expectations that arise from the social discourse.

Langellier & Sullivan (1998) explored in-depth how breast cancer women felt about their breasts and the main theme was that all women see breast cancer as an assault on their femininity and sexuality.

In summary, despite the assumptions society makes about the meaning breasts have for women, Langellier & Sullivan (1998) found that women ascribe different meanings to their breasts on what is important to them. Contrary to what authors stated, the quotations provided in the study by Landmark & Wahl (2002) supported the contention that women value living, 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.



## **2:9 The Stress Discourse**

“Stress” is a widespread concept and is familiar to everybody and whose definition is highly ambiguous (Newman, 2005). It 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 that they get a headache in “moments of stress” (Newton, 1999) but why is stress such a popular subject?

The answer is that we believe in stress because we have, in fact, become more stressed than our predecessors (Newton, 1999). It could 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 successful than other social science discourse (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 as it is subjective. Second, the stress discourse promotes the idea of an individual as someone who defines her psychological and physical well being in terms of her ability to cope well with stress and the person has to cope with the issues in the world. Third, the concept of stress provides a “catch-all” for the range of subjective experiences found in the modern world. The stress discourse provided reassurance by explaining how it is normal to feel stressed in certain conditions, and providing strategies to cope. For the breast cancer woman, the stress discourse means the burden is solely on her to manage her stress (Mulhall, 1996).

In summary, “stress” is a concept that, although ubiquitous in our society, is poorly understood. There is 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 this study, through open ended interviews, women had the opportunity to identify their salient stressor during treatment and how they coped.

## **2:10 Stress and Coping**

The concept of coping began to originate during 1960s and 1970s, along with an increased interest in stress (Lazarus, 1993). The current dominant psychological theory of stress and coping was developed by Lazarus & Folkman (1984) and this theory would be a framework to use when exploring stress and coping of women treated for breast cancer.

The definition of stress given by Lazarus & 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, p19). 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, p 141). The concepts of appraisal 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).

In summary, Lazarus & Folkman’s (1984) theoretical framework of stress and coping is the current dominant psychological 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 during treatment. In this study, the process nature of stress and coping were used to guide my interview questions. The women were asked to recall their most salient stressor and how they coped with that stressor during and after treatment. In order to investigate stress and coping over a period of time that presented a variety of stressors, I defined “treatment” as both breast surgery and at least one adjuvant therapy.

## **2:11 Breast Cancer Stress and Coping literature**

Breast cancer presents many 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 different physical side effects such as nausea, vomiting, fatigue and pain (Irish Cancer Society website, 2010). 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). People who have not undergone breast cancer treatment may assume that once the treatment has been completed that the stress is over. However, Thomas-MacLean (2004) found different evidence where twelve women (age 42 – 77) were interviewed after one year post breast cancer treatment and the data revealed that breast cancer treatment involved suffering and pain. One participant described the process of having a port for her chemotherapy installed as “stressful” and “distressing” and wondered if “maybe the cure

was worse than the disease”. Perhaps the stress a woman with breast cancer experiences also depends on her developmental stage and disease trajectory.

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 changes over time. In this study, the uses of interviews allow the women to recall and explain in-depth, their most salient stressor during and after treatment. 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 et al ,1992); Lazarus, 1993; Wengstrom et al., 2001). Advances in medicine has reduced the side effects women must endure, and increased the survival rates (Jacoby, 2003). On the surface, the literature on coping with breast cancer seems contradictory.

In summary 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 the literature that examined both stress and coping with breast cancer and the treatment. Very little research has placed the coping strategies into the context of the stressors. 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 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, 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 (Saares & Suominen, 2003; Thomas-MacLean, 2004). 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). Thomas-Maclean (2004) found that the end of treatment might also be distressing for some women. There is a strong correlation 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. Coping strategies used during breast cancer change with the changing stressors and changing context. A plethora of coping strategies have been identified in the breast cancer literature but the studies did not fully describe or explain the coping strategies that they found. In addition, the stressors, or what the women were coping with, were rarely mentioned in any detail. However, a close observation of the literature revealed several commonalities.

Some researchers have found avoidance strategies during breast cancer, where the women avoid the situations or thoughts that may concern them anxiety. For example, women may avoid information relevant to their illness, they may avoid looking at themselves, or may avoid social situations (Heim et al., 1997; Osowiecki & Compass, 1999). Research has found that some women use minimization and denial where they minimize or deny the idea of danger (Hilton, 1998). Diverting strategies have also 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 themselves (Heim et al., 1997; Hilton, 1998; Osowiecki & Campas, 1999; Wengstrom et al., 2001).

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 outlines that there is overlap among 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 journey of treatment, and (b) places the coping strategies in the context of their stressors. This study will address the gap in the literature by asking the question: **“What was the most salient stressor and how did you cope with that stressor during and after breast cancer treatment?”**

## **2.12: Literature Pertaining to the Lived Experience of Breast Cancer**

Cancer is a chronic illness, but it is also a series of experiences that profoundly affect the person who has the cancer and those who share the experience. O’Connor et al. (1990) & Landmark et al (2002) point out that it is amazing how little has been studied about the lived experience of having cancer. Most often it seems to be a great shock to be diagnosed with cancer, even more of a shock than to be diagnosed with another serious disease. People who are diagnosed with cancer seem to go through existential crisis for approx 100 days, in which everything revolves around life, the disease and death (Halldorsdottir & Harmin, 1996). Often the role of the healthcare professional is to help people with cancer live a life that is as good as possible. To do that, healthcare professionals need information about the lived experience of having cancer to enable them to offer support and caring that has meaning for the person with cancer.

Several studies have been performed to explore aspects of living with breast cancer. Although much research has been done in the field of psychosocial aspects of breast cancer, most of this research has been focused on predefined subissues such as social

support, quality of life, body image, depression and psychological reactions, etc. few studies have researched living with breast cancer in a holistic manner. According to several studies, the period following confirmation of a cancer diagnosis is dominated by worries concerning life and death (Carlsson & Hamrin, 1994; Luker et al, 1996). These concerns influence women's attitudes toward future possibilities, their hopes for the future and their experience of health and quality of life (O'Connor et al, 1990; Carlsson & Hamrin, 1994; Luker et al, 1996; Rusteon et al, 1999). Carlsson and Hamrin (1994) completed a literature review from the period 1989 – 1992 on the psychological and social aspects of breast cancer. Results showed that one of the best predictors of a woman's post-cancer adjustment is her psychological state before breast cancer. The results also showed that the difference in psychological outcome between mastectomy and breast-conserving surgery was small and not significant. Another finding was that the social context and social support from partner, family, relatives and medical professionals are important for survival. Smyth et al, (1995) provides an overview of literature on women's experiences of breast cancer. They place particular emphasis on the support available to them and highlight the necessity for assessment of women's needs. Furthermore, in a study exploring the psychological consequences of breast cancer on health and lives, Kasper (1995) demonstrates that breast reconstruction fails to meet the expectations of these women. To be able to understand woman's suffering with breast cancer, and their families it is important for caregivers to have knowledge about the family's cancer journey, (Leydon et al, 2003). Muraoka & Gotay, (1998) reviewed the breast cancer literature and highlighted some of the controversies associated with breast cancer, as they indicate that there are studies that proclaim no differences in psychological indications in relation to treatment, and there are studies that show significant differences. In another review Glanz & Lerman, (1992), concluded that breast conservation yields better results for body image. Other researchers

have suggested that breast cancer research is problematic, qualitative studies of women's experiences of breast cancer have suggested that the physical aspects of topics such as chemically induced menopause and lymphodema are neglected, (Carter, 1997; Davis, 2003). Furthermore Langellier and Sullivan, (1998), assert that prior research emphasizing the effects of a mastectomy replicate sexist power dynamics and that women speaking for themselves about breast cancer suggest that issues other than breast loss are more important.

According to Thomas-MacLean (2004) much of the research on breast cancer also refines dichotomies of health and illness through assumptions that once the breast cancer treatments have been completed, women have few concerns. The researcher found this to be a very general finding and did not agree that this was the case for women diagnosed with breast cancer. Dow & Laffery (2000) have suggested that women experience changes in quality of life and psychosocial adjustment that might not be observed readily in clinical practice. Although, Arman et al (2003) were most interested in existential questions about life and death that occur as a result of breast cancer, they suggested that suffering experienced by these women may not be recognised by healthcare professionals. Watson (1988), has argued that although medical research is becoming more 'phenomenologically inductive' it is not evident that this method is being used in breast cancer research.

Bredin (1999) when writing about breast cancer stated 'despite the wealth of literature, there has been few studies directly quoting a women's private perspective, on how in her own words she views her changed body' (p.113). Loveys and Klaich (1991) concurred suggesting that women's concerns ought to be addressed as women describe them, not following clinical models of research.



Several authors have reviewed the incidence of breast cancer and the possible causes for women diagnosed. Taylor, (1995), reviewed patients' views on the meaning of cancer. Most of the patients gave more than one reason or cause for their cancer as well as assumptions of what might not have been the reason. Both scientific and psychological factors were noted. Clarke & Lavery (1996) studied perceived causes among 244 women with breast cancer. Of the sample, 70% gave a casual explanation, with most attributions focusing on stress (34%) followed by heredity (13%). Tishelman (1997) found in her study that cancer patients' explanations of the genesis of their cancer were an intricate combination of possible influences, where patients distanced themselves from personal guilt but opened possibilities for their own positive effect in a cure and recovery.

Few studies have focused on the existential dimension of living with breast cancer. Ferrell et al (1998) identified three major themes within the domain of spiritual well-being. These were the support of spirituality, aspects of spirituality and having altered life. Women often described uncertainty about the future as one of the most difficult aspects of living with breast cancer. Altered life priorities, altered life meaning and thoughts regarding transcendence from their current life to their death were also described in this study. Much of the research in the field of breast cancer and the impact of the diagnosis on different life domains has been descriptive, using standardized questionnaires (Rustoen & Begnum, 2000). This study provides information about how women themselves can describe their illness and captures the wholeness of their experience. Only the women themselves can describe how they experience living with diagnosed breast cancer. Awareness of women's experience of their new and changed life situations is vital in supporting them in their process towards coping. Based on this healthcare professionals can help women and their families to develop coping strategies where present facts and the

current situation is accepted, and the families' positive expectations of future coping encouraged. Therefore, this study explores breast cancer patients' experiences of living with disease, what were the most salient stressors and how did they cope. The study aims to provide a deeper understanding of the suffering and stress facing these patients.

### **2.13: Summary**

This literature review highlights that the breast cancer women's experience of breast cancer treatment is predominately based on an empirical psychological framework. This research largely relied on quantitative approaches to measure and quantify various elements of the women's experience using questionnaires. Most of these questionnaires adapted a structured and closed-ended approach, which limited the responses of the participants. As a result, an in-depth, detailed account of the women's experience was not achieved.

Because of a personal and professional 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 the women to recall through their experience of their most salient stressor during and after treatment, and how they coped with those stressors to survive. 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 to choose their most salient stressor during treatment.

There is a paucity of literature on patients' perceptions and knowledge of having breast cancer treatment for breast cancer women. Prior studies are lacking in rich description and a holistic view, as they focus on one specific aspect of breast cancer, for example

mastectomy. In order to uncover a holistic view of concerns held for women with breast cancer there is a need to examine the impact of a disease in its entirety and offer a contextual explanation. While there were a number of qualitative research studies, which explored the women's experience of breast cancer, these studies were also primarily grounded within a psychological framework. Hence, they adapted psychological concepts and theories to explore the women's subjective experience of breast cancer. Although there is an extensive body of literature on the quality of life in breast cancer patients, more qualitative research for a better understanding of the psychological needs of breast cancer patients is needed to offer targets intervention for survivorship (Montazeri, 2008). It is felt that women speaking in their own words about the experience of chemotherapy and radiotherapy for breast cancer can contribute much to knowledge for healthcare professionals surrounding the complexity of this journey. 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 a strong theme in the literature that breast cancer treatment is a process and a journey, however, most research has examined treatment that 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 used at different times. The findings of this study aims to provide a deeper understanding of the women's experience and identify the stressors and their coping strategies and to inform practice and contribute to future research. In the next chapter, the research method will be described.

## **Chapter 3: Methodology**

### **3.1: Introduction**

This chapter outlines the methodology selected for this study following a discussion on the research paradigms in healthcare.

Methodology refers to questions concerned with the manner in which knowledge about what exists can be gained. Methodology alludes to the philosophical/theoretical framework and the assumptions that underpin that framework. Included in the process is the way in which we generate data, (Koch, 1995). The aim of healthcare research irrespective of the design is to improve the knowledge base about that particular subject, (Hockey, 1991).

Factors influencing the research design are proposed by Holloway and Wheeler (1996, p.9) as:

- The epistemological science of the researcher.
- The nature and type of the research problem.
- Skills and training of researcher.
- Resources available for the research project.

However the purpose of this study is to identify, describe and generate a theoretical understanding of the participants' (breast cancer patients) perspective and experience that are treated with breast cancer.

In this study the Glaserin (1992; 1998; 2001) style of grounded theory is chosen in order to allow the main concept of the participants to emerge from the data. First of all the research methodology will be selected for this study, then a discussion of the research paradigms in healthcare followed by a discussion of grounded theory as a qualitative method of data collection and analysis. The application of the method in this study will be presented, including a description of the planned study design, the selection of the participants, data

collection and analysis and finally the study closes with a discussion relating to the issues of rigour in grounded theory.

### **3.2: Background**

Any process of research enquiry is guided by a set of 'basic beliefs'. These beliefs, that form the basis of, in this case, the qualitative research paradigm, are designed to answer three questions: 'what is the nature of reality?', 'what is the relationship between the researcher and the knowledge?' and 'how should the researcher go about finding out knowledge?' (Guba, 1990). These key questions help clarify the following terms: 'ontology', 'epistemology', 'axiology', 'rhetoric' and 'methodology'. According to Crotty (2006), ontology is the study of being and it is concerned with 'what is', with the nature of existence, with the structure of reality as such. Creswell (1994) states the only reality is that constructed by the participants (patients in this study).

Epistemology deals with 'the nature of knowledge, its possibility, scope and general basis' (Hamlyn, 1995, p.242). Crotty (2006,p.8) explains the relevance of epistemology to what we are here about: "epistemology is concerned with providing a philosophical grounding for deciding what kinds of knowledge are possible and how we can ensure that they are both adequate and legitimate". Here the researcher is closely interacting with the participants. This close interaction has implications for axiology, the role of values in a qualitative research. Due to the close involvement of the researcher, personal values and biases are actively reported (Creswell, 1994).

A theoretical rhetoric refers to the language of the research. Lincoln and Guba, (1985) emphasised the qualitative paradigm by constructing a new language which differed from traditional research. Creswell (1994) states that it is "personal, informal and based on

definitions that evolved during a study” (p.7). Methodology refers to the strategies used in the data collection and analysis processes. In a qualitative methodology, categories emerge from the participants. According to Creswell (1994), this emergence provides “context-bound” information that leads to the development of theories.

### **3.3: Grounded theory As a Research Method**

A grounded theory is induced from the data rather than preceding the data, (Lincoln & Guba, 1985). Glaser & Strauss (1967) developed the systematic approach to the study of interactions, known as the grounded theory method, to bridge a perceived gap between theory and research and the consequent undervaluing of qualitative studies that were relatively uncommon at the time. Glaser & Strauss came from very different backgrounds. Glaser was trained in quantitative research whereas Strauss was strongly influenced by the Chicago School of Sociology and the symbolic interactionist perspective. Their goal was to produce a research method that would be of value to practitioners and to develop theory that fitted with reality. The method was developed originally to investigate interactions in social settings (Glaser, 1998). The objective in grounded theory is to develop theory from the data which is encompassed in a core category and related categories and concepts. This methodology has been frequently used in many disciplines and healthcare professionals. In this research study the grounded theory approach was chosen to discover the experiences of breast cancer patients while enduring treatment. McCallin (1999) explains that “the aim in grounded theory is to explain and predict behaviour and discover the underlying social processes shaping interaction and human behaviour”. Grounded theory is an appropriate choice for addressing research questions about complex relationships, clinical situations or new areas of inquiry. The initial question starts out broadly and becomes progressively

narrowed and more focused during the research process. However, grounded theory is guided by, and has its roots in symbolic interactionism (Chenitz et al, 1986).

While the type of grounded theory used in this study is Glaserian, for the purpose of understanding I have read and researched widely for this final research thesis. Literature from other sources is, therefore, integrated into the discussion. In recent years, Glaser & Strauss have differed over interpretation of the grounded theory method but both have continued with grounded theory research. Glaser (1978; 1992; 1998; 2001; 2005) has extended the original 1967 text to detail concepts such as emergence, theoretical sampling, theoretical coding and use of theoretical memos, while Strauss, working with Juliet Corbin (1990), focused on developing the structure for the analytical techniques.

Glaser (1978, 1992) emphasises the importance of the emergence of the data and theory through the analysis of 'basic social processes'. He advocates gathering data without forcing preconceived questions, structure or frameworks on the participants.

Both Glaser (1998) and Strauss & Corbin (1990) describe coding as an essential aspect of transforming data into theoretical constructions of social processes. Glaser distinguishes two types of coding: open and selective, while Strauss and Corbin describe three: open, axial and selective.

In this study I followed the principles and method of Glaser (1998) because this method allows the main concerns of the participants to emerge from the data. Emergence is useful as it sets an environment to access understanding of the practical realities of understanding experiences of breast cancer patients while enduring treatment. It also sets the scene to understand the behaviour of these breast cancer patients. In their original text, Glaser and Strauss (1967, p.41), state that emergence remains the key throughout theory development: "integration of the theory is best when it emerges, like the concepts. The theory should never be just put together". According to Glaser (1998, p.32) "in grounded theory there is

no need to force meaning on a participant, but rather a need to listen to his/her genuine meanings, to grasp his/her perspectives, to study his/her concerns and to study motivational drivers”.

### **3.4: Philosophical Perspective and Grounded Theory**

Philosophy and grounded theory is a contentious topic and has been adopted in healthcare and education. A theoretical perspective is the philosophical stance informing a methodology, providing a context for the process and grounding its logic and criteria (Crotty, 2003). The theoretical perspective informing this study was symbolic interactionism. Symbolic interactionism outlines that the individual’s realities are created through attaching meaning to situations and symbols, which in turn are used to express their meanings and beliefs (Jeon, 2004). Symbolic interaction is a theoretical perspective that stresses the interrelationships of human activity to experiences, especially interpersonal encounters (Schroeder, 1981). It is an appropriate framework to guide this study because the major emphasis is on the meaning of the situation to the person (Saunders, 1997). This viewpoint asserts that interaction among people over time is motivated by the symbolic meaning that actions, objects, and events have acquired for those people both individually and together (Saunders, 1997). Symbolic interactionism is basically a theory about human behaviour and an approach to the study of humans conduct and human life (Chenitz & Swanson, 1986). The second concept of symbolic interactionism is self which according to Klunkin & Greenwood (2006) is constructed through social interaction. It is essential to note that all theoretical perspective is influenced by an epistemology. Epistemology refers to the theory of knowledge embedded the theoretical perspective and thereby in the methodology. In other words, epistemology deals with the nature of



knowledge, possibility, scope and general basis (Crotty, 2003). My preferred epistemological view about the nature of knowledge and truth is constructionism. Crotty (2003) describes constructionism as the view that all knowledge and therefore all meaningful reality is contingent upon human practices, constructed in and out of interaction between human beings and their world and developed and transmitted within an essentially social context. According to constructionism, meanings are constructed by human beings as they engage with the world they are interpreting. Thus, meaning cannot be created, only constructed. The unity-transformative and simultaneity healthcare paradigm stem from the overall interpretative paradigm of constructionism. This epistemology posits that knowledge is derived from experience, that cognition and perspective and experience affect what is seen or conceptualized, and that observation are value laden (Monti & Tingen, 1999).

I believe that the theoretical perspective of interpretivism, informed by constructionism, is most congruent with studying breast cancer women and the stressors endured during treatment. According to Crotty (2003), interpretivism emerged in contradistinction to positivism in an attempt to understand and explain human and social reality. The interpretivist approach to human inquiry has been affected by three streams: hermeneutics, phenomenology, and symbolic interactionism (Crotty, 2003). Crotty (2003) states that symbolic interactionism explores the understanding aboard in culture as the meaningful matrix that guides our lives. In order to understand the experiences of women with breast cancer experiencing stressful symptoms, you have to look as it through their eyes. This is in keeping with the symbolic interactionism perspective, in that a researcher can only understand what is going on if and only if he/she understands what women believe about their worlds and their experiences (Crooks, 2001). Grounded theory is an inductive research method that generates theory from data that is examined systematically during

data collection and analysis (Glaser & Strauss, 1967). The aim is to explain behaviour and to discover the basic social processes shaping that behaviour. Glaser (1992, p.4) states that there are only two questions that need to be asked, “What is the main concern of the participants and what accounts for most of the variation in processing the problem? Then what category or property of what category does this incident indicate? Glaser (1998) states that the researcher must trust that uncertainty, ambiguity and confusion are a useful path to being open to emergence. He/she must trust to emergence and trust that the social organisation of social life exists to be discovered” (p.44). The philosophy of emergence is not attached to any specific philosophical viewpoint. Glaser (2005) expresses concerns regarding the symbolic interactionist takeover of grounded theory and that this is the only theoretical perspective that may have emergent fit. The consequences of this takeover are clearly expressed by him as a “remodeling and eroding” of classical grounded theory. Glaser (2005) argues that this symbolic interactionist takeover limits the “data, the substantive categories and subsequent theoretical concepts that the researcher will use or hopefully let emerge”. This allows true grounded theory to emerge and the researcher can be open to all possible theoretical concepts.

### **3.5: Key Components and Grounded Theory**

Grounded theory method involves systematic steps of data collection, coding and analysis to develop an inductively derived theory. Using this method, each piece of data is continually compared with each piece of relevant data so as to generate theoretical concepts that encompass as much behavioural variation as possible (Glaser & Strauss, 1967). Concepts identified in the data are then compared with subsequent and prior data to generate their interrelationships and theoretical suppositions.

*Theoretical sampling* focuses and limits the collection and analysis of data by responding to the need for more data that is relevant to the emergence of new categories. In order for concepts and categories to emerge during the data analysis, the need for sampling of specific data sources continues until each category is saturated. At the beginning of the study there are no limits set on the number of the participants, interviewees or data sources. The researcher makes preliminary sampling decisions. Sampling within theory is therefore described as theoretical rather than purposeful (Glaser & Strauss, 1967) in that it is driven by the emerging theory.

Although grounded theory is an inductive method of research, the use of theoretical sampling requires deductive thinking on the part of the researcher. As such, according to Glaser (1998,p.43) “deductive reasoning comes into play through the sampling procedures as sources of more data are looked for and the researcher is able to deduce where they may need to go to get more”.

This sampling method allows data to be collected from informants who are best able to answer the questions emerging analytic questions, rather than sampling a pre-determined group of participants or setting (Glaser, 1978). Sampling continues until theoretical saturation, *data saturation* is reached. This occurs when no new data emerge relevant to particular categories or subcategories, categories have conceptual density, and all variations in categories can be explained (McCann & Clark, 2003).

*Coding* initiates the process of theory development. Glaser (1978) and Strauss and Corbin (1990) describe coding as an essential aspect of transforming raw data into theoretical constructions of social processes. Coding is structured through line by line or word by word analysis. This kept me focused on what the participants were describing, instead of my own pre-conceptions. Initial, substantive (open) coding describes the process through which

concepts are identified and their properties and dimensions are discovered in the data. Glaser (1978; 1992) describes the process of emergence as generation of codes and categories directly from the data and are often labeled from words found in the data themselves.

Using the constant comparative method of analysis, the coded concepts are refined, extended and cross-referenced with the data as a whole. The concepts are grouped with more abstract explanatory terms called categories which depict the problems, issues, concerns and matters that are important to those being studied.

Theoretical coding is more conceptual than open coding and it is important to identify the type of core code being used. At this stage when the core category is identified, the researcher concentrates on modification of the categories and integration of the theory with the categories and subcategories (Carpenter & Brockopp, 1995): the categories are clustered around three phases of care: engaging, advancing self-determination and developing linkages. The phases, in turn are embedded within two domains or foci of care: interacting with the participant and interacting with others. The writing up of a substantive theory which is grounded in the data is final step of the research process.

### **3.6: The Design and Method of the Present Research**

In this section application of the research method is presented. The study design, setting, access to the field , participant selection, researcher involvement, ethical considerations, data collection and analysis strategies and the rigorousness of the research will be discussed.

### **3.7: The Study Setting and Access to the Field**

The setting for this study was provided within an acute general hospital within an oncology day services with breast cancer participants experiences while enduring breast cancer treatments.

Qualitative research is interpretative research, as such, the biases, values and judgement of the researcher are stated in the report (Creswell, 1994). Glaser (1992) warns the researcher who is familiar with the area under study to resist the tendency to force the data. As an oncology clinical specialist for five years, I appreciate the importance of putting my preconceptions to one side but continually reflecting during the research process. Dowling (2004) believes reflexivity to be a continuous process of reflection by the researcher regarding personal values, preconceptions, actions or presence and those of the participants which can affect the responses.

### **3.8: Purposeful/Selective Sampling**

One of the crucial tasks in designing a research study is deciding the number and characteristics of the participants invited to participate in the study (Parahoo, 1997).

Sampling is defined as the process of selecting representative units of the population for study in a research study (Lo-Biondo-Woods & Haber, 2002). Purposeful sampling is based on the assumptions that a researcher's knowledge about the population can be used to hand pick the cases to be included in the sample (Polit & Hungler, 2001). Purposeful sampling is used in the collection of descriptive data and is seen as a useful method to investigate the participant's (patient) perception otherwise known as the lived experience of a particular phenomenon or when the focus of the study population relates to a specific

diagnosis. A purposeful sample may also be selected in a study when a highly unusual or specific group is under investigation. The aim of most qualitative studies is to discover meaning and to uncover a multiple of realities. Hence, the use of purposeful sampling may be deemed appropriate as it will allow the selection of eight women with breast cancer, who indicated that they had experienced stressors in the course of their breast cancer treatment. The sample was drawn to capture broad variations in demographic and clinical characteristics such as age, occupation, disease development and type of cancer treatments. During the initial telephone contact 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. Eight women met the inclusion criteria and were interested in participating. I informed the participants that they needed to read and sign a consent form before the interview. All eight 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 my office). Before the interview begin, each participant read and signed the consent form (see Appendix D). None of the participants had questions at that time, and all were given a copy of the consent form for their records.

### **3.9: Ethical Considerations**

The inclusion of ethical consideration is vital in any piece of research undertaken, regardless of the methodological underpinning of the research design. The Nuremberg Code has set out ethical standards that protect human rights, the researcher will endeavour to follow these standards. The Code of Professional Conduct (ABA,2000) laid down by An

Bord Altranais articulates the primary ethical principles on which the standards of this proposed research would be based. Cohen et al, (2000) point out that most hospitals, universities and other institutions where research is conducted have established formal committees and protocols for reviewing research plans. The common principles of ethical research practice emphasize four guide underpinning codes of ethics: Informed consent; deception; anonymity and confidentiality; and accuracy (Denzin and Lincoln, 2000). First of all initial consent was obtained from the medical oncologist, then each prospective participant was contacted by telephone and written to and the study and its implications are explained. When patients agreed to take part an appointment was made. Prior to the interview they were given the opportunity to ask questions and to sign a consent form. They were informed of measures taken to ensure the confidentiality of the data and of their right to end the interview at any time (Appendix C). Approval was sought from the organizational ethics committee prior to the commencement of the interviewing process in order to ensure the preservation of participant's rights within studies (Appendix C). Since qualitative methods, such as interviews and observation, are essentially processes of human interaction, potential risks of interaction may arise, including misunderstanding and conflicts of opinions and values (Vivar, 2005). Participants had an opportunity to ask for clarification and to raise any issues of concern with the research prior to signing the consent form. A copy of the signed form was provided for the participants (patients) in order to remind them of their agreed conditions. The vulnerability of those breast cancer patients under investigation was acknowledged. The researcher was aware of the potential for emotional responses during the interview process. These could include informed consent, relative status relationships, data ownership, thesis accessibility, etc.

The selection of cases during the study was a high challenge for the researcher, as it required seeking participants after their diagnosis of breast cancer and their experiences

while enduring breast cancer treatments, when they were most vulnerable. The diagnosis of cancer and further impact of having to have cancer treatment made approaching those patients very difficult.

On reflection the need to conduct interviews within a specific time frame made the researcher feel intrusive to the women's personal space at a difficult time in their lives.

During the study the ethics committee granted permission to access eight patients and then received posted information regarding the study detailing the researcher's contact number and the consent form should they decide to participate. They all agreed to be involved and met the standard for voluntary informed consent. It was important to make it clear that they that they could withdraw at any time without jeopardising their future follow-up care. To ensure confidentiality all audiotapes were transcribed by the researcher and to ensure privacy, participants were asked to choose a pseudonym. The transcripts were kept in a locked filing cabinet along with the audio files, demographic and contact information, signed consent forms, and a notebook that contained all my notes and memos.

### **3.10: Selection Process**

The selection of cases was a high challenge for the researcher, as it required seeking participants enduring breast cancer treatments, when they are most vulnerable. The diagnosis of cancer and the further impact of having ongoing treatments regime made approaching the population very difficult. Interviewing the participants that endured breast cancer treatment was important as the aim of the study was to identify any views held by participants (Appendix D). On reflection the need to conduct interviews within a very specific time frame made the researcher feel, intrusive to the women's personal space at a difficult time in their lives. The ethics committee granted permission to access eight



patients and then each received posted information regarding the study detailing the researchers contact number and the consent form should they decide to participate. The eight patients agreed to participate. They were then contacted via telephone and interview times and locations were agreed. The time frame was two weeks which was too short. Five participants were interviewed in the out patients department and the other participants opted to be interviewed in their home which was satisfactory.

During the interviews I reminded the participants prior to commencing the interview that I would have to record the interview. As an experienced Oncology specialist nurse I had built up a strong relationship with them and empathised with them discussing issues pertaining to their chemotherapy treatment.

Interviews lasted 30 - 45 minutes and the process started by thanking them for agreeing to be part of this study and my first question 'Tell me about yourself....What did it feel like to be a woman treated with breast cancer?' The use of open question was beneficial as it allowed dialogue regarding initial presentation of the cancer to the present day. This was then followed by another open question 'In relation to your chemotherapy schedule can you describe any thoughts/feelings you have?' Again this was useful as it allowed any potential negative and indeed positive aspects regarding chemotherapy treatment to be identified.

Immediately after the interview the researcher noted key points such as observations and reflections in the reflective diary which proved a useful memory tool during the analysis phase as it reacquainted the researcher with the data.

### **3.11: Data Collection Methods**

Data was collected by personal, semi-structured interview as a conversation only using the technique described by Glaser and Strauss (1967). All interviews were based on a theme guide to give structure to the conversation:

- Experiences and stressors connected with living with breast cancer.
- Reactions to the diagnosis and treatments.
- Dealing with everyday living and coping strategies.
- Being strong and support.
- Thoughts regarding the future and enduring the breast cancer.

The women were informed about the study both orally and in writing. Oncology nurses in the out-patients department gave the first information when the women attended a check-up. Requests to partake in the study were reviewed by the medical oncologist. The women, who freely gave their written consent, met the standard for voluntary informed consent. It was now clear that the participants could withdraw from the study at any time, without jeopardizing their future follow-up and treatment. Due to the sensitive issues connected with the study, an arrangement with the out-patient clinic was established, and women were offered follow-up consultation after the interview with a doctor or oncology nurse according to the women's need. Glaser suggests that writing up the field notes after the interview allows the researcher to code and analysis the data immediately. I followed this approach and wrote up my field notes immediately after the interview.

Consistent with the tenets of grounded theory, in the unstructured formal interview, the researcher used an interview guide containing a set of briefs, general questions, a topical outline or a major theme (Chenitz & Swanson, 1986) (see Appendix D).

### **3.12: Data Analysis**

Data were analysed using the main steps in Grounded Theory described by Strauss and Corbin (1990). In grounded theory data analysis is both inductive and deductive (Glaser, 1978; Glaser & Strauss, 1967). The strongest motive for using this method was the wish to discover knowledge about the dimensions and connections in women's experiences, in relation to what is involved and how they coped when living with a serious and life-threatening illness. The method searches for which is true for a specific person in a given situation and statements are informed from the person's interpretations and meaning (Glaser & Strauss, 1967). Data were continuously examined for meaning, common patterns and emerging concepts from the beginning of data collection until the final draft step by step. During the interview process, patterns that seemed to appear were included in the theme guide. Each word and each sentence in the text were analysed to identify descriptive categories. Substantial phenomena were named and the code written in the margin beside the relevant data.

Glaser (1992) described coding as an essential aspect of transforming raw data into theoretical constructions of social process (Kendall, 1999). In Glaserian grounded theory (GT), the essential relationship between data and theory is a conceptual code (Glaser, 1978). A conceptual code is part of the researcher's larger theoretical framework in which he/she specifies conditions, offers explanations, and makes predictions (Charmaz, 2000). Glaser distinguished two types of coding processes, substantive (open) and theoretical (Kendall, 1999).

Substantive coding consists of two phases, open and selective coding, and is concerned with producing categories and their properties (Walker & Myrick, 2006). In the process of coding, the researcher breaks down the data line by line, in order to explore all possible aspects of issues and ideas in the data, and to develop descriptive codes as labels for the

meaning of the issues and ideas (Jeon, 1994). Selective coding on the other hand aims to identify a core category and then attempts to establish a link between the core category and other categories (Charmaz, 2000).

Selective codes conceptually sum up the patterns found in the substantive incidents in the field (Glaser, 1992). Theoretical coding occurs at the conceptual level, weaving the substantive codes together into a hypothesis and theory (Walker & Myrick, 2006). It is a refitting and refinement of categories which integrate around an emerging core (Heath & Cowley, 2004). All data in the study was coded according to this cyclical process. Based on the open coding, identifying qualities in the data developed each of the preliminary categories. The connection between each category was clarified in an attempt to raise the data to a higher level of abstraction. Questions were raised and the data compared in order to assemble data in new ways. Theoretical considerations were made during the whole process of analysis. All the interviews were conducted by the same researcher.

Memos are the analyst's written records of the analytical process, and they were also written during the process to ensure that the researcher's impressions, ideas and reflections were not lost during the analysis. It is in memos that hypotheses are recorded, compared, verified, modified, or changed as new data comes in (Chenitz & Swanson, 1986) Glaser (1998) describes memos as the theorizing write-up of ideas about codes and their relationships as they occur to the analyst while coding. They reflect the researcher's internal dialogue with the data at a point in time (McCann & Clark, 2003). Glaser (1978) suggests that the writing of theoretical memos, which are written reflections of thinking is the core stage in the process of generating theory, and that if the analyst skips this stage by going directly from coding to sorting or to writing than it is not grounded theory. Field notes are kept throughout the research process to document the researcher's ideas, insights and observations about the data. Furthermore memoing began with the data analysis after

the first interview and continued throughout the data collection and analysis process. In addition to recording the interviews, the researcher observed the women's attitudes, body communication, facial expressions and their ways of verbal communication. These observations were documented as part of the process and could thereafter be compared with the processed original data. All field notes were analysed for codes and categories which were simultaneously compared with other emerging data. Glaser (1978) states that coding is constructed line by line or word by word analysis, or fracturing the data, to avoid missing important aspect that may escape during a cursory of the data.

### **3.13: Rigorousness of the Research**

Hutchinson & Wilson (2001) observed that researchers using grounded theory methods must address the issues of believability and rigor in their research. In relation to research, rigour means the "strictness in judgment and conduct which may be used to ensure that the successive steps in a study have been set out clearly and undertaken with scrupulous attention to detail" (Roberts & Taylor, 1998, p.172). This checking process allows others to decide that the study's findings can be relied upon to reflect the "truth" of the matter. A quality grounded theory has codes that fit the data and the practice area from which it is derived. The data then falls naturally into place. Different criteria of rigor exist in scientific inquiry. General rigor requirements for qualitative data include auditability, credibility, and fittingness.

Auditability relates to consistency of findings, meaning that another researcher can clearly follow the "decision trail" or thought processes used by the researcher in the study and arrive at a comparable conclusion (Sandelowski, 1986). Auditability is enhanced by indicating the criteria used to formulate the researcher's thinking, and by detailing how and

why the participants in the study were chosen (Chiovitti & Piran, 2003). The researcher's journal that was maintained throughout the data collection and analysis period provided a record of memos and observations as well as provided a record of the researcher's thoughts and actions. This journal served as an audit trail.

Credibility in a qualitative study refers to the use of accurate descriptions or interpretations of a human phenomenon so that the individual having the experience would recognize their experience from the descriptions or others would be able to recognize the experience after having read about it (Sandelowski, 1986). Creditability was achieved by letting the participants guide the inquiry process, checking the generated theoretical construction against the participants meaning of phenomenon, using the participants' verbatim words in the theory and by disclosing the researcher's own personal views and insights regarding the experiences explored (Chiovitti & Piran, 2003). Interpretation of the data was verified through follow-up with the participants during the interview. In addition, during the data analysis, the researcher had phone and email contact with the supervisor frequently to review notes, memos, transcripts and the analysis process or any issues that arose.

Fittingness refers to when study findings are meaningful and applicable to readers in terms of their own experience and when the findings are reflective of life experiences being studied (Sandelowski, 1986). All coded data was reviewed by the researcher's supervisor.

Fittingness can also be accomplished by delineating the scope of the research in terms of the sample, setting and level of theory generated are concerned, and by describing how the literature relates to each category which emerged in the theory (Chiovitti & Piran, 2003).

I opted to follow Glaser's (1978) criteria for checking rigour. Glaser suggests that fit, workability, relevance and modifiability are criteria for judging the rigour of a grounded theory study. Fit is said to occur when the categories within the theory relate directly to the data. It can be described as categories that are generated from the data instead of a previous

theoretical perspective thus ensuring that the resulting grounded theory will fit empirical situations. In this study the criteria of fit were automatically met as the categories arose from the data. Workability is said to occur when the theory explains what is going on in the area of the study. The criteria of work is met when the categories fit the data and explain what happened, what will happen and what is happening in the area of concern. Relevance occurs when the emergent theory focuses on the core problems and processes. By modifiability, Glaser (1978) suggests that a grounded theory may go through changes when new data emerge, generating qualifications or elaboration to the theory. The criteria of modifiability are met when the theory is able to adapt as new data appears. Throughout the process of data collection and analysis, changes were made to accommodate the evolving concepts when new data presented variations in the emergent grounded theory.

### **3.14: Summary**

This chapter has outlined the background to the qualitative research paradigm with a discussion of grounded theory as a qualitative method of data collection and analysis. The application of the research method to this study of experience of treated breast cancer patients outlining their stressors and coping mechanisms in the acute services has been presented including examples of data collection and analysis. The feedback I received provides some evidence that I accurately represented these women's experience with breast cancer treatment, as they were told to me in the interview process. Ethical considerations and the sampling plan and criteria for judging rigor in qualitative studies have been identified and discussed. The next chapters contain the findings of the study, organised around the key concepts identified in the process of grounded theory generation.

## Chapter 4: Findings and Discussion

### 4.1: Introduction

The purpose of this chapter is to provide the study results from the data analysis of eight women participants with breast cancer and how they coped with the stressors while enduring treatment. The model developed in a grounded theory study typically centres around a core theme to which all of the categories that were identified in the data are related. The core theme identified in this study was *Returning to Normality*. This theme characterises the adjustment for those women and how they coped while enduring breast cancer treatment. The theme of “Returning to Normality” was developed through the use of the paradigm model – symbolic interactionism. The question that guided the interviews was **“Enduring breast cancer treatment, what was the most salient stressor, and how did you cope with that stressor?”**

The next section of this chapter will present and explain the core category and emerging themes. Following the explanation of the theory the chapter will conclude with a summary. Constant comparative analysis of the interview transcripts revealed several themes and sub-themes. The theme of Returning to Normality emerged as the central theme and core category. The Returning to Normality core aspects and themes were:

1. Making Sense of the experience,
2. Seeking Support and Loneliness,
3. Reclaiming their Life,
4. Managing Threat of Recurrence.

Eight women with breast cancer who had treatment were interviewed for this study. The characteristics of these eight women differed greatly and had a variety of different



treatments. Women in the study were between 66 years old and 44 years old with diverse backgrounds and were at different life stages (see Appendix A). The self-defined religious background of the participants was predominantly Catholic, two were married, and others single, widowed, divorced or separated. The participants also had diverse educational backgrounds, ranging from a Degree to Leaving Certificate. One participant was unemployed; one participant was a homemaker; one was on a temporary disability; two were retired and two of the participants were currently working. All of the participants had private health insurance at the time of their disease. More than half of the participants were diagnosed with breast cancer in their 50s or earlier. Two of the participants had breast cancer twice. One participant was diagnosed with breast cancer at 46 years old and then again at 57 years old; another participant was diagnosed at 54 years old and then again at 58 years old. Only four of the participants had a family history of breast cancer, although one participant had a distant relative with breast cancer. For these women, treatment of breast cancer was a process that was constantly changing and as such, linear relationships are not apparent among the themes.

#### **4.2 Stress and Coping**

In the explanations of the themes in this chapter, I was careful not to impose Lazarus's theoretical language on the women and I kept the women's own language in order to accurately reflect their experience. In the findings, I described the particular events as the women described them to me – some women used the word “coped” and others did not, sometimes the women outlined that an experience was “stressful” and others described an experience as “distressing”. The word “distress” encompassed both what the women stated was “stressful” and what they described as “distressing”. The word “helpful” involved the

things that the women stated helped them, and the specific coping strategies the women used.

During the interviewing and transcribing process which was 45 minutes approximately, I realised that some women spoke openly and at length about their stressors during breast cancer treatment, others less. I began my analysis with what I thought were the richest interviews with those who spoke freely, giving the most detail about her experience, and responded in-depth to my questions.

However, as I worked through the interviews, I found that each woman had a unique response to treatment. It is apparent from the interviews that these women breast cancer treatments had many different dimensions. Different treatments affected different women in different ways. Nausea, for example, was experienced by some women even though they all had treatment, others mentioned it but were not distressed by it, and some did not mention it at all. Pain, for example, was often distressing after surgery. But pain could also be distressing during tamoxifen treatment as oestrogen was removed from the women's bodies joint -pain became distressing. One woman complained of pain during her radiation sessions and pain could occur during treatment any time.

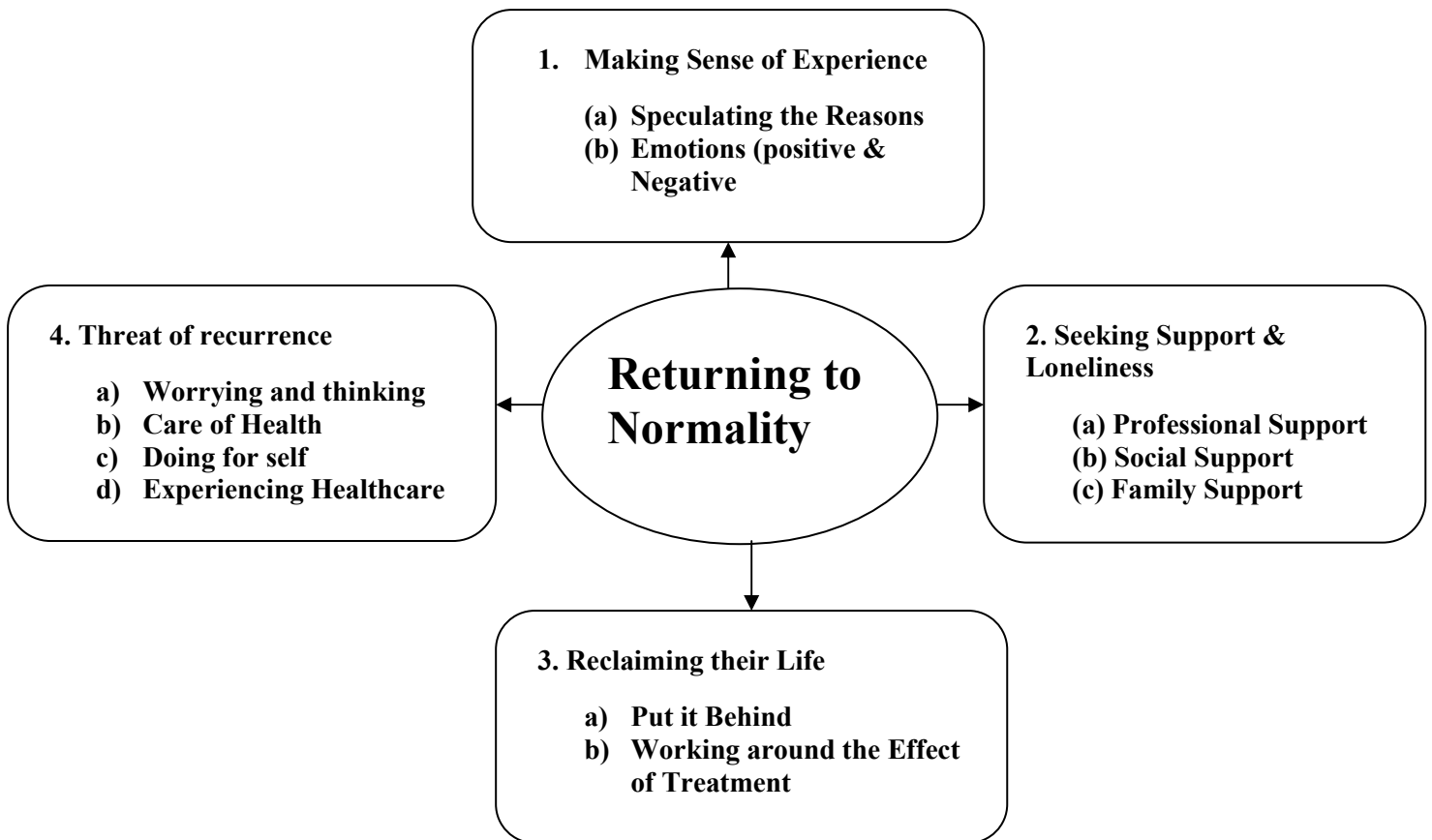
It became apparent to me that even though the women had some of the same treatments, the effects of the treatments were not identical.

The diversity of responses from the participants was very different at first review.

However, closer inspection revealed that the different responses could be organised under four common themes that reflected the women's core experiences.

A conceptual framework of the themes is presented in figure 1. Further, the women felt that their responses and other contributing factors (family support) influenced future conditions and responses.

**Grounded Theory: Figure 1**



#### **4:3 Descriptions of Phases:**

##### **Returning to Normality**

The core category is the main theme of the data that helps to link multiple subcategories together and explains much of the data variation. Returning to Normality was a dimension of treatment mentioned by all participants and this was the core category that emerged. The phenomenon of “Returning to Normality” is a universal lived experience of health that is significant to maintain quality of life. All people experience living “Returning to Normality” at some time in their lives, possibly in relation to overcoming traumatic life events (such as traffic accidents, cancers or others), confronting life’s struggles, living with a condition not of their choice or carrying on after losing self worth (Lane, 2005; Tang et al, 2008; Teixeira, 2008). Jefferies & Clifford (2009) define getting back to Normality as asking questions aimed at giving an experience purpose and placing it in the context of total life pattern, by reworking and redefining past meanings while at the same time Returning to Normality in the current life situations as part of the coping process. The process of Returning to Normality was developed through the use of the paradigm model. The paradigm model relates the theme of Returning to Normality to casual conditions that led to Returning to Normality. Despite modern advances that have led to improved prognosis and symptom management, a cancer diagnosis and its treatments continues to evoke images of pain, suffering and stressor and fear of death. The current literature suggests that the “existential plight of cancer” refers to what is now commonly known as the “search for meaning” following a cancer diagnosis and treatment in order to discover back to Normality (Lee, 2008). For these women, Returning to Normality could be either a stressor, or a way of maintaining hope to cope with the stress of treatment. This theme emerged as the core category in the data analysis and the Returning to Normality core

aspects that emerged were: 1. Making Sense of the Experience; 2. Seeking Support and Loneliness; 3. Reclaiming their Life and 4. Managing the Threat of Recurrence.

Making Sense of the Experience was the first category. Two sub-categories of making sense were identified (a) speculating on reasons, and (b) emotions (positive and negative).

The second category Seeking Support and Loneliness related to the experiences of high levels of emotional distress and how they sought to find a sense of personal meaning and growth while enduring breast cancer treatments by seeking support.

Three sub-categories of support were identified: Professional support; Social support; Family support.

The third category Reclaiming their Life refers to (a) putting it behind and, (b) working around the effects of the cancer treatment.

The fourth category was the Managing the treat of Recurrence which fell into three sub-categories: Worrying; Taking care of your health and setting boundaries; Doing for Self and finally Experiencing healthcare.

The following section will explain each category and sub-categories of the social Returning to Normality process in greater detail. In addition data from the participant interviews will be used to validate each category and sub-category of the grounded theory. These four themes and sub-themes are composed of themes that were stressors, themes that were coping strategies, and themes that were either stressors or coping strategies.

#### **4.4 Category One – Making Sense of the Cancer Experience**

The first category of Returning to Normality that will be discussed is Making Sense of the Cancer Experience. Wanting to understand why something happens seems to be inherent in humans' nature, and it is evident in this study. Some participants wondered what caused the cancer, speculating on specific things that they believed could have triggered its development. They also addressed the 'why' question by looking for reasons that the cancer had come into their family – what was its purpose and how have they benefited or not from the experience. These ideas are reflected in the sub-categories: (a) speculating on reasons, and (b) emotions (negative and positive).

##### **Speculating on Reasons**

Although the participants recognised that for the most part it was pure speculation and probably would never really be known for sure, they were curious about what might have caused the cancer to develop. All speculated at least a little on possible reasons, and for some they had a major discussion. Perhaps because there really are no definite answers, but there was some confusion and searching for answers. Some women suspected fairly concrete causes for why the cancer might have developed, such as family history, environment, or stress:

..... It's a total stress related thing that your body cannot cope with a lot that gets thrown at you and they have a feeling like a has-been giving them a sense of isolation. But, you know, then everything eventually sorts itself out and you would have hoped that you'd come out of it but obviously sometimes you've taken one blow too many and that may have been the cause.

Other women found less tangible reasons for the appearance in their life.

Bea who was diagnosed with the cancer had had several serious illnesses some years earlier, and she suspected that getting was a way for her to test the medical system and the family and keep them on their toes.

Three of the women talked about their belief that the cancer occurred in order to give them “a second chance”. In no case were these musings about reason a source of any significant frustration, nor were they fuelled by frustration or anger with the cancer. Instead they appeared to try to bring some order and logic to an otherwise chaotic event. Finding meaning or reason in the cancer experience helped to facilitate the Returning to Normality process.

### **Emotions**

Emotions during breast cancer treatment were the second category of Returning to Normality which referred to the inner strength and fortitude that all participants possessed throughout their experience with breast cancer. Two subcategories of Emotion were identified: (a) positive emotions; (b) negative emotion. Most participants reported some positive feelings with most of them reporting negative emotions.

#### **(a) Positive Emotions**

The second sub-category of Making Sense of the Experience was being (a) Positive and acceptance. This referred to not having doubts of not thinking negatively and has the ability to cope with stress and recover and acceptance is related to acknowledging that you have cancer and living with it (cancer) but focus in on the mind and soul.

The first sub-category of Emotions was being Positive with resilience and acceptance. Being Positive with resilience referred to not having doubts or thinking negatively and have the ability to cope with the stress. All of the participants strived to remain positive throughout their experience by keeping busy, not thinking negative thoughts, and not succumbing to fear by using good coping skills.

Bea remained positive by not letting her breast cancer get to her:

... I just believed that I could overcome this ... I got up and I kept going and I've always been on the go, you know so I never let it get to me to the point that it was going to drag me down. My thing was if is that you have to fight this thing, and I guess I'm a fighter you know so I was determined that I was not going to get me down but I have to get on with life and live normal like always.

Deirdre had a positive attitude too and attributed her positive feelings to her belief in empowerment. She felt that her positive feelings provided her with the ability to handle treatment. She described:

I'd just a positive attitude I think and my friends for the most part ... I don't know why but I just did what I had to do and didn't really look back. My thing was you know you can survive it and get re-living their Life, living like before. I had positive feedback from the doctors, so I just went with that. That I was going to make it. I think you have to empower yourself and that is key.

Gemma was able to maintain a positive attitude because of her faith:

..... I think the majority of women say how I'll make it through, you know I'm going to make it through this, because our faith help us make it through. I think faith heal you more so than anything else ..

Hannah limited her stress which helped her to have a positive emotional attitude:

I think that what really got me through too because I didn't stress, when you stress you tear your body down especially while on treatment. So like me like I said I just went to the doctor and they said you need to do this. I said okay when, what time and you know I didn't stress. I just want to move forward and be normal again.

All of the participants reported that being positive with strong resilience assisted them in dealing with breast cancer and increased their ability to cope. They indicated that that while they initially felt angry and experienced some denial, this phase tended to be short lived, moving rather quickly into the acceptance stage and wanting to fight the disease. These women tended to put their breast cancer experience behind them rather quickly, move forward and look to the future.



Accepting it was also part of the second sub-category of which related to acknowledging that you have breast cancer while moving forward but stay focused in on the mind and soul. All of the women in this study amazingly accepted the hand that life dealt them from the very beginning of their journey with breast cancer. Acceptance came with the recognition of one's inability to change one's cancer situation and a need to live with from the breast cancer experience.

Ann gave an example of her acceptance of breast cancer when she stated:

... well that's part of me I guess, I realise I'm no better than any other women you know, so there are other women that's going through the same thing or that has gone through the same thing ... so here its my turn, her I go, keep myself busy ... in spite of it, I'm just trying to cope with it. Honey that's all you can do you know you can't run away from it. No you just have to deal with it one day at a time and keep preoccupied.

In this instance, Ann's sense of powerlessness over the cause of her breast cancer, positively contributed to the acceptance of having this disease. To live and be normal, one needed to accept her cancer history and / or late effects.

Bea accepted her breast cancer because she considered it to be just one more thing in her life, as did Mary:

...It wasn't a shock to me because I guess I'm just not shocked by such things. It's just another bump in the road. You must be determined to fight the battle yourself to the end while getting the treatment and get to a normal life again. Carole easily accepting her breast cancer because she believed that women had a natural capacity to manage adversity:

Women are a strong breed ..... they bounce back and go on with their lives.

Deirdre basically just took her diagnosis in her stride, as did Hannah:

I'm not a real emotional type of person. So when they told me I was like okay what I need to do and they look like are you okay and my sister was with me and she was the one crying not me. So I think just because I'm not really emotional and I just knew I had to be strong, and get through this and be here for my son. Ok I had my lone time to look inward and lay in bed at times very upset.

Gemma's acceptance was supported by faith:

.... The blind man accepted he was blind. When they told me I had the cancer, I accepted I had cancer, but where I go from here now is that I go to my Saviour, who can save me ..... I kept a diary and rested a lot which helped me.

Most participants recognised, and have gone through, a “necessary” process of denial before they were able to accept their breast cancer and the late-effects as being a price paid to keep them alive. All of the participants easily accepted their breast cancer and the treatment because of their faith and the belief that breast cancer was just one more thing to deal with in their lives. They turned inward in a variety of ways so that they could restore themselves for the challenges ahead.

### **(b) Negative Emotions**

Negative emotions were emotions that participants found distressing or troubling. They experienced negative emotions both in anticipation of a particular stage of their treatment, and throughout the cancer treatment stage. In the time leading up different stages of treatment, participants reported anticipatory negative emotions, such as anxiety, fear, and worry. These emotions seemed to stem from the unknown- participants what their experiences were going to be like.

Mary reported being fearful before her lumpectomy because of her “fear of not knowing”. Carole found that the first day of chemotherapy stressful because “you didn't know what you were going into”.

Anticipatory negative emotions had the potential to contribute to participants' feelings of isolation and going it alone. This was expressed by Frances:

..... I was so frightened about it (mastectomy), that I found it difficult to talk to people about it so I always was very silent.

And Carole also expressed the same feeling of being alone during treatment:

.....So here I am with ice packs round my head, again heading to the hospital, again by myself...because my husband was at home and God knows how he was feeling.

Knowledge was not necessarily helpful in alleviating these negative emotions.

Before her lumpectomy, Ann experienced fear and attributed her fear to the knowledge she held from her former post in the healthcare setting:

..... Because I worked in a hospital, so I was also aware of all the possibilities, of all the things that could happen.

Hannah 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 because I had both breast removed.

Mary on the other hand was cautioned by her general practitioner 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 probably this would have me more anxious than I would have had to be.

Throughout the treatment phases, 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 treatments, and (b) the effects of the treatment. The nature of the treatments referred to the characteristics of the treatment, this included the physicality of treatment (e.g., the oncology day rooms in which the participants received treatment), the structure of treatment (e.g., when appointments had to be booked), and the oncology clinical staff with whom the participants had to interact. The effects of the treatments 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), and the 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 different.

Carole found that chemo and radiation was a pretty freaky thing. This radiation room isolated the women as outlined by Carole:

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

The daily appointments were also difficult. Some participants found it impossible to structure their days to their comfort level. Mary remembers this frustration:

.....It felt very disempowering to have no control over my life that way. 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 medical oncologist.

Mary and Carole felt unsupported and unempowered and they were not given sufficient information. Carole stated:

.....You know, I'm sure it's like that with a lot of things, but you're going through treatment, you just magically figure that whoever you're seeing knows all the answers and they just don't.....so it' can be very frustrating but sure I will keep going as normal as I can and live from this experience.

Hannah was annoyed with the lack of knowledge from her oncologist (looking distressed and angry):

..... I got some lymphedema, which I found difficult, too...but I contacted the oncologist and he said you can't get lymphodema if you haven't had chemotherapy. (Hannah met the physiotherapist) I'm in there, she measured my arm and said "yes", ordered me the sleeve and she said "I don't know what he is talking about as

she had ordered the sleeve...this was very annoying as he didn't know what he was talking about. I just wanted to get better and move on with my normal life once and for all.

The effects of treatment were something that each participant struggled with, particularly the effectiveness of treatments in terms of whether or not the treatment was working.

Bea felt anxious throughout her chemotherapy although she completed her chemotherapy and radiation treatment:

..... 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?

Side effects were a major issue for participants. Sometimes the physical side effects meant that the participants could not do something she wanted to do. Hannah had time off work after her bilateral mastectomy, but the physical effects of surgery kept her from pursuing her gardening:

..... I relished the six 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. I found that at times you shut down emotionally and not able to think about the future...don't ask me about tomorrow. Just have to think about today, and get through today. And the next step, whatever it is .. I just had to live in stages to get through the experience and try to be as normal as I could.

Gemma was unable to do some housework tasks due to her lumpectomy:

..... I had send the laundry out after my surgery, that was hard, as I always do this myself and that effected me emotionally as I couldn't do it now as it wasn't normal.

Hannah developed lymphoedema from radiation therapy and was frustrated and felt isolated when she lost the full use of her right hand:

..... That was really frustrating because being right-handed...everything on the right but I just bottled it up as I didn't want anybody to know how I was feeling.

The physical side-effects of some treatments prevented Deirdre 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 the support groups, and to these relaxation sessions in Rock House clinic regularly, because I found that really helped to boost my spirits and start getting on with my life. But sometimes I felt like staying in bed because I was so weak, just a low-grade nausea that accompanied the treatment. And so that was the worst part.

Bea was also ill from the treatment, and wondered how she got 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 as I just wanted to be normal again like before this all happened.

Some participants experienced depression. Frances saw a psychiatrist during her treatment because of depression. Gemma experienced depression, an emotional side-effect of medication, while she was on the tamoxifen:

..... It also caused a bit of depression, in the beginning. It's a physiological reaction and it was like being in dark hole.

However participants reported a variety of negative emotions while enduring breast cancer treatments. 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 which was experienced by all participants.

### **Summary of Category One – Making Sense of the Experience**

The first category of the Returning to Normality process was Making Sense of the Experience which describes the wanting to understand why something happens to be inherent in human nature and speculating what were the triggers to the cancer development.

Two sub-categories were identified (a) speculating on the reasons, and (b) positive and negative emotions. The majority of the emotions reported by participants was negative and could be classified as anticipatory or reactionary. Each participant's experience of breast cancer treatment was unique, as well as their view of the world and resources. Therefore 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 while enduring cancer treatment. In comparison to the large frequency and range of reported negative emotions, positive emotions occurred also. In retrospect, two participants felt they shut down their emotions and felt isolated, and this "shutting down" seemed to be an automatic response that helped the women to deal with the stress of treatment and live their normal lives. The next section will explain seeking support as the second category of the Returning to Normality process.

#### **4.5 Category Two – Seeking Support and Loneliness**

Seeking Support and Loneliness was the second category of Returning to Normality which referred to the types of high levels of emotional distress and assistance that the participants sought to help sustain themselves while enduring breast cancer treatment and also the lack of support. Women frequently used the word "alone" or "isolated" to describe how they felt when others failed to understand their ongoing symptom burden, fears of recurrence, and heightened need to find meaning in their lives. Among the participants, three different types of support were identified to help them find a sense of personal meaning which will be discussed in the next section. The first type of support identified was professional support which referred to support from health care professionals such as doctors, psychologists, nurses and social workers. Participants sought professional help in several

ways. The second type of support identified was social support which referred to support from friends, co-workers & neighbours. A third type support was family support which referred to support from parents, children, spouses, siblings, partners and extended family.

### **Professional Support**

Professional support referred to support from health care professionals such as doctors, psychologists, nurses and social workers. The participants' experiences with professional support varied. A few participants even sought professional support in the form of second opinions. Some of the participants on their own sought either medical or psychological health support immediately when they recognised that there was a problem. Other participants had very compassionate and caring healthcare professionals that were supportive to them and communication and information was pivotal in making decisions. Clinical Nurse Specialists in particular played a positive role in affecting participants' feelings throughout treatments.

For example, after discovering a lump in her left breast and discussing it with her family.

Ann sought medical attention, she stated:

I didn't hesitate. I went straight to me General Practitioner and he suggested that I get a mammogram and then came back to him, but it came back you know there was something in the breast so he sent me to a breast surgeon. After a week he did a biopsy and in doing the biopsy I would tell from the expression on his face that it wasn't good, so I left the office that day, but I went back because my appointment was scheduled and he gave me the results of it, that it was cancerous.

Deirdre sought medical attention from a female doctor and received good support:

I did get a second opinion at another hospital because most of the doctors that I had were men and not to say that men don't make good doctors, but I had wanted a female opinion ...

Bea was one of the participants that believe that her health care professionals really connected with her and therefore provided greater support. Bea described her relationship



with her health care professionals and explained in detail and provided me with information:

... I had an excellent consultant on the first go round, I'll never forget him. He was just really on top of it. The second person was a lady physician, she was okay, but she wasn't like the first one you know but my experience with him was great .. I mean he walked me through it and it was as if you know he was saying your going to make it you know ... So I mean I got a lot of emotional support from him.

Frances also received compassionate support from her health care professional. She described how her doctor was supportive to her after she learned she had an aggressive form of breast cancer but she kept her emotions to herself:

I was afraid to know ... when I went to the oncologist after they did the biopsy he called me into his office and she sat me down and he told me it is cancer, and he told me that your cancer's stage three and he's like it's a pretty aggressive cancer and it was like it went in one ear and out the other ... all you can hear is you have cancer and I wasn't comprehending all the information that he was telling me. You know he was like I want to this, that and the other for you but I wasn't able to comprehend or understand or even believe. All I was hearing is that I have cancer and it's serious and he saw that I was scared and he saw that I was holding back the tears. He was like you know it's okay if you want to cry, you can cry. He said.. I know it's a very overwhelming time [starts crying] for your to go through ... even to think back now about the experience it kind of brings tears to my eyes

Frances described the radiotherapy treatment as lonely:

.....the radiotherapy process was very cold and just very business like, I was often left alone and felt isolated at times.

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 this did not happen always for these women.

Carole was actually one of the few participants who sought out Psycho Oncology care and how she felt on receiving her diagnosis. She reported:

When I had cancer the second time I went into a very deep depressions and felt down and I sought psychological help and it was real hard and the person that was my psychologist she was going to have me referred to psychiatric services, but then as she talked to me she realised that I was just sad and not really suicidal or

anything like that, but when she first met me I was a nut case because as soon as I found out that I had it a second time that's the first thing I sought cause I knew I needed other help to get through this .... why me again.(anger in her voice). I just have to through this again and try to be normal.

Carole also confided why she felt she needed professional psychological health support but she was disappointed when she had her second surgery. She described:

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're being sent home to deal with it alone .... thats how I felt.

Well just somebody listening to me and feeling my pain and letting me know that I am not cuckoo for one thing [laughs] and just that just somebody that I could tell everything to that didn't know me and I could get it off my chest that I didn't want to burden my family with. I needed somebody that I could vent with and I was just teary all the time and I was very upset and confused but the nurse made the experience "easy to handle" through their friendly and supportive behaviours....

Mary received professional support from her Clinical Nurse Specialist (CNS) on Oncology.

She described the bond they formed even though she expressed being isolated at times during treatments:

.... My nurse who I'm really beginning to appreciate is four years older than I am. I will never forget her and we still meet for dinner. We have some great talks about aging okay and so that's where we really make our bond, its hell we're both getting old and some of the things that I am experiencing that I think are a part of my depression she says no you're just getting old [laughs].

Gemma had high accolades for her doctor and the support he provided her. She gave an account of her experience which was not lonely even though she worried:

.... I finally asked him. I said why you never push me? He said because I have to be very honest with you I agree with you totally. He said but I had to let you make that decision and I can't tell you I agree .. so God gave me the right doctor, he never pushed me ... He would call me on the phone and talk and I would call him [laughs] and we would talk. I could have got somebody crazy ... He said, every time I came in, he said are you doing every thing you're supposed to do? Are you eating right? Are you exercising? Are you resting? I said yes I'm doing everything. He said okay.

Hannah was able to be light-hearted with her doctors and thus was able to form a close supportive relationship with them. She said:

My doctors used to tell my sister and my mom she's off the hook because even though I was going through cancer I was still joking with them and you know doing different things, but we had a close we had a very close relationship with the doctor (smiling). My oncologist sometimes stressed me because he didn't tell me everything and he wasn't very knowledgeable as he left it to the nurse (annoyed looking)

Although the participants' experiences of professional support varied, it still provided a great deal of comfort and relief. When this support was not forthcoming, participants felt distressed and lonely. The end stage seemed especially important to participants, at this time in particular they craved some form of meaningful interaction with medical and nursing staff. Lack of social support from hospital staff was experienced as an extra burden for some of the women and often appeared as lack of continuity in treatment follow-up. The concept of waiting time included the length of waiting after discovery of the lump to the first consultation, the time lapse before further diagnosis investigation, waiting for the results, waiting for hospital admission, and waiting once admitted could be stressful.

Ann described her experience in this way:

I was to choose whether I wanted to remove my whole breast or have a lumpectomy. A shocking experience. It was left to me to make the decision the evening before my operation. I felt very alone with the decision.

The end of radiation was distressing for some participants and often a lack of emotional support. This was outlined by Gemma saying 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 Oncology department about anything. Your name is off the list and you're advised to go back to your General Practitioner. Somebody else's turn. You can see that, there more women waiting for the same treatment. So, you can see that, but it feels you're left adrift. This is a feeling of being alone to get on with it. (Looking bewildered and anxious).

Carole also felt unsupported at the end of the radiation sessions, and was fearful and lonely:

.....because that really what the feeling was, now what do I do oh my God? You know, I had so much radiation. So there was always someone looking at you, poking at you, asking you how you were, taking your observations, taking your blood pressure, checking this, checking that, and now we're done with you, see you in six months. That's scary.

Frances felt a connection with the clinical nurse manager, and on her final treatment day she had a present for her and wanted to thank her but she was on a day off and Frances remembered how she felt:

.....I was sorry about that because I couldn't ....there wasn't anyone else meaningful that I could say good bye to. She was always there for me and there's all this involvement and then, nothing. There was nobody there to say give us a call, I think approachability; if you felt that they were a little more approachable.

### **Social Support**

The second type of support was Social Support referred to support from friends, co-workers and neighbours. The majority of participants were fortunate enough to receive support from sources outside of their families throughout their breast cancer experiences.

The social support from friends was most often mentioned and was most highly valued.

Yet, interestingly in this study very few of the participants used support groups for Social Support.

Ann had friends who visited her and offered their assistance but she said very little about her treatment:

... I have three ladies other than my good friend to come out and be with me, talk to me and bring me little goodies and see if I need transportation for anything. At times I was feeling so unwell, I just couldn't do pretty well anything socially, I wanted to go out with friends but I couldn't. I used to be a sick as a dog and didn't want to see anybody as I was tired, and all I wanted was to be alone in peace. I hide away the effects of the treatment and I could sense the curious glances but I then struggled with that thinking.

Bea also had an outpouring of Social Support from her co-workers and friends. She reported:

I'll never forget the second time around, the people on my job, my family, I mean whenever I came home I had somebody here pampering me. The people on my job they came every day, so a nurse would come or a doctor would come just to see how I was doing. They just wanted to be helpful ... with the love that was expressed I was able to walk through it, I mean the public health nurse they wanted to make sure that I was comfortable ... I mean that's what got me through I mean I know that's much of what's got me through, is the people that gave me support ... so if you don't have it, if you come from families that that don't have that, you might be in trouble.

Deirdre described how her friend supported her after she started to lose her hair and decided to just shave it off:

...I was afraid of the hair thing and my eyebrows are also going ... I was losing night sleep and was very emotional, what if it doesn't fall ... except you know it will but my friend rallied behind me and encouraged me to shave it off ... I was so sick during the treatment and in the end it was isolation, and the isolation was, a lot of it was the result of not having the energy to participate, not having the energy to interact with people what so ever. (Feeling down).

Gemma received Social Support from both strangers and people she knew:

I had a lot of support even people I didn't even know cared, you know what I mean? One of the first persons from my parish, a real quiet lady she's an occupational therapy and she came and told me all of the exercises I needed to do ... immediately I started doing the exercises she told me. She would come to clinics with me and ask the questions as I found it difficult to take in what the doctor said.

Hannah also did not have much Social Support from friends, and she felt abandoned and alone during her treatment she mentioned:

I don't have many friends and I felt lonely and isolated when I was having the treatment. I didn't want to dwell on my experience but talking about it helped to move on. I had two close friends who abandoned me and that was hard .. and I know that one of them was slightly depressed. That's true, but that doesn't seem like a good excuse to me.

Mary had Social Support that was available to her, but she did not always want to accept it.

She stated:

I have a friend, who is really sick right now okay. My friend insisted upon going to my chemotherapy with me. I didn't need anybody to go. I would have preferred it if she hadn't, but it was important to her. So I knuckled under and basically between you and me I endured it okay [laughs] ... I had told her I don't want anybody there because if you're there I feel as if I need to say something to you know [laughs] and I need to pretend to be pleasant or something, so I just assume you not been there. I like to be in control as that helps me to feel normal.

Carole expressed that she used support groups at first, but then stopped because she felt they were not useful:

I went to support group when I had it the first time after I had the surgery and was healing I found out about a support group beside the hospital and I went there for over a year I think and then I got away from that because it was okay but it was more or less listening to other people's problems and things like that and I'm the type of person that I want to deal with what I have ...

Deirdre found the support groups of tremendous support as well as friends. She stated:

Well in the beginning, yeah when I first got diagnosed like I said the hospital has a support group there for women who just get diagnosed, where you go and they show you how to apply makeup cause you lose your eyebrows but I really didn't lose much of my eyebrows or my eyelashes, but they show you how to put on makeup which helps my esteem and meeting new friends.

Frances attempted to attend a support group, but believed that she could not identify with the group so she stopped going. She described:

I did attend a support, a couple of support groups but I didn't find them very helpful for me, because I didn't want anyone to like feel sorry for me and I know that there were other people there and they found the groups excellent

Hannah did report that she would be willing to attend a support group:

Well me I'm kind of nosy so [laughs] I like listening to people and I'm a people person because I could just start talking to you .. I think I would probably like the support group, but I didn't feel like it was a need for me to go.

Mary also did not attend a support group, but it was because she felt that her doctor was not genuine when suggesting it:

Dr. XXXX wanted me to join a support group but I got the feeling she wanted me to join it because she was pleased with my attitude and she thought I would be a good support in the support group, rather than a recipient of support.

The majority of the participants did not receive social support from their support groups. Instead their social support came from friends, co-workers, neighbours and even strangers. Some felt that support groups would impede their ability to put their breast cancer behind them as they would be more likely to dwell on their experience, while others felt that talking about their experience may facilitate their ability to move on and live a normal life.

### **Family Support**

The third type of support identified was Family Support which referred to support from parents, children, spouses, siblings, partners and extended family. This type of support was very important to the participants. Some of the benefits of family support were that it provided encouragement, physical assistance, and comfort. For the participants that received it they reported being better off and dealt with the stressors better during the cancer treatments.

For example, Ann recounted that her siblings call her on a regular basis to express their concern:

I have a older brother that lived in the UK and he calls me every two weeks. He called me today matter-of-fact .. I have a sister, a younger sister that lives in Dublin and she calls me once a week at least sometimes she'' give me an extra call .. they are quiet concerned. It was a shock on my family when I told them what was going on with me and to take it easy until I could give them more information and whatever information I gave them just know that God is in the plan and he'll work it out

Receiving Family Support often encouraged the participants to provide support to others themselves. Bea described:

.... My family and everybody were supportive and that help get through the situation that you're in .. you know that support I got from my family, I got it from people that I work with and so I felt that that was my best support, and which gave me an incentive that when somebody else came down with breast cancer I was always one that they could talk, this was really good for me to get over the trauma....

Carole was one of the participants that was better off because of the Family Support she received. In fact she shared that she received both family and social support:

My husband was excellent and he doesn't deal with illness or death well at all but during this time he was just you know a little soldier and my family were great. The people at work were wonderful and the neighbours.

Deirdre described the Family Support that she received as:

I have lots of relatives living locally that will call me all the time, so like I said again I mean I always had people supporting me to move on and dwell on the future but I didn't tell them everything.

She further stated her immediate family supported her immensely but she also hid her emotions at times:

I mean you know tears here and there but for the most part they were strong too in supporting me in everything and like you know my mom would take me to the doctor and pick me up, or my sister so somebody was always there during the whole time. She found it difficult to cope with me losing a breast and she didn't usually talk about it and I didn't talk about it and often I felt alone as she didn't understand.

Frances received Family Support primarily from her mother before she died, as much as she could she still tried to do everything on her own:

The first time I went in with my mom and my mother you know she's your mom. She's like concerned and she's like it's going to be okay and I'm not that kind of person. I don't like people to baby me and I just want to handle it on my own, so after I went the first time I'm like I can do it. I know how long it's going to take and I knew you know once I went to chemotherapy just come straight home and usually I would make it home and maybe I would be able to change my clothes and put on something more comfortable before I would start getting sick. By the time it was



coming to end of the treatment, I felt my family was burned out and were not giving emotional support and this was depressing me and I felt lonely at times.

A lack of Family Support also affected the participants. Frances actually had weak Family Support despite the fact that her mother supported her. Frances felt the lack of expressing and dealing with emotions limited her ability to cope effectively and, put the experience behind her and move on. She had this to say about her family:

... my sister she had like a two-year-old and a newborn so she wasn't really able to do much and my dad, he's not the kind of person that can function well around sick people...hiding in a bottle. So he didn't really do anything so it was mostly my mom. .. are you okay .. I felt isolated at times.

All of the participants received Family Support, although some received more than others. Family Support appeared to increase their ability to cope.

### **Summary of Category Two – Seeking Support and Loneliness**

The second category of Returning to Normality was Seeking Support and Loneliness, which referred to the high levels of emotional distress and types of assistance that the participants sought to help sustain them through the experience of breast cancer. Three types of emotional support were identified: Professional Support, Social Support, and Family Support. These factors all contribute to the sense of Returning to Normality process. Positive support enabled participants to cope effectively with having the disease and treatment effects, which contributed to the normalising strategies used by these women. Participants indicated that support from others was helpful, and allowed them to better deal with the stressors they were experiencing while enduring their breast cancer treatment. Accessing support from others was a coping strategy for these women. Overall these women all suffered a degree of loneliness and isolation and the majority of them felt that it was normal to behave like this. Interviews with these women showed that “hiding”

and “feeling lost” were common to cancer patients and were used repeatedly in the course of the conversations to describe their physical, psychological and/or social behaviour while enduring breast cancer treatment. However, when participants desired support was associated with distress and loneliness (lack of support was a stressor for these women). The next category will discuss the Reclaiming their Life category.

#### **4.6 Category 3: Reclaiming their Life**

The third category of the Returning to Normality process was Reclaiming their Life and how the participants are rejoining the world of normalcy while enduring their breast cancer treatments. It is in fact, reconfiguring a new normal. Rejoining the world of normalcy combines what many participants talked about as ‘living their Life’- the resumption of previous ways of being before their diagnosis – with new ways of being that take into account the whole cancer experience. To do this, participants needed to acknowledge that the diagnosis and treatment phases were over subjectively evaluating and appraising how they felt when they received their diagnosis as well as deliberately choosing to consider the cancer experience in the past tense. These women also had to recognise the effects and impact of diagnosis and treatment, then work around those in order to achieve the normalcy they desired. Reclaiming their Life involves: (a) putting it behind, and (b) working around the effects of the breast cancer treatments.

### **a) Putting it Behind**

Putting it behind was a strategy that emerged from the data where participants moved through life situations that they were faced with while enduring breast cancer treatment and existential symptoms at the same time.

Family dynamics or the quality of the relationships the participants had with their family members played a role in their recovery which helped them put it behind them. For the most part, all of the women except one had amicable family relationships.

Frances was a participant that had a dysfunctional relationship with her family and since her mother died, she was no longer able to act as a buffer in those relationships. Her family did not understand the toll that cancer took on her. Frances described her relationship with her father and sister in this way:

..... unfortunately my dad and sister are not that strong. it .. What's wrong with you? You know oh you, you're not cooperating.

Poor family dynamics can increase stress and decrease coping. In this study only one of the participants had a poor relationship with her family, in that they did not support her.

Family Responsibilities referred to the on-going obligations that the participants had to their families. Carole realised that what was happening to her was also happening to her family:

... you're not the only one involved. I mean whole circle is involved in it and I didn't want them to see me in that state, so I tried to keep most of it hidden and depend on prayer and inner strength.

Carole also had to deal with illness that her family members were experiencing as well:

Maybe about six months after I went into remission, my mom got sick and then she'd come back home and then she would go back downhill only to discover she also breast cancer too (looks upset)

Many of the participants had tremendous family responsibilities that they continued to meet even though they were all dealing with breast cancer too and this enabled them through the experience.

Employment and resources' referred to the job responsibilities of the participants and how they gained income. Only three of the participants were currently employed. The toll of breast cancer took more than half the women out of the workforce.

Carole ended up taking early retirement because of her breast cancer. She stated:

I did have to take a disability retirement after the second time because I couldn't stay at work. I couldn't function .... I wasn't able for the job with the way I felt ...

Hannah had to stop working because she needed to be home to take care of her child:

You know I used to work, then when my son got sick I stopped working to take care of him then I got sick ....

The employment status of several of the participants changed because of breast cancer, which is important to note because employment impacts financial, resource ability and insurance and this increase their vulnerability.

Facing Challenges and suffering losses refer to how the participants confronted stressors and the various detriments they experience. The women in this study encountered multiple stressors that challenged their ability to cope with breast cancer. Although the stressors they faced were all different they were each afflicted in their own way. Several of the participants experienced impactful losses in addition to the challenge of breast cancer. Bea lost two sisters to breast cancer and Deirdre, Mary and Frances also had family members that died.

Frances had a long history of medical problems and negative experiences with health care providers, so just going to the doctor was a stressor for her:

You know I had a lot of medical problems prior, you know I have diabetes and I was extremely overweight and going to the doctor was always a negative thing for me, you know whenever I go to the doctor ohh you're too fat.

Hannah had the stressor of caring for her severely ill child:

The only challenge I had was, which really wasn't a challenge like I say trying to still take care of my ill son at the same time, knowing what I'm going through, but like I said my mom and my sister and my dad we all worked through this together. It could be worse

More than half of the participants faced challenges in addition to their breast cancer and this created additional stress for these women and influenced their ability to cope. They all expressed a need and desire to put the experience behind them once the treatment had finished.

### **(b) Working around the Physical Effects of Treatments**

The second sub-category of Reclaiming their Life was working around the physical effects of treatment. This discussed how the participants managed the physical side-effects of having breast cancer treatment which were difficult. Physical effects that were reported as being important to the participants fell into two further sub-categories: Body Image and Dealing with the Residual side effects including sickness; pain; and other effects due to treatment.

#### **Body Image**

The first sub-category of Physical effects of treatment was Body Image which related to how the participants perceived their bodies after having breast cancer. Every single participant's appearance in this study was altered by breast cancer. They lost their hair,

some lost breasts, they ended up with scars and they saw their hands take on a necrotic appearance. The women in this study reacted differently to the effects treatment had upon their bodies. They used different expressions when describing their experiences of the treatments such as, fed up, drawn, miserable, depressed, alone, enough is enough, worn out. This illustrated an extensive drain on human resources. Data showed that the suffering worsened as the treatment progressed. Some of the women dealt with the physical changes better than others but the women were convinced that life was worth living.

Ann lost her hair and her nails turned black. She described:

The chemo took all my hair left me completely bald [takes off scarf and shows me her head] and my fingernails are turning .... It's really no joke what it's doing. No it's no joke, but I just don't bother to polish them. I just leave them so that they can breathe .... so I can notice the colour. It's really bad and a constant battle.

Frances described how she felt when she lost her hair:

.. I think the one, the really most humiliating thing was when I had to go buy a wig [laughs] I still had like a little bit of hair here and there, and I just went ahead and I just pulled it out ... I'm goin to go buy wig because I didn't like the scarf look, so I went and I bought a wig and I just looked so weird with the wig on, and it took a long time for me to get accustomed to looking at myself with the wig on.

Hannah tried to make the best of going bald, but still was saddened:

When I went bald, first I tried wearing scarves and they kept turning and twisting and then I tried hats, then I was having the hot flashes .. I went and paid €45 for a wig wore it one time, with the hot flashes you get so hot so I said you know what? I don't care what nobody thinks and I went bald ... and then I had my granddaughter and she looked and then she said ...all you hair came off and then I kind of got sad again.

Bea's perception of her body did not change after she lost her breasts. She stated:

I'm not a person in vain, so it didn't bother me I mean I guess it would bother some people but I'm mean I have my prosthesis .. I'm not vain so it didn't bother me .. so you don't have them you can live without them so that was my thing. There is nothing that will change things now .. it is what it is and I accept that and get on with life for my family's sake.

Mary actually gained weight:

It wasn't the second time, it was the first time I was having radiation. I'm in there and they're a couple of other patients' and each time, day we came in they'd weight us and there's this little old lady. Ohh I've lost another pound. [laughs] I was gaining two to three pounds a week and then when I went through it the second time. They said oh but you don't look sick at all. I said honey it's hard to look weak and emaciated when you're up over 200 pounds [laughs]. Of course I don't look sick I'm fat. If I dropped a few pounds I'd only look better [laughs]...it doesn't bother me, I have accepted the way I am.

Many of the participants struggled with body image changes. The physical changes that they experienced altered how they saw themselves.

### **Dealing with the Residual Side Effects**

The second sub-category of managing the physical effects of treatment was dealing with residual side-effects related to how the participants managed the remaining after effects of having breast cancer. Breast cancer took an exacting toll on so many of the participants. The after effects of breast cancer were visible to the participants in a variety of ways from depression, pain, sickness to loss of function to obvious scarring.

Ann reported depression and sickness especially after surgery despite the consultant telling her she would get something for nausea:

... I do get depressed sometime and it's not a cheerful thing at all and as ...after the surgery I woke up and got a sick as a dog,... where I could wake up in time to vomit and then fall back to sleep. I found the various side effects of chemotherapy "gruesome and I would say that the physical misery through the treatment was the thing that really got to me".

Deirdre also suffered depressive symptoms residually and experienced pain in her joints when on tamoxifen, a hormone treatment that induces a chemical menopause:

I think I was depressed about not being able to have kids and not having any kids and then knowing that I will never be able to have kids, that was the most, I guess hard thing. The pain in my joints was difficult and was very stiff like an old lady ... that was difficult part, the stiffness of the treatment.

Frances during treatment found herself as did all the other participants in a difficult position, they knew that the treatment was intended to heal, but they were experiencing distressing side-effects and she summarised her feeling:

.....you know both the chemo and 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 into your body that aren't just destroying the cancer, its making your hair fall out, it's making eyelashes fall out, it's giving you a sore mouth, you then can't eat, the radiation, you know what goes through your mind, I was quite fortunate, I didn't get burnt, but that's all going through your mind, your skin's going to get burned, it can affect the bones, it is radiating something it's not supposed to radiate?

Mary became depressed and started taking an anti-depressant as well:

.....I went all through the chemotherapy, but with the radiation at one point it was like I hit a wall. I just was exhausted. They didn't describe it as depression, but I was just exhausted and then to flow on from that I had the realisation yeah I'm depressed .... I still see a psychologist and I'm on anti-depressant and as I'm beginning to reconnect. I realise I've been depressed for quite awhile. Yeah so it could be the cancer. It could be, it could be just a combination of things .....

Carole had a loss of function (residual of treatment) and Gemma reported a loss of sensation. She stated:

... only residual I have left is that, I have some numbness from when they took the lymph nodes. Some numbness under my armpit, but other than that the doctor told me never to lift weights and I have never stopped. Even though the doctor gave me something for the sickness to help bit it didn't....it was terrible. Constant nausea really got to me which left me very fatigue. You feel like death and remembering saying to other women that I wouldn't do this again, I would refuse any more chemo.



In addition to fatigue, participants discussed a host of side effects that included hot flushes, night sweats, weight gain, hair loss and mouth ulcers. Tamoxifen causes a chemical menopause, and some participants found those symptoms very disturbing and abnormal.

Carole also had residual pain:

You know the burning is a lot of the problem and the pain and stuff that I'm having now and they said it was caused by radiation and that was part of the reason I couldn't get the implants either because the reconstruction because of the radiation the scarring and everything that's in there. The radiation was probably the worst because I got a frozen shoulder and it was very painful because you have to lie on a table for 15-20 minutes with the arm way up and you cannot move. And I had the tears pouring down my face because it hurts so much. And having to do that everyday. That I think is stressful entirely and this was experienced by all the radiotherapy patients.

Mary also had residual left lower lobe infiltrates that resembled tuberculosis:

... I came up with this x-ray that shows infiltrates in my left lower lobe and it turns out that it's from the radiation therapy. I wasn't upset, just another pain in the butt. So now I carry my x-ray around with me [laughs], well I had to start doing that anyways. Because I have too many doctors and so you know I just tell them. I have left lower lobe infiltrates, so and it's probably from the radiation and Dr XXX said she thinks it's probably from the radiation. Okay but I don't have TB ....

All of the participants experienced some residual effects from breast cancer, such as body image changes or depressive symptoms. These were new challenges that they had to learn how to manage if they were to live normal again.

### **Summary of Category three – Reclaiming their Life**

The third category of Returning to Normality process explained where the participants had to work to move on past the diagnosis and treatment into a reclaiming their Life by rejoining the world of normal. This category had two sub-categories (a) putting it behind them by evaluating the whole experience and try to consider it as being in the past. The second sub-category was (b) working around the effects of the physical effects of treatment

which distressing for many participants which caused them the most distress and it related to how the women coped through those side-effects that they were faced with. For these women, many physical effects of breast cancer treatment perceived as stressors but they have learned to accept the effects and move on with their lives.

#### **4.7 Category Four: Managing the Threat of Recurrence**

Managing the threat of recurrence was the fourth and final category of Returning to Normality which related to a range of issues that the participants encountered as a consequence of enduring breast cancer treatments. During the treatment period, worrying and thinking about the possibility of the cancer coming back was inevitable to some degree and learning how to deal with those thoughts and the uncertainty they provoked was a major part of managing the threat of any further recurrence and, ultimately, Returning to Normality once the treatments were finished. These women also took steps towards regaining and taking care of their own health, hoping to influence the risk of recurrence or indeed another cancer, by instituting a variety of lifestyles changes. Managing the threat of recurrence had three sub-categories: (a) Worrying and thinking; (b) Taking Care of your Health and setting boundaries; (c) Doing for Self; and finally the (d) Experiencing Healthcare.

Worrying and thinking was the first sub-category and referred to the persistent troubling concerns that each participant dealt with. The second sub-category of Managing the threat of recurrence was Taking Care of your Health and setting boundaries which referred to the actions that the participants took to be responsible for their own well-being and how they set limits to protect and shield themselves. The third sub-category was Doing for Self whereby the participants chose to do some activities for themselves while enduring breast

cancer treatments. The last sub-category of Managing the threat of recurrence was related to the encounters and experiences the participants had with the healthcare system.

### **Worrying and Thinking about It**

Worrying and thinking about it was the first sub-category of Managing the threat of recurrence. Worrying and thinking referred to the persistent troubling concerns that each participant dealt with. All participants in the study thought about the cancer, however the degree to which these thoughts occupied their mind, and the specific nature of these thoughts varied. Despite the incredible resolve that each participant possessed worry still managed to creep into the lives of each woman at some point in time. While fears of recurrence were generally low for this cohort of women, when present they appeared to interfere the most in one's ability to move on. Therefore, strategies for decreasing fears became important for the participants. Despite the feeling that their breast cancer risk was beyond control, they did recognise the importance of medical follow up for monitoring their status and possibly discovering a recurrence early enough to prompt appropriate action. Additionally, dealing with late-effects was an important means of Returning to Normality, and follow-up care provided an opportunity to learn how to cope with any disability.

For most participants thoughts of the cancer were always there in some form or another and Mary outlines.

.....it's like a drug, I guess, in a way. Once you're, once you're an addict, they say you're an addict for life, well once you introduced to the cancer, uh, that thought never goes out of your mind. I mean I have no idea whether it is going to come back or recover or it may never...but it may, but that thought is always there, what if....I'm gonna just carry on my normal ways.

Frances stated that she was less stressed 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 but I will get over it and be normal.

However, thinking or indeed worrying about the cancer all the time did not mean that participants were actively or constantly dwelling on the subject. In fact, it was common for participants to describe the cancer as being "in the back of their minds" and Hannah explains:

.....it's gone not totally out of my mind but right to the back of it and it's not, is not forefront in my thinking, you know.

Ann worried about practical matters:

..... There were times I've had to wonder whether my taxi going to be here on time or not. I have a car downstairs but I'm disabled to drive so I was wondering, wondering, wondering. I have to call. Are you coming? Where are you? Very stressful ... you know it creates a headache for me so I don't need that but I have to make do with what I have for right now

Bea worries about being given the ominous diagnosis of cancer as did Frances:

Just being scared you know to think that you have cancer, for somebody to tell you that you have cancer, it's just a very scary thing you know so I mean I know I was very lucky and most people don't have the same results that I have because my doctor told me that my stage of cancer was pretty severe and if it had went untreated you know it probably would end spreading throughout my entire body but I have to be positive and move on in life to survive.

Ann worried about not knowing:

Even though I'm done with chemo. I did the surgery. I finished the radiation. It's the fear, the uncertainty you know all those feelings that for me that I can't keep hiding. I keep it bottled up and tried to move on, but at some point you can't keep doing that ..... so I have to for me, help myself to work through it, say it's okay to feel those feelings you know helplessness, sadness, you know not sleeping at night, fear, anxiety, all those feeling that come up or indeed it is often triggered by a specific incident or interaction.

This happened when I had to go to the dentist and when I was filling in the check questionnaire I had to check off that I had cancer.

Carole, Gemma and Frances all worried about having to go through the experience again.

They had the stalker effect about the cancer coming back. Frances stated:

I just still like have flashbacks of the symptoms from the chemotherapy. I don't know if they told me you know tomorrow ..You have cancer again you need to have chemotherapy and go through the whole process again. I don't think even know what I would do because its such a hard thing to go through. It is very hard ..... sometimes you know, I'll just think about it. Just like when I was talking to you. It just brought tears to my eyes that just to think how scared I was ....

For the most part Mary spent her time strategising so she didn't have to worry:

If I have a problem I come up with an action plan, actually it's just a plan, then I start working on it and I'm okay. I'm not going to fret about it, if something goes and I have to change my plan then I change it.

Regardless of concerns about worry or recurrence, all participants were most likely to be concerned when they attend the out-patient clinics to meet the oncologist. Often, while temporary interfering with their ability to be normal because of thoughts of recurrence, these check-up clinics in the long- term contributed to their ability to move on as they typically receive positive feedback overall. Mary stated:

.... the only time I was frightened was when I was going to the clinic but meeting the oncologist gave me a sense of security.....

All of the participants in this study experienced worrying and thinking about the cancer at some point and like some of the other sub-categories of Managing the threat of recurrence; such as Body Image, Dealing with the Residual Side Effects of Cancer and Experiencing Health Care, all contributed to their ability to cope and survive.

## **Taking Care of your Health and Setting Boundaries**

Taking Care of your Health and setting boundaries was the second sub-category of Managing the Recurrence. This referred to the actions that the participants took to be responsible for their own well-being and setting limits to protect and shield themselves. These actions and strategies considered health in a holistic manner, addressing psychological, emotional and physical issues. The most common and obvious strategy that these women employed was to change lifestyle habits especially while enduring their treatments and this gave them back some control on their lives to help them make choices and be normal. The diagnosis breast cancer changed the way that some of the participants managed their health and for other it didn't and also it limited contact with the outside influences. Some participants found that focusing on their nutrition was helpful during treatment and also while they were on tamoxifen therapy.

Bea took care of her health by completely subscribing to the health care directives that she was given:

... like when they told me when I was going through chemo you have to feed chemo .. you have to eat right, you have to drink your liquids, you have to do all that. There were times when I didn't want to eat going through chemo, but I knew that I had to survive. So whether I wanted to eat it even when it tastes like I was eating spoons, I said I got to eat this food, because they kept saying you got to feed chemo ... I forced myself to eat, and to drink, I forced myself because I knew I had to in order to survive and move on with my life....

Gemma began following a complete naturopathic course. She reported:

Two years before I was diagnosed, a friend gave me a diet book and that's when I decided, I was already vegetarian but to become a stricter vegetarian. Also I started running marathons and they say oxygen kills cancer and my doctor said what was so surprising was the tumour was the size of any egg that it was nothing wrong with none of my lymph nodes

For Frances nothing changed she still did not do breast self exams, even breast cancer did not alter the way she managed her health:

..... I always have lumpy breast tissue, so I never could tell whether or not it was a lump. My GP would do them and I don't know how it just crept up on me that I had the lump, and I just happened to brush up against my breast cause I didn't do them on a regular basis and even though I've had breast cancer. I still don't do them on a regular basis.

This traumatic experience caused the women to limit contact with outside influences.

Ann confined herself to home:

I don't have the stamina to get up or the desire to go out right now ... I'm more or less home. I wouldn't say confined, but I am confining myself to home quite a bit I just don't care to get up and go out and hear too much right now

Frances also set boundaries by isolating herself:

..... basically when I first found out that I had breast cancer I as scared and very depressed and more than being scared I was embarrassed for anybody to know. I had lost my hair and like the purple nails and toenails and stuff like that .... So it was more for me just being embarrassed and ... I just didn't want anybody to know ...

Like Bea, Frances tried not to listen to others' experiences with cancer:

.....when I would go for the chemotherapy some people would like be in little groups where they could chitchat. I wanted to be far away. I didn't want to see other people going through chemotherapy or hear their stories. I just wanted to get my treatment and I wanted to leave..... it was just too much

Taking Care of your Health can prevent additional health problems. Some of the participants in this study took better care of their health as a result of experiencing breast cancer, but not all. The majority of the participants set boundaries to protect themselves from external influences by mostly limiting contact with others, so that they could cope privately with what was happening to them. These coping strategies helped these women to manage the cancer stressors.

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

### Exercising

Some participants found exercising helped them during their breast cancer treatments.

Gemma stated that since her lumpectomy:

.....exercise became very important in handling stress in general and kept me preoccupied and positive, and used it as a defence to fight for a normal life again.

Ann noted that many people have terrible stories about chemotherapy:

...I kept going, that's really important and I kept up exercising during chemotherapy like walking regardless, daily.

Hannah spent two years on tamoxifen and weight gain is one of the side-effects:

.....now, I have been power-walking. A lot of moving and walking, and that has helped with my weight, but that is very difficult.

Journaling: Gemma has journaled for years, and found it very helpful during her treatment:

It helps me to clarify my feelings and my thoughts and it also helps me to let go of them, like once it is on paper then I don't have to carry it around.

Attending groups: Opinions about support groups was mixed- some found them helpful while others did not.

Mary attended relaxation groups as a variety of places during her radiation treatment, and found them helpful:



They helped me because I felt stressed all the time. I felt I couldn't relax. It was like the cancer was taking over my life.

Deirdre also found the 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 felt better when I went to the groups, so I knew there was something positive about that as it boosted my spirits. The support groups also useful for me....knowing other people that were going through it helped, and talking to people.

Faith and Religion: Carole described an instance when she used her faith to get through a challenging situation:

..... the oncology nurse that saw me when I found the cancer said you know I do think that you do have cancer. She says ... I'm pretty sure it is and then she left the room and .... At first I'm like I really want to cry, and started praying that I could you know get through this and get home safely....I guess I just knew that this was between me and God and this was my fight and I had to do it....

Similarly Deirdre also practised her faith by praying:

I had the muscles; the muscles ached where you didn't want to move so ... every time that I knew it was coming .... I would lay in bed praying like I can't wait for this part to be over ... I won't say like on a regular basis but yeah in the beginning I did pray, that I hoped that everything will be okay ...I just wanted my life reclaiming their Life again.

Hannah also prayed:

I always prayed to God ... my prayer was like God if something happened I don't want my son to be here. I want us to die together so that I won't leave him here on nobody or if he could die before me ... so not to be a burden on anybody.

Mary attended church as a way of reasoning why she developed breast cancer. She stated:

I have this argument with God all the time. Why me? Never more than I can bear? Oh well, I argue about well how much do I have to put up with this time? Okay but we don't have to make it so much ... I talk to God about all the other things I probably should do and don't do enough ... I kind of short-circuit it. Well you know where my heart is [laughs]. I may have to pay for these things later but going to church with people..

Another aspect of practising your faith was attending church. Ann had a strong desire to attend church but was unable to do so because of feeling weak from her chemotherapy. She discussed:

Yes, but oh yes my church and I want to get back there so bad. That's my heart's desire to get back and pray and get on with my life.

Like Deirdre, Frances practised her faith by praying and by having others pray for her too. Frances stated that sometimes she was so sick she didn't have energy to pray, so instead others prayed for her. She stated:

I would pray for myself, but you know I was just so out of it and a lot of times it just took all I could give to get up and just go to the bathroom or brush my teeth or take a shower. So a lot of times I would just sleep, not able to really think or anything like that, so I think it was more other people praying for me to help me get back living normally again.

Gemma wonders why she developed the cancer, thinks about the future and she desperately wants to be normal and get through the treatments:

Lots of people say they cry buckets I didn't cry but then (long pause) once I got back to the stage where I was past the fright if it and the fear died a little bit, I got back in there with my prayers and I would have a great belief in God and get better (laughing).

Bea also had strong belief and hope to help her through her experience:

I went through it fine I think because of my belief in God, my spiritual part of my life was the major part of helping me to get through this, in that I just believed in God, and that I was going to get through this thing ... You know so, my experience was a not a bad experience in terms of I mean yeah I lost two breasts, but I'm still here ..... and I believed in God that he is my source of recovery and protection to get better.

You got to have the hope in him that he's going to get you through, and then the peace come ... it was amazing to me ... (with relief)....

All of the participants all had strong faiths and speculated on all the reasons why they developed breast cancer. These activities enhanced feeling of contentment and happiness, and also gave comfort in their everyday lives. These attitudes help them to cope and gave the ability to be strong and live a normal life into the future.

### **Experiencing Healthcare**

The fourth sub-category of Managing the threat of Recurrence was Experiencing Healthcare which related to the encounters and experiences the participants had with the health care system. The participants had a myriad of experiences with the health care system. However, interestingly the majority were not offered mental health services or even asked about the state of their mental health. Some of the participants had poor experiences that only served to increase their stress level while others had great experiences that helped them along their trajectory.

Ann had a difficult experience with the health care system. She reported:

..... I was like In and Out .... In for surgery, they prep me, surgery. I had to stay in the hospital overnight because I had a little problem, you know I guess they said it's you know an outpatient procedure, but I had a little problem ... with my blood. Nobody asked me how I felt ....I felt isolated.

Carole also had a difficult health care experience. She recalled:

Well the hospital to me is the worst place in the world for sick people [laughs] .... it isn't conducive to healing .... The patients don't get the care that they need to have .... the nurses they really don't come, when you really need them .....

Ann also believed that she did not receive enough information regarding her health care.

She stated:

.....right today I don't know if I'm stage one, two or three, no I don't know. All I know is he said, he told my family that that he got the cancer and when I visited with him in the office he didn't tell me what stage I was in, if so I truly don't remember ... no I really don't, so I don't believe I was told

Bea, Deirdre, and Mary did not receive information about psychological health. Mary stated:

... I don't think people look at people and think about how a person feels...have the treatment and leave ....(sounds disappointed and let down by the system).

Mary felt that she had to really work to make sure her insurance give her everything she needed:

.....and to some extend they're so pissed and annoyed at me it was like just go on and do it rather than having to spend time a lot of time on the telephone to me,

Frances, Gemma and Hannah all had good experiences with the health care system.

Gemma stated:

... my doctor never gave you the impression that he was rushing. He would lean up against the wall and say how are you today and he gave you the impression, take your time and even though I didn't want to really use all his time, he gave you the impression .... Whatever you need take your time. God sent him to me ... he just gave you the impression that I'm here for you.

All of the participants described some experience with the health care system, the majority of which were negative.

#### **Summary of Category Four – Managing the threat of Recurrence**

The fourth category of Returning to Normality was Managing the threat of Recurrence which related to the various issues that the participants encountered as a consequence of breast cancer. Managing the threat of Recurrence had four sub-categories: Worrying and thinking, Taking Care of your Health and setting boundaries; Doing for self; and finally Experiencing Healthcare.

#### **4.8 Summary**

This chapter presented the findings from the data analysis of this research study for eight women, and to answer the question “Enduring breast cancer treatment, what was the most salient stressor and how did you cope with that stressor?” The participants engaged and adjusted in a process of Returning to Normality from their breast cancer experience and history that began while enduring treatment. During treatment, their ability to be “normal” and participate in activities with the world had been adversely affected. Thus, they often felt that the opportunities and support that enabled them to continue with their lives while enduring breast cancer treatments were of utmost importance. The 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 complex quality of stress and coping endured during breast cancer treatment for these women. It was difficult to find many clear relationships between stressors and coping strategies (x was a stressor, so the women did y). Treatment presented a variety of stressors, and different women could experience identical stressors (pain) at different stages of their treatment (feeling distressing pain after surgery versus feeling distressing pain during radiation therapy sessions). When the process Returning to Normality is linked to resolution, a person makes sense of the phenomenon they have experienced, and accommodation where they are able to accept their experience and resolutions. Most of the women choose a coping strategy in response to a stressor while other women enacted a coping strategy to deal with the distress they were feeling, but did not link the strategy with any particular stressor. 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. The grounded theory of Returning to Normality has demonstrated a helpful way of describing the meaning and impact of the lived

experience of women with breast cancer. The sub-categories of Making sense of the Experience; Seeking Support and Loneliness; Reclaiming their Life; and Managing the threat of recurrence were also explained and illustrated with data bits from the interviews with participants. These women often looked at the positive aspects of their encounter with breast cancer, in many instances incorporating these aspects and sub-categories into their lives while recognising the importance of Returning to Normality and looking to the future.

## **CHAPTER 5: DISCUSSION OF THE FINDINGS**

### **5.1: Introduction**

The purpose of this chapter is to examine the subjective experience of women while enduring breast cancer treatment and will provide an interpretation of the results and the integration of the findings with the literature. The basic psychological process that emerged from the data analysis was “Returning to Normality” to move on (Figure 4.1). Returning to Normality was the process that these women used to conquer the stressors while enduring breast cancer treatments and it was used by the eight participants in this study in some form or capacity to triumph over whatever trials they were faced with including breast cancer treatment and the salient stressors. This section will compare the results from this study with the literature review that was presented in Chapter two.

Breast cancer is the most prevalent form of cancer among women in Europe and is a major health concern for Irish women (HIQA, 2010). Women undergoing breast cancer treatments must find ways to cope with the stressors that treatment presents. Despite the impact that breast cancer treatment has on Irish women, there is a dearth of research that has investigated stress and coping while enduring breast cancer treatments in its entirety. Interviews were analysed following grounded theory methodology, and led to the development of a theoretical model. This model provides an understanding of how breast cancer women enduring treatment cope with their lives as survivors. Several of the participants in this study reported good psychological health but the majority of the women participants would have tremendously benefited from psychological services if they would have received them. Many of them experienced stress, fear, social isolation, vulnerable and feelings of helplessness. These findings were consistent with the explanation given by Rodgers (1997) of the effects of vulnerability on health and this study also echoes these findings. 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 this study was "Enduring breast cancer treatments what was the most salient stressor and how did the women cope with that stressor?" Based on the framework, and in returning the research question, a number of interesting and new issues related to the Returning to Normality of these women emerged.

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 & 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 necessary threatened for these women during their experience with breast cancer. This study offers support for that finding, as distress due to the effects of breast cancer treatments on their breasts did not emerge as a dominant theme. The women in this study did not talk very much about their breasts and most of the participants outlined that survival and gaining Returning to Normality was more important than their breasts. These comments regarding the greater importance of survival mirrored quotations outlined in a study by Landmark & Wahl (2002).

## **5.2: Returning to Normality**

Returning to Normality was the core category that emerged in this study. This basic social psychological process that emerged from this study describes a number of phases that women process through as they deal with breast cancer treatment and stressful symptoms. Returning to Normality was an interesting phenomenon in this study, and it could act as a stressor or as a coping strategy, depending on the viewpoint of the particular woman.



Returning to Normality is a human experience intertwined with all life events, embracing ideal and values, desires and dreams, relationships and plans, hope and uncertainty. It is a particularly vivid experience for persons who have had to find ways to go on with their lives amid the challenges inherent with successful living after injury (Chen, 2010). The four phases of the Returning to Normality category that emerged during the data analysis were Making Sense of the experience, Seeking Support and Loneliness; Reclaiming their Life; and Managing the threat of Recurrence. The next section will link the specific phases or sub-categories of this social psychological process of Returning to Normality to the literature.

- **Making Sense of the Experience**

The women in this study experienced both positive and negative emotions throughout their treatment but have exemplified being strong in the face of adversity. The women reported more negative emotions than positive emotions. The strategies used by the participants included being positive, resilient, and accepting it. They strived to remain positive by not thinking negatively, nor allowing themselves to have fear and by keeping busy as normalizing strategy. These findings are similar to the findings of other studies. For example, Henderson et al. (2003) found that women having a positive attitude, avoiding negative people and having a will to live assisted in coping with breast cancer.

Furthermore, Ashing-Giwa et al (2004) found that women with breast cancer cope with psychological problems by engaging in activities for distraction. Use of positive emotions as a way of coping with breast cancer treatment has been found in other studies (Wengstrom et al. 2001). Although not a prevalent coping strategy in this study, it seems that some women find positive emotions a useful coping strategy. It is not impossible from

the study to determine if women who use positive emotions as a coping strategy have shared characteristics.

Strong determination, trust in God and inner strength were consistent findings among the women in the study. These findings are consistent with other studies. Gibson (2003) reported high levels of hope in European American breast cancer women. Simon et al (2007) found that a positive and hopeful attitude increased coping and determination among breast cancer patient and encouraged them to be strong thus reduced their stress. Furthermore, several of the women reported their experiences as just another bump in the road, another hurdle to clear or as just one more thing to deal with in their lives. The variety of coping strategies reported by these women in the study mainly involved some form of action taken. The women indicated a desire to be prepared for treatment, and several women prepared when they gathered information about their forthcoming treatment. This helped them to make informed decisions about their treatment, and be ready for the possible side-effects. The women also were prepared in many ways, such as cooking sufficient foods to last during their radiation therapy. Some felt prepared because of their family history of breast cancer. Therefore this enabled some of the women to be less stressed when they were prepared. This study also revealed that turning inward by focusing and distancing themselves these participants were able to transcend their experience. In addition, the majority of the women also described their acceptance of breast cancer as not being difficult to embrace.

The women did experience some distressing emotions throughout their treatment. Some women experienced anticipatory negative emotions while enduring their breast cancer treatment, in part due to the fact they did not know what was going to happen. This study replicated findings from other studies that some women experience anticipatory fear,

anxiety, and worry, while enduring their treatment (Montgomery et al., 2003; Saares & Suominen, 2005; Thomas-MacLean, 2004).

Negative emotions continued to be distressing while enduring the treatment for these women, and this attributed to two things: (a) the nature of treatment, and (b) the effects of the treatment (i.e., the side-effects and the effectiveness of the treatment). The negative emotions that the women in this study found distressing enduring treatment included anxiety, frustration, and anger. Previous studies highlight that emotions experience as been more difficult to deal with than physical (Lethborg et al, 2000). Some of the women in the present study found that there was a point at which they shut down their distressing emotions, a similar finding by Lethborg, who found that the women in their study had times when they concentrated on being normal, and had a blinkered approach to their treatment. The findings from this study and the study by Lethborg indicated that both physical and psychological emotional effects of treatments could be overwhelming for some women. It is therefore interesting to note that very few studies ask women about the emotional distress while enduring treatment; in contrast, many studies lump all distressing emotions under the titles of “distress” or “stress” (Koopman & Spiegel, 1998; Manne et al, 2005).

- **Seeking Support and Loneliness**

These women in this study experienced high levels of distress and loneliness as they sought to find a sense of personal meaning and support while enduring treatments. Results showed that three types of support were identified as being important among these women which were family, friends, and professional support. Seeking support was the active strategy that was used by the women. 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 from evidence that emotional, tangible, and informational support is helpful to women undergoing breast cancer treatment, and that the lack of these types of support are associated with distress ( Landmark & Wahl, 2002; Saares & Suominen, 2005; Wengstrom et al. 2001). In the interviews with these breast cancer women, the issue of being alone and isolation was a common theme that seemed to manifest itself while enduring the treatment. Women emphasised the need to be alone, preferred not to talk or discuss issues with people, and also they experienced a dislike of being surrounded by other people. This common problem may be related to the experience of women in relation to the issue of torture (family members constantly gossiping about them, which was a constant reminder of their illness) and issue of extreme discomfort felt by the women in relation to relationship with close relatives.

Women in this study strove to accept their personal sense of loneliness and live more authentic, connected, and normal lives even as they withheld truths and participated in inauthentic acts to protect others e.g. acting like a hero for the sake of others or withholding aspects of one's experience to protect others. An unauthentic act preserved a sense of connection and created an impression of normalcy and a condition of hope and optimism, which reassured and positively influenced those relationally connected to the participant. This concurs with a study by Rosedale (2009) whereby the 13 breast cancer women conveyed a unique description of loneliness. They described how they felt alone in the awareness of mortality and were invalidated in the experience of ongoing symptom burden, and the isolation they experienced as they sought to work through an altered sense of self, connection, and identity as a breast cancer woman.

Overall these women all suffered a degree of isolation and often led to some kind of alienation feelings and the majority of them felt that this was normal to behave like this. Interviews with these women showed that “being stunned” and “feeling lost” were

common to cancer patients and were used repeatedly in the course of the conversations to describe their physical, psychological and/or social behaviour while enduring their breast cancer treatment. Although loneliness was experienced to some degree by all participants as in the study by Rosedale (2009), findings suggest that some women may be more vulnerable to heightened psychological distress.

Distress intensified when women in this study expected symptoms to disappear but symptoms persisted instead which impacted on their quality of life and being normal. This was also evident in a further study by Rosedale (2010) whereby increased distress was associated with sudden and expected situations or when symptoms elicited feelings of loss about pre-cancer being causing a feeling of isolation.

For these women in this study, the impact of the breast cancer treatments represented an essential change in their lives. Because of their understanding of that and the social stigma attached sometimes to cancer, some of them made a decision to hide the problem(s). They decided to hide thinking of protection. First, they think of protecting themselves because they were feeling very bad and people used to come to visit them with curiosity so it was easier to hide away and not meet people if possible. Second, many of them decided to hide thinking of protecting their families. They became concerned with their relatives, and with their reaction. In their thoughts, if they told them about their condition, they would become more desperate. Hence some of these women decided not to tell anybody to preserve them from their pain. These women in this study passed by an important decision: to share their experience or hide their problem. The decision of sharing means that these women started to widen their circle of friendship and also it is a way of getting support for their needs while passing by the experience. This is when they go to friends or support groups. As pointed out by Radin (2005), the sharing of confidences and fears enables women to think

about and face the problems that are inserted in their lives because of breast cancer. This idea is similar to the one pointed by Lindop and Cannon (2005); according to them, to look for support is an important contribution to the well-being and survival of these women. The situation of isolation caused by breast cancer was pointed out by Vargens & Bertero, (2007), showing that that it increased distress in women and the women did choose self-isolation for hiding themselves from the cancer. Billhult and Segesten (2003) conducted a study with breast cancer women and who were mothers of dependent children. The result showed that these women experienced a constant conflict between telling the truth and protecting their children from the truth and also between being needed and perhaps not existing. The authors also pointed out that for these women, to carry on as usual and continue their everyday life became very important.

The interviews identified both positive and negative aspects of support. Family and friends were acknowledged as important sources of support in this study. Informal supports such as peer support and support from family and friends help navigate the emotional course of breast cancer (Badger et al. 2005). The women in this study most often sought informal sources of support, such as support from family and friends. This study was consistent with the literature. Knobf (2007) reported that family members are viewed as a major source of support among cancer patients and he further outlined that social support as an important factor influencing coping with breast cancer.

Likewise, the majority of the women in this study described supportive relationships with their friends, extended and immediate family, and coworkers. Additionally, the support that these women received encouraged them to in turn is supportive to others. The women obtained support from informational sources. According to Barg & Gullette (2001) patients cope best by seeking information and educating themselves about disease and treatment

either through the internet or from individual who had a personal experience with breast cancer. Morgan et al. (2005) found that couples use the internet as a resource when dealing with breast cancer. Most of the participants in this study used the internet to research information about breast cancer and treatment options. However, the participants also described the use of mainstream media sources, written material and videos.

Professional sources of support were also reported by the women in this study. Support from healthcare professional has the ability to decrease stressful symptoms. Knobf (2007) reported the lack of or limited communication with healthcare professionals about physical and psychological symptom distress can result in adverse psychological morbidity. Morgan et al. (2005) found that a supportive healthcare professional can have an effect on the coping of women with breast cancer. The majority of the participants described supportive relationships with their healthcare professionals. However, Ashing-Giwa et al. (2004) found that the majority of breast cancer survivors did not express receiving significant support for recovery from their doctors. In this study, all but two of the participants described receiving support from their medical doctor. This is different from the literature. The lack of professional support in the community services has been found in other studies, where women did not feel that they adequate emotional support of guidance from medical professionals (Landmark et al.2002). Some of the participants in this study felt a lack of support at end of treatment and felt isolated once the planned care was completed in the acute setting. Thomas –MacLean (2004) also found that the end of treatment was associated with distress for some women. It is clear from the findings of this study, and the current literature that support from others is an important coping strategy for women while enduring breast cancer treatment.

- **Reclaiming their Life**

Physical changes while enduring breast cancer treatments were mentioned repeatedly in the data. Results show that women have unanswered questions. They needed detailed information from health professionals, provided in ways that could help them to fully understand their situation. All the women in this study had undergone surgical treatment, and the results were visible, both for the women themselves and others. All the participants found that physical effects of treatment distressing. They described distressing changes, including loss of breast, reduced mobility in shoulder and arm and loss of feeling in fingers and arm. This study is identical to other studies when describing these distressing symptoms (Saares & Suominen, 2005; Thomas-MacLean, 2004; Wengstrom et al, 2001). Two women developed lymphodema. Cytotoxic, hormone and radiotherapy treatments gave side effects, including nausea and vomiting, loss of hair, fatigue, skin and mucous membrane changes and an increased of infection. Bodily changes were reported and influenced self-image, sexuality, activity and rest. Physical changes and loss of strength had a marked effect on the women who had returned to work and this evident in the literature (Kennedy & Lingard, 2006). Some of the women had learned that the side effects would be reduced over time, even though they experienced the opposite themselves.

“That’s the worst of it, it takes so long to get back your strength and energy – I’ve tried everything. I was not aware that it would take over a year to get back to work”. Weight increase and attacks of sweating were also troublesome side effects: ‘I’ve put on so much weight, it’s awful. It breaks down your self-confidence, putting on several kilos. When you get back to work everybody says ‘how great you look’ – that really hits hard!’ sometimes, the physical symptoms were so overwhelming that these women felt they were simply surviving, and not really coping. Maybe the women’s inability to mobilize effectively 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 & Folkman (1984).

The data showed that cognitive impairment affected several of the women in this study.

- **Being Strong**

Several of the women in this study encountered seemingly insurmountable challenges in addition to their breast cancer that most certainly impacted their experience, which were namely the life situations that they faced. According to the literature, concerns and problems noted among those breast cancer women include physical problems, financial problems, concerns related to mortality and reoccurrence of breast cancer, social support, worry about others, reactions of others to their breast cancer, and work related concerns (Shelby, et al, 2006; Kennedy & Lingard, 2006) in ability to attend to one's own health, unfamiliarity with breast cancer in the health care system (Ashing-Giwa et al, 2004).

Several of these concerns were reported by the participants in this study.

The majority of the participants in this study were also carers in their families which created stress among these women. Some of the participants discussed distress about their family worrying about them, maintaining normalcy for their family, and being able to meet their responsibilities. These findings have also previously been reported. Yates (1999) reported that living with a family member who has cancer is an especially difficult challenge and such strains have a significant impact in the day-to-day lives of family members. Im et al, (2008) found that American women often gave priority to family members needs over their own. Additionally, Mellon et al, (2006) found that family stressors were a significant contributor to breast cancer survivors' quality of life. Moreover on-going concerns and problems facing the individual and family are important determinants of adjustment and quality of life.

Inadequate finances or other resources in addition to employment status can potentially impact persons with serious illnesses. In fact this has been found in other studies. Aishing-Giwa et al (2004) reported that financial status was an important determinant in the quality of care for everybody. However only three of the participants in this study expressed concerns about their finances. In fact all the participants had full health insurance at the time of their diagnosis and treatment and were also entitled to a medical card while enduring their treatments. Significant other relationships can also be challenging and have the potential to cause great deals of stress especially regarding disclosure of breast cancer and loss of a breast to their partners. Lastly this study also revealed that many of the participants experienced impactful losses and other hardships in addition to breast cancer that certainly had bearing on their development of stressful symptoms. The losses that were described by the study participants were deaths of significant family members and friends. Other challenging hardships included chronic health problems, and some had parental responsibilities.

- **Managing the threat of Recurrence**

The women in this study reported body altering changes and expressed concern over those changes. The concerns expressed by the participants are similar to previous reports. Wilmoth & Sanders (2001) reported that concerns about body appearance in American breast cancer women include hair loss and body scars. Aishing-Giwa et al (2004) also reported that many breast cancer survivors described negative feelings about their bodies after breast cancer and its treatments such as decreased self-worth, attractiveness and feeling deformed whereas Halberd et al. (2008) reported weight gain in patients was a concern and stressor.

Several of the women in this study expressed worrying and fear of recurrence at some point in their breast cancer experience. This finding is similar to other studies. Bradley (2005) found varying degrees of worry about breast cancer symptoms in breast cancer women. Furthermore, Ashing-Giwa et al. (2004) reported that women's responses to breast cancer often include fear, worry, denial and anxiety about reoccurrence.

Experiences with the healthcare system can either help or hinder the recovery of breast cancer women with stressful symptoms. In fact, Maley et al. (2004) suggest that patient-provider interaction may even perpetuate or moderate health disparities. Several of the participants in this study described negative experiences with the healthcare system. The participants believed that they were not provided with enough information, that their care was rushed, that the professionals were too forceful with them, that they did not feel considered as people and more time was required to allay their fears. These findings are consistent with other reports. Ashing-Giwa et al. (2004) found that many American women breast cancer survivors described negative relationships with doctors. They reported that their doctors lacked sensitivity and their communications skills need to be improved. Other findings of the study were the ways in which some participants changed the way they managed their healthcare, the residual effects of breast cancer that the participants experienced, and the strategies that the women used to cope and set boundaries in their lives.

The reliance on spirituality was pervasive in the lives of the women in this study. The belief and faith in God among the participants especially the older women was very evident to help them to move on. This study found that the women with breast cancer and stressful symptoms particularly relied on faith to cope and transcend their circumstances and lives. They practiced their faith in a variety of ways and rested on the promises of their faith to get better and in terms of outcomes of their breast experience rather than as a coping

mechanism. It is evident from the literature that faith played an important role in cancer survivors in their coping and adjusting to a history of cancer (Cava, 1992). In fact, the belief of God and strong religious convictions is a deliverer of oppression and sickness which continues among many people especially during illness (Hamilton et al, 2007) and this is not surprising in this study. Taylor (2001) suggested that people with cancer have been found to benefit more from religious coping strategies and this is often combined with prayer and this helps them cope with their cancer.

Additionally, all the women in this study engaged in some type of religious practice such as praying, and attending the church as coping strategies. These findings are similar to other studies. Merviglia (2006) found that prayer was positively related to psychological well-being in breast cancer survivors. Prayer is talking to God on a personal level which the women found comfort and helped to cope with distress. Im et al (2008) reported that African American women cancer patients received emotional comfort and managed fear by praying and going to church. Spirituality and religious expression appears to have mitigated the way in which the women in this study viewed the circumstances in which they found themselves help cope with their breast cancer treatments. This is also a previous finding in the literature. In fact, Leak et al. (2008) found a positive relationship between spirituality and quality of life in breast cancer female survivors. Hensch & Danielson (2009) outlined that religious/ spiritual beliefs may aid in Returning to Normality and move on in their lives. Higher levels of existential and religious beliefs were associated with lower rates of anxiety and depression amongst patients with cancer. Moreover, a higher level of spiritual/religious beliefs was associated with higher levels of social and family adjustment, (i.e. adjustment and adaption amongst family members). Although this result is not directly comparable to the current study both excerpts discussed identified a “loss of fear” once

over the shock of diagnosis. This loss of fear was associated with prayer and the participants' faith in God, therefore aided in a positive attitude.

### **5.3: Breast Cancer, Stress and Coping**

The findings from this study are discussed in terms of Lazarus and Folkman's (1984) transactional model of stress and coping. The majority of the women reported stressors while enduring their breast cancer treatments at some time throughout the treatment. First there is a focus on the appraisals made by the women during their breast cancer treatments, given that appraisals are a central construct in the transactional theory. Then consideration was given to the major stressors the women outlined, along with the coping strategies in order to help them move on. Finally, consideration was given to 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 this study, the women appraised a number of concerns as overwhelming and displacing their well-being throughout their breast cancer treatment. The appraisal process of each individual was unique, as outlined by the concept of Returning to Normality. What each woman appraised as stressful depended on her particular values, beliefs, and resources and how well they tolerated it psychologically. Some women perceived that they would return to Returning to Normality and move on once the treatment finished while others perceived that it would take much longer and they had the tolerance to wait before achieving Returning to Normality in their lives.

The themes that emerged in this study even though they dove-tail with each other represent the events that these women found to be stressors, and what they used as coping strategies throughout their breast cancer treatments. All of the women appraised the physical effects

of treatment as distressing, and some women lacked confidence in their ability to cope with the stressful physical effects of treatment. Some women found that they were so overwhelmed by the nausea and sickness during their treatment that they did not even think about coping, but just survived as it was a constant battle for them. Many of the women found that the physical effects of treatment interfered with their ability to implement coping strategies. In other scenarios women decided that they could not cope with the harm the physical effects were doing to their bodies, and did not want any more treatment (i.e. coped by avoiding treatment). The women's fight to cope with the physical side-effects of treatment indicated the overwhelming nature of breast cancer treatment. In addition to the effects of treatment, the women also experienced other events as stressors – worry and negative emotions that accompanied treatment or not receiving the type of support they wanted from family, friend or professionals. It seemed life was a struggle all the time as they grappled to adjust to Return to Normality while enduring their breast cancer treatments.

#### **5.4: Summary: Researcher's Reflections**

It is the aim during the study that reflexivity would be developed throughout the discussion. Reflexivity is a concept central to qualitative research in general, where it is viewed as a means of adding credibility (Dowling, 2005). Throughout the course of the study, I was able to meet individuals who had not only experienced a life-threatening illness, but who also appeared to be doing reasonable well. I felt very fortunate to meet and talk with such fascinating people. I think that perhaps the most outstanding feature of completing this study was learning how my assumptions affected not only the research question, but also the way in which I spoke with the participants during the first few interviews. The

questions I asked during the interview were reflective of what I thought would create “interesting” and “deep” dialogue about the participants’ stress and fears of recurrence and understanding how the breast cancer had affected their lives would be the central part of the interview.

The discrepancy in what I believed would be the important questions to ask, and what participants felt were important to discuss, highlights the need for qualitative research. This is particularly critical when dealing with an area where there is little knowledge and where the environment is changing. Investigator-driven research may sometimes underestimate or miss what is actually of most value or interest to those being researched. As well, our own biases around certain behaviours and the meaning behind them are used in interpreting results. In talking to the participants themselves, I discovered that they provided answers that had not previously been considered. For example, the initial assumption that participants would engage in a healthy lifestyle choices to help them to cope to decrease their risk of recurrence was not found. Had it not been discovered that participants were not engaging in healthy lifestyle choices without talking to them, it may have been hypothesized that they were in denial about chance of recurrence and their coping strategies to minimize stress while enduring breast cancer treatment.

I believe such examples highlight the importance and significance of this study. These findings illustrate the discrepancy between some underlying assumptions of the study and what the breast cancer women felt was important to be normal again. As well, it illustrates how, in talking with those who experience and live the phenomenon being studied, we can increase our understanding, and subsequently increase our capability to work with them. On reflection, 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 that women implemented. The stressors and the

coping strategies (the branches) were intertwined, overlapping and influencing each other. The tumbleweed moved on as normal, from the start of treatment to the end. Also reflecting back it would be important to explore their deeper interpretation and look at an in-depth process of adjusting to “Return to Normality”. Professional need to recognize this for future research as it is important how information and treatments are delivered in order to maintain a balanced approach for cancer patients. This only comes with intuition and maturity in order for patient empowerment and participation. This is in line with the National Integrated Quality, safety and Risk Framework, QSRF (DOHC, 2009) which was developed as a result of the Report of the Commission on Patient Safety and Quality Assurance (2008). One of the core processes of the QSRF (2009) was the service user and look at quality from the service user’s (patient) perspective delivering a more effective and efficient health care delivery.



## **CHAPTER 6: RECOMMENDATIONS, LIMITATIONS AND CONCLUSION.**

This chapter discusses the recommendations of the study for healthcare professionals. Recommendations based on comparatively small-scale studies should always be cautious, and this approach will be adapted within the recommendations section of this thesis. The recommendations for research and practice of the study are discussed followed by a discussion on the theoretical perspective of symbolic interactionism in this study. Then finally there is a discussion on the limitations of the study, and an overall conclusion to the study.

### **6.1 Implications for Healthcare Theory**

Grounded theory derives from the real world experience (Nathaniel and Andrews, 2007).

The women in this study offered contextual descriptions of how breast cancer and stress impacted on their lives that has not been described previously in the literature. The grounded theory emerged from this research is significant because it adds to the theory base for designing future intervention studies to address stress management and coping strategies in women with breast cancer and allows women to have a voice.

Grounded theory methodology allows theories to evolve as newer facts emerge, create dynamic tools which remain useful over time and continue to be applicable even when situations change (Nathaniel and Andrews, 2007). Thus, the results of this study also have the potential to guide the exploration of instrument development that may lead to tools that can better predict psychological distress or stress levels in women with breast cancer and lead to earlier intervention.

## **6.2 Implications for Healthcare Research and Practice**

This study revealed the salient stressors and coping strategies for the eight women, however it did not find a link between particular stressors and coping strategies, nor did it find that certain coping strategies were more useful while enduring 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 a particular treatment stage with use of a longitudinal design and although the authors did not focus on the stressors, they presented some aspects of the psychosocial 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 coping strategies.

Support from others was a key coping strategy for the women to adjust and be normal again with their lives in the study. There are a number of avenues of research that stem from this finding. Receiving support was helpful to the women, but may have an associated cost for the family member or friend. For example, one participant in the study noted that her desire to know and discuss every detail of her treatment was in direct opposition to her family'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 especially family relationships. A perceived lack of support was distressing for the women in this study, especially the lack of support when the acute treatment stage was finished when they went into the community setting. Most participants felt supported during treatment stage as it was a planned programme but felt isolated and alone when this treatment finished. This merits further investigation, if future studies can reveal what women need at the end of treatment to feel supported, perhaps some form of psychological intervention can be put in place and

strategies for treating pre and post-treatment symptoms. Also further research is needed to understand what intervention work best with women having breast cancer treatment.

Lastly, this research is specific to a group of women living in the west of the country thus future research should also include participants of other geographic areas as their experiences may be different to influence the coping strategies.

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

Also this study revealed that there was 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. The women in this study were from a socio-economic class that are allowed to use internet and are able to source the information that helps them to cope. If they cannot source the information they require to help them cope then the inability to get information may become an additional stressor.

Healthcare professionals need to be aware of their patients' preferred coping strategies and whether she has the coping resources that will allow her to implement those strategies.

When women undergoing breast cancer treatment are overwhelmed some form of supportive counseling may be more beneficial rather than attempting to provide in-depth counseling. 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 enduring treatment exist in the context of their relationship with others. Supportive communications, especially the attitudes of hope and respect, seem to be key features desired by the women within the context of their interactions with healthcare professionals while enduring breast cancer treatment. It is important to be human when treating and communicating with these patients as it can be very individual and this comes with knowledge and experience. It was evident that there was a lack of support following completion of acute treatment in hospital and going into the community services and women felt isolated and lonely and depressed at times. Continued support which is individually tailored for the women's phase of life is essential for the women and her family after discharge from medical treatment to ensure they adjust to this changed life sequel (Coyne & Borbasi, 2009). This finding indicates that there is a need to have a holistic approach which includes psychological services not only at time of diagnosis and acute treatment stage but through their journey of further treatment to help them to back to Returning to Normality.

### **6.3 Theoretical Perspective**

The theoretical perspective that informed this study was symbolic interactionism. The major emphasis in symbolic interactionism is on the meaning of the situation to the person (Edwards & Saunders, 1990; Saunders, 1997). Symbolic interactionism seeks to explain behavior by finding what meaning and value individuals attach to specific experiences, based on the premise that human beings are constantly evaluating and acting upon events based upon their interpretation of these events (Schroeder, 1981). This study remained

consistent with the symbolic interactionist perspective by seeking to understand what women believe about their experience and world in regards to breast cancer treatment and stressors. Symbolic interactionism dictates that situations must be seen as the actor sees it, its meanings of objects, and acts must be determined in terms of the actor's meaning, and the organization of a course of action must be understood as the actor organizes it (Crotty, 2003).

#### **6.4 Limitations of the Study**

This study was based on the in-depth interviews of eight participants. The undertaking of a grounded theory study is a significant endeavor that requires a variety of skill sets. Most importantly it requires the ability to conduct clear and concise interviews that capture the complete perspective of participants. As a researcher my interviewing skills and abilities were not always apparent in the early interviews, but improved as the study progressed as subsequent interviews focused on the emerging core categories. The qualitative nature of the study, the small sample size, and the participants' characteristics mean that the findings are not generalized 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 help in clinical work with other populations.

Another limitation of this study was that the participants were only interviewed once and additional interviews with each participant may have generated more concise data. 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 there

were not comfortable sharing with me. All efforts were made to ensure that the interviews were safe for the eight participants by seeking ethical approval, signed a detailed consent form that outlined the participants' rights and steps taken to ensure confidentiality and 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 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 and also some may be less stressed than others and coped better. I do not know if these hypotheses are true, but it is interesting to note that these women possessed the combination of coping resources, view of the world, and the environment that allowed them to do so. Lastly grounded theory studies are specific to the population studied. However the results of this study may have transferability, in that the findings may fit other contexts as judged by readers or when readers find the report meaningful in regard to their own experience (Crooks, 2001).

## **6.5 Summary**

This chapter discussed the recommendations for healthcare research and practice. It also discussed the theoretical perspective of symbolic interactionism used in the study. Symbolic interactionism fit particularly well with this study. Crooks (2001) stated research based on symbolic interactionism reveals the world view of participants by seeking to understand the social construction of meaning and action by asking questions about point

of view, influences on action, problem-solving strategies, definition of action and situation, effect of past experiences, and finally of this study. In addition, implications for healthcare theory, research and practice were presented as well and finally the limitations. Grounded theory is a respectful methodology in which the participants views are sought, listened to, and valued (Crooks, 2001). This type of methodology was used to in this research to study women enduring breast cancer treatments and stressors. This study provided new insights into how women manage and cope when enduring breast cancer treatments. Lazarus and Folkman's (1984) transactional theory of stress and coping provided the theoretical framework for the concepts of "stress" and "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 while enduring breast cancer treatments. The explanatory theory that resulted was Returning to Normality which offers a new contextual view on stress and breast cancer treatments for those women. Overall, this group of women appeared to be living well-adjusted lives. The theoretical model developed in this study provides a conceptual view of the process of Returning to Normality that participants were engaging in response to the stressors of the breast cancer history and treatments. The strategies used by these participants to be normal and cope were their support, being strong, dealing with life and managing the threat of recurrence and not dwelling on their breast cancer. The consequences of adjusting and Returning to Normality with life and using these strategies included living life to the fullest, positive thinking in their cancer experience and a feeling of control and empowerment. This new perspective will serve to increase understanding of these disease processes among this population of women. For women in this study, breast cancer treatment presented a number of stressors, and was sometimes overwhelming. When overwhelmed, the women focused on Returning to Normality, and when they processed the

necessary coping resources they mobilised predominately 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, and the healthcare professional staff. In keeping with the nature of interpretative inquiry there is no intent to generalize the findings of this study rather the intent is to produce credible findings (Sandelowski, 1993). While the number of participants in this study was small it is feasible that women with breast cancer in matching settings will experience similar issues.



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## **APPENDIX A:**

### **Participants' Profile**

#### **Interview 1 – Bea**

Bea was a widowed woman in her early sixties. She was a retired administrative assistant who worked in healthcare. She had her Leaving certificate. Bea lived in her own home with her adult daughter. She also recovered her breast cancer through a self breast exam. She was diagnosed first with stage 11 breast cancer at the age of 49 years and then had a reoccurrence of stage 1 breast cancer approximately 10 years later. Bea was treated with chemotherapy, radiation and a bilateral mastectomy. She was currently in remission. Bea had a significant family history of breast cancer as two of her sisters had breast cancer and actually died from it. Her religion was Catholic and this gave her strong religious and also she had strong social support.

#### **Interview 2 – Deirdre**

Deirdre was a single woman in her 40's. She was currently employed and worked in an administrative capacity. Her education was at degree level and she was currently in ongoing adult education to do an MBA. She was diagnosed with stage 11 breast cancer at age 44. She had no family history of breast cancer. Deirdre's treatment consisted of a lumpectomy with lymph nodes removal and is on tamoxifen hormonal treatment, chemotherapy, and radiation. She was Catholic and had full health insurance. She found support groups good.

#### **Interview 3 –Ann**

Ann was a disabled woman in her mid-sixties and she became ill due to a long standing seizure history. Prior to becoming disabled she worked as a nurse. Her education level was leaving Certificate and then went on to do her Nursing exams. She has been separated from her husband for years and lives alone. Ann discovered her breast cancer through a breast self exam. She was recently diagnosed with breast cancer 18 months ago. She had a lumpectomy and radiation therapy. Ann did not know her stage of breast cancer and her religion was Catholic.

#### **Interview 4 –Carole**

Carole was a married woman in her early sixties with two grown up children. She was retired and had some education at secondary level. Carole had breast cancer twice. She was first diagnosed with stage 11 A breast cancer at the age of 54 and then again at the age of 58 years, but she did not know the stage at the time. She received radiation but refused chemotherapy. She had a bilateral mastectomy with no reconstruction but had radiation therapy. She had full health insurance. The second time Carole was diagnosed with breast cancer, her mother was also diagnosed. She was Catholic and had a strong faith. Her husband was excellent support to her.

### **Interview 5 – Frances**

Frances was a divorced woman in her mid-forties. She had secondary school education with some adult learning courses. She was currently unemployed. Frances had a history of chronic health problems suffering depression also and was under the care of a psychiatrist. She had recently lost weight. She was diagnosed with stage 111 breast cancer at the age of 39 years and had a mastectomy. Frances no longer had medical insurance, but had full insurance at time of diagnosis. She was catholic and was very involved in the church. Frances struggled with being embarrassed because of having breast cancer so she tried to hide it early on from others. She was treated with a lumpectomy, chemotherapy and radiation.

### **Interview 6 – Gemma**

Gemma was a married woman in her mid fifties. She was diagnosed with stage 11 breast cancer at age of 49 years. Gemma had a lumpectomy, and then against the advice of her oncologist refused chemotherapy but had radiation therapy and 2 years of tamoxifen therapy. She had some depression but believed in her faith to cope with the cancer. Her education was at master's level and she worked as a social worker. She had full health insurance during her breast cancer experience.

### **Interview 7 – Mary**

Mary was a single woman in her sixties. She was never married and most of her family was deceased except her brother but she had no family history of breast cancer. She worked in healthcare and had a BA degree. She had breast cancer twice first at age 44 with in situ breast cancer and then again in her mid fifties, but she didn't know what stage it was at. The first time she had cancer, she had radiation and a lumpectomy, and the second time she had chemotherapy, radiation and a lumpectomy. Mary had several chronic health problems but had full health insurance.

### **Interview 8 – Hannah**

Hannah was a single woman in her early forties and worked in a factory. She was the mother of a cystic Fibrosis child who died the past 2 years. She was diagnosed with stage 1V breast cancer at age 40 years. Hannah found a lump while showering but waited eight months before seeking treatment and only sought treatment after the encouragement of her family. She received 16 sessions of radiation therapy and a bilateral mastectomy. She developed lymphodema and had 2 years of tamoxifen therapy. She had secondary school education. She had full health insurance during her breast cancer experience. She is currently considering reconstructive surgery on her breast following this radical surgery.

**APPENDIX B:**  
**PARTICIPANT FLYER**

**Participant Flyer**

You are being offered the opportunity to participate in a research study that is designed to explore the experience of women with breast cancer.

If you would like to participate in this study, please contact Mary T. Gibbons (details below) who will describe the study, and ask you to sign a consent form.

What will you be asked to do?

- *Participate in one or two one hour audio taped interview when and where convenient to you.*
- *Each interview will be conducted privately and all information will be confidential.*
- *There is no cost to participate in this study, nor is there any compensation for your participation in the study.*

Your willingness to consider participation in this study is greatly appreciated. You may withdraw from this study at any time if you chose.

Mary T. Gibbons (087) 3838880 or email me at [mary.gibbons@hse.ie](mailto:mary.gibbons@hse.ie)

**APPENDIX C:**  
**RECRUITMENT LEAFLET**

**Informed Consent**

**Title of study: A Grounded Theory of the lived experiences of women with Breast Cancer.**

**Researcher: Mary T. Gibbons  
Senior Nurse Manager  
Mayo General Hospital,  
Castlebar.  
Co. Mayo.  
Telephone 0949042324**

**Introduction**

You are being invited to take part in a research study. The information in this form is provided to help you decide whether or not to take part. This leaflet is designed to give you some information about a research study that I am undertaking as part of my PhD studies. Study personnel will be available to answer your questions and provide additional information. If you decide to take part in the study, you will be asked to sign this consent form. A copy of this form will be given to you.

**What is the purpose of this research study?**

You are being invited to participate voluntarily in the above-titled research project. The purpose of this study is to describe the lived experiences of women with breast cancer.

**How many people will be asked to participate in this study?**

Approximately 7 to 8 people will be asked to participate in this study.

**What will happen during this study?**

If you agree to participate, you will be asked to consent to the following: participate in an interview with the primary researcher concerning your experience after the diagnosis of breast cancer. The interview will be scheduled at a time and place that is convenient for the participant and will last one hour approximately. A second interview may be requested at a later date during the course of the study if more information is deemed necessary. The interview will consist of two phases. The first phase is designed to provide general background information, such as age and marital status. The second phase will allow you to describe your experience while enduring breast cancer treatment. While the researcher will ask some questions and guide the interview, you will have the opportunity to tell your story. The interview will also be tape recorded and later transcribed for review by a professional transcriptionist. The Researcher may also take a few notes during the interview to supplement the information from the taped interview.

**How long will I be in this study?**

About one hour will be needed to complete this study. However, for some participants an additional interview lasting one hour may be necessary.

**Are there any risks to me?**

The things that you will be doing have minimal risk. The risk may be emotional or psychological. Although we have tried to avoid risks, you may feel that some questions we ask you to do may be stressful or upsetting but the interviews will be conducted in a sensitive way. If this occurs you can stop participating immediately. We can give you information about individuals who may be able to help you with these problems and psychological support will be provided.

**Are there any benefits to me?**

You will not receive any benefit from taking part in this study. You may feel relief as you talk about experiences, especially if you have not told anyone before. There are also social benefits. You will be contributing to the development of a theory that will be used to help other women who have been diagnosed with breast cancer and who may be experiencing the same problem.

**Will there be any costs to me?**

Aside from your time, there are not costs for taking part in the study. The total time commitment will range about one hour per interview. A maximum of two interviews may be conducted with all participants. However, most participants will only require one interview.

**Will I be paid to participate in the study?**

There will be no monetary compensation.

**Will video or audio recordings be made of me during this study?**

We will make an audio recording during the study so that we can be certain that your responses are recorded accurately only if you check the box below:

I give my permission for audio recording to be made of me during my participation in this research study.

I do not give my permission for audio recording to be made of me during my participation in this research study.

**Will the information that is obtained from me be kept confidential?**

The only persons who will know that you participated in this study will be the research team members: the principal Researcher and the Supervisors. Your records will be confidential and kept with the researcher after the study is completed. You will not be identified in any reports or publications resulting from the study.

**May I change my mind about participating?**

Your participation in this study is voluntary. You may decide to not begin or to stop the study at any time. Also any new information discovered about the research will be provided to you. This information could affect your willingness to continue your participation.

**Whom can I contact for additional information?**

You can obtain further information about the research or voice concerns or complaints about the research by calling the Principal researcher Mary T. Gibbons (087) 3838880. If you have questions concerning your rights as a research participant, have general questions, concerns or complaints or would like to give input about the research and can't reach the research team, or want to talk to someone other than the research team, you can call Dublin City University at [01 7005223](tel:017005223).

Thank you for reading this information and for considering this project.

**Your Signature**

By signing this form, I affirm that I have read the information contained in the form, that the study has been explained to me, that my questions have been answered and that I agree to take part in this study. I do not give up any of my legal rights by signing this form.

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Name (Please Print)

---

Participant's Signature

Date signed: \_\_\_\_\_

**Statement by person obtaining consent**

I certify that I have explained the research study to the person who has agreed to participate, and that she has been informed of the purpose, the procedures, the possible risks and potential benefits associated with participation in this study. Any questions raised have been answered to the participant's satisfaction.

---

Mary T. Gibbons,  
Principal Researcher

Date signed: \_\_\_\_\_

**APPENDIX D:**  
**INTERVIEW QUESTION GUIDE**

Questions for the Interview: Living with Breast Cancer

Maintain consistency and note the emerging themes

1. Thanks you for letting me interview you and just my first question is, just in your own words please tell me about yourself.
2. Again and in your own time tell about your cancer journey.....how does it feel to be a women treated with breast cancer?
3. I suppose your fear...you wanted to sort out how you felt yourself really, how did you.....?
4. How did you feel...were you nervously sick...or what are your thoughts in relation to the treatment you have had?
5. And how are you feeling today?
6. I suppose my next question leading on from that would be that you starting chemotherapy/radiotherapy, what would be your biggest fear about starting chemotherapy/radiotherapy or what would be your anxieties, if any at all.....
7. What stands out for you that occurred while receiving treatment?
8. Have you spoken to other people who had the treatment.....?
9. Ask about the side effects of the treatment and medication...any fears having spoken to other people.
10. Any other issues around the treatment.....vulnerability and taking control.
11. What are some way cancer has affected your outlook in life and your world view?
12. Was your life somewhat changed...and has it impacted on your decision about family, work and life generally? It is important to use probes when possible.
13. Can you talk to me a little about this.....(leading questions but maintain sensitivity throughout)
14. Did you ever feel alone or insecure? Probe: How was that for you?

15. Did you feel the services supported you enough and was there any thing you would like to discuss with me about this?
16. What are the good things in your life at the present and what helped you to adjust easier?
17. What else is there that you think I should know so that I can better understand the things we have just talked about?
18. Is there anything else you would like to ask me? Feel free to ask me any questions.  
Probes : How you behave? Act? Feel? Belief?