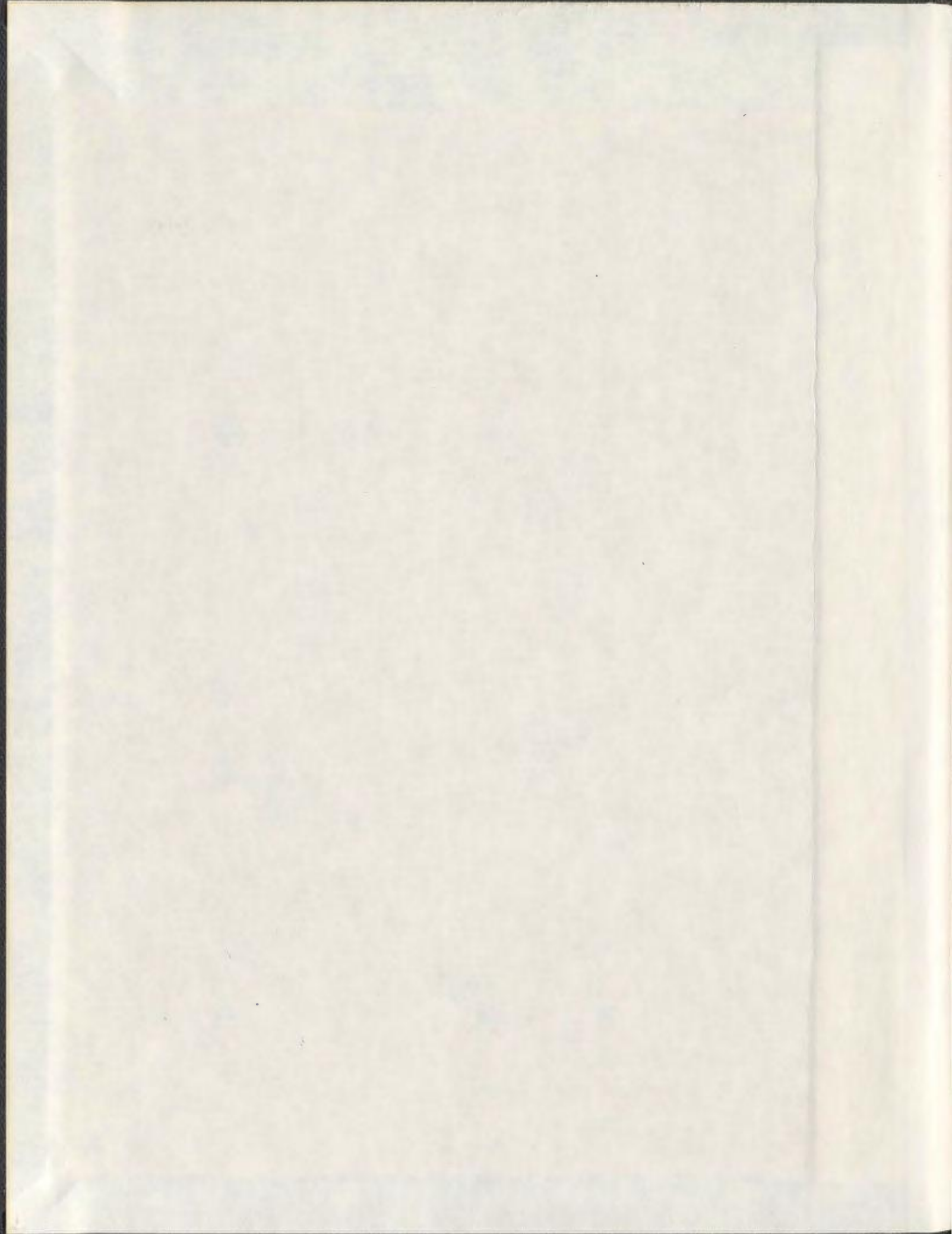


YOUNGER WOMEN'S EXPERIENCES WITH DISTRESS
AT TIME OF BREAST BIOPSY AND DIAGNOSIS

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**Younger Women's Experiences with Distress
at Time of Breast Biopsy and Diagnosis**

By
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Abstract

In Canada, over 23,000 women are diagnosed with breast cancer annually with approximately 19% of these women under the age of 50. Younger women diagnosed with breast cancer often have inferior survival rates and higher recurrence rates compared to older women. The purpose of this research was to bring attention to younger women's experiences with distress from the time they are informed of a breast detected abnormality requiring biopsy until a diagnosis is confirmed. The study focused on women 50 years of age or younger and who were pre-menopausal.

The breast cancer discourse often focuses on women's ability or inability to adapt or cope with a diagnosis of breast cancer. Feminist epistemologies of standpoint theories provided a theoretical framework to guide this study to understand the structural organization of the health care system that may induce or exacerbate distress from younger women's point of view. Principles of Feminist Participatory Action Research were applied as part of the methodology to engage young women in a dialogue to share their personal experiences and make recommendations for the health care system to be more responsive to younger women's breast health needs.

The uniqueness of this qualitative study is that 14 younger women were interviewed prospectively prior and after diagnosis. Research methods included 28 in-depth interviews and two focus groups; participants also kept journals. Data was analyzed using a voice centered relational method. Three themes are discussed as part of the findings: (1) The Unexpected: Finding of a Breast Problem and the Beginning of Anticipatory Illness—Loss of Innocence, The Vulnerability of Living with the Unknown, The 'Being' in Being a Patient and Mobilizing Support While Caring for Others. (2) The Journey from the other Side—I don't have Breast Cancer. (3) The Journey from the Other Side—I have breast cancer.

The research undertaken brings awareness to the experiences of younger women undergoing a breast cancer investigation who have defined distress from their perspective with the hope that the delivery of health care policy and services, including psychosocial services, at time of breast biopsy and diagnosis can be improved.

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Chapter 1: Introduction

1.1 Background of Study

Breast cancer is the most common cancer in the world for women (World Health Organization, 2008, p.13) with the highest incidence rates observed in North America (Ravichandran & Al-Zahrani, 2009). In Canada, breast cancer continues to be the most frequently diagnosed cancer in women with an estimate that one in nine women will be diagnosed with the disease (Canadian Cancer Society (CCS), 2011). For 2011, over 23,400 Canadian women were diagnosed with breast cancer and 19% of these women were under the age of 50 (CCS, 2011). Ontario, the province with the most breast cancer cases in the country, was in 2011 projected to have 9,000 women develop breast cancer and 1,950 women die from the disease (CCS, 2011). In essence five women lose their life to breast cancer every day in this province.

A special report by the Canadian Cancer Society (2009) detailing the impact of cancer on younger people revealed that breast cancer mortality rates in Canada have declined over the past 30 years, however the survival rate for women aged 20-39 is significantly worse compared to other age groups up to the age of 79. Younger women diagnosed with breast cancer often have inferior survival rates and higher recurrence rates compared to older women (Anders et al., 2008). This finding is partly explained by the biological aggressiveness of the disease linked to negative prognostic variables such as the type of tumor, lymph node receptor status (Cancello et al., 2010; Klauber-DeMore, 2005; Maggard et al., 2003; Peppercorn, 2009), and oncogenic signaling pathways found in younger women (Anders et al., 2008).

Young women are not targeted to be recruited into organized breast screening programs thus recommendations for their breast health may vary depending on family history and the clinical practice of their primary care physician. In view of the fact that breast cancer is a disease that more often affects older women (CCS, 2011), young women sometimes experience more difficulties in having breast symptoms taken seriously by health care professionals. This lack of attention can result in delays to diagnosis and potentially lead to more advanced disease (Desmond Pinkowish, 2002; McMahon, 2001; Manly-Lampkin, 2003). Such delays are reflected in a U.S.A. study that found most breast cancer malpractice litigation cases are won by young women, mean age 40 years, who experience delays with their diagnosis (Kern, 1992).

A diagnosis of breast cancer is devastating because women fear the side effects of treatment (Jacobson, Bovbjerg & Redd, 1993) and ultimately the threat that is associated with cancer – death (Dentschuk, 2006). The impact of the illness is great as it may challenge women physically, mentally, emotionally, socially and spiritually (Fitch, Porter & Page, 2008). It affects women and their families in various ways throughout the cancer trajectory from early detection, diagnosis, treatment, and survivorship/rehabilitation to palliation (Fitch et al., 2008).

Breast cancer is not only viewed through a medical lens, where the affected breast can be partly or completely removed, but it is also viewed through a social lens where the loss of the breast can have special meaning in a woman's life. Starting at a young age, girls identify what it means to be female from the multiple messages they receive from society and these messages shape how they view themselves and how society views them (Ferguson & Kasper, 2000). Women live in a society where they are often judged for

their appearance including their breasts. The loss of a breast can threaten the core of a woman's identity because she may be perceived as not being 'whole' after treatment. Many stereotypes exist about youth and beauty, which makes younger women more vulnerable to social pressures (Schover, 1994). For some women the loss of a breast symbolizes the loss of sexual identity (Masood, Edwards, & Arnold, 1996). While a diagnosis of breast cancer is a threat to a woman's health, it can also be an attack on her femininity, nurturance, motherhood, and personal identity (Donegan, 2002).

1.1.1 Breast Cancer: The Differences for Younger Women

Younger women's quality of life is negatively affected in the first year of being diagnosed with breast cancer compared to healthy women in the same age group, with the greatest impact on role limitations caused by physical problems attributed to treatment (Bloom, Stewart, Johnston, & Banks, 2000). Oncology health care professionals often make assumptions about the care provided to younger women based on research conducted with older women diagnosed with breast cancer (Thewes, Butow, Cirkis, & Pendlebury, 2004).

In the first year after a breast cancer diagnosis, studies examining age-related differences find that younger women experience higher levels of anxiety and depression (Burgess et al., 2005; Harrison & Maguire 1995; Vinokur, Threatt, Vinckur-Kaplan, & Satariano, 1990) and greater levels of distress (Bloom & Kessler, 1994; Judin 1996; Stanton, Danoff-Burg, & Huggins, 2002) while older women diagnosed with breast cancer experience more physical and health related problems (Cimprich, Ronis, & Martinez-Ramos, 2002; Vinokur et al., 1990). Compared to older women, younger women also report experiencing more problems with self-esteem, finances, family

relationships (Harrison & Maguire, 1995; Wang, Cosby, Harris, & Liu, 1999), sexuality and worry more about the future (Harrison & Maguire, 1995; Hassey Dow & Lafferty, 2000). Higher levels of pain, lower levels of self-esteem, and less emotional support are risk factors for depressive symptoms in younger women (Wong-Kim & Bloom, 2005).

Younger women diagnosed with breast cancer may be at greater risk for prolonged distress after the first year of diagnosis compared to older women (Politi, Enright, & Weihs, 2007). Compared to older women, younger women experience poorer sexual functioning due to early menopause induced by chemotherapy (Bloom, Stewart, Chang, & Banks, 2004; Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998). They experience more gynecological (e.g., irregular or painful periods, vaginal dryness, loss of libido, lack of information for safe contraception alternatives) and reproductive (i.e., ability to conceive) problems as a result of receiving treatment compared to older women (Thewes et al., 2004). Younger women report that the breast cancer experience has a greater impact on their lifestyle especially with how they socialize and make career choices compared to older women (Thewes et al., 2004). Younger women may also be inclined to seek additional professional counseling compared to older women and demonstrate interest in healthy lifestyle practices wanting more information about diet, exercise, stress management, and complementary therapies (Thewes et al., 2004). It is not uncommon for younger women to experience lingering effects from treatment (Bloom et al., 2004; Cimprich, Ronis, & Martinez-Ramos, 2002) and have regrets five years after their diagnosis about the type of treatment they initially received for their illness (Bloom et al., 2004).

In summary, the quality of life of young women who have breast cancer is negatively impacted in the first year of diagnosis compared to healthy women in the same age group. They also experience more emotional and psychological distress compared to older women diagnosed with breast cancer. The impact of the breast cancer diagnosis and treatment can linger several months and possibly years after active treatment.

1.2 The Purpose and Rationale for the Study

The purpose of this research was to increase the understanding of younger women's experiences with distress from the time they are informed of a breast detected abnormality requiring biopsy until a diagnosis is confirmed. Feminist epistemologies (see Chapter 3, for full description) provided a theoretical framework to guide the study and principles of Feminist Participatory Action Research (see Chapter 4, for full description) were applied as part of the methodology. Women who are under the age of 50 years and not menopausal were interviewed prior to and after learning the pathology results of their breast biopsy. Some women were also invited to participate in a focus group as part of this prospective qualitative study.

The research questions that guided this study were:

- How do women 50 years of age and younger, not menopausal, describe their experience with distress from the time they are informed they require a breast biopsy for a breast detected abnormality to the time they learn their diagnosis?
- How do these women describe factors in the health care system that they perceive contribute to their distress?

- How do these women describe expectations they have about themselves, their social environment and the health care system for resolving their distress?
- How do these women propose the system barriers be resolved?
- What can social workers learn from younger women's experiences of a breast cancer investigation and diagnosis to inform their practices of screening for distress and providing psychosocial services?

This study sought to hear and learn from young women about how they lived the experience of a breast cancer investigation and diagnosis. Their experiences and knowledge can provide a clearer understanding of the personal and system challenges of a breast cancer investigation and can heighten awareness for how to best address distress with young women at the time of diagnosis. The study arose out of several personal and professional life experiences: (a) personally, having been through a breast cancer investigation at the age of 38 and having friends who were diagnosed with breast cancer who shared the challenges they encountered with their diagnosis; and (b) professionally as a social worker, counselling several young women who had experienced delays with their breast cancer diagnosis. For some of these young women, the disease had progressed leaving them wondering at end of life care if life would have been different had they been diagnosed in a timely manner. As a health care professional working in oncology, it is common to hear that distress is experienced with a cancer diagnosis however what is the distress related to and when does it start? My interest in having certain questions answered was shared by women I knew; women who had been diagnosed with breast cancer in their 30s and 40s and health care professionals who understood clinically the

challenges that some of these young women face when diagnosed with the disease. Going through a breast cancer investigation means that for some women, they will receive positive news by learning they do not have breast cancer; while for others, their journey with breast cancer begins. Both scenarios represent life changing experiences albeit with different implications for the young women as they move forward with life.

The women I knew and had discussions with supported my belief that not all health care professionals and family members truly understand the plight of young women undergoing a breast cancer investigation. Very few studies have been conducted with young women at the time a breast problem is detected. Young women I counselled indicated that they did not know what support services were available to them to help them cope with their distress at the time of diagnosis. The delivery of supportive care services to address distress is often sparse during the investigational process (Mayer, 1999). The discourse in the breast cancer literature is often focussed on women's ability or inability to adapt or cope with the diagnosis; these studies rarely comment on how the health care system is organized and how it can induce or exacerbate distress from women's point of view.

What we understand from the literature on breast cancer is that the symptoms, experiences and quality of life of younger women diagnosed with breast cancer are different compared to older women diagnosed with breast cancer. What we also understand from the literature is that the time surrounding a cancer diagnosis invokes a high level of anxiety on the person and the family (Fitch, Porter, & Page, 2008). As shown in Chapter 2 as part of the literature review, studies conducted specifically on breast cancer and time of diagnosis are predominantly retrospective, and the few

prospective studies undertaken have focused mostly on women of all ages. One challenge confronted by younger women going through a breast cancer investigation that is missing in the literature is a description and understanding of living over several weeks with the knowledge that one's life may be changed forever because of a potential life threatening illness and the implications of having that knowledge. Prospective qualitative studies have not been conducted with younger women to explore their experience of a breast cancer investigation, diagnosis, and feelings of distress. I made a commitment to conduct a study where young women's voices could be heard and understood as they stood at the brink of a breast cancer diagnosis.

1.3 Contribution of the Study

Very few studies have described prospectively the experiences of young women undergoing a breast cancer investigation and how they are affected by the process. The aim of the research undertaken was to let young women describe these experiences so that distress could be defined from their perspective. An increased understanding of young women's experiences, their perceptions and meanings of distress could better inform the planning and delivery of health care including supportive care services at the time of breast biopsy and diagnosis. The study also permitted the young women to enter a discussion about the broader context of the cancer trajectory and comment on some of the elements that surfaced during their breast cancer investigation that caused an 'awakening' or awareness about breast health practices or the lack of promotion of breast health practices in public health policy and education. The findings from this study can raise awareness about the gaps that currently exist in addressing the breast health needs of young women as a means to mobilize action for change.

1.4 Organization of Chapters

A brief overview of breast cancer is provided in the first chapter to understand the context for pursuing this study based on the medical and psychosocial challenges caused by the illness and how younger women's experiences with breast cancer are different than older women diagnosed with the disease. The research questions for the study are introduced with the rationale for pursuing the study and the contributions the study findings will have to improve the overall experiences of young women undergoing a breast cancer investigation. The second chapter introduces the reader to the literature review that shapes our current understanding of the psychosocial and medical issues relating to the pre and post breast cancer investigation process for young women presenting with a breast problem. The chapter starts by defining distress in oncology, followed with a rationale for the movement to develop programs that screen for distress. There is a brief overview to explain national and provincial strategies initiated in recent years to ensure people's psychosocial distress issues are screened and addressed as part of improving the overall experience with cancer although these current initiatives are not necessarily linked to diagnostic clinics for cancer. A series of studies are presented to outline what we currently know about distress and the breast cancer investigation process although limited studies specifically address distress for young women going through a breast cancer investigation. Another series of findings are presented based on studies completed with young women who speak about their experiences being diagnosed with breast cancer. Although the studies are mostly retrospective in nature, the information gained from the findings is cross-referenced with the findings of this study as part of the discussion in chapter seven.

The third chapter provides an overview of the epistemological lens that guides the study – feminist epistemologies through the application of principles of standpoint theories. There is a description of the social position of the researcher to create transparency for how she located herself in the research process that shaped the conceptual framework of the study. The fourth chapter introduces the methodological orientations and research methods applied to this study with a description and rationale for how the data were analyzed. In the methodology section there is a description of how principles of feminist participatory action research were implemented to guide the study to arrive at a standpoint to depict the experiences of younger women undergoing a breast cancer investigation and diagnosis. Immediately following this section, there is a description of the method applied utilizing a feminist qualitative research design and applying principles of qualitative inquiry. There is a brief overview of how the study was approved by three different research ethics committees followed by a detailed description of how the participants were invited to join the study, how the interviews and focus groups were conducted, how the journals kept by the participants were utilized for the study and how the medical information was collected from the participants' health records. The chapter concludes with a detailed account about how the data were analyzed using a voice-centered relational method as described by Gilligan, Spencer, Weinberg and Bertsch (2003) and Mauthner and Doucet (1998).

In the fifth chapter, a summary of each participant's story of their breast cancer investigation and diagnosis is presented. The themes identified across the women's stories and the various standpoints of the young women's experiences are provided in chapter six. The themes are: (1) The Unexpected: Finding of a Breast Problem and the

Beginning of Anticipatory Illness—Loss of Innocence, The Vulnerability of Living with the Unknown, The Being in Being a Patient and Mobilizing Support While Caring for Others (2) The Journey From the Other Side—I don't have Breast Cancer (3) The Journey From the Other Side— I have Breast Cancer. Each theme has a set of sub-themes to fully describe the knowledge the younger women shared in the interviews about their experiences with a breast cancer investigation and diagnosis. The discussion is presented in chapter seven based on the findings of the study compared to findings in the literature. The conclusions are presented in chapter eight to address the five research questions supported by the study findings. The limitations of the study are presented followed by clinical, policy and research recommendations.

Chapter 2: Literature Review

This study focused on distress experienced by young women undergoing a breast cancer investigation and diagnosis. As already noted, the experiences of younger women are different than older women given how breast health policy shapes the health care system and the fact that younger women are less frequently faced with a diagnosis of breast cancer. Before describing studies that have investigated distress for women undergoing a breast biopsy, the following section introduces the concept of distress in psychosocial oncology and some of the current health policies being developed to screen for distress in cancer programs.

2.1 What is Distress?

The challenge in defining distress for this study is that the word is used interchangeably to describe many negative stressors that impact the person physically, emotionally, psychologically, socially and spiritually when diagnosed with cancer. The United States' definition of distress reflects the psychosocial and spiritual impact of cancer on the person and is most often referenced by Canadian authors (Bultz et al., 2011; Dudgeon et al., 2011; Canadian Partnership Against Cancer, 2012). Distress is defined as:

a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, and existential and spiritual crisis (National Comprehensive Cancer Network (NCCN), 2009, p. 2).

In essence, if a person is not coping psychologically, socially, or spiritually, they may be experiencing a difficult time coping with the physical symptoms of the disease and its treatment. However physical symptoms are highly prevalent in cancer and they can be predictors of emotional distress such as depression and anxiety (Dudgeon et al., 2011), therefore physical symptoms are also sources of distress. It is difficult to differentiate what comes first, psychosocial distress, the physical distress or a combination of both. For instance, physical pain may cause anxiety therefore treating the pain symptom may result in the natural decline of the anxiety symptom. Measurement scales chosen to screen patients for distress screen for physical and psychosocial distress as described later in this section. For the purpose of this study it was important to establish a definition of distress that encompassed the physical and psychosocial dimensions of a breast cancer investigation. It was also important, for this study, to find a definition that was applicable to younger women, undergoing a breast cancer investigation. Therefore, for the purpose of this study, the definition of distress was adapted from the NCCN's (1999) definition to reflect the pre-diagnostic stage of cancer: distress is a multifaceted unpleasant experience of an emotional, psychological, social, spiritual, and/or physical nature that may interfere with the ability of young women to cope with their potential diagnosis of breast cancer and/or diagnosis of breast cancer and treatments. Feelings of vulnerability, sadness and fear are common and have the potential to become disabling leading to depression, anxiety, panic, social isolation, existential, and spiritual crisis. As we continue with the literature review, distress will be referenced based on the context of the articles being discussed. This means the word will continue to be used to reflect different forms of distress: emotional, psychological, social, spiritual, and/or physical.

2.1.1 The Prevalence of Distress in Oncology and the Call for Screening Programs

Medical, psychological, and social factors all contribute to the level of distress experienced by people¹ diagnosed with cancer (Sivesind & Baile, 2001). The prevalence of significant emotional distress, defined as anxiety, depression, and adjustment disorders, ranges from 35% to 45% across studies in North America (Carlson & Bultz, 2003; Zabora, Brintzenhofesoc, Curbow, Hooker & Piantadosi, 2001). Study results show that 20-25% of people diagnosed with cancer will experience major depression with percentages increasing when there are higher levels of physical disability, advanced illness, and pain (Carlson & Bultz, 2003). In a sample of 4,496 people who were screened for distress at initial consultation with an oncologist, 32.8% of women diagnosed with breast cancer (n = 1249) experienced significant levels of distress (Zabora et al., 2001). Depression has been found to decrease quality of life and adherence to medical treatment for a variety of chronic health conditions (Palmer & Coyne, 2003).

There is also a greater burden on health care system resources when distress symptoms are not managed in people diagnosed with cancer. A Canadian survey conducted with 913 patients demonstrated that people, who experienced unmanaged cancer-related fatigue, or physical distress, were more likely to visit their primary care physicians, the emergency department, and/or access other community services (Ashbury, Findlay, Reynolds, & McKerracher, 1998). There were actual cost benefits to the health

¹ Making reference to people as 'patients' can be disputed as for some critics it implies lack of autonomy and self-determination. Therefore I have tried to use other terminology when appropriate such as people with cancer, young women with breast cancer, a person with cancer etc. However there are times I do make reference to patients depending on the context of the literature and to explain the transition of young women into their new role of becoming a 'patient'.

care system when people were provided with appropriate and effective psychosocial support. A randomized control trial comparing women diagnosed with breast cancer who participated in a professionally led support group post diagnosis, to women who received general information, showed that those women who participated in the support group had fewer medical visits (Simpson, Carlson & Trew, 2001).

Oncologists and nurses are the gatekeepers of referrals to psychosocial oncology unless people self-refer. People often do not disclose to the oncologists and nurses their symptoms of depression because of language and cultural barriers: they see their depression as being a normal reaction given the severity of the illness; they believe nothing can be done; they are afraid to be judged as ungrateful, uncooperative or inadequate; or they perceive the health care team as being too busy to be bothered with these concerns (Butow, Brown, Cogar, Tattersall, & Dunn, 2002; Sivesind et al., 2001). People may also dismiss or minimize what they are feeling, thinking it is silly or they are embarrassed to discuss their feelings with their health care team – afraid it will reflect poorly on their coping abilities (Ryan et al., 2005).

Although it is recognized that individuals with medical conditions such as cancer experience distress, a person's level of distress is not consistently recognized or assessed in routine interactions between patients and their physicians. A German study, with the purpose of assessing oncologists' awareness of distress and social support by comparing their assessment with the assessment by validated tools, found that radiation oncologists were able to detect moderate distress when interacting with patients; however they were less able to detect severe distress. Their recommendation for supportive counseling did not correlate with the patients' levels of distress (Sollner et al., 2001). Butow et al.,

(2002) conducted a study to explore the frequency of direct and indirect informational and emotional cues occurring in a cancer consultation. Their findings showed that physicians were effective in identifying and responding to peoples' informational needs but less consistent in addressing the cues for emotional support (Butow et al., 2002). Also, patients may not have their symptoms of depression detected when consulting their primary care physician (Coyne, Schwenck, & Fechner-Bates, 1995). These findings may explain why people with cancer are not referred for psychosocial counselling. Other patients claim they are just not aware of the support services available to them, even though they may have received information about them at some point in time during their treatment (Plass & Koch, 2001). This finding is not surprising based on the reality that patients are often overwhelmed with the amount of information they receive initially as they enter the cancer system and they may not remember information about the services available to them.

The need to implement screening tools for distress has evolved out of the recognition that few people are referred for psychosocial interventions (NCCN, 2009; Ryan, et al., 2005; Zabora et al., 1990). Implementing preventive counselling strategies by doing full psychosocial assessment on every person is not feasible due to the time involved, and the increased costs to the health care system; therefore, effective means to screen for distress are required (Ganz et al., 1993; Zabora, 1990).

Screening for distress is a rapid method to prospectively identify people who are at risk for distress (Zabora et al., 2001). Assessment on the other hand is a series of tasks that follows the initial screening. The follow-up assessment includes estimating the severity of the distress, defining a course of action, developing an understanding of the

person, establishing a diagnosis and developing the initial steps of a therapeutic relationship (Zabora et al., 2001). The need to systematically implement screening tools has evolved out of the recognition that few people are referred for psychosocial interventions when diagnosed with cancer.

2.1.2 Distress: Implications for Policy and Practice in the United States

A United States panel consisting of social workers, nurses, psychiatrists, psychologists, spiritual care workers, oncologists, and a patient representative worked together from 1997 to 1999 to develop 'treatment' guidelines to manage the symptoms of distress in recognition that the psychosocial needs of cancer patients were not being met (NCCN, 1999). The panel concluded that the stigma associated with seeking counselling to deal with a diagnosis of cancer was far too great for cancer patients. Busy clinics also prohibited oncologists and nurses in routinely asking patients about their emotional state (NCCN, 1999). The panel selected the word distress to describe the psychological and emotional trauma experienced when diagnosed with cancer as they found the word distress to be less stigmatizing than the words psychiatric, psychosocial or emotional. Hence, health care professionals could ask patients about their distress the same way they ask patients about their physical pain on a scale of 0 to 10, 10 being extreme pain or, in this case, distress (NCCN, 1999). The ultimate goal for developing practice guidelines was to ensure distress was recognized and treated. Thus early detection of distress could facilitate positive outcomes such as preventing severe symptoms of anxiety and depression from escalating, improving the quality of life of cancer patients, and reducing demands on the health care system (NCCN, 1999). Despite these guidelines, the up-take for integrating routine screening for distress in clinical practice is less than optimal.

Findings from a 2005 survey conducted with 15 NCCN member institutions involved in the development of the guidelines suggested that there was low up-take (20%) of routine screening for distress in cancer clinics (Jacobsen & Ransom, 2007). Another United States national survey found that only 14.3% of oncologists used a standardized measure to screen patients for distress (Pirl et al., 2007). Results of a pilot study recently conducted with fifteen oncology social workers who participated in focus groups, demonstrated that social workers recognized the benefits of screening cancer patients for distress such as the opportunity to establish relationships with them, seeing patients in most need of psychosocial assistance, fostering interprofessional collaboration and demonstrating the value of social work (Oktay, Nedjat-Haiem, Davis & Kern, 2012). However concerns were also identified such as the possibility of the inability to respond to identified needs, choosing a tool to reduce the false positives and false negative screens, addressing increased caseloads and respecting the wishes of patients who may not be interested in addressing their psychosocial needs (Oktay et al., 2012). The development of practice guidelines and training for social workers may be required to support the clinical practice of screening patients for distress (Oktay et al., 2012).

2.1.3 Distress: Implications for Policy and Practice in Canada

In 2004, the Council of the Canadian Strategy for Cancer Control, known today as the Canadian Partnership Against Cancer (CPAC), endorsed the practice to screen for distress based on a position paper from the Rebalance Focus Action Group (Bultz, 2004). It recognized that the lack of assessment for distress symptoms by health care professionals resulted in very few patients being referred for psychosocial or supportive care services. Implementing systematic screening programs would prompt health care

professionals to assess symptoms of distress (Bultz, 2004). In 2006, distress was added as the 6th Vital Sign following temperature, respiration, heart rate, blood pressure, and pain as a means to recognize distress is embedded in the cancer journey (Bultz & Carlson, 2006). Despite the endorsement of Screening for Distress, the 6th Vital Sign, very few cancer centres across Canada engaged in screening cancer patients for distress (Vodermaier & Linden, 2008).

When a group of clinicians, policy makers, and researchers met in Calgary in 2008, the purpose of the meeting was to review clinical practices to screen for distress and gain consensus for moving forward a national strategy to ensure every cancer patient has their symptom of distress screened and assessed. At this meeting there was a commitment for the development and implementation of guidelines and standards for distress screening to be implemented nation-wide (Canadian Partnership Against Cancer (CPAC), 2008). By 2009, Accreditation Canada would recognize Screening for Distress, as the 6th Vital Sign with the expectation that health care teams evaluate and monitor distress when working with people diagnosed with cancer. Today, any organization providing cancer services and seeking to be accredited is required to meet this new standard (Accreditation Canada, 2009).

In 2008 under the umbrella of the CPAC, the Cancer Journey Action Group (CJAG) released a toolkit report with guideline recommendations for implementing Screening for Distress, the 6th Vital Sign in Canada (Bultz et al., 2011). The premise being, if patients are screened routinely for distress, their symptoms can be identified and managed and levels of distress can be prevented from escalating. The toolkit describes the elements of a distress screening program and the processes to follow when implementing

such a program (CPAC, 2009): (1) all people diagnosed with cancer should be screened; (2) screening should start at the point of entry and at critical points in the cancer trajectory; (3) electronic and paper methods of screening tools should be accessible based on availability in each jurisdiction; (4) screening tools should assess three domains – physical, practical, and psychosocial and; (5) screening tools of choice are the Edmonton Symptom Assessment System (ESAS) scale and the Canadian Problem Checklist (see Appendix A). The combination of these tools screen for the three domains of: psychosocial, practical, and physical (CPAC 2009).

The ESAS is a nine item visual analogue scale that permits a person to indicate the severity of their symptom. Patients rate their pain, fatigue, nausea, depression, anxiety, drowsiness, appetite, overall feeling of wellbeing, and shortness of breath on a scale of 0-10, with 10 being the worst (Bruera, Kuehn, Miller, Selmser, & Macmillan, 1991). As well, the tool provides a person with the option for identifying other problem(s). The ESAS scale is a validated, reliable tool widely utilized in palliative care (Bruera et al., 1991) and in other oncology patient populations (Chang, Hwang & Feuerman, 2000). A score of 1-3 is considered normal distress; 4-6 indicates moderate distress that requires further assessment for intervention; and 7-10 demonstrates severe distress where immediate assessment and intervention is required (CPAC, 2009). The Canadian Problem Checklist (CPC) is a self-rating tool that asks people to indicate problems they are experiencing under the headings of emotional, spiritual, practical, social/family, informational and physical concerns (CPAG, 2009).

There were nine jurisdictions funded through the CPAC-CJAG to implement screening for distress across Canada starting in 2009² (CPAC, 2012). Over the past three years screening for distress programs have been implemented in 26 rural and 13 urban locations through this Pan Canadian initiative. All nine jurisdictions screen with the minimal dataset that includes the ESAS and CPC (CPAC, 2012). Screening programs have mostly focused on screening people for distress while going through cancer treatment and not during the diagnostic phase of the cancer journey. Results from the various jurisdictions are just starting to be shared through conference meetings³. The knowledge gained from these projects will provide several insights: how to implement screening for distress as a program; increase the understanding of the prevalence of distress in different populations across Canada; determine if the tools, ESAS and CPC, are effective at detecting distress; determine if routine screening results in effectively managing symptoms of distress identified by patients; identify additional interventions that may need to be developed to manage symptoms of distress and; identify service gaps where patients cannot access services to manage their distress (Mayer & Damore-Petingola, 2011). Key learnings from these projects can inform health care professionals about how to screen for distress during other critical points of transitions in the cancer journey such as during the cancer investigation/diagnostic and cancer survivorship phases.

² Sudbury was the 3rd jurisdiction to implement Screening for Distress, the 6th Vital Sign at 14 Community Oncology Clinic Network sites where people receive chemotherapy closer to home. The quality improvement project was conducted from April 2009 to March 2011 with patients screened for distress at each cycle of chemotherapy (Mayer & Damore-Petingola, 2011).

³ Several jurisdictions presented their results at the Canadian Association of Psychosocial Oncology in Vancouver, British Columbia, April 2012

2.1.4 Distress: Implications for Policy and Practice in Ontario

Cancer Care Ontario (CCO) is the provincial agency in Ontario responsible for continually improving cancer services and is the government's cancer advisor (Cancer Care Ontario, 2012). Since 2006, 14 cancer centres across the province have been mandated to screen patients for physical and psychological symptoms of distress with the ESAS scale (Dudgeon et al., 2011). CCO does not mandate that the CPL be incorporated into routine screening hence patients are not screened for their social, practical, informational, spiritual needs and other emotional and physical needs not identified on ESAS (see Appendix A). Findings from the nine jurisdictions who have implemented screening for distress using the minimal dataset as recommended by CPAC-CJAG will serve to support the change of practice in Ontario to screen for distress with the CPC in addition to the ESAS to ensure patients are screened for the physical, psychosocial, and practical domains.

In summary, Canada is the first country to endorse Screening for Distress, the 6th Vital Sign. The screening for distress initiatives, led by the CPAC-CJAG in Canada and the NCCN in the United States, have been instrumental in North America to shed light on the importance of meeting the psychosocial needs of women and men diagnosed with cancer. Health care professionals must become proactive in identifying distress and providing the appropriate interventions to reduce distress in the cancer patient population. These initiatives emphasize the position that we are not treating an illness but we are treating people affected by an illness that impacts on every aspect of their lives. More attention must be focused on the emotional, psychological, spiritual, and physical health of people diagnosed with cancer ensuring they have access to services when they need

them. In essence, the health care system must move away from a focused biomedical to a biopsychosocial model of care.

It is important to recognize that distress screening programs are meant to identify symptoms of distress and not necessarily the causes of distress. This implies that the onus for change lies with the people diagnosed with cancer who require support to manage their symptoms. There is no recognition for the structural deficiencies of the health care system that may be causing distress e.g. fragmented services that lead to delays to diagnosis and causes anxiety. It is therefore imperative that organizations look at the root of distress symptoms to identify system changes that are necessary to reduce distress.

Studies reporting results for young women undergoing a breast cancer investigation who have been screened for distress are non-existent. There are relatively few prospective studies conducted with younger women that truly explain what distress is like during a breast cancer investigation. Until we know more about younger women's experiences with a breast cancer investigation, there will be no efforts to improve the level of services provided to women at this stage of the cancer trajectory. We now look at studies conducted with women undergoing a breast cancer investigation and how they experience distress during this stage of the cancer journey. Most of these studies are conducted with women of all ages undergoing a breast cancer investigation therefore not specific to young women.

2.2 Understanding Cancer Distress: Pre-diagnosis and Immediately Post-Diagnosis

The diagnostic phase of breast cancer is different from other parts of the cancer trajectory as it forms the interface where women receive confirmation that they are either healthy or ill with a potential life threatening illness (Poole, 1997). The diagnostic phase

is recognized as being one of the most stressful times during a breast cancer investigation (Northouse, 1989). Very few studies have been conducted with younger women undergoing a breast cancer investigation thus the review of the literature encompasses studies with women of all ages⁴. The studies were chosen if the study purpose focussed on women undergoing a breast cancer investigation. For the following study descriptions, this literature is divided into two groups: (1) studies conducted solely with women with a benign breast biopsy result and; (2) studies conducted with women with a benign breast biopsy result or a diagnosis of breast cancer. A summary of the studies and their results are presented for each section followed by Table 1. (p.31) and Table 2. (p. 44). Information is grouped under the headings of: first author and year of study, purpose of the study, the population and eligibility criteria, study design, participant characteristics, relevant measures and outcomes.

2.2.1 Distress: Women with a Benign Breast Biopsy Diagnosis (see Table 2.1. p. 31)

Andrykowski et al. (2002) examined distress and perceptions of breast cancer risks in women with a benign breast biopsy result compared to women from the general population. A total of 100 women with a benign breast biopsy result, recruited from a comprehensive breast clinic in Kentucky, were compared to a healthy comparison group comprised of 76 women recruited through community advertisement. The findings of this study demonstrated that the benign breast biopsy group overestimated their lifetime risk

⁴ The most recent and final literature search undertaken for this study was in December 2011. Databases searched include CINAHL, Academia Search Complete, Social Work Abstracts, PsychInfo, and PubMed. Keywords searched; breast cancer + young women or premenopausal + psychosocial + breast biopsies + (finances or information, or sexuality, or screening guidelines or presentation or physical activity or smoking cessation). Articles were also retrieved from the electronic newsletter "Breast Cancer Network News" that is sent at least once per week citing all the latest publications on breast cancer.

of breast cancer compared to the healthy comparison group, $t(175) = 4.41, p < .01$. The benign breast biopsy group had higher scores on the Intrusion and Avoidance subscales of the Impact of Event Scale (IES) (all $ps < .05$) compared to the healthy comparison group. The difference between the two groups on both IES indices were in the range of 0.5 SD , a reasonably large effect reported by the authors supporting the hypothesis that women with a benign breast biopsy result experienced a negative psychological impact. (Andrykowski et al., 2002). Analysis of the IES-Avoidance and IES Intrusion scores for the benign breast biopsy group at the four and eight month interviews compared to the scores of the healthy comparison group from the first assessment interviews revealed significant group difference (t -test, all $ps < .05$). The authors concluded that distress remains significantly elevated for at least eight months following a benign breast biopsy result (Andrykowski et al., 2002).

The authors recommended the development of psycho-educational interventions to ensure women can cope with a benign breast biopsy outcome. They cautioned that the findings should not be generalized to all women who have a benign breast biopsy as the sample was mostly Caucasian and similar results would need to be replicated in a racially and ethnically more diverse sample. Also, minority women and women who had perceived elevated risks of developing breast cancer were less likely to complete the second and third interviews (Andrykowski et al., 2002). This study is one of the few longitudinal studies to assess the level of distress in women several months after receiving their benign breast biopsy result. The finding that women may experience high levels of distress several months after learning they do not have breast cancer underscores

the importance of assessing and discussing the impact of a breast cancer investigation with women in a proactive manner as a means to reduce distress.

Benedict, Williams, and Baron (1994) mailed 412 questionnaires to women who received a breast biopsy with a benign result in the previous two years. The purpose of the study was to describe the amount of anxiety recalled by women and to describe the coping mechanisms used by women from the time they discovered the abnormality to the time they learned that the tumor was benign. A total of 238 surveys were returned for a 58% response rate. Women rated the degree of worry they experienced on a visual analogue scale with scores ranging from 0 to 15. The majority (90%) of the women scored over 6, which the authors classified as moderate to severe levels of worry. The strategies women used to cope during the stressful time were grouped under five themes: (1) diversionary theme, keeping busy physically or/and mentally; (2) interpersonal theme, talking with people as a means to seek reassurance and information; (3) spiritual theme, relying on a higher power to resolve problem; (4) hopeful theme, thinking positively; (5) avoidance theme, blocking thoughts about the experience from entering the mind (Benedict et al., 1994). This work is one of the earliest studies demonstrating that women with benign breast biopsy results recall a lot of worry from their breast cancer investigation.

Lebel et al. (2003) conducted a pilot study to identify women at risk for experiencing distress after receiving an abnormal mammogram and waiting for a breast biopsy. A total of 25 women from a breast centre in Montreal participated in the initial telephone interview and 76% of these women completed the second interview. Study results showed that 30% of the women experienced levels of depression that reached

clinical significance at both points of measurement using a cut-off score of 16 on the Centre for Epidemiologic Studies Depression Scale (CES-D). Data analysis for the State Trait Anxiety Inventory (STAI) revealed that close to 20% of the sample score was in the 97th percentile of a normative community sample. The mean score of the STAI at the first interview ($M = 35.4$) and second interview ($M = 34.6$) were comparable to women newly diagnosed with breast cancer (Lebel et al., 2003).

The women identified the nurse as the person that was the most helpful at the clinic. Women waited on average 26.1 days to receive their breast biopsy and they reported that the wait time was too long. Women relying on cognitive-avoidant coping strategies, who were employed, who had a history of previous breast biopsies and who had a family history of breast cancer experienced the most distress (Lebel et al., 2003). Although the sample was small ($N=25$), the results from this pilot study are consistent with other studies demonstrating that women experience distress when undergoing a breast biopsy (Andrykowski et al., 2002; Benedict, Williams, & Baron, 1994; MacFarlane & Sony, 1992). It is important to note that women with a highly suspicious lesion for malignancy and scheduled to receive a breast biopsy within two weeks, were excluded from the sample. It is not clear if they were excluded because of the research design or if the researchers were not comfortable approaching women to participate in a study who may have been experiencing high distress knowing there was a good chance their breast lesion was cancerous. If the latter explanation is true, it should be noted that women are often required to make decisions about treatment and about participating in clinical trials at a time when they may be experiencing high distress. Asking women to participate in a study that asks them about their distress when they are under distress is feasible when a

study is well designed, researchers have the appropriate training to interact with the participants (Kvale & Brinkman, 2009) and the informed consent process is clear permitting the participants to make an informed choice to join the study or not (Leisey, 2009). The act of excluding voices from the research process when people are competent to judge if they want to share information about their personal lives risks losing invaluable insight and wisdom for the inquiry sought (Leisey, 2009).

MacFarlane and Sony (1992) investigated the anxiety of women scheduled for breast biopsy. Forty-two women participated in a telephone interview within one week of being discharged from the hospital after receiving an excisional breast biopsy and learning their tumour was benign. Forty-eight percent of the participants reported concerns they experienced with their breast biopsy. The most frequently reported concerns (more than one concern could be identified) were fear of having cancer (14.3%), lack of information received from their physician (11.9%), concern about the health of their families (11.9%) and pain at the operative site (11.9%). Other concerns identified were the size of the lump, soreness in the arm, body image, wound drainage, and the possibility of having another lump (MacFarlane & Sony, 1992).

For the 42 women who participated in the interviews, 33.3% reported speaking with friends as being the most helpful in reducing anxiety followed by speaking with their husbands (23.8%). The most helpful person in the health care setting was identified as the nurse (45%). The items selected most frequently in the extreme category on the Trait Anxiety Inventory were scared (54.7%), anxious (33.3%), worried (42.8%), nervous (33.3%) and concerned about a possible misfortune (33.3%) (MacFarlane & Sony, 1992).

This study was conducted in the early 1990's at a time when women were hospitalized for excisional biopsies. Today less intrusive procedures are conducted as part of the diagnostic work-up therefore when women receive an excisional breast biopsy under local or general anesthetic, they are discharged home on the same day; thus their concerns or worries may be different. As well, women in this study were asked to retrospectively comment on their experience of breast biopsy knowing they did not have breast cancer, whereas interviewing them prior to breast biopsy may have yielded different results. Despite these limitations, this was one of the first studies to describe specific concerns and worries that women may experience at time of breast biopsy.

A phenomenological study explored women's lived experience with a breast biopsy (O'Mahony, 2001). Eight women ranging in ages from 22 to 55 were interviewed 7 to 14 weeks after their breast biopsy confirmed a benign tumour. These women reported that finding the breast lump was the most distressing experience encountered. Their reactions to finding the lump ranged from seeking immediate medical attention to delaying reporting symptoms and denying the symptoms to thinking about a shorter lifespan. Waiting for the surgery itself and waiting for pathology results also caused distress. Women reported not necessarily being concerned about the biopsy procedure although some women reported a negative experience when they received a fine needle aspiration. Women reported coping with finding the lump by keeping busy, talking with others, remaining hopeful and optimistic (O'Mahony, 2001).

The finding that women were pleased with the support received from their social network is contrary to results of Seckel's and Birney's (1996) study which showed that women perceived having less support from their social network and experienced more

distress. The fact that Seckel and Birney (1996) administered questionnaires prior to biopsy and had a larger sample, may explain the difference in findings between studies. Regardless, O'Mahony's study results confirm that finding a breast lump, waiting for procedures and test results can induce distress.

2.2.2 Distress: Women with a Benign Breast Biopsy Diagnosis or Breast Cancer Diagnosis (see Table 2.2 p. 44)

Chappy (2004) interviewed 22 women after they received the pathology results of their biopsy confirming their benign or breast cancer diagnosis for the purpose of obtaining descriptions of their perioperative experiences with distress. Fourteen women had stereotactic core biopsies; seven women received excisional core biopsies; and one woman had a core needle biopsy. Six of the 22 women were diagnosed with breast cancer. The qualitative analysis revealed four themes reflecting the women's experiences. The first theme was certitude representing the need for women to be well informed about procedures, to know when they will receive results and to ponder the ramifications of a breast cancer diagnosis on their families while waiting for results. The second theme referred to care depicting the support received from health care professionals that included customizing information to the needs of the woman's unique situation and providing reassurance in a hopeful and realistic manner. The third theme, focusing on me, illustrated the importance of trust between a woman and her physician and seeking a second opinion when necessary. The last theme was justice reflecting the principles of equality, reciprocity, and fairness, that included the thought of being too young to be diagnosed with breast cancer, the need for advocacy for timely appointments, the need to be in contact with other women who have been through a breast biopsy, and

Table 2.1. Studies Conducted with Women with a Benign Breast Biopsy Diagnosis

First author, year	Purpose	Population and eligibility	Study Design	Participant characteristics	Relevant Measures	Outcomes
Andrykowski 2002	Identify the psychological impact of BBB in women by comparing women who underwent a breast biopsy with a benign tumor to a HC group of women	<u>BBB group</u> -Breast Clinic -Scheduled for BB or FNA <u>HC group</u> -Media advertisement <u>Both Groups</u> -Age > 18 years of age -No history of BC or FNA -Read and understand English -Telephone in the home -Signed consent form	-Quantitative -Prospective -Longitudinal design <u>-BBB group</u> interviewed 21.4 days, 4 and 8 months post biopsy <u>-HC group</u> interviewed at initial interview for the BBB group	-BBB group, $N = 100$ -Age range 19 to 84 -HC group, $N = 76$ -Age range 21 to 82 years	<u>BC risk variables</u> -Information collected to estimate relative (Gail et al., 1989) and lifetime risk (Benichou, 1993) of developing breast cancer; also age at menarche, parity, history of BBB, # of first-degree relatives with BBB <u>Dispositional variables</u> -MBSS-SF -LOT <u>Social Support</u> -DUKE-SSQ <u>Psychological distress</u> -CES-D -POMS-F -IES <u>BC worry</u> -BC-Worry Impact (adapted) <u>Perceived BC risk</u> -Personal BC Risk scale -Typical BC Risk scale	-BBB group had higher objective lifetime risk for BC than the HC group $t(175) = 4.41, p < .01$ -For all other measurements, the only difference between the BBB group and HC group is that the BBB group had higher scores on the Intrusion and Avoidance subscales of the IES (all $ps < .05$). Group differences on both IES indices were in the range of 0.5 SD – reasonably large effect. Evidence to support hypotheses that BBB may have a negative psychological impact on women -A t -test of the IES-Avoidance and IES Intrusion scores for the BBB group at the 4 and 8 month interviews compared to the scores of the HC group from the first assessment interviews revealed significant group difference (all $ps < .05$) -Authors concluded that women who undergo breast biopsy may have higher levels of breast cancer specific distress after 8 months even if malignancy is not found

Note. BBB = Benign breast biopsy; HC = Healthy comparison; FNA = Fine needle aspirate; BC = breast cancer; MBSS-SF = Miller Behavioral Style Scale-Short Form; LOT = Life Orientation Test; DUKE-SSQ = Duke UNC Functional Social Support Questionnaire; CES-D = Centre for Epidemiologic Studies Depression Scale; POMS-F = Profile of Mood States Short Form; IES = Impact of Events Scale

Table 2.1. (Continued)

First author and year	Purpose	Population and eligibility	Study Design	Participant characteristics	Relevant Measures	Outcomes
Benedict 1994	Determine the amount of anxiety recalled by women who had an excisional breast biopsy -Describe the coping strategies used from time of learning the abnormality to time of definitive diagnosis	-Two private practices and one academic medical centre across five southern states -Women who had excisional breast biopsies with benign results within the previous two years	-Quantitative -Retrospective -Cross-sectional -Survey mailed to women who had received a breast biopsy in the past two years	<i>N</i> = 238 women -Age <i>M</i> = 52, range 21 to 81 years	-Questionnaire developed by Benedict (1994). Women asked to recall their worry about having received a breast biopsy using a visual analogue scale of 0 'not worried at all' to 15 'the most worried I have ever been' -Qualitative data collected for the following question: If you were worried during the time from first finding the lump until you were told the diagnosis, what did you do to decrease or control the worry?	-10% of the participants recalled mild (0-10) level of worry, 32% moderate (6-10) level of worry and 58% severe (11-15) level of worry -Strategies to cope: (1) diversionary theme; staying physically busy and mentally occupied (2) interpersonal theme; seeking reassurance and information through sharing and talking with others (3) spiritual theme; relinquishing the problem to a higher power (4) hopeful theme; thinking positively (5) avoidance theme; blocking the experience from the mind
Lebel 2003	Quantify distress and describe the experience of a sample of women placed on a waiting list to receive a breast biopsy	-Breast cancer clinic -Women referred for breast biopsy after a breast screening mammogram	-Quantitative -Prospective -Longitudinal -Women interviewed same day or day after being placed on a wait list for breast biopsy and two days prior to breast biopsy	<i>N</i> = 25 -Age <i>M</i> = 56, <i>SD</i> = 12	-STAI -CES-D -IES -Brief Cope Inventory -Open ended questions regarding information received, opinion for wait times and recalling information received at initial appointment with nurse	-CES-D scores 30% of the women experienced levels of depression reaching clinical significance at both points of measurement using a cut-off score of 16. -STAI revealed close to 20% of sample scored in the 97th percentile of a normative community sample. The mean score of the STAI at the first interview (<i>M</i> = 35.4) and second interview (<i>M</i> = 34.6) were comparable to women newly diagnosed with breast cancer

Note. STAI = State Trait Anxiety Inventory; CES-D= Centre for Epidemiologic Studies Depression Scale; IES = Impact of Event Scale

Table 2.1. (Continued)

First author, year	Purpose	Population and eligibility	Study Design	Participant characteristics	Relevant Measures	Outcomes
						<ul style="list-style-type: none"> -Over half of the women overestimated their personal risk of the biopsy being malignant Women waited on average 26.1 days to receive their breast biopsy; wait time too long according to women -Women who relied on cognitive-avoidant coping strategies, who are employed, who had a history of previous breast biopsies and who had a family history of breast cancer experienced the most distress
MacFarlane 1992	Investigate the anxiety experienced by women who had an excisional breast biopsy	<ul style="list-style-type: none"> -Private practice of surgeons -Age 18 or older 	<ul style="list-style-type: none"> -Quantitative -Retrospective -Cross-sectional -Telephone interviews with women one week after discharged from the hospital post excisional biopsy 	<ul style="list-style-type: none"> <i>N</i> = 42 -Age range 21 to 75 years 	<ul style="list-style-type: none"> -Interview guide consisting of 30 items to measure various variables e.g. demographic information, date discovered the lump etc. -STAI of the Self-Evaluation Questionnaire (adapted) 	<ul style="list-style-type: none"> Concerns most frequently identified by 20 (47.6%) women: fear of having cancer (<i>n</i> = 6, 14.3%), lack of information received from physician (<i>n</i> = 5, 11.9%), concerned about the health of their families (<i>n</i> = 5, 11.9%) and the pain at the operative site (<i>n</i> = 5, 11.9%). Other concerns identified: the size of the lump, soreness in the arm, body image, wound drainage, and recurrence of lump

Note. STAI = State Trait Anxiety Inventory

Table 2.1. (Continued)

First author and year	Purpose	Population and eligibility	Study Design	Participant characteristics	Relevant Measures	Outcomes
						<ul style="list-style-type: none"> -14 (33.3%) women reported speaking with friends as most helpful to reduce anxiety followed by speaking with their husbands ($n = 10$, 23.8%). -Person most helpful in the health care setting is the nurse ($n = 18$, 45%) -Items selected most frequently in the extreme category on the Trait Anxiety Inventory were: scared ($n = 23$, 54.7%), anxious ($n = 14$, 33.3%), worried ($n = 18$, 42.8%), nervous ($n = 14$, 33.3%) and concerned about a possible misfortune ($n = 14$, 33.3%)
O'Mahony 2001	Explore women's lived experience of breast biopsy with a benign finding with a view to gain a deeper understanding of their individual experiences and the meanings that it holds for them	<ul style="list-style-type: none"> -Breast clinic -Age > 18 years of age -Read and write in English -No previous history of BC -Not undergoing psychiatric treatment -Six weeks post biopsy -Confirmation of benign diagnosis 	<ul style="list-style-type: none"> -Qualitative -Retrospective -Cross-sectional -Open, unstructured face to face interviews 7 to 14 weeks after biopsy 	<p>$N = 8$</p> <p>Age range 22 to 54 years</p>	In-depth interviewing	<ul style="list-style-type: none"> -Finding breast lump most distressing experience -Reactions ranged from seeking immediate medical attention to delaying reporting symptoms, to denying the symptoms to thinking about a shorter lifespan. -Distress caused by wait times for procedure and pathology results. Few concerns reported about biopsy procedure although some women reported unpleasant experiences with FNA -Coping strategies when finding the lump — keeping busy, talking with others, remaining hopeful/optimist.

Note. BC = breast cancer; FNA = fine needle aspirate

the ability for women who have received a breast biopsy to educate other women on breast health practices (Chappy, 2004).

Both groups of women, women with breast cancer and women with a benign tumor, were interviewed after their breast biopsy giving a broader perspective on the issues women face when going through a breast cancer investigation. The uniqueness of the study is that the qualitative interviews elicited information from women about their distress and identified deficits in the health care system where improvements are required particularly in the area of wait times and support to women.

A phenomenological study was conducted with 20 Turkish women who received an excisional breast biopsy under general anesthetic during day surgery to understand the women's experience with biopsy and the meaning it holds for them (Demir, Donmez, Ozsaker, & Diramali, 2008). The women were interviewed one week after their biopsy prior to their post-operative follow-up visit. Three themes identified from the experiences of these women were fear, the need for information and spiritual needs. Upon finding a breast lump the women reported being afraid the lump was cancerous, they feared the surgery, and they were also afraid of waking-up without their breast. Some women reported not being well prepared by their surgeon while others reported developing trust in their surgeon who had prepared them for the procedure. Women indicated that information provided post-biopsy should be given both verbally and in writing as women are drowsy following anesthesia making it is difficult to remember instructions received about post-care biopsy. Spirituality was a mean to cope for these women who reported praying that the lump was not cancerous (Demir et al., 2008). The age of the participants was not reported in this study making it difficult to interpret the findings to a specific age-

group of women undergoing a breast cancer investigation. The authors did not provide information about the diagnostic findings from the pathology reports thus it is unclear if the women had a benign or malignant tumor.

A group of Taiwanese researchers investigated the level of uncertainty and anxiety experienced by women undergoing a breast cancer investigation (Liao, Chen, Chen, & Chen, 2008). The average onset age for breast cancer in Taiwanese women is 45 to 49 years, five to ten years earlier than women living in Western Countries (Liao et al., 2008). The purposes of the study was to compare the levels of uncertainty and anxiety experienced by women who received a benign biopsy result versus women with a malignant biopsy result, determine if uncertainty and anxiety were correlated, and identify predictive factors for uncertainty.

Results indicated that uncertainty and anxiety levels were significantly higher before diagnosis for all participants. Women in both groups had higher levels of anxiety before diagnosis ($M\ 60.0 - 61.0$, $SD\ 9 - 1.0$) compared to Western Countries ($M\ 41.4 - 45.3$, $SD\ 11.1 - 11.6$) (Drageset & Lindstrom, 2003, 2005; Haun, Mainous & Looney, 2001 as cited by Liao et al., 2008). However women diagnosed with breast cancer had significantly higher levels of uncertainty and anxiety at all three data collection times compared to women with a benign biopsy result. Higher levels of uncertainty were positively correlated with higher levels of anxiety for all participants. Being married, having limited education, and being over the age of 50 were some of the predictive factors for higher levels of uncertainty. The authors attribute these findings to cultural practices within Chinese society and the roles of women within families (Liao, et al., 2008).

The same group of authors published an earlier paper based on the same study (Liao, Chen, Chen, & Chen, 2007), however the focus of this paper was on health care and support needs of women undergoing a breast biopsy. Results showed that women with a benign biopsy result and women with a malignant biopsy result had moderate to high levels of needs throughout the investigation, however their overall need was significantly higher ($p < 0.01$) prior to diagnosis. As well, prior to diagnosis women ranked their health care needs higher than their emotional needs. Thus, having timely access to diagnostic tests and timely access to biopsy results were the most pressing needs. The authors explained that emotional needs may be ranked lower because Chinese women are discouraged from openly discussing illness (Liao et al., 2007). Another plausible explanation may be that women are so preoccupied with wanting to live that getting access to health care in a timely fashion takes precedence over their emotional state. The findings reported in the two papers by Liao, Chen, Chen, and Chen (2007, 2008) confirmed that women experienced high anxiety prior to breast biopsy. These findings also provided insight into how the experience of a breast cancer investigation may vary for women based on cultural differences.

Schnur et al. (2008) compared the levels of anticipatory distress in 143 women scheduled for an excisional breast biopsy to confirm a breast cancer diagnosis with 44 women with an already confirmed diagnosis of breast cancer and scheduled for lumpectomy. The responses for the two groups of women were compared for the outcomes of emotional well-being, surgery specific worry, and mood disturbance. Results showed that women undergoing a lumpectomy for curative treatment were significantly more distressed than women undergoing an excisional biopsy for diagnostic

breast surgery (Emotional Well Being (EWB) *Ms* 16.73 versus 18.27 respectively, $p < .04$; Visual Analogue Scale (VAS) Emotional Upset, *Ms* 50.02 versus 32.97 respectively, $p < .001$; Impact of Event Scale (IES)-Intrusion, *Ms* 13.18 versus 8.78 respectively, $p < .002$). When comparing their findings to results published by DiLorenzo et al., 1999, Schnur et al., (2008) found that both groups of women in their study had levels of mood disturbance similar to women starting chemotherapy for breast cancer. Women scheduled for lumpectomy worried significantly more about what the surgeon might find compared to women scheduled for excisional biopsy (lumpectomy $M = 55.21$, $SD = 27.95$; excisional breast biopsy $M = 45.98$, $SD = 27.04$; $p = 0.05$). The authors were surprised by these findings and suggested that women undergoing a lumpectomy may worry more about the results of surgery as they will impact the type of treatment they may receive afterwards. Nevertheless, both groups of women exhibited considerable worry. The authors called for interventions to address women's worries prior to diagnostic and curative surgeries (Schnur, 2008).

Seckel and Birney (1996) studied the relationships among stress, age and social support in 30 women undergoing breast biopsy. Participants were women recruited from the practice of a surgical oncologist who had consented to receive a breast biopsy. The participants completed a demographic questionnaire, the State Trait Anxiety Inventory (STAI) and the Norbeck Social Support Questionnaire (NSSQ) prior to their biopsy. The data were analyzed based on two sample groups: 15 women ≤ 40 years of age and 30 women > 40 years of age.

Results showed that the women experienced high stress levels prior to breast biopsy (STAI scores, *t*-test, women ≤ 40 , $M = 40.26$; Women > 40 , $M = 37.2$).

Bivariate statistical analysis showed a positive Pearson correlation coefficient of $r = 0.26$ between stress and age in women ≤ 40 years and a stronger negative Pearson correlation coefficient of $r = -0.44$ in women >40 years. It appeared that women had more stress with aging up to the age of 40 and stress diminished afterwards (Seckel & Birney, 1996). The authors explained this finding based on the assumption that younger women are making career choices, they are establishing their family life and they have less experience with illness compared to older women (Seckel & Birney, 1996).

The NSSQ results showed that the women's network size was not a factor in the anxiety women experienced however there was a statistically significant relationship ($r = -0.356$) between social support strength⁵ and the women's anxiety. Women reported higher anxiety in response to a breast biopsy when they had decreased social support strength. The authors stressed the importance of assessing women's support networks at the time of a breast cancer investigation and the need to explore the role of support groups as a supplement to women's support network (Seckel & Birney, 1996). The study sample was small ($N=30$) and definitive conclusions could not be drawn between age and anxiety related to breast biopsy. Despite these limitations, this is one of the few studies suggesting that stress during a breast cancer investigation increases up to the age of 40 and then diminishes. Understanding younger women's experience with distress with breast biopsy may provide information about what types of support network are important and required.

⁵ Social support strength is determined by the total function on the NSSQ; the total function score is the summation of the affect, affirmation and aid scores (Seckel & Birney, 1996)

Stanton and Snider (1993) studied personality, cognitive appraisal, coping and mood in a group of women 40 years of age and older who were undergoing a breast cancer investigation. They applied the stress coping theory of Lazarus and Folkman (1984) which describes four classes of variables that mediate how people adjust in stressful encounters: (1) characteristics of the stressful situation which in this case includes the threat of a breast cancer diagnosis; (2) personal attributes such as age at diagnosis of breast cancer; (3) cognitive appraisals which influence emotional well-being and; (4) coping processes that relate to cognitive and behavioral efforts to manage stressful encounters.

The sample size consisted of 117 women 40 years of age or older, $M = 57.30$, $SD = 11.90$, with 31% ($n = 36$) of the women diagnosed with breast cancer. The measurement periods were 24 hours (first measurement) prior to breast biopsy to measure personality attributes, cognitive appraisal, coping processes and mood. The women diagnosed with breast cancer ($n = 81$) completed all measures 24 hours prior to surgery (second assessment) and three weeks after surgery (third assessment). The women with a benign tumor who agreed to participate in the study after their breast biopsy ($n = 47$) only completed the emotional-status measure scale at a second assessment period. They were split into two groups; one group completed the questionnaire at the second assessment period to correspond to the second assessment of the women with breast cancer (24 hours prior to surgery) and the second group completed the questionnaire at the third assessment period to correspond to the third assessment of the women with breast cancer (three weeks after surgery) (Stanton & Snider, 1993).

When comparing the benign group to the cancer group pre-biopsy, women in both groups that were younger experienced more anger and tensions than older women. A significant multivariate effect for age emerged for the Profile of Mood State scales $F^6(6, 88) = 2.83, p < .05$. Univariate analysis revealed that age was significantly related to tension; $F(1, 93) = 9.43, p < .005$ and; anger $F(1, 93) = 5.96, p < .05$. Older women were found to have less tension ($r = -.29, p < .005$) and less anger ($r = -.24, p < .05$) compared to younger women (Stanton & Snider, 1993).

Other findings were that women diagnosed with breast cancer reported more negative emotional affects post biopsy and prior to their surgery, compared to women with a benign tumor; tension $F(1, 48) = 23.17, p < .0001$; depression $F(1, 48) = 16.78, p < .005$; anger $F(1, 48) = 10.87, p < .005$; low vigor $F(1, 48) = 9.06, p < .005$; fatigue $F(1, 48) = 10.30, p < .005$; confusion $F(1, 48) = 24.95, p < .0001$. Fatigue scores remained high after surgery for women diagnosed with breast cancer compared to the women with a benign tumor, $F(1, 40) = 5.88, p < .05$ and vigor scores remained lower after surgery, $F(1, 40) = 4.58, p < .05$ for the breast cancer group.

Women who reported more distress prior to their breast biopsy were younger (age accounts for a significant 5% of the variance, $F(1, 94) = 5.22, p < .05$); less optimistic (17% of variance, $F(1, 92) = 19.25, p < .0001$); more threatened (20% of the variance, $F(1, 86) = 30.75, p < .0001$); and engaged in more cognitive avoidance coping (12% of variance, $F(3, 83) = 6.95, p < .005$)⁷ (Stanton & Snider, 1993). This is one of the first longitudinal quantitative studies conducted prospectively that showed age was

⁶ F statistic reported is that associated with Wilk's criterion (Stanton & Snider, 1993)

⁷ Data based on a hierarchical regression for the Profile of Mood States five negative (POMNEG) scales. Results reflect 54% of the variance in POMNEG

correlated with distress. A qualitative prospective study may further help explain from younger women's point of view the distress they are experiencing at time of breast biopsy and how they cope with distress.

The overall findings from the studies reviewed confirm that the process of undergoing a breast cancer investigation provokes distress in women (Andrykowski et al., 2002; Benedict et al., 1994; Chappy, 2004; Demir et al., 2008; Lebel et al., 2003; Liao et al., 2008; MacFarlane & Sony, 1992; Schnur et al., 2008; Seckel & Birney, 1996; Stanton & Snider, 1993). Women who suspected they had breast cancer experienced high levels of distress, sometimes equivalent to distress levels of women newly diagnosed with breast cancer (Schnur et al., 2008). Unfortunately distress may persist for several months even after a benign breast biopsy result (Andrykowski et al., 2002; Lebel et al., 2003). Only one study (Stanton & Snider, 1993) reported distress as being correlated with age showing that younger women experienced more distress with a breast biopsy, although the authors called for more research to be conducted in this area (Stanton & Snider, 1993).

Nine of the twelve studies presented are quantitative and although they unveil findings that distress is present for women undergoing a breast biopsy, we do not necessarily understand the reasons why these women experience distress. A prospective qualitative inquiry may help explain some of the findings. The three qualitative studies provide a wider spectrum of explanations for the sources of distress; e.g., wait times are too long, concern about dying, and others. However, all twelve studies were done with women of all ages and may not necessarily reflect the experiences of younger women. More research is needed to understand distress in younger women in the days prior to

receiving the results of a breast biopsy and in the days and weeks following a diagnosis of breast cancer to bring awareness to the needs of these women early on in the cancer trajectory.

2.3 Distress: Young Women Diagnosed with Breast Cancer Identify their Needs

A series of qualitative studies are reviewed in this section to highlight the experiences of younger women diagnosed with breast cancer, the service gaps they identify in the health care system and their recommendations to improve the patient experience for other young women facing the same disease. The literature review addresses the research question: How do young women propose the system barriers be resolved? Although the studies are retrospective and do not necessarily focus solely on the investigation and diagnosis of breast cancer, the findings provide insight about younger women's experiences and recommendations for change as they reflect on their diagnosis and treatment for breast cancer.

Young women experience several unique challenges and expectations throughout the cancer journey. For example, when presenting with a breast abnormality younger women are often provided with a false reassurance that their symptom is benign because they are too young to have breast cancer (Siegel, Gluhoski, & Gorey, 1999). It is not surprising that they react with dismay when learning their diagnosis: "I was totally shocked. Everyone sort of led me to believe that this was not gonna be anything. It was probably benign if it was anything - that I was too young to have anything happen to me. So I was absolutely not prepared" (Siegal et al., p. 4). The media often portrays young women as being courageous, which sets up unhelpful expectations for other young

Table 2.2. Studies Conducted with Women with a Benign Breast Biopsy Diagnosis or Breast Cancer Diagnosis

First author and year	Purpose	Population and eligibility	Study Design	Participant characteristics	Relevant Measures	Outcomes
Chappy 2004	Obtain descriptions of the perioperative experiences of women who underwent breast biopsies with local anesthesia	-Private practices of 14 surgeons -Age 18 or older -Speak and understand English -Ability to remember and describe the surgical phase -Provide written informed consent	-Qualitative -Retrospective -Cross-sectional -Face to face interviews within one month after the biopsy and pathology results	<i>N</i> = 22 -Age range 19 to 82 years -14 women had a benign tumour -6 women diagnosed with breast cancer	Interview guide	Four themes identified 1) Certitude 2) Care 3) Focusing on me 4) Justice
Demir 2008	Explore the lived experiences of patients undergoing an excisional breast biopsy	-Academic health centre -Age >18 years of age -Undergoing excisional biopsy under general anesthesia	-Qualitative -Retrospective -Cross-sectional -In-depth interviewing one week after biopsy and before post-operative follow-up visit	<i>N</i> = 20 -Age not reported -Diagnosis of participants post biopsy not reported	Open, unstructured interview	Three themes identified 1) Fear 2) Need for information 3) Spiritual needs
Liao 2008	Investigate: (1) Uncertainty and anxiety changes for women with suspected BC	-Academic health centre -Age 18 and older -Read Mandarin Chinese	-Quantitative -Prospective -Longitudinal -Self-administered questionnaires, three measurement points:	<i>N</i> = 127 -Mean age 48.14 -Age range 19 to 82 years	-MUIS (modified and translated in Mandarin) -Chinese version – STAI Personal Attribute Scale	Women in both groups had higher uncertainty learning the need for breast biopsy and while waiting for procedure than after learning the biopsy results. Women diagnosed with BC had significantly higher levels of uncertainty and anxiety at all three data collection times compared to women with a benign biopsy result.

Note. BC = breast cancer; MUIS = Michel Uncertainty in Illness Scale; STAI = State Trait Anxiety Inventory

Table 2.2. (Continued)

First author and year	Purpose	Population and eligibility	Study Design	Participant characteristics	Relevant Measures	Outcomes
	(2) Differences in uncertainty and anxiety changes between women with benign and malignant diagnoses during the diagnostic period (3) Correlation between uncertainty and anxiety (4) Predictive factors of uncertainty	-Speak Mandarin Chinese or Taiwanese dialect -No previous history of BC -Clinical finding of possible BC -No history of psychiatric disorder and no current oral treatment for psychological problems	(1) the day women learned need for breast biopsy; (2) while women waited for biopsy procedure (3) right after learning biopsy result	-47 women had a benign tumour -80 women diagnosed with breast cancer		Anxiety higher prior to diagnosis than after knowing biopsy results -Both groups had higher levels of anxiety before diagnosis ($M = 60.0 - 61.0$, $SD, 9 - 1.0$) compared to Western Countries (mean, $41.4 - 45.3$, $SD, 11.1 - 11.6$) -Women with higher levels of uncertainty had higher levels of anxiety -Being married, being over the age of 50, having less education were some predictive factors for uncertainty
Liao 2007	Same as above	Same as above	Same as above	Same as above	Developed and validated the Suspected Breast Cancer Patient's Needs Questionnaire	-Moderate to high levels of needs reported throughout the investigation, however overall need was significantly higher ($p < 0.01$) prior to diagnosis -Women ranked their health care needs higher than their emotional needs prior to diagnosis -Emotional needs may rank lower because Chinese women are discouraged from openly discussing illness

Note. BC = breast cancer

Table 2.2. (Continued)

First author and year	Purpose	Population and eligibility	Study Design	Participant characteristics	Relevant Measures	Outcomes
Schnur 2008	-Determine whether differences in anticipatory distress are related to surgery type, i.e. excisional breast biopsy versus lumpectomy -Investigate whether relationship between procedure and/or worry about prognostic surgery type and distress is due to worry about the consequences of the procedure	-Academic hospital -Age 18 or older	-Quantitative -Prospective -Cross-sectional -Survey-take home questionnaire package prior to procedure returned on day of procedure -Additional questionnaires completed on day of procedure	-N = 187 -Age M = 47.4 Age range 18 to 77 years -143 women undergoing breast biopsy compared to 44 women undergoing surgery for breast cancer	-EWB Subscale of the FACT-G, Version 4 -Short Version POMS -IES-Intrusion -VAS- Emotional Upset	-Average number of days from time procedure scheduled to time procedure performed was 4.36 days (SD = 8.93). The time interval of 4.36 days was neither significantly related to surgery type nor any of the outcome variables (all p s > 0.20) -Women undergoing a lumpectomy for curative treatment were significantly more distressed than women undergoing an excisional biopsy for diagnostic breast surgery (EWB Ms 16.73 emotional well-being), $p < .04$ -VAS-emotional upset, Ms = versus 18.27 respectively (higher scores = better 50.02 versus 32.97 respectively, $p < .001$; IES-Intrusion, means 13.18 versus 8.78 respectively, $p < .002$) -Women scheduled for lumpectomy worried significantly more about what the surgeon might find compared to women scheduled for excisional biopsy (lumpectomy M = 55.21, SD = 27.95; excisional breast biopsy mean = 45.98, SD = 27.04; $p = 0.05$)

Note. EWB = Emotional Well-Being; FACT-G = Functional Assessment of Cancer Therapy General; POMS = Profile of Mood State; IES = Impact of Events Scale; VAS = Visual Analogue Scale

Table 2.2. (Continued)

First author and year	Purpose	Population and eligibility	Study Design	Participant characteristics	Relevant Measures	Outcomes
Seckel 1996	Examine the relationship among the variables of age, social support and stress in women undergoing a breast biopsy	-Surgical oncology practice in an academic health centre -No previous cancer diagnosis -Independent ability to sign informed consent -Ability to read and write at a minimum of a 10 th grade level	-Quantitative -Prospective -Cross-sectional -Women completed the questionnaires while awaiting their pre-admission laboratory blood work necessary prior to breast biopsy	N = 30 -Age M = 43.1 Age range = 21 to 68 years -13% (4 out of 30) women were diagnosed with breast cancer	-STAI -NSSQ	-Increased stress prior to breast biopsy (STAI scores, t-test women <40, M = 40.26; Women >40, M = 37.2). Bivariate statistical analysis showed a positive Pearson correlation coefficient of $r = 0.26$ between stress and age in women <40 years and a stronger negative Pearson correlation coefficient of $r = -0.44$ in women >40 years. More stress detected with aging up to the age of 40 and stress diminished afterwards. -NSSQ results showed network size not a factor in the anxiety women experienced however there was a statistically significant relationship ($r = -0.356$) between social support strength and the women's anxiety.
Stanton 1993	-Test predictions for associations of personal attributes, cognitive appraisal and coping strategies with emotions experienced	-Surgical practice -Women undergoing a breast biopsy	-Quantitative -Prospective -Longitudinal Time 1: All women provided with a package of questionnaires to complete 24 hours prior to biopsy	N = 117 -Age range 40 to 89 years -36 (31%) women diagnosed with breast cancer -81 (69%) women had a benign tumour	-Personality attributes-Nine item scale used by Taylor et al. (1984) -Cognitive appraisal- Two scales modeled after those of Folkman, Lazarus, Dunkel-Schetter, DeLongis and Green (1986) -WOC -POMS-Distress and Well-being	-More anger and tension observed in younger women compared to older women; a significant multivariate effect for age emerged for the POMS scales $F(6, 88) = 2.83$, $p < .05$. Univariate analysis showed age significantly related to tension; $F(1, 93) = 9.43$, $p < .005$ and; anger $F(1, 93) = 5.96$, $p < .05$. women

Note. STAI = State Trait Anxiety Inventory; NSSQ = Norbeck Social Support Questionnaire; WOC = 66-item Ways of Coping Questionnaire; POMS = Profile of Mood State

Table 2.2. (Continued)

First author and year	Purpose	Population and eligibility	Study Design	Participant characteristics	Relevant Measures	Outcomes
	over the course of a cancer diagnosis -Examine whether particular predictors had direct, mediated or interactive effects on emotional status		<u>Women with breast cancer:</u> Time 2: 24 hours prior to surgery Time 3: 3 weeks after surgery <u>Women with benign tumour</u> Only complete the emotional-status measure a second time. Group split in two and the interval time to complete the questionnaire for each group matched time 2 or 3 for women with breast cancer			Older women found to have less tension ($r = -.29, p < .005$) and less anger ($r = -.24, p < .05$) compared to younger -Women diagnosed with BC reported more negative affect post biopsy and prior to surgery, compared to women with a benign tumor: tension $F(1, 48) = 23.17, p < .0001$; depression $F(1, 48) = 16.78, p < .005$; anger $F(1, 48) = 10.87, p < .005$; vigor $F(1, 48) = 9.06, p < .005$; fatigue $F(1, 48) = 10.30, p < .005$; confusion $F(1, 48) = 24.95, p < .0001$. -Younger women reported more distress prior to breast biopsy (age accounted for a significant 5% of the variance, $F(1, 94) = 5.22, p < .05$); less optimistic (17% of variance, $F(1, 92) = 19.25, p < .0001$); more threatened (20% of variance, $F(1, 86) = 30.75, p < .0001$) and engaged in more cognitive avoidance coping (12% of variance, $F(3, 83) = 6.95, p < .005$) (Data based on hierarchical regression POMNEG scales. Results reflect 54% of variance in POMNEG)

women who are making treatment decisions (Dunn & Steginga, 2000). An example provided by Dunn and Steginga (2000), is that young women diagnosed with breast cancer while pregnant, are making difficult choices about cancer treatment and pregnancy. A young woman delaying her chemotherapy to permit the natural delivery of a pregnancy is portrayed as courageous through the media leaving other young women to feel stigmatized for making different decisions and not following through with the pregnancy (Dunn & Steginga, 2000):

The Camellia effect normalizes exigent and unrealistic standards of behaviour set through popular press coverage of individual newsworthy cases. In doing so, media narratives potentially contribute to women's psychosocial distress by distracting individuals from their own priorities in adjusting to the challenges of a life threatening illness (Dunn & Steginga, 2000 p. 144).

As part of a qualitative descriptive study, five women ranging in ages from 20-39 were interviewed about their experiences with recovery after receiving a mastectomy for early stage breast cancer once they had completed chemotherapy (Abrashoff Schutte, 1996). They identified the fear of dying, the need to rediscover the self, and the need to seek help from others as part of their recovery. These young women also made system improvement recommendations such as raising awareness about breast cancer with younger women, improving early detection, improving access to timely treatment, and timely access to support services such as the American Cancer Society (Abrashoff Schutte, 1997).

A phenomenological study conducted with nine women diagnosed with breast cancer in their 20's were interviewed one to seven years after their diagnosis to reflect on their experiences (McMahon, 2001). These young women reported that their breast symptoms were not taken seriously upon presentation for medical care. Once a diagnosis

of breast cancer was confirmed, the physicians focused on a cure while disregarding other important aspects of the disease and treatment such as fertility. The women reported feeling isolated during that time as resources and programs did not address their age related needs. They were often left to care for their families while ignoring their own needs. They believed there was a lack of resources to support spouses. Finally their self-esteem was affected with the loss of hair from chemotherapy, which was considered worse than losing one's breast (McMahon, 2001).

A Canadian qualitative study had 65 women under the age of 45 diagnosed with breast cancer participate in focus groups one to five years post diagnosis (Gould, Grassau, Manthorne, Gray, & Fitch, 2006). Study findings showed that these younger women experienced difficulty accessing information that was specific to their age group and relevant to their stage of life. Professional counselling and peer support were not easily available to them. They struggled with the changes to their bodies, the impact the illness had on their families and they also experienced major financial burdens (Gould et al., 2006).

Recommendations from the young participants in this study addressed issues such as age appropriate information about breast cancer to address topics of fertility, early menopause, body image, and talking to children about cancer (Gould et al., 2006). Program recommendations included: (1) Peer navigators to help young women understand processes and where they can access resources; (2) Workshops to address topics on dating and breast reconstruction; (3) Financial assistance to help pay for medication and travel costs related to treatment; (4) Instrumental support when it comes to childcare and housekeeping tasks in the home and childcare programs available in

health care facilities and; (5) Professional services available to provide emotional or/and spiritual support to young women and their families (Gould et al., 2006).

In Australia, where 25% of breast cancer diagnoses affect women of childbearing years (Australia Institute of Health and Welfare, 2005 as cited in Coyne & Borbasi, 2006), a study was conducted with six women, ages ranging from 29 to 43 to explore their psychosocial needs and the impact a diagnosis of breast cancer has on their families (Coyne & Borbasi, 2006). An additional purpose of the study was to gain women's perspective about how the system could be improved during treatment to support a more positive experience for younger women diagnosed with breast cancer (Coyne & Borbasi, 2006). This study demonstrated the complexities of psychosocial issues faced by younger women as they described the diagnostic experience as traumatic (Coyne & Borbasi, 2006). The participants reported they were preoccupied with issues such as motherhood as they confronted their own mortality wondering if they would live to see their children grow. They had many family concerns ranging from not always finding support from family yet being placed in a position of supporting family members. These young women also worried about the impact their illness had on family finances. Concerns about losing one's femininity due to the loss of a breast and not being capable of conceiving children because of chemotherapy induced menopause were also sources of distress. The young women also reported that life after treatment was a difficult transition for them and their families. Some young women joined activities of interest such as dragon boat racing; while for others it was a time to re-appraise life goals (Coyne & Borbasi, 2006). Recommendations for system improvements were: (1) greater participation of family members in the decision making process; (2) friendlier children's spaces in patient

waiting lounges and; (3) better coordinated medical, chemotherapy and radiotherapy appointments to facilitate childcare (Coyne & Borbasi, 2006).

Connell, Patterson and Newman (2006) reported results of the first phase of a three-phase longitudinal study exploring the experiences of young women diagnosed with breast cancer. Semi-structured interviews were conducted with a convenience sample of 35 Australian women diagnosed with breast cancer, age at diagnosis $M = 35$, range 20-40. The authors described two categories: personal concerns based on women's experience and general concerns based on opinion rather than experience. The most frequently identified personal concerns (54%) were fears about recurrences and the future and these two issues were also the most (31.5%) perceived general concerns. Women who received a lumpectomy instead of a mastectomy were found to worry the most about recurrence (Connell et al., 2006). Other major (20%) personal concerns related to the children and family in the event the women died of their illness. The authors indicated that the concern related to the care of children when mothers have breast cancer was also a general concern reported by women who did not have children (Connell et al., 2006).

Women expressed concerns about the unrealistic expectations placed on the partners to assume all responsibilities for childcare, household chores and finances while the women underwent treatment (Connell et al., 2006). Under the theme of consumer issues, women identified that information and education relevant to younger women diagnosed with breast cancer and the emotional support services needed were missing (Connell et al., 2006).

Fitch, Gray, Godel, and Labrecque (2008) held in-depth individual interviews with 28 young women diagnosed breast cancer to better understand their experiences and

perspectives with the illness. The women, ranging in ages from 28 to 42 years, were interviewed between three and four years after their initial diagnosis. Three overarching themes emerged from the study: (1) 'Everything depends on acting now' – the will to live after learning they had breast cancer, the urgency to find information and make treatment decisions, the challenge of placing their own needs first while wanting to take care of their families; (2) 'Everything is out of sync' – the expected order of life events was changed; the perception that their breast cancer investigation was delayed because they were young and they were not expected to have breast cancer; dealing with the side effects of treatment such as fatigue, cognitive difficulties, hair loss, and others; not having access to information specific for their age group and; not having access to peer support groups relevant to their age group; (3) 'Cancer invaded my whole life' – the impact of the illness on the multiple roles of young women as partners, mothers, daughters, friends and others; and pursuing a career and taking care of family while ill. The authors recommended that health care professionals become more aware of the challenges young women face and tailor the provision of information and support to meet the needs unique to this population (Fitch et al, 2008). The findings of this retrospective qualitative study support the argument that young women diagnosed with breast cancer require tailored information and interventions to meet their needs (Coyne & Borbasi, 2006; Gould et al., 2006).

A phenomenological study was conducted with four Australian women, ages ranging from 31 to 42 years, to understand the lived experience of recovery from breast cancer (Elmir, Jackson, Beale, & Schmied, 2010). The women participated in semi-structured in-depth interviews where they were encouraged to express their concerns and

feelings in relation to their recovery post surgery. Four themes were generated from the data analysis: (1) 'It absolutely encompassed me' – the shock of learning the diagnosis; (2) 'Being overwhelmed' – facing the news of the diagnosis while trying to manage day to day activities in the household and working externally; (3) 'Living with fear and uncertainty' – afraid of recurrence and potential inability to pursue life plans; afraid of losing attractiveness and desirability and; (4) 'Finding strength within' – finding the strength within to survive and having the support of family and friends. The authors stressed the need for clinicians to understand the issues young women may be facing at the time of breast cancer surgery and the possible role for counselling (Elmir et al., 2010). Only four women participated in this study and the timeline is unclear as to when they were interviewed about their recovery post breast cancer surgery. However the findings are in keeping with the literature showing younger women diagnosed with breast cancer may experience challenges keeping up with responsibilities internal and external to the home, and they struggle with body image issues and uncertainty about their future (Abrashoff Schutte, 1997; Connell et al., 2006; Coyne & Borbasi, 2006; Fitch et al., 2008; Gould et al., 2006; McMahon, 2001).

In summary, qualitative studies conducted with younger women confirm that the experience of being diagnosed with breast cancer is a life changing event which has implications on the physical, social, and psychological well-being of these women. Some young women report not having their breast symptoms taken seriously resulting in delays to diagnosis. Younger women worry about the well-being of their partners and children during diagnosis and treatment and they also worry about the future of their family if they die from their disease. More human and financial resources are required to assist spouses

while women are undergoing treatment. The treatment for breast cancer takes a physical toll on the body and women often do not have access to information about the long term side effects of treatment. Fertility, body image, sexuality, and finances are real concerns that challenge the resilience of these younger women who are often left on their own to find the means of adapting and coping. Peer support and professional services are often not available or services are not tailored to their age group. It should be noted that the focus of these retrospective qualitative stories was not specific to the breast biopsy experience.

2.4 Summary

The literature review provided an understanding of how distress is defined in psychosocial oncology and how a definition of distress was developed for this study. The historical perspective of screening for distress in cancer programs was reviewed including the current Canadian national and provincial policies to implement Screening for Distress, the 6th Vital Sign. What this review highlights is that screening for distress has not been formally implemented in the diagnostic phase of the cancer journey, meaning that cancer distress may not be detected until a young woman presents for consultation at a cancer centre which can be several weeks after the initial diagnosis of breast cancer.

Findings of qualitative retrospective studies conducted specifically with younger women were reviewed to understand their experiences with the diagnosis and treatment of breast cancer and the recommendations made for system improvements. This literature was reviewed in the context of one of the research questions for this study that focuses on understanding how younger women propose that system barriers be resolved during a breast cancer investigation and diagnosis. The literature review provides a forum to

compare the results of these studies with the findings of the current research project. We now turn to the theoretical framework of the study that supported the research process undertaken and the interpretation of results.

Chapter 3: Theoretical Framework: Feminist Epistemologies

The purpose of the study was to understand distress experienced by younger women undergoing a breast cancer investigation. Although distress is experienced at the personal level as described in the literature review of Chapter 2, it is important to explore how public health policy and health care services are structured to address younger women's breast health and determine if and how they are contributing to distress. A theoretical framework that goes beyond the 'personal' to get to the 'political' is necessary for such an analysis and principles of standpoint theories helped shape the theoretical framework for this study. A description of standpoint theories and how they were applied to the study is provided in the first half of this chapter. A standpoint project requires the researcher to declare their social position and how it relates to the research undertaken. The social position of the researcher and how it relates to the current research project is found in the second half of the chapter.

3.1 Standpoint Theories

The lenses that guided this study were feminist epistemologies through the application of principles of standpoint theories⁸. Standpoint theory is a feminist critical theory that emerged in the 1970s and 1980s examining the relationship between the production of knowledge and practices of power within society (Harding, 2004). It encapsulates "a kind of organic epistemology, methodology, philosophy of science, and social theory that can rise whenever oppressed people gain public voice (Harding, 2004,

⁸ Originally standpoint theory was spelled singular. In recognition of the multiple standpoints that have emerged over the years through feminist projects, the plural is utilized in the literature—standpoint theories. I use the terms interchangeably depending on the context of the sentence however I do recognize that there are multiple standpoint theories.

3). The concept of 'situated knower' is at the core of feminist epistemologies (Anderson, 2009):

Feminist epistemology conceives of knowers as situated in particular relations to what is known and to other knowers. What is known, and the way that it is known, thereby reflects the situation or perspective of the knower (Anderson, 2009 p. 2).

The inquiry begins from the standpoints of women who can best define their experience (Andrist, 1997). This study recognizes young women as the 'knowers' who can best describe the experience of going through a breast cancer investigation. Doing research from a feminist standpoint gives voice "to women's experience, to illuminate the oppressive effects of patriarchy, and to empower women to make positive changes in their individual lives as well as in the society at large" (Lindsey, 1997, p. 59). It permits us to analyze how social structures contribute to the problem studied (Nan Van Den Bergh, 1995); in this case, understanding how the structure of the health care system contributes to distress experienced by young women with a breast problem that needs to be investigated and diagnosed.

According to Harding (1987) there are epistemological features when conducting feminist research or what she refers to as theories of knowledge that inform how the study will unfold. First it is important to use 'women's experiences as resources for social analysis' (Harding, 1987, p. 7). These experiences reflect realities that in turn determine what further questions need to be asked (Harding, 1987). Part of this principle is that feminist research projects originate from women's experiences of political struggle (Harding, 1987). Over the years standpoint theories have been used with diverse groups recognizing the various standpoints:

The gender-resistant feminists focus on standpoint – the view of the world from where you are located physically, mentally, emotionally, and socially-is a major theoretical contribution and springboard for action. Although women's voices were the original source of standpoint theory, the concept has been successfully used by women and men of diverse classes, racial ethnic groups, nations, and cultures. (Lorber, 2005, p. 15)

Most of the studies conducted so far on the experience of a breast cancer investigation (see Tables 1., p. 31 and Table 2. p. 44) have not fully explained or described what that experience is like as it unfolds for young women. It is important to understand the process of a breast cancer investigation from their perspective if we are to address young women's needs in the health care system. Young women with breast cancer are starting to speak about their struggles with the illness and they inform us that their struggles are unique and they want the health care system to be responsive to their needs (Coyne & Borbasi, 2006; Dun & Steginga, 2000; Gould et al., 2006; Manly-Lampkin, 2003; McMahon, 2001).

Harding (1987) explains that the goal of research is to permit an inquiry that appears problematic from the perspective of women's experiences:

That is, the goal of this inquiry is to provide for women explanations of social phenomena that they want and need, rather than providing for welfare departments, manufacturers, advertisers, psychiatrists, the medical establishment, or the judicial system answers to questions they have. (Harding, 1987, p. 8)

A standpoint project looks at principles and assumptions of dominant institutions including research disciplines that constrain women's every day lives (Harding, 2012).

We know that young women experience distress when undergoing a breast cancer investigation however it is important to look at what are the causes of distress from a structural perspective. For the purposes of this study it can be argued that breast health practices for younger women have not been adequately addressed through public health

policy. Prior to starting this study I spoke with women who had been diagnosed with breast cancer at a young age. They supported the study based on their own experiences of feeling isolated and experiencing service gaps while going through a breast cancer investigation. The discourse on breast cancer as a disease that affects older women creates the illusion that there is no burning platform for young women to be paying attention to their breast health. When these young women are faced with a breast problem there is disbelief and shock they potentially could be diagnosed with the disease. They often encounter barriers to having their health needs addressed in that particular situation as it is not “the norm” for younger women to be going through a breast cancer investigation.

In Ontario, the concept of early detection is promoted for women 50 years of age and over who are actively recruited into the Ontario Breast Screening Program (Shabas, 1998) but there is no clear message through public policy for how younger women should take care of their breast health. Younger women indicate that they often feel marginalized because breast screening campaigns targeting women 50 years of age and older give the impression that younger women cannot get breast cancer (Dunn & Steginga, 2000). Young women speak of feeling isolated and stigmatized hence these campaigns may have negative impacts on people who are not part of the targeted group (Dunn & Steginga, 2000). These campaigns do not make a distinction between screening mammograms and diagnostic mammograms. They also do not address the issue that some younger women will develop breast cancer and the importance of investigating a breast abnormality in women of all ages. There are no counter provincial public campaigns to educate the public and health care professionals about these differences. It is not surprising that study results reveal that younger women have more difficulty having their

breast symptoms taken seriously (Desmond Pinkowish, 2002; Fitch, 2008; Manly-Lampkin, 2003; McMahon, 2001). Consequently, there are no explicit directives, guidelines or public health campaigns defining early detection for the 19% of the women diagnosed with breast cancer who are under the age of 50. Younger women want more awareness raised about breast cancer as it relates to younger women (Abrashoff Schutte, 1997).

We know that the risks for developing breast cancer can be reduced through lifestyle changes related to diet, alcohol consumption, physical activity, types of medication ingested, and tobacco use (World Cancer Research Fund/American Institute for Cancer Research, 2007). However public health policy has failed to increase younger women's knowledge of breast cancer and steps they can take to reduce their risks for developing the disease. Findings from focus groups conducted with young Canadian females ranging in ages from 15 to 24 years showed that young women associated smoking with lung cancer and were not aware that active smoking and second hand smoking could cause breast cancer (Bottorff et al., 2010). Survey results from an international study revealed that younger women were not aware that alcohol, obesity, and lack of physical activity are risk factors for breast cancer (Peacey, Steptoe, Davidsdottir, Bahan, & Wardle, 2006). When it comes to knowing the possible symptoms of breast cancer that require further medical assessment, with the exception of a breast lump, many women have limited knowledge about other potential symptoms of breast cancer such as nipple retraction, dimpling of the breast tissue, discharge (other than milk) or bleeding from the nipple, a rash or redness of the breast tissue, or any skin changes (Almeida & Barry, 2010, p. 174). A survey conducted in Ontario found that

women were not familiar with the variety of breast changes that could be indicators for breast cancer (Trussler, 2007). Symptoms other than a breast lump need to be taken seriously as ignoring their significance by women or primary care physicians may lead to delays in the diagnosis of a malignancy (Burgess, Ramirez, Richards, & Love, 1998; Facione & Facione, 2006).

Feminist critics of the health care system argue for symmetry in provider – patient relationships defined as the attempt to reduce inequalities that exist in the health care environment (Andrist, 1997). It can be argued that inequalities exist for younger women whose symptoms of breast cancer are often not taken seriously (Fitch et al., 2008; McMahon, 2001). Delays in diagnosis have been attributed to system challenges or women not seeking care in a timely fashion (Weingart et al., 2009). However for younger women, the delay of a diagnosis is often due to the primary care physician not coordinating the necessary diagnostic tests in a timely fashion (Afzelius et al., 1994; Caplan, Helzlsouer, Shapiro, Wesley & Edwards, 1996). Unfortunately there are knowledge gaps on the part of some clinicians about the effective management of breast symptoms (Nekhlyudov, Nicola, Jung, & Buechler, 2008). One study showed that delays to diagnosis were caused by primary care physicians not doing an adequate physical examination (Weingart et al., 2009). Another mistake observed in the practice of primary care physicians is the tendency to monitor women with a breast lump who have a normal mammogram instead of referring them for a breast biopsy to confirm a diagnosis (Tartter, Pace, Frost, Jonine, & Berstein, 1999). This ‘wait and see’ approach can result in a missed diagnosis of breast cancer (Chappy, 2004; Desmond Pinkowish, 2002).

Delays to diagnose breast cancer can lead to more advanced disease resulting in decreased survival outcomes (Afzelius et al., 1994; Arndt et al., 2002; Caplan et al., 1996; Richards, Westcombe, Love, Littlejohns & Ramirez, 1999). This argument is not supported by all researchers based on study findings showing that women who wait three months or more to have their breast cancer diagnosed do not have poorer survival rates or more advanced disease (Sainsbury et al., 1999; Tartter et al., 1999). But it is known that breast cancer tends to be more aggressive in younger women underscoring the need for a timely diagnosis (Anders et al., 2008; Klauber-DeMore, 2005; Maggard et al., 2003). As scientists argue over the clinical impact of delayed diagnosis with respect to morbidity and mortality, somehow the distress of living with that uncertainty is minimized and accepted as part of the experience. Delays in diagnosing breast cancer are the leading cause of medical malpractice claims (Caplan et al., 1996; Nekhlyudov et al., 2008; Sainsbury et al., 1999) with most claims being won by younger women (Kern, 1992).

My professional experience working with women with breast cancer, the conversations I had with friends who were diagnosed with breast cancer and findings in the literature that identify gaps in policy and services for younger women requiring breast care are the reasons I pursued this study. The study provided a space for young women to inform us about their experiences with a breast cancer investigation and have the ability to have their voices heard to inform us about how services should be organized to meet the needs of young women going through such an investigation to minimize distress.

Harding (1987) stresses the importance of studying ourselves and 'studying up' instead of 'studying down'. The researcher is open about his or her class, race, culture, gender assumptions, beliefs, and behaviours as part of the research process. Therefore,

the beliefs and the behaviours of the researcher “are part of the empirical evidence for (or against) the claims advanced in results of research. This evidence too must be open to critical scrutiny no less than what is traditionally defined as relevant evidence” (Harding, 1987, p. 9). By incorporating this subjective matter into the analysis, it “increases the objectivity of the research and decreases the objectivism which hides this kind of evidence from the public” (Harding, 1987, p. 9). This process includes transparency, that is revealing who you are and how one’s location shapes the research process and reflexivity – meaning the inclusion of oneself in what is being studied (Ristock & Pennell 1996). This approach to research builds on developing a connection between researcher and participant, which is the primary theme of a female research methodology (Davis, 1986).

At the most basic level, the researcher and subject are interconnected in an ongoing relationship that influences the data that are produced. No “objective” data can be collected because all data depend on the specific individuals and their relationship with one another (Davis, 1986, p. 37).

Harding (2012) explains that it is not enough to describe one’s background but to provide the reader with an understanding of how one’s social position has shaped questions asked and assumptions made about research. Later in this chapter I describe my own social position to provide an understanding of the values I hold as a researcher and how they impact decisions I make about research processes.

Critics of standpoint theory oppose the position of privileged knowledge. They argue that it oppresses other groups who are not represented as part of the standpoint; for example, grand theories were applied to women without recognition of the various standpoints that existed (Olesen, 2000). Standpoint theory has evolved over the last

fifteen years to recognize pluralism or the various standpoints and, reject theories that speak on behalf of all women (Anderson, 2009). Quoting Wylie (2003), Anderson (2009) explains that feminist epistemologists have reached consensus on two points:

(1) a rejection of “essentialism” (the idea that the social groups defining any standpoint have a necessary and fixed nature, or that their members do or ought to think alike) and (2) a rejection of attempts to grant “automatic epistemic privilege” to any particular standpoint. Instead, Wylie stresses how the social situation of “insider–outsider (members of disadvantaged groups who need accurate knowledge of the worlds of the privileged in order to navigate them successfully) can sometimes afford a *contingent* epistemic privilege or advantage in solving particular problems (Anderson, 2009, p. 46).

There are many different standpoints of women diagnosed with breast cancer: older women, younger women, lesbian women, women of color and others. That is not to say that one experience is better or worse than the other, albeit recognition of these differences and commonalties is required if we are to meet the needs of all women diagnosed with breast cancer. For this particular study, the standpoints of younger women undergoing a breast cancer investigation were sought.

3.2 Positioning the Researcher in the Research Process

Harding (1987) stresses the importance for the researcher to unveil the personal ‘subjectively’ for increasing the objectivity of the research process. I offer examples of my work and personal life that brought me to this point of conducting this research project. Although I attempt to describe a chronological sequence of these life experiences, many of the events happened in a parallel fashion.

I grew up in a white middle class francophone catholic family where I lived with my parents, grandmother and one older sister. It was not until a few years ago that my father informed us that we are fifth generation *Métis*. I pursued obtaining my status as

Métis, to honor my great-great-grandmother knowing she must have been silenced in so many ways. Learning about my ancestors and culture is an ongoing life journey. My father had thirteen siblings and my mother had seven siblings; needless to say, the importance of family was a core value of my upbringing. Our lifestyle was different from other families. Six months of the year (fall/winter) we lived in a small village with a population of approximately 800 people. The other six months of the year (spring/summer) we moved to our tourist camp which was accessible only by boat in early spring until the road opened by late May. Most of the tourists were Americans so my sister and I learned to speak English at a young age.

My parents owned two businesses for a good part of my childhood and teenage years. The division of labour was shared according to traditional roles; for example, my father was a guide who brought tourists fishing and hunting while my mother oversaw the dining room, laundry and other traditional roles associated with women. Both my parents were busy in the summer, thus aunts and cousins often provided childcare for my sister and me. Once we were older, we did our share of chores including delivering wood to the cottages, serving gas at the marina, cleaning cabins, assisting in the dining room and store etc. In the winter, we were caregivers for our grandmother who was ill. Our parents instilled in us a good work ethic and an expectation that we would be compassionate towards others.

My parents both wanted to pursue their education however their parents could not afford to send them to school. My father left school after grade 8 to work on the family farm and my mother completed grade 9. Although my parents never explicitly articulated their wishes for us, there was an understanding that my sister and I would pursue some

form of education after high school. They never spoke to us about careers, marriage, or plans for the future; it was something you figured out on your own or you observed the paths of other girls. There seemed to be an assumed life pathway of going to school (or not), getting married and having children. I tried to follow this path but it did not exactly work out for me. I basically had to challenge my own beliefs and values after ten years of marriage. Today, I am very proud to say that I am a single mother who raised her son while pursuing an active career and graduate school. Together we created our own definition of family that works for us.

My first recollection of a discussion about cancer was with my grandmother when I was very young. She explained that cancer was a bad illness; cancer was like small parasites with claws eating away the good cells in the body. It made you very sick and people died. The interesting thing is that many years later, in my clinical practice, I had clients describe cancer in a similar fashion. The symbol of the crab to depict cancer from the era of Hippocrates was still present in the cancer discourse. As a young girl I remember my father's sister being diagnosed with breast cancer at the age of 40 and she had a mastectomy. I remember my mother and father being upset. I was old enough to understand that this was a serious illness that made people sad. Unfortunately, this sad story would be repeated many times over the years in our family; including my father's diagnosis with prostate cancer and five of his other siblings being diagnosed with cancer. My mother would also have three siblings diagnosed with cancer, and the disease claimed the life of one sister. I witnessed my father's 'will to live' and the toll a cancer diagnosis has not only on the person but also on the spouse and family. I also saw family and community rally to offer support. Although the joy of surviving cancer is celebrated

publicly, there are private sufferings that continue in every day life such as dealing with the long term side-effects from treatment and grieving the loss of what used to be.

I started my career as a medical social worker in 1986 working in the hospital and then transferring to a brand new cancer centre/program three years later. I was the first social worker to be hired and breast cancer was one of the largest cancer populations. Although I worked with people diagnosed with cancer in my previous work, my new position involved concentrated time working with women and families affected by a breast cancer diagnosis.

In 1995, women from the community recognized that there was no peer-led support group for women with breast cancer. I was asked if I would assist with the establishment of a peer-led breast cancer support group that could run independently in the community. Although some health care professionals in the cancer centre were skeptical, I understood that women needed a way to provide support to each other without formal professional intervention. I worked with a colleague from the Ontario Breast Screening Program (OBSP) as well as women diagnosed with breast cancer to establish the Circle of Strength Sudbury Breast Cancer Support Group that continues to be offered in the community today. At the same time we were establishing this group, the women identified a gap of information for women newly diagnosed with breast cancer. Together, we wrote a grant and were successful in securing funds from the Provincial government to develop 'An Information Guide About Breast Cancer'. The 3rd edition of this booklet continues to be given to women newly diagnosed with breast cancer. What I had not anticipated from this work were the bonds I would develop with the women from the

Executive Committee and the losses I would grieve as many of my dear friends died of breast cancer over the years.

In the mid 1990's I facilitated a group at the cancer centre for women with metastatic breast cancer who were facing end-of-life care. Many of these women were young and had young families. We originally offered this group participation in a Canadian clinical trial that was replicating a U.S. trial based on the work of Dr. David Spiegel's work with groups that focused on supportive expressive therapy. We could not maintain recruitment according to the research protocol therefore the trial was cancelled in our cancer centre. However the group members wanted the group to continue and be open to any woman regardless of her type of cancer. I have to admit that this was one of the most profound experiences of my career.

As these women faced their end of life care, they challenged each other in their grief to live their best possible life. They became active participants in making complicated decisions about end-of-life care and ensuring their wishes were respected. Women who had experienced delays to diagnosis were angry and they often revisited their stories for what 'could have been'. Solidarity formed between these women, more powerful than anything I had ever witnessed before. Although we experienced the loss of women in the group over time, new members joined the group and solidarity was established again. It was challenging work but extremely rewarding. As much as my role was to be the professional facilitator these women taught me to confront my own mortality, live my best life and not take time for granted.

Over several years in the 1990's, I worked intermittently with a young woman diagnosed with breast cancer. The system had failed her in so many ways. Prior to her

death, she asked me to keep three promises, one of them was to bring attention to the challenges young women face being diagnosed with breast cancer. Within a year from her death, I was seconded from my social work position to conduct a needs assessment to determine wait times for diagnosing breast cancer in Sudbury. I saw this as my opportunity to keep my promise and hopefully improve the system for women's health.

As part of this needs assessment, focus groups were conducted with women of all ages to identify services gaps. I worked with provincial databases to estimate wait times. The mean time from detection of a breast abnormality to a breast cancer diagnosis was 55 days, for women participating in the OBSP (Mayer, 1999). It was suspected that women not participating in the OBSP had longer wait times to be diagnosed; unfortunately data was not available to confirm this suspicion (Mayer, 1999). Clinical pathways for a new breast assessment program had to be developed to improve the wait times for diagnosing breast cancer in Sudbury based on findings from the needs assessment. The working committee was comprised of administrators, physicians, health care professionals, volunteers from the community including representation from the Circle of Strength. The Circle of Strength made its position clear; they would only support a breast assessment program that accepted referrals for women of all ages. The recommendation was endorsed by the working committee and it was included in the proposal for a new breast assessment program for Sudbury.

I was seconded from my position of social work for a second time to develop a breast assessment program that aimed to organize diagnostic services under one roof in order to reduce wait times for diagnosis and provide women of all ages access to support services. The program was developed based on various models of care along with input

received from the women who participated in the focus groups. The breast assessment program opened in 2000 and I managed the program until 2004. While managing the program, I worked in partnership with the Circle of Strength writing proposals that successfully secured funds for developing a library, and offering education classes on breast awareness practices and a collaborative workshop with community partners to educate the public about breast health and breast cancer. Although we had many successes, there were many controversies concerning the program's funding, space allocation and the advocacy role women played to support the ongoing operations of the program. The program, however, continues to be offered under a different name and different clinical pathways.

My formal introduction to Participatory Action Research (PAR) was in 2000 when Dr. Jenifer Keck, Associate Professor in the School of Social Work at Laurentian University and member of the Circle of Strength, invited me to be a member of a research team to explore why women join peer-led breast cancer support groups and why other women prefer not to join them. My experience participating in this PAR study with women diagnosed with breast cancer (Keck, Hammell, Hyatt, MacEwan, Mayer, 2002) challenged my own perceptions of how research could be conducted in health care. What I did not anticipate during this PAR study was finding myself standing at the brink of breast cancer.

For many years I had been followed by a surgeon for a left sided breast abnormality. In April 2002 the texture and size of the lump started to change. We were in the middle of analyzing data for this study and the stories were difficult to hear. I kept touching the lump thinking I was imagining the change—it was not that bad. Every day I

worked with a team in the breast assessment clinic that specialized in diagnosing breast cancer yet I never brought it to their attention. Meanwhile our research team had two members in active treatment for breast cancer. I finally disclosed to Dr. Keck that I had this breast mass that seemed to be changing. She knew her health was failing and she urged me to get medical attention, reminding me that life is too short and about the importance of family.

I finally told my family and the team I worked with in the clinic. I insisted that I did not want to be treated differently than other women coming through the program. The surgeon examined me and informed me that she could not promise this was not breast cancer. Due to the size and the rapid growth of the mass, she recommended surgery. I was scared, not to die, but to leave my son; who would raise him? There was still so much I needed to teach him. I felt numb. I remember thinking 'so this is how it feels'. Family and friends who tried to convince me that it was probably 'nothing' only provided a sense of false reassurance. What was helpful was when people said they would support me if it was cancer and I would not be alone. The plan was for my mother and sister to bring me to the hospital for my surgery. I was touched when my father also insisted on being there with me, explaining he understood what I was going through.

I received my lumpectomy on June 5, 2002 to be told a week later it was not cancer. Unfortunately Dr. Keck died a few weeks after my surgery. I experienced conflicted emotions that included feelings of celebration for good health while mourning the loss of a great colleague and friend; and feelings of relief (I was healthy) with feelings of guilt. For several years I have often wondered why I behaved the way I did, not seeking immediate medical attention. I knew better. Why did I distance myself so much

from what was happening in my body? It was only through conducting this study and listening to the women's stories that I started to put the pieces of my own experience together with a cancer "scare".

Today I am an administrator and researcher with three mandates: manage the day to day operations of supportive care services in a cancer centre, expand supportive care services across Northeastern Ontario and conduct research. I am committed to research that brings light to the struggles people confront when diagnosed with cancer as a means to improving health care. As a breast cancer advocate for the past 26 years I have built my work on the concepts of equality (using women's voices to shape breast care/services), justice (ensuring women have access to breast care) and an ethic of care (working with women in an environment fostering trust, mutual respect and support). It is through the knowledge that I have gained from these personal and professional life experiences that shaped how I pursued this study.

3.3 Summary

Understanding distress of younger women undergoing a breast cancer investigation required hearing from younger women about their experiences and moving beyond the immediate 'personal' to understand the social structures that were contributing to distress. Applying principles of standpoint theory, a feminist critical theory, as part of the theoretical framework of this study supported such an analysis and provided guidance for how the research process should unfold. The methodology, methods and data analysis are described in the next chapter and aligned with standpoint theories.

Chapter 4-Research Design

Feminist epistemologies shaped the theoretical framework for this study applying principles of Feminist Participatory Action Research through a qualitative inquiry. The research methods employed were in-depth interviews and focus groups; participants also kept personal journals to track events and help them recall information during interviews. Medical information was verified through the participants' health record. The process followed to analyze data was a voice centered relational method based on the work of Gilligan et al. (2003) and Mauthner & Doucet (1998). The implementation of this research design permitted answering the following questions:

- How do women 50 years of age and younger, not menopausal, describe their experience with distress from the time they are informed they require a breast biopsy for a breast detected abnormality to the time they learn their diagnosis?
- How do these women describe factors in the health care system that they perceive contribute to their distress?
- How do these women describe expectations they have about themselves, their social environment and the health care system for resolving their distress?
- How do these women propose the system barriers be resolved?
- What can social workers learn from younger women's experiences of a breast cancer investigation and diagnosis to inform their practices for screening for distress and providing psychosocial services?

The methodology, the method and data analysis are further elaborated in the remainder of this chapter.

4.1 Methodology: Feminist Participatory Action Research

Principles of feminist participatory action research were applied in this study to create a collaborative process between participants and researcher that built on the principle of empowerment. Feminist participatory action research is congruous with standpoint theories as these frameworks are meant to empower those who are marginalized by having them engaged in a research process that generate standpoint themes (Harding, 2012). The intent for this study was to develop a research process oriented to social and individual change as a means to change the status quo (Reinharz, 1992). Participatory action research (PAR) is a combination of participatory research and action research (Nelson, Ochocka, Griffin, & Lord, 1998). Participatory research evolved in the 1970s as an approach to fight oppression in developing countries by involving people in the research design and process (Hick, 1997; Nelson et al., 1998). Paulo Freire's writing on adult education is an exemplar illustrating this approach where individuals participated together in critical analysis and were encouraged to organize action to improve their situation (Nelson et al., 1998). Action research was introduced in the mid 1940's by Lewin who believed that the best way to learn about social systems was to try to change them (Nelson et al., 1998). The research process involves taking notice of findings at different stages of the research to inform actions to be taken throughout the process (Nelson et al., 1998). The strength in combining these two research approaches is that within participatory research, "we recognize power imbalances and the need to engage oppressed people as agents of their own change. From action research, we recognize the value of engaging other stakeholders and using research findings to inform intervention decisions" (Nelson et al., 1998, p. 885). A feminist participatory action

research framework evolved as an alternative to meet women's emancipatory needs based on the critique that traditional participatory action research models held the same androcentric bias found in the positivist scientific model (Maguire, 1987). Feminist participatory action research is grounded in feminist theories and values (Maguire, Brydon-Miller & McIntyre, 2004). Reid and Frisby (2008) offer the following definition:

Feminist participatory action research is an approach to producing knowledge through democratic interactive relationships that are committed to making diverse women's voices more audible by facilitating their empowerment through 'ordinary talk' (Maguire, 2001/2006). The aim is to connect the articulated and contextualized personal with the often hidden or invisible structural and social institutions that define and shape our lives. This can foster the development of strategies and programs based on real life experiences rather than theories or assumptions, providing an analysis of issues based on a description of how women actually hope to transcend problems encountered (Barnsley & Ellis, 1992). (p. 98)

The concept of involving people diagnosed with cancer in participatory research projects is relatively new in psychosocial oncology (Hubbard, Kidd & Donaghy, 2007). I adapted the feminist participatory action research framework developed by Reid (2004) to guide the study process as the model articulates the parameters of the research process. The framework can be applied to a health care setting where a full feminist participatory action research framework is not feasible to implement however principles of the framework may be applied. It addresses:

- Inclusion: building on the principle that all social practices or activities are open to discussions, and that no one should be forced into privacy; gender and women's experiences are central and shape all phases of the research process including how women and men as groups benefit from the research; there is potential to develop strategies and programs based on the lived experience instead of theories or

assumptions. The study permits young women the opportunity to share their experience with distress as the process unfolds for a breast cancer investigation and diagnosis instead of making assumptions about the process based on study findings not necessarily specific to younger women.

- Participation: women taking part, joining or sharing with others; the process allows women's voices to be heard and facilitates empowerment through 'ordinary talk'; includes questions such as who is participating, why are they participating, to what degree and in what phase of the project are they participating in and having an awareness of where the true power lies in the research process (see 4.2 and 4.3).
- Individual and collective action: using reflexive knowledge, people becoming aware of their own cause and acting on insight; action can be at the individual level like someone deciding to join a support group or at the collective level such as a group becoming involved in political activism (see 7.3).
- Social change: the envisioned outcomes of the research process; taking action toward the desired social change (see 7.3).
- Researcher reflexivity: a process of being transparent and appreciating the methodological, epistemological, and political influences, contradictions, and complexities throughout the research phases (Reid, 2004) (see 3.2 and 4.4).

The parameters of this feminist participatory action research framework guided the research process taken with younger women undergoing a breast cancer investigation. A feminist qualitative inquiry was chosen to engage the young women to share their stories

of going through a breast cancer investigation and make recommendations for changes to improve the health care systems for younger women's breast health. The rationale for choosing this research method is further elaborated in the next section.

4.2 Method: A Feminist Qualitative Research Inquiry

A qualitative inquiry was chosen for this study as it is conducive to feminist epistemologies and methodologies (Devault & Gross, 2012; Reinharz, 1992; Weber & Castellow, 2012). Methods for data collection in this study were interviews, focus groups and journaling. Denzin (2009), who paraphrases the work of Hammersley (2005), describes four pedagogical stances unique to a qualitative inquiry. First, a qualitative inquiry is the accumulation of fundamental knowledge about social processes and institutions. Second, the qualitative inquiry provides the ability to impact current programs and practices. Third, critical qualitative inquiries aim to disrupt and destabilize current public policy or social discourse. Fourth, a qualitative inquiry is led by public intellectuals, public social scientists and cultural critics to address problem areas and crisis in the public arena (Denzin, 2009). Lindsey (1997) emphasizes common threads between traditional qualitative research and feminist qualitative research in terms of the importance of experiences and voices of individuals being central to the inquiry, the importance of reflexivity on the part of the researcher and making subjectivity explicit throughout the research process. How a feminist qualitative inquiry differs is how it "...has a political agenda: to give voice to women's experiences, to illuminate the oppressive effects of patriarchy, and to empower women to make positive changes in their individual lives as well as in the society at large" (Lindsey, 1997, p. 58).

A description of feminist participatory action research methodology and feminist qualitative inquiry are presented to contextualize the study. We now look at how principles of these frameworks were applied in practice as the study unfolded.

4.3 Process Followed for a Feminist Participatory Action Research and Qualitative Inquiry

4.3.1 Developing the Research Focus: Input from Women

How a researcher becomes integrated as part of a community within a feminist participatory action research framework varies based on the specific circumstances of that community and how needs are identified to pursue a research topic (Maguire, 1993; MacEwan, 2006). The ideal feminist participatory action research framework involves women being part of the initial research design although it is recognized that this situation is not always possible (Reid & Frisby, 2008). For logistic and ethical reasons, it was impossible to involve young women undergoing a breast cancer investigation in the research design. It was unrealistic to expect young women undergoing a breast cancer investigation to take part in developing a research study therefore only principles of a feminist participatory action research framework was applied for this study. The premise adopted for the project was that young women could be made aware of the study and it was their choice to participate or not.

The concept of the study was initially discussed with friends who were diagnosed with breast cancer, and some of them were young at the time of their diagnosis. They had also heard stories of other women from their peer-led breast cancer support group. These women stated that the time to diagnosis is one of the worst experiences in the cancer trajectory and that this type of study was needed. Based on all the feedback I received

over the years from young women diagnosed with breast cancer, I made a commitment to pursue a study with younger women undergoing a breast cancer investigation.

Given that the young women who participated in the study could be part of the original design, I decide to establish an advisory committee in the fall of 2005 to develop the study protocol. The advisory committee members reviewed the proposed research protocol I presented to them and they provided input especially for how to introduce the study to participants and how to phrase questions from the interview guide. Members were also available for consultation if needed during the study. Two women diagnosed with breast cancer, one in her 30s and the other in her 40s, participated as members of the advisory committee along with a surgeon and nurse from the breast assessment clinic, an administrator from the Ontario Breast Screening Program and a researcher who conducts qualitative inquiries with people diagnosed with cancer. One of the breast cancer survivors had previously participated in a PAR study (Keck et al., 2002). Members of the Advisory Committee were not involved in the actual individual and group interviews which were conducted by the researcher.

4.3.2 Ethics Approval

The research protocol and consent forms were developed to meet criteria of the Tri-Council Policy. The ethical issues addressed were: scholarly review; harms and benefits; free and informed consent; parental or third party consent; classroom administration of questionnaire if applicable, deception; documentation of informed consent; consent to various aspects of the study; privacy and confidentiality; barriers to anonymity; conflict of interest; inclusiveness and research specific to Aboriginal people if applicable.

More specifically harms and benefits, confidentiality and anonymity were addressed as follows in the research ethics board(s) submission. In terms of potential harm, it was explained that participants may experience intense emotions as they described their experiences in relation to distress and that this response would be a normal reaction, as one cannot discuss these issues without having emotions. However this potential concern was mitigated by taking several precautionary measures to ensure that there were minimal chances of participants having a negative experience in relation to the research. These measures included: the extensive interviewing experience of the researcher; the protocol that was in place for referring participants to the Supportive Care Program linked to the breast assessment clinic, if they wished to access this service; the flexibility for scheduling interviews based on the place and time preferred by the participants to minimize any disruption; the assurance that young women's willingness to participate in a participatory action research framework was voluntary; and the assured option provided to the young women that they could terminate their participation in the research process at any time without any negative consequences to them including the approach to their medical care (see Appendix B).

There were potentially several benefits to the young women if they chose to participate in the study such as having a certain level of satisfaction knowing they were contributing to an area of research that would benefit other young women in the future. Through self-reflection, women could self-evaluate their level of distress and identify strategies that worked for them. They could also benefit by meeting other women in the focus groups who shared similar experiences, and could validate how they were feeling. The research process itself could be empowering to women, as their opinions were being

sought about how distress should be addressed in the health care system. They could also choose to have input into the research process, ultimately deciding what action plans should be taken and if or how they wanted to be involved in the process (see Appendix B).

Privacy and confidentiality requirements meant taking all reasonable steps to ensure that a participant was not identified in the study. Participants were informed that data was going to be presented to various professional bodies in the form of presentations, written papers or/and published articles in peer reviewed journals, however no personal identifiers would be disclosed. The data collected from these interviews would be kept in locked offices within the cancer centre where the researcher works. All audiotapes would be destroyed after seven years (see Appendix B). The researcher and transcriber were employees of the hospital where the study was being conducted and both had signed an oath of confidentiality.

Barriers to anonymity were addressed in the consent form (Appendix B) clearly indicating that anonymity (privacy) could not be guaranteed if women participated in the focus groups because they would be joined by other participants; although participants would be asked to respect privacy, the researcher could not guarantee that privacy would be respected. Also anonymity was not possible if women disclosed they had participated in the study.

The research protocol was approved by the research ethics committees of the following institutions: the Interdisciplinary Committee on Ethics in Human Research at Memorial University of Newfoundland (October of 2006); the Research Ethics Committee at Laurentian University (February 2007) and; the Research Ethics Committee

at the Hôpital régional de Sudbury Regional Hospital (HRSRH) where the study was conducted (December 2006). Application for yearly renewal was granted based on the requirements of each committee.

4.3.3 Engaging Participants and the Process of Informed Consent

Women who were under 50 years of age, not yet menopausal and referred to the breast assessment clinic at the hospital because of a breast abnormality suspicious for malignancy were asked to participate in the study. The cut off age of 50 was chosen because women under 50 years of age are not recruited into organized breast screening programs. The women were not menopausal therefore the option of considering pregnancy was still possible. The breast diagnostic clinic at the hospital offers assessment and diagnosis in a timely fashion to women presenting with a breast abnormality. The process for study recruitment was reviewed, revised and agreed upon by members of the Advisory Committee. I met with the administrators, surgeons (N = 4) and staff of the breast clinic to explain the study and they supported the protocol.

Nurses in the breast diagnostic clinic screened potential study participants for age and menopause status. In accordance with the program's usual clinical pathway the nurses contacted the young women prior to their first appointment by telephone. As part of this first telephone contact, women were informed of a study they would be invited to participate in at their first appointment, based on the potential need for a breast biopsy. At this time during the telephone interaction, the nurse assessed the woman's initial interest in participating. This step was recommended by the breast cancer survivors of the Advisory Committee who felt strongly that young women should have a chance to think about participating in a study without having to make a commitment either way. It

was also recognized that women were likely to feel anxious at their initial appointment and the research study should not be new information they had to process and make a decision about during the consultation.

Surgeons and nurses then provided general oral and written information about the study to potential participants at their first clinic appointment. Women who were interested in participating signed a consent form permitting their names to be given to the researcher in order to contact them (see Appendix C). The women who agreed to have their names released to the researcher were given the choice of meeting with the researcher on the same day or to being contacted a few days later by telephone.

Upon meeting with participants for the first time, I reviewed the purpose of the study and consent form (see Appendix B), and provided background information about myself and answer any questions. I explained the concept of the study including: the study participation that was comprised of two interviews, one focus group, and keeping a journal to record their experiences with a breast cancer investigation; and the opportunity through their participation to frame questions for the next participant (s) that were going to be interviewed; to provide feedback on the process to move forward and on data analysis/results, and to present findings/be involved with publications after the dissertation. How much they chose to be involved with a participatory action research process was their choice. Women were also informed that this was part of my dissertation work. Women could choose to refuse to participate, give consent at that time, contact me later, or have me contact them a day later by telephone to inform me of their decision to participate or not. This two step approach to consent, where the nurse and surgeon obtained permission from the young women to first have their names given to the

researcher and then the researcher contacting the young women and obtaining full consent to participate in the study, is a common practice for research protocols in the breast assessment clinic.

4.3.4 Data Collection

Multiple data sources were utilized for this study for the purposes of triangulation.

Ristock and Pennell (1996) describe triangulation as:

...using multiple methods in order to obtain more thorough coverage of a subject by viewing it from different angles. This can be achieved in two ways: by using different methods for different questions about the same topic, or using different methods to explore the same set of questions (p. 51).

Using multiple methods or triangulation as part of a qualitative inquiry provides richness and depth to the data collected and improves the validity⁹ of the study (Ristock & Pennell, 1996). The concept of triangulation is defined differently in the literature by others.

Richards and Morse (2007) define triangulation as “gaining multiple perspectives through completed studies that have been conducted on the same topic and that directly address each other’s findings” (p. 91). When the proposal for this study was developed in 2006, I was familiar with the definition of triangulation as defined by Ristock and Pennell (1996) which I retained for the project. The different data sources were the individual and group interviews, the health records of the women to confirm medical information and dates, information from the women’s personal journals they chose to share and the field notes and journal kept by the researcher.

⁹ Ristock and Pennell (1996) provide a definition for feminist research validity defined as the “integrity and value of research achieved through accountability both to the participants and to those who will be affected by the outcome” (p. 50).

4.3.4.1 Interviews. Interviewing is a method of collecting non-standardized information that permits the researcher to appreciate and make use of differences among people (Reinharz, 1992). It allows participants to express their ideas, thoughts, and memories in their own words instead of the words of the researcher (Reinharz, 1992). As Reinharz (1992) explains “This asset is particularly important for the study of women because in this way learning from women is an antidote to centuries of ignoring women’s ideas altogether or having men speak for women” (p. 19). For this particular study, there was concern identified about interviewing women at a time when emotions and tensions were potentially high. Kvale and Brinkmann (2009) stress the importance of the interviewer having knowledge of the topic, and the skills and judgment to pose questions at the appropriate time. My clinical and research background (see section 3.2) provided me with the confidence and ability to interview these women while recognizing the need to be sensitive and create a safe space for them to express their thoughts and emotions.

The semi-structured interviews were meant to be exploratory and descriptive thus permitting women to freely express their thoughts and emotions on a variety of topics about what was happening with their breast cancer investigation. To help them develop the interview guide (see Appendix D) I referred to the supportive care definition developed by the Supportive Care Task Force Group (1994):

The provision of necessary services defined by those living with or affected by cancer to meet their physical, informational, emotional, psychological, social, spiritual and practical needs during the pre-diagnostic, diagnostic, treatment and follow-up phases (p. 15).

The draft interview guide was reviewed by members of the Advisory Committee who made minor revisions with the wording to increase clarity. The open-ended questions

were directed at understanding the young women's physical, informational, emotional, psychological, social, spiritual and practical needs at the pre-diagnostic (first interview) and diagnostic/treatment (second interview) phases (see Appendix D).

It was anticipated that most of these women would require a biopsy such as a fine needle aspirate, core needle biopsy, needle localization, ultrasound guided core biopsy, or open biopsy (see Appendix E). At the time the study was conducted, it usually took one to two weeks to schedule these types of procedures, except for the needle biopsies which were done on the same day of the first appointment. In light of this, it was important to have the first interview at the pre-biopsy phase and diagnosis or, at the very least, prior to the woman's knowledge of the pathology results of her needle biopsy.

Once consent was obtained from the young women at the first interview, they were asked a series of questions to collect demographic information (see Appendix F). Once this information was collected, I usually started the open-ended part of the interview with the question "Can you tell me about when you first learned about your breast problem?" This open-ended question triggered a conversation with the young women who shared their thoughts and experiences about going through a breast cancer investigation. The interviews were filled with emotions where sometimes there was laughter and other times there were tears; at that point the interview was paused to permit the women to regain composure; however in all cases they wanted to resume the interview.

All young women were interviewed a second time after learning their pathology results. There were two groups: women diagnosed with breast cancer; and women not diagnosed with breast cancer. Originally, the second interview was to be scheduled two

weeks from the time the women were informed of their pathology results or post-diagnosis. The waiting time for women to receive news about whether they had a diagnosis of cancer or not based on their pathology results was usually seven working days. It was not possible to keep the second interview scheduled within that two week period for various reasons which included: conflict with women's personal schedules and, other diagnostic tests being scheduled; women's preference for waiting until all tests were completed or; the wish of women diagnosed with breast cancer to meet with the oncologist prior to doing the second interview. I accepted these changes understanding that a qualitative inquiry can have unexpected turns of events (Maguire, 1993) and recognizing that within a feminist participatory action research project women have input in how the study unfolds (Reid & Frisby, 2008).

Each interview was digitally recorded with the young women's consent. They had the choice to do the interview in English or French; the interview guide and consent forms were available in both languages and the researcher is bilingual. The women also had the choice of being interviewed at the hospital, in their home or at a location of their choice. Tokens for parking and funds to cover the cost of childcare and travel expenses were available.

A summary of the young woman's plot/story (see Section 4.1.6) was presented to her at the second interview for her feedback. This step was repeated with all the young women based on my understanding of the data collected from their first interview and I provided them with an opportunity to clarify or add information as necessary. I usually read the narrative to them at the end of the second interview. The women were often amazed hearing their narratives, commenting how impressed they were with the accuracy:

“I forgot all of this, this is interesting” (Kathy, Interview 2, 511); “It is actually exactly, you know, I remember it, it is like we are going back and remembering how I felt” (Joan, Interview 2, 672). I provided debriefing with the young women at the end of all their interviews to elicit feedback on process and to ensure they were emotionally stable prior to leaving the interview. There was a protocol in place where they could call the Supportive Care Program at the cancer centre and access psychosocial resources if required. I also asked the young women if I had missed any questions and if there was anything they wanted me to ask other women at their second interview or in the focus groups. Most of the women found that the topics covered in the interviews were comprehensive and did not add other questions with the exception of one young woman. She did not have any children and she wanted to know how other young women with young children coped with the recovery after receiving an open breast biopsy. She indicated it was important to ask the question because of the recovery involved and physical limitations experienced after surgery. I proceeded to ask the question when I interviewed other young women with children who had received an open biopsy.

4.3.4.2 Focus Groups. Different terminology exists to explain a group of people coming together to participate in a research interview. These terms include focus groups, group discussions, group interviews, focus group discussions and focus group interviews with each term reflecting a theoretical or epistemological underpinning (Barbour, 2007). Barbour (2007) explains that any type of group discussion can be called a focus group as long as the group facilitator is actively encouraging and attentive to the group interactions. Focus groups permit people to formulate their own opinions about an issue

by listening to opinions, arguments and stories of others in the group (Marshall & Rossman, 2006; Reinharz, 1992).

The facilitator should have a non-directive style of interviewing to encourage the expression of a variety of viewpoints from the participants on a topic of discussion. "The aim of the focus group is not to reach consensus about, or solutions to, the issues discussed, but to bring forth different viewpoints on an issue" (Kvale & Brinkmann, 2009). Feminist researchers employ focus groups as a research method as it facilitates 'vertical interactions' between moderator and participants and most importantly 'horizontal interactions' between participants (Madriz, 2000). "Group interviews are especially significant in that they allow the researcher to witness one of the most important processes for the social sciences—social interactions" (Madriz, 2000). Group interviews permit hearing the 'plural voices' of participants who share a similar background (Madriz, 2000).

For this study, the young women were invited to participate in a focus group. There was one group for women with breast cancer and one group for women without breast cancer. The purpose of these focus groups was to present the preliminary themes generated from the data collated from the interviews, receive input from the women on these research findings, provide clarification about any information that may have been vague or ambiguous during the interviews, and permit the women to voice their opinions about recommendations for improving health care services for young women undergoing a breast cancer investigation.

One of the challenges of a qualitative researcher is to decide what findings are presented. Do you present the collective findings to the group and leave out findings that

may only be expressed by a few participants? The advantage of doing a feminist participatory action research study was the ability to go back to the women and ask their advice. For example, not every young woman identified financial concerns yet the six young women who participated in the focus groups agreed that it was an important theme to highlight in the presentation of the data. They recognized that the financial burden caused by a breast cancer diagnosis may affect many women. Hence when I present the data in this thesis, I provide examples about young women who expressed distress related to financial concerns knowing this was an important issue agreed upon by the women.

Although the titles of the themes generated from the study data were not explicitly developed at the time of the focus groups, I was able to present the content of the themes. The six young women who participated in the focus groups agreed with the content although they placed more emphasis on some issues. For example, timely access to diagnostic services was identified as one of the most important issues even though some women had not encountered problems being diagnosed. The focus group discussions with the young women provided clarity about the study findings. It facilitated the next step to further develop the themes based on the content while representing the views of the young women. The discussion also inspired me to be more creative with naming the themes using language that the young women used to describe their experiences with distress. For example, when Louise spoke about living a 'modified life' after her mastectomy, she adapted language from the name of the surgery "modified radical mastectomy". The language of "modified living" was actually picked-up in the focus group by the other young women diagnosed with breast cancer after Louise introduced the terminology in the discussion. I decided to name the theme related to body image

“modified living” as it encapsulated the juxtaposition of two important issues where the young women felt no choice but to choose life over appearance.

The focus groups also provided the opportunity for the women to ask questions of each other in terms of their experience with a breast cancer investigation and diagnosis. Each focus group was planned to take place once all young women had completed the second interview. Therefore the length of time between being interviewed to participating in the focus group was expected to vary for each woman depending when they were asked to participate in the study. Members of the Advisory Committee were consulted prior to the first focus group to share some of the preliminary themes based on the data gathered from the first and second interviews. Examples of themes that were reviewed included how young women found their breast problem, the challenges some young women faced accessing services, and the distress they experienced going through the breast cancer investigation. I reviewed the process for conducting the focus groups and invited any recommendations they had about the process I planned to follow. The preliminary themes generated interest and stimulated a good discussion with members of the Advisory Committee. They were supportive of the process described to conduct the focus groups. What was not anticipated, yet comforting, was the support they demonstrated towards me by asking how I felt emotionally to proceed to conduct the focus groups. This question permitted me to have a frank discussion to speak about my roles as researcher and clinician and the challenge at times in separating the two.

All participants in both groups were mailed a calendar with potential dates for holding the focus group. Several options were given including days, evenings, weekdays and weekends. The young women were asked to indicate their preferred date and return

the package of information. The date favored by most women was chosen for the time of the focus group. I spoke to each woman by telephone to confirm the date and follow-up with a mailed letter. A call was made a few days prior to the meeting to remind the young women of the focus group. Refreshments and snacks were available for each focus group.

I began each group by welcoming the young women and allowing them to introduce themselves. I reminded them that the terms (e.g. confidentiality, freely able to decide to answer questions and share information etc.) found in the research consent form still applied. I presented a summary of the preliminary themes generated from data gathered from the two interviews and elicited feedback from the young women on each theme. This information was the focal point of the discussion to obtain young women's views and opinions about the findings and clarify information that was not clear from the transcripts. The young women also provided feedback about their views for improving public education on breast health/cancer and how services for younger women going through a breast cancer investigation could be improved.

4.3.4.3 Journals. The use of expressive writing through research journals or diaries by women diagnosed with breast cancer is studied for its therapeutic effects on emotional, psychological and physical wellbeing (Creswell, et al., 2007; Low, Stanton & Danoff-Burg, 2006; Smith, Anderson-Hanley, Langrock & Compas, 2005). Feminist researchers have used diary research as an alternative method for capturing people's daily life experiences (Hyers, Swim, & Mallet, 2006; Reinhartz, 1992; Tedlock, 2000). The benefits of journal research are that:

By asking people from these groups to keep incident diaries as soon after they occur as possible, we obtain a different set of experiences than other methodologies, allowing us to capture characteristics and frequencies of mundane incidents and any immediate responses to those incidents, thereby better capturing some of the subtle, sometimes ambiguous, and often forgotten aspects of experience (Hyers et al., 2006, p. 317).

For the purpose of this study, journaling was used by participants as a means for capturing dates of medical appointment, writing about their thoughts, emotions or/and experiences with their breast cancer investigation. At the first interview, young women had the choice of choosing their journal from an assortment of different colors and they were informed that the journals were their personal property. They were asked to bring their journals to the interviews (including focus groups) as a means to help them recall information about their experiences. They were invited to share the content of their journals at the time of the interviews if they wished. Sharing content from their journals included reading excerpts, discussing content or allowing for photocopies to be made. As part of the interview process, the participants were asked if there was anything they wanted to share about their journal. If the young women referenced their journals to recall dates or read excerpts than this information was captured as part of the oral interview.

4.3.4.4 Health Record. As participants in the study, the young women had consented to allow the researcher access to their health records to confirm demographic information, investigational tests ordered, diagnosis, staging and treatment recommendations. I originally planned to review the women's health record when receiving the referral from the breast clinic. After the initial few referrals, I opted to wait and review the health record after the second interview. I realized that I did not want to be in a position of possessing information the participants may not have received about

their diagnosis or potential next steps of treatment. I wanted to hear from the participants themselves how the process was unfolding for their breast cancer investigation.

4.4 Relationship Between Participants and Researcher: Role of Reflexivity

Feminist researchers acknowledge the presence of power and control that exists in a research process and argue that a self-reflective practice can mitigate some of these issues (Reinharz, 1992). The position of the researcher as 'outsider' or 'insider' to a community is not always explicit to the point of drawing a line and belonging to one side. I found this line to be blurred as I proceeded with the study. I was an insider from the personal point of view of having been through a breast cancer investigation and having experienced family and friends being diagnosed with cancer, yet I was an outsider to the young women diagnosed with breast cancer because I had never been diagnosed with the disease. I was also an outsider to all participants from the perspective of presenting myself as a social worker, a student pursuing her PhD and an administrator working within the cancer centre. This last role also placed me as an insider to the agency (although being a breast cancer advocate can sometimes place you in an ambiguous insider position within your own agency). In addition, I had knowledge about breast health and breast cancer due to my years of working in the field, while most of the young women participants were learning about breast health and breast cancer for the first time.

In her work as ethnographer, Naples (2003) explains: "Outsiderness and insiderness are not fixed or static positions. Rather they are ever-shifting and permeable social locations that are differently experienced and expressed by community members" (p. 49). As the study process unfolded, "we" the women became insiders to a research process where trust and mutual respect was established. While respecting the uniqueness

of each other's position (s), there was space to express what was common and what was different. For example, after spending some time with a young woman prior to her first surgical consultation for her breast problem, she wanted to learn more about my career and how I had made decisions to work in oncology. Trust and the exchange of information happened early in the process.

To mitigate any potential power differences between myself and the women, given my research role, I attempted to foster an environment where the participants had input into the research as part of the interview process (see 4.3). It was important for the young women to understand they were contributing to my knowledge of younger women's experiences undergoing a breast cancer investigation; as 'knowers' of their experience, they were educating me and helping me with my Ph.D. dissertation. I reminded the young women of this key message during the interviews.

I willingly informed young women of resources available if it was appropriate. For example, one woman after she was diagnosed with breast cancer, wanted to meet with a spiritual counsellor outside her church. I made some inquiries and provided her with the information if she wished to pursue the referral. This type of direct assistance is common in feminist research ethics where a distinction is made between the roles of participants as human beings instead of subjects (Stanley, 1990).

It is also common for a feminist researcher to reveal information about her personal life in relation to the phenomenon being studied thus blending the 'public' and 'private' (Reinharz, 1992). One of the limitations of this approach is that the researcher may start projecting her experience onto the participant laying the groundwork for solipsism (Reinharz, 1992). I never used my experience with lumpectomy as a focus in

the interviews because my interest was to learn about other women's experiences with a breast cancer investigation; however, if a young woman had questions about processes and recovery I shared what I knew from my experience reminding her to check with the health care team, as each experience is different. I also kept journal entries about what I was feeling when interviewing the young women; my journal entries happened sometimes before the interview and always after the interview. This strategy was a way to reflect on process and how I was being emotionally affected by the study which is part of the voice centered relational method for analyzing data (see section 4.5). These journal entries also helped me recall information when I was collating and analyzing the content of the interviews. For example I offer an excerpt of my journal based on my first interview:

I just completed my first research interview for my dissertation. Of course what I least expected happened; I did not expect to have a young woman referred to me for this study that would be [teenager]...Although she is young, I found myself forgetting her age for a few seconds at different times during the interview. I was impressed with her knowledge. I want to believe, as much as she believes, that everything is going to be ok; my gut tells me that she is going to be ok. Is that my own denial? I'm not sure. (Journal entry April 14, 2007)

All precautionary measures were taken to foster a research process that created a safe environment for participants in the study. We now look specifically at how the data was analyzed.

4.5 Data Analysis and Interpretation of the Interviews

All interviews and focus groups were tape recorded and transcribed. Transcripts were saved as Word documents and securely stored electronically. All Word documents were transferred to NVIVO 7 software (2002). The software was utilized to code part of the data and to also organize files specific to this study as described below.

I used the voice centered relational method to analyze the transcripts of the interviews. This method of data analysis is also referred to as the 'Listening Guide' developed by Carol Gilligan in her work on identity and moral development (Gilligan, 1993). It is further expanded through the work of Lyn Brown, Carole Gilligan and their colleagues with the Harvard Project (Brown & Gilligan, 1992). They explain that the method "directs attention to the unspoken as well as the spoken. It highlights the relational dynamics of the research situation, and builds into the analysis a recognition of the layered nature of psychological processes and the interplay of psychology with biology and culture" (Gilligan & Machoian, 2002, p. 321). The voice centered relational method has four steps that are focused on listening rather than coding categories from the interview text (Gilligan, Spencer, Weinberg, & Bertsch, 2003). Each step requires the researcher, often referred to as the listener, to keep notes and summaries of each step. At minimum, the researcher will have gone through the text at least four times (Gilligan et al., 2003). The process I followed for the data analysis using the voice centered relational method, is based on the work of Gilligan et al. (2003) and Mauthner and Doucet (1998). I now describe the four steps they developed for data analysis and how these steps were applied to analyzing the data of the first and second interviews.

The initial step of the data analysis was conducive for answering the first research question: How do women 50 years of age and younger, not menopausal, describe their experience with distress from the time they are informed they require a breast biopsy for a breast abnormality to the time they learn their diagnosis? The first step in the data analysis was to listen for the story, the 'plot', and for the researcher to be sensitive to his or her own response to the interview (Gilligan et al. 2003; Mauthner et al. 1998). This

step was accomplished by reading the manuscript and creating a summary of the ‘plot’; the researcher then wrote her own reflections based on what she was hearing. This writing engages the researcher in a process of reflexivity (Gilligan et al. 2003; Mauthner et al., 1998). Immediately after the first interview, I recorded some of my thoughts and feelings about the interview while they were fresh. These notes were later summarized in a Word document stored in NVIVO that I could easily reference electronically if necessary. It was important that I make a summary of the plot or what I refer to as the young women’s stories to facilitate a review of data with them at the second interview. I listened to the recording, sometimes several times to ensure I understood and captured the women’s stories accurately. I paid particular attention to the tone of their voice, the pauses, and sometimes the hesitation in their voices as they described their experiences with their breast cancer investigation. The multiple layers of data analysis permitted building the plot/story of each woman that I presented at the second interview. Hence, there were only minor corrections pointed out in the stories by the young women such as the sequence of an event or a date they remembered. The Word files for these plots/narratives were edited for these corrections.

The second step entails listening for the first-person pronouns and creating a list of all these pronouns, referred to as the “I” poems (Gilligan et al. 2003; Mauthner, et al., 1998). This process draws the researcher’s attention to the participant’s first person voice and facilitates hearing how that person speaks about him or herself before the researcher starts writing about that person (Gilligan et al., 2003). For this study, I Poems were created parallel to the process of creating the plot/story of each woman. The Is were underlined in the transcripts for a visual first glance while preparing the plot/story. The I

Poems were later coded in NVIVO making them accessible electronically for printing without the narrative text.

Initially it was not clear how to incorporate the I Poems in the data analysis however, after the second and third interviews I started to understand the value of this process. For example, I noticed the intensity of the women's distress when reading the different I Poems. The women who found their lump had a different I Poem to describe the event e.g. "I was taking a shower, I just kind of felt it, I kind of panicked" (Joan, Interview 1, 87), compared to women who were informed by their primary care physician that they had a breast abnormality that required further investigation and reassured that it was a precautionary measure e.g. "I went for my check-up, I went back, he told me that he was going to send me" (Melanie, Interview 1, 174). I also noted that the young women changed their vocabulary from 'I' to 'we' when generalizing their statement to include all women including me as a female interviewer. It appeared at times that referencing 'we' was their way to confirm with me that I understood what they were saying because I am a female. These nuances were helpful to understand how young women perceived some issues to be tied to their personal stories and other issues generalized to all women.

The third step is focused on reading for relationships; how is the participant speaking about their interpersonal relationships with their partners, relatives, children and broader social networks (Mauthner et al., 1998). This step was helpful to answer part of the third research question: How do women describe expectations they have about themselves, their social environment and the health care system for resolving their distress? For this study, analyzing data looking specifically at relationships happened

parallel to the process of developing the plots/stories and the I Poems so the information could be included in the stories shared at the second interview. Transcripts were reviewed and data pertaining to relationships were underlined and analyzed for content to understand the nature of those relationships.

This final step of data analysis was instrumental for answering the second and fourth research questions: How do young women describe factors in the health care system that they perceive contribute to their distress? How do young women propose the system barriers be resolved? This step entails placing participants' stories within a broader social, political, cultural and structural context (Mauthner et al., 1998). This form of data analysis is conducive to what I was trying to accomplish with the research; that is to understand young women's distresses from the personal, interpersonal and broader social context. I went through the transcripts and underlined data that captured these issues so that I could interpret them as part of the summary of the plot/story.

A huge amount of data was collected throughout this process yet I was not clear about how to collate the data so I could build the analysis while reviewing each transcript. I decided to use elements of thematic analysis¹⁰ to capture themes in an organized fashion using NVIVO so I could build on each young woman's story and find the commonalities and differences with a breast cancer investigation while staying true to the voice centered relational method.

The story of each woman collated from the voice centered relational method was referenced to code the raw data from the transcripts into NVIVO. Each woman had a

¹⁰ Thematic analysis can be used by a researcher to interpret his or her information, regardless of his or her ontology or epistemology (Boyatzis, 1998).

way to describe how she found her breast abnormality, describe access to diagnostic procedures, access to information and so on. The interview guide was developed based on the definition of supportive care (see p. 85) therefore the women's answers could be coded under the categories of physical, informational, emotional, psychological, social (capturing relationships from step three of the voice centered relational method) and spiritual. Another category called structural captured the broader social, political, cultural and structural context. The raw data of each transcript was coded under these general categories. Each general category was further analyzed to generate themes that captured variances and differences in young women's experiences with a breast cancer investigation: e.g. the different emotional and psychological sources of distress associated with finding the breast problem, access or lack of access to information, preference for how to receive information, the nature of relationships and so on. The coding scheme was applied to the transcript of each participant. The next step involved comparing the themes that emerged when looking at the data of all participants. These processes allowed seeing where repetition of themes existed and merging themes when necessary. It was also an opportunity to observe the description of events that were unique to only a few participants and identify where I needed to provide the rationale for including these events in the study findings. The final step was clustering themes that had common meaning defining a particular part of the experience of undergoing a breast biopsy and diagnosis. The themes with sub-themes formed the presentation of findings for this study.

4.6 Data Analysis and Interpretation for the Focus Groups

The voice centered relational method was not conducive to analyzing the content of the focus group interviews as the purpose of the focus groups was different than the interviews. The focus group transcripts were read several times and thematic analysis was applied to code the data of each group. The raw data were coded based on responses to questions from the focus group interview guide (see Appendix G). Themes were developed from the raw data based on patterns identified from the responses of younger women. This process was helpful to clarify information from the first interviews and to establish consensus of the preliminary themes that were identified from the first and second interviews.

It is important to stress that all the data sources starting with the audio recordings of the interviews, the full transcripts, the data generated from the voice centered relation method, the printout of the themes developed in NVIVO for the interviews and focus groups were all referenced interchangeably to arrive at the final results.

4.7 Summary

In this chapter I described how principles of feminist participatory action research were applied as part of the methodology to permit young women to have input into a research process, share their stories of going through a breast cancer investigation and diagnosis and, have input in the development of recommendations to resolve system barriers that contribute to the experience of distress. The method encompassed a feminist qualitative inquiry and a description of the research process was reviewed: how input was solicited from women for the research question and design of the study; how ethical approval was obtained; how participants were engaged in the study and; how data was

collected from interviews, focus groups, research journals and health records. The role of reflexivity in the research process was described to address how the power imbalances between participant and researcher were addressed as part of a feminist participatory action research framework. The framework and process utilized to analyze the data using the work of Gilligan et al. 2003 and Mauthner and Doucet (1998), and thematic analysis were described to explain how the findings of the study were derived. The findings are presented in the next two chapters starting with the introduction of the participants.

Chapter 5: Introduction to Participants and their Stories

The purpose of this chapter is to describe the demographic and medical information of the young women who agreed to participate in the study and present a summary of their stories. The summary of each young woman is based on the “plot” generated through the data analysis from the first and second interviews.

5.1 Descriptive data

Eighteen young women were referred for this study between April 2007 and April 2008 from the surgical practices of three female surgeons working in a breast assessment clinic in a teaching hospital. It was determined that one woman was not eligible to participate in the study because she was over 50 years of age and menopausal. Three young women declined to participate in the study; two women identified not being able to schedule the first interview prior to their breast biopsy because they were too busy and one young woman was too upset to talk about her experience with a breast cancer investigation.

A total of 14 women met criteria for the study although two women were previously diagnosed with breast cancer and were now going through a second breast cancer investigation. It was not clear initially if their interviews should be included into the data analysis with the other interviews. The content of these interviews were included into the findings of the study as the women expressed similar concerns to the women who were going through the breast biopsy for the first time. Also the anticipated concerns of the young women who had never been diagnosed with breast cancer mirrored what the two young women knew about breast cancer treatment. This additional content brought richness to the study that was not anticipated. All individual interviews and focus groups

were held between April 2007 and September 2008. The first interviews for 12 participants were conducted prior to the biopsy, mean days = 12, range 0 to 42 from the time of the first interview to the time of the biopsy. Two initial interviews were conducted three days after the biopsy before the women learned their results. The second interviews were held after the participants learned their diagnosis, mean days = 66, range 6 to 176 from the time of the biopsy to the time of the second interview.

Originally, the focus groups were scheduled once all the young women were recruited into the study. However the referrals to the study were sporadic and recruitment took longer than expected. There were concerns that the young women would lose interest in the study if they were not offered participation in a focus group in a six month period after the second interview. In February 2008, three of the seven young women with a benign pathology result participated in a focus group after it had been rescheduled three times since November 2007 due to weather concerns, a bomb threat in the building where the focus group was to be held and cancellations to participate from young women who felt unwell. The two young women who were recruited after the focus groups and who had a benign finding were informed that a focus group would possibly not be held depending on recruitment however the content of their interviews would be included in the study findings. The second focus group was held in September 2008 with three of the five young women diagnosed with breast cancer.

The mean age of the 14 participants¹¹ was 41 years, with ages ranging from <20¹² to 50 years (see Table 3) at the time the women participated in the study. The majority of

¹¹ To note that I chose not to provide tables outlining the demographics and medical information of each women individually in order to protect anonymity; a practice supported by Richards and Morse (2007).

the young women were Caucasian and spoke English. Three participants were single, eight were married, three were partnered and a total of eight participants had children. Most of the women had a college or undergraduate degree. Besides two participants who were pursuing their education, the other young women were employed or stay at home mothers. A total of four women identified they were the main income earners in their family.

A total of nine young women did not have breast cancer and five young women were diagnosed with the disease. For the young women who learned they did not have breast cancer, the mean time interval from referral date to the breast clinic to being informed about their negative biopsy results was 53 days. The overall mean time interval, from breast symptom presentation with the primary care physician to the time the young women learned they did not have breast cancer was 72 days (range 25-161 days). For women diagnosed with breast cancer, the mean time interval from referral to the breast clinic to being informed of their biopsy results indicating a diagnosis of breast cancer was 18 days. The overall mean time interval from breast symptom presentation with the primary care physician to the time the young women were informed they had breast cancer was 218 days (range 21-543 days). Table 4 displays the time intervals in days for presenting with a breast problem to learning results of the breast biopsy¹³. It should be noted that the time interval between presenting to the primary care physician and a referral being initiated to the breast assessment clinic was estimated based on the young women reporting an approximate date when they saw their primary care physician for

¹² To protect anonymity the exact age of youngest participant is not presented

¹³ The number of each participant does not necessarily correspond with the number of participants in section 5.2 again to protect anonymity.

Table 5.1. Socio-Demographic Information (14 Participants)

Characteristics	Participants not diagnosed with Breast Cancer (<i>n</i> = 9)	Participants diagnosed with Breast Cancer (<i>n</i> = 5)
Mean age at study (years)	38	44
Age range (years)	<20-44	37-50
Mean age overall study: 41 years		
Age range overall study 16-50		
Cultural background X		
Caucasian	X	X
East-Indian	X	
Francophone	X	X
Italian		X
Métis		X
First language X		
English	X	X
French		X
Second language X		
English		X
French	X	
Italian	X	
Tamil	X	
Relationship status <i>n</i>		
Single	3	
Married	5	3
Partnered	1	2
Women with children <i>n</i>	3	5
Children <i>n</i>	9	8
Age range all children (years)	5-18	1-22
Education <i>n</i>		
Secondary (in progress)	1	
Completed Secondary		3
College	7	1
University	1	1
Occupational sector X		
Accounting		X
Clerical		X
Counsellor	X	
Food service industry		X
Health care	X	
Mining	X	
Pursuing education	X	
Self-employed	X	X
Stay at home mother	X	
Main income earner <i>n</i>		
Yes	3	1
No	6	4

Note. Specific numbers are omitted from certain categories to protect confidentiality given the small numbers; X indicates one or more than one person is in that category

Table 5.2. Time intervals- Presenting with breast problem to learning results of the breast biopsy

	P1 BB	P2 BB	P3 BB	P4 BB	P5 BB	P6 BB	P7 BB	P8 BB	P9 BB	P10 BC	P11 BC	P12 BC	P13 BC	P14 BC
PCP visit	X	X	X		X	X		X		X	X	X	X	X
Test(s) ordered														
CBE	X		X					X		X		X		
Ultrasound	X		X					X		X			X	
Mammography	X							X		X			X	
Referral to clinic	X	X	X		X	X		X		X	X	X	X	X
Current patient in clinic/visited				X			X							
Estimated # days from 1st PCP visit to RD in clinic	14	41	11		—	12		94		12	219	18	573	0
Estimated # days from oncology visit to RD in clinic									3					
# of days from RD to first visit/surgeon	34	36	15		—	28		8	2	8	4	7	3	16
# of days from mammogram to seeing surgeon				15			10							
# days from FNA to PR										*4	1			
# days from PR to informing woman										6	14			
# days from CB to PR										*4			3	0
# days from PR to informing woman										6			4	7
# days from visit with surgeon to UGCB				13		16	5	31	15					
# days from UGCB to PR				7		5	2	3	5					
# days from PR to informing woman				0		2	14	1	0					
# days from visit with surgeon to EB/lumpectomy	10	6	76					11						
# days from EB/lumpectomy to PR	5	3	9					5						
# days from PR to informing woman	1	3	0					8						
# days from visit with surgeon to NL					13							6		
# days from NL to PR					15							7		
# days from PR to informing woman					42							3		
Total days from PCP to diagnosis	64	89	111	35	70	63	31	161	25	30	238	41	543	21

Note. P = participant; BB = benign result; BC = breast cancer; X = confirmation of visit, exam or test; PCP = Primary Care Physician; CBE = Clinical breast exam; Clinic = breast assessment clinic; RD = referral date; FNA = Fine needle aspirate; PR = Pathology Results; CB = Core Biopsy; UGCB = Ultrasound guided core biopsy; NL = Needle localization; *FNA and Core biopsy performed same day, counted once

their breast abnormality and information that was identified on the referral form to the breast clinic. The other dates were verified through the health record of each participant. Table 5 displays the staging of disease of the five young women¹⁴ diagnosed with breast cancer and the treatment they received.

Table 5.3. Diagnosis and Treatment for Breast Cancer

Diagnosis for Five Participants:

Stage I: $n = 1$

Stage IIB: $n = 4$

Surgery:

Lumpectomy with sentinel lymph node biopsy, $n = 3$ followed by mastectomy, $n = 2$

Mastectomy, with sentinel lymph node biopsy $n = 2$

Systemic Treatment:

Chemotherapy: $n = 5$

Tamoxifen: $n = 4$

Herceptin: $n = 2$

Radiation Treatment:

Radiation therapy: $n = 3$

5.2 Introduction to Participants and their Stories

The stories of each young woman are split in two sections: first young women with a benign breast tumor and secondly, young women diagnosed with breast cancer. The story of each participant is presented in order of chronological age starting with the youngest woman.

5.2.1 Women with a Benign Breast Tumor

5.2.1.1 Joan. Joan, a teenager, was taking a shower when she noticed a lump in her breast. She described feeling panic when she found the lump and urgency to find

¹⁴ To note that I chose not to link the diagnosis to a specific participant to protect anonymity; a practice supported by Richards and Morse (2007).

immediate information. She already had an appointment scheduled with her primary care physician the next day because she was unwell. The primary care physician performed a clinical breast exam (CBE) on Joan and he recommended an ultrasound of the right breast, which she received. She was eventually referred to the breast assessment clinic for a surgical consultation. The surgeon conveyed to Joan and her mother that she did not think the lump was malignant however a right breast lumpectomy was recommended to confirm a diagnosis. Joan had day surgery and the pathology report indicated she had a fibroadenoma (a benign tumor). The nurse from the clinic was able to inform Joan of the good news over the telephone. The surgeon saw Joan in a follow-up appointment at which time her breast care was transferred back to her primary care physician.

I met with Joan for the first time at the hospital on a weekend, a few days after her initial surgical consultation. She was accompanied by her mother who was present for the research consent process and offered to excuse herself from the interview to permit Joan to be interviewed alone. Joan identified that her distress was greater upon finding her breast lump and going through the investigational tests. Her distress was less amplified after seeing the surgeon. The distress she described was reflective of that time period when she was not sure how serious her breast problem was which caused her to imagine the worst possible case scenario. She explained that she had a young friend who was in remission from cancer. She realized upon finding her own breast lump that people her age can get cancer and now the reality was sinking in that it could be her. When I asked her what she worried about she replied:

Well if it was cancer, like breast cancer. Well I was mostly worried because I have a friend who just went into remission for cancer so I was kind of nervous like maybe it would happen again to someone else I know and then like I found this

lump. Because she was my age too and she got cancer and then I was like okay, you know, the thought that it can happen, so. And then you know, all your friends are like happy because they don't have anything to worry about and you are just thinking 'I have this lump'. So it is kind of stressful. (Joan, Interview 1, 276)¹⁵

After Joan provided information about her friend I asked her: "Does it take away the feeling that I am healthy and nothing is going to happen to me?" (Researcher, Interview 1, 294). She replied: "Yeah, that is what I thought before, you know the whole, I am a teenager and I am invincible kind of thing" (Joan, Interview 1, 296).

Joan stated that she had trouble keeping her concentration in the classroom as her thoughts wandered from the discussion. She was experiencing difficulty falling asleep at night. She started thinking about death after finding her lump. It prompted her to read about her religion to understand what would happen if she died, was there an afterlife? Her father was interested in religion and he had books in the home that Joan decided to read. Reading brought her comfort knowing what to expect if she died:

Yeah and then you know, my dad was reading this book about past life experiences when people go through hypnosis and then they start talking about past lives and he gave it to me to read because I thought it might be interesting so then I read it and it actually kind of calmed me down because I thought well you know, something is going to happen after you die and you know; I started to look up reincarnation. If that is religious or spiritual I don't know.... But I didn't start praying or anything you know. I just started getting curious. Worried you know? (Joan, Interview 1, 616, 648)

I asked Joan about her information needs and how she accessed information on breast health and/or cancer. She reported searching the words 'breast lump' on the Internet right after finding her lump in the shower:

¹⁵ Each reference to the transcripts indicates the pseudonym of the participant, the source: Interview 1, Interview 2, Non Breast Cancer (NBC) Focus Group (FG), Breast Cancer (BC) Focus Group (FG); and the first line where the quote starts in the transcripts. The quotes are formatted based on the Publication Manual of the American Psychological Association, 6th Edition, 2010.

Well at first I did a lot of research because I thought if I could figure out what it was it would help me deal with it. Then once I found out about the cysts it tells you how to recognize them like if they are easy to move around and if they have like a definite shape to them and I just kind of compared and it helped me feel better. (Joan, Interview 1, 396)

Joan was the only participant who spoke about the lack of information for her age group.

She also identified the lack of information on preventative measures for breast cancer:

Well mostly when I looked it up, it is people who are like 40-50 or above. That's because it is not really common, well it is common to have cysts, but at my age not like malignant cysts. So, there is not really much for like [teenagers], you know? What to do, what you have to do after it has been removed to like prevent anything. How to deal with it and everything. (Joan, Interview 1, 209)

She identified that information about survival rates was not helpful as it caused her to worry.

Joan, who had never been seriously sick before, developed trust in her health care team based on her belief that health care professionals behaved in an ethical and professional manner. When she spoke of having a clinical breast exam and other tests, she explained that it was uncomfortable for her however she realized that health care professionals conducted these exams on a regular basis. She changed her pattern of speaking from first singular person to the first plural person. I sensed that the change in pronoun use was because I am a woman and Joan was confirming with me how uncomfortable it is for women to have their breasts examined, especially the first time, and Joan used the phrase: over time, "we" learn to tolerate it:

Well I guess you would be nervous because it is your first experience and you know, you are self-conscious about your body and everything but they are professionals and they have done it many, many times so you know. But it is pretty nerve racking at first. But afterward when you look back, it is not that bad. (Joan, Interview 1, 153)

Her trust in the surgeon and nurse in the breast assessment clinic was also reinforced as they provided her with information about what was happening to her and what she could expect as the next steps. Joan also spoke about the nurse in the clinic and how the nurse made her feel comfortable:

Well just before [the surgeon] came in, she [the surgeon] was with another patient, so she [the nurse] just like, she gave me the pamphlets and then she was just going through them and then she asked me if I was nervous and I said "not really, not as nervous as I thought I would be". So yeah, she just kind of talked to me for a while and asked me about school and everything, kind of calmed me down. (Joan, Interview 1, 540)

Joan and her mother decided not to tell Joan's sister and father about her breast lump and the need for her to have a lumpectomy. Joan's sister was about to write her university exams and her father was involved in a big project at work. Joan's mother knew that if Joan told them about her pending surgery they would worry about her so she encouraged Joan to wait for a while before she disclosed that she needed a lumpectomy. At the second interview, I asked Joan about her decision to delay disclosing this information to her sister and father. She explained how she eventually talked to her sister about her breast abnormality:

...I said 'well remember on the March break and I went to all those doctors appointments' and then I told her 'you know I went for an ultrasound and I had a cyst?' At first she thought I was joking.... She was like 'why didn't you tell me, you know months ago?' And then you know, she gets stressed out about the littlest things and since it wasn't serious and she had her, you know, university exams, I didn't want to tell her, because you know?.... She is really conscientious about her marks. (Joan, Interview 2, 382, 392, 396)

Joan planned to tell her father about her news the same day she told her sister however she delayed speaking with him for a few weeks because of his workload. She realized there was never a good time to break the news however she had managed to shelter her

sister and father from additional stress while they dealt with their own life stressors. Joan felt better when she was able to talk about what she was going through and so her circle of friends were a good source of support to her: “Then talking to my friends and just talking. It made me feel better because it was like taking a load off of yourself and like you know, so” (Joan, Interview 1, 396).

Joan delayed starting her summer job by a few weeks while she recovered from her lumpectomy. She took pain medication for two days after the procedure. She was instructed not to get the bandage wet and limit her daily activities. She was not concerned about the appearance of her breast after her lumpectomy.

Joan shared in her first interview that the surgeon had taught her how to do a proper breast self-examination and she was provided with information about healthy eating. This triggered a discussion about when is it appropriate to teach younger women to become breast aware. She realized that finding a breast lump may cause distress but it was her impression, that young women should be introduced to become breast aware starting in high school:

Well I guess it is better to be on the safe side than not to be, like carefree. But still some people can get really, really stressed out over it and that would be worse if they had nothing wrong with them.... I guess if they just taught them in grade 10 or 11. Like a health class, cause then they are more mature and everything, but probably not grade 7 or 8. (Joan, Interview 1, 448, 452)

Joan was the first research interview I conducted for the study. Her point of view about breast awareness prompted me to ask other women about their thoughts on breast awareness which was further discussed in the focus groups. There was consensus amongst the women that breast awareness should be part of high school curriculum.

5.2.1.2 Mona. Mona described finding a lump in her left breast while taking a shower. She immediately contacted her primary care physician who saw her the next day. He could also feel the lump when he performed a clinical breast exam. He referred her for a mammogram and ultrasound. A follow-up mammogram and ultrasound was recommended in six months. Mona followed through with these diagnostic tests and the radiologist recommended another ultrasound in six months. Her primary care physician decided to refer her to the breast assessment clinic for a surgical opinion. She saw the surgeon who recommended that she have an excisional breast biopsy. She had the procedure done through day surgery and the pathology report was negative for malignancy. Mona was informed of her results by the nurse who contacted her by telephone. She had a follow-up visit with the surgeon after her surgery and was discharged from the breast clinic.

Mona requested that I meet with her in her home because of her young family and childcare needs. She was married and had three children under the age of ten. She was very welcoming and the interview felt more like a conversation you would have with someone in their living room. Mona revealed that her breast problem was something she thought about often: "Oh, I think about it everyday.... It has been on my mind everyday since I have seen the doctor [surgeon] (Mona, Interview 1, 363, 371). She and her husband understood that a breast cancer diagnosis could lead to death if the disease spread. When Mona thought about potentially being diagnosed with breast cancer she wondered "Am I going to survive it" (Mona, Interview 1, 299). Mona thought about the worse case scenario; she did not want to die and leave her husband and her children,

however she was not afraid of death. Her father had died seven years earlier prompting Mona to read about afterlife which gave her comfort:

Like say the worst case scenario, if I had cancer and they couldn't cure it and I, you know, I passed over, you know or whatever, I would know where I am going. It is not like I would be gone. You know, so that is all.... Like as my husband says, 'are you not scared? Like if it was really bad like are you'? Like he says 'I am scared, are you'? I said 'well no'. I said 'I would miss you guys and that but, but from what I have read, I would be around you all the time anyways'. So you know? (Mona, Interview 1, 554, 558)

In terms of her information needs during the breast cancer investigation, Mona preferred to receive information from the surgeon instead of searching the Internet. She also felt comfortable asking her questions:

I haven't done it yet though, but I do have the Internet. I could, I usually check out stuff like that but I haven't checked anything.... I don't know, I just, I didn't bother looking it up, I thought maybe the doctor [surgeon in breast assessment clinic] would give me all the information I needed.... They answer all my questions, like if I have any questions they have no problems answering them. (Mona, Interview 1, 351, 355, 518)

Mona was experiencing distress worrying about the procedure based on her understanding that she would be awake and aware of her surroundings: "Just the actual part of cutting me open to take it out. I have never had to have that done before so I am a little nervous about it. Even though I am not going to feel it, I still know what they are doing, you know (Mona, Interview 1, 159)? Mona was also concerned about recovery and how fast she would be able to resume her routine at home. Her husband worked shift work while she cared for their children at home:

I am worried like when I come home. They said I might not be able to lift anything for about a week or so and so my husband is going to help me out with the kids and help out as much as he can. I guess I will just deal with it day by day. Hopefully I recover pretty quickly. (Mona, Interview 1, 171)

Mona felt better when she talked to her husband and mother about her pending lumpectomy. Her mother had previously received a breast biopsy and she was able to share with her daughter what the experience was like which Mona found helpful:

Oh, I talk to my mom a lot about it. She has been talking to me about it, how there is nothing to it; you will be in and out, no problem, and talking to my husband too. It just helps me to, you know, I can't keep it in. I have to talk about it, just to get it out in the open. (Mona, Interview 1, 431)

When I met with Mona after her biopsy, she explained that she was so anxious about getting the lumpectomy that she contacted the breast assessment clinic in the days leading up to her surgery and the surgeon prescribed medication to help her relax prior to the procedure. On the day of the procedure, she was not sure when she should take the pills, so she took one pill when she got to the hospital and she took the second pill prior to the procedure without informing the nurse in day surgery:

So I took it and then I was pretty good. Like I remember like just lying there while they were doing it [lumpectomy] but I could feel like tugging and sometimes a little bit of pain once in a while and I would tell them 'okay I can feel that' and she [surgeon] would say 'oh okay'. So she would give me, they gave me the freezing once and then they gave it to me about maybe half way through again and the needle hurt more than anything. It really, it hurt. Like usually I don't say ow, but I was like 'ow, that hurt' and she [the surgeon] said 'yeah it hurts a little bit. (Mona, Interview 2, 22)

Mona also took pain medication without questioning the interaction it could have with the anti-anxiety medication she had already taken. She described feeling 'spaced out' while her husband drove her home and she was sick to her stomach which she believed was caused by all the medication she had taken:

But I think what happened was that they didn't realize that I had taken this [anti-anxiety medication]. I never mentioned it. Well, I never thought of it and then they gave me these [pain medication] and I just didn't think. I think I was too relaxed and they just said 'here take these'. I just popped them and I didn't realize

I guess that there could be an interaction, that there could be problems I guess...
(Mona, Interview 2, 40)

When Mona returned from the hospital, her children wanted to see her incision:
“They are kind of curious. Can I see what it looks like”? So I said “yeah okay, if you want to” and they were like “oooh” (Mona Interview 2, 308). She was fortunate to have her mother staying with the family to assist with the care of the children while Mona’s husband worked. Mona did not like depending on others while she recovered from her lumpectomy:

...I wasn’t allowed to do anything. Well I couldn’t lift, like our laundry is down here and to lift anything down, I couldn’t do it for about three weeks after. I had to get somebody like my husband or my mom to bring it down.... She would takeover and I felt a little like, what am I, an invalid or what you know, for a while. (Mona, Interview 2, 64)

She developed an infection in her incision delaying her recovery “...it was red and sore and itchy and I thought oh, there is something wrong with it. It just doesn’t seem like it is healing as fast as it should....” (Mona, Interview 2, 92). She went to a walk-in clinic and was prescribed a cream to apply to the infected area. In her first interview, Mona was not concerned about what her breast would look like after the biopsy, however, at the second interview she had concerns. She wondered if the scar would become less visible over time. Mona was happy to have gone through with the biopsy despite her setback with the infection and the appearance of the scar “...it was a positive experience pretty much. It was nothing really bad that had happened out of it, so I am glad that I got it done” (Mona, Interview 2, 120).

Mona reported thinking differently about her own health after her breast cancer investigation. She was cognizant of the need to become more proactive to deal with her

health issues in a timely manner “I am going to make sure anything that pops up, get it checked right away because I used to let things go. You know? Sometimes I would just let things go. Now I just, no, I will get it done, get it checked” (Mona, Interview 2, 128).

5.2.1.3 Melanie. Melanie saw her primary care physician who found a lump in her left breast while performing a clinical breast exam. He referred her for a breast ultrasound and mammogram and saw her again for a follow-up appointment at which time he referred her to the breast assessment clinic for a surgical consultation. Melanie saw the surgeon who recommended an excisional biopsy of the lump in the left breast.

She basically said that I had a large fibroid mass in the breast and that she advised that I should get it taken out. She thought that it was really nothing to worry about, it would just be better for me to have it taken out because my breasts couldn't be examined properly. (Melanie, Interview I, 186)

Melanie had the procedure done through day surgery and the pathology report was negative for malignancy. Melanie received a telephone call from the nurse in the breast assessment clinic informing her that she did not have breast cancer. She saw the surgeon after receiving a follow-up breast ultrasound and was discharged from the breast clinic.

When I met with Melanie for the first interview, in her home a few days after her consultation with the surgeon, she was pretty confident that she did not have breast cancer however she had some anxiety about getting the lumpectomy. She worried about complications and she was not sure how long it would take before she regained the full use of her arm after the procedure: “I did ask them but I don't know that I understood fully like how much I would be able to use my arm” (Melanie, Interview 1, 254).

When I met with Melanie for the second interview, she explained that she was nervous throughout the procedure and she cried when it was over “...It went very, very

well. I was very, very nervous though...Extremely nervous, yeah. I don't like surgeries or I don't think anybody does...But I just get extremely nervous. Once it was over I was crying...Then I was fine. I just get worked up. I don't know why" (Melanie, Interview 2, 55, 59, 67, 75). When I asked what was going through her mind she said:

I am just worried that something is going to go wrong. I have a lot of allergies so I was scared that I would have a reaction to something... Umm, but it went very, very well. It is just I think it is because I don't know what is going to happen and I am not aware and like I didn't really know if it was a minor surgery, I think it was minor surgery but just I think about complications and that is just me though. My personality, I always think that something could go wrong. (Melanie, Interview 2, 79, 83)

Prior to her lumpectomy, Melanie did not like examining her breasts because she was afraid of finding something wrong. She had a history of having breast cysts and she usually relied on her primary care physician to do a yearly clinical breast exam. Her breast cancer investigation prompted her to become more breast aware:

I have to start examining them [breasts] and being more careful. It has just made me more aware of breast health...Like not take it for granted. Not to leave it up to my doctor to check them, you know, once a year and it is my responsibility as well as his. If I find something he can check it. (Melanie, Interview 2, 209, 213)

Melanie did not appear to have any lingering distress after her breast biopsy.

5.2.1.4 Donna. Donna had seen the surgeon six months earlier in the breast clinic for a lump she found in her left breast. She received an ultrasound guided core biopsy and it was recommended that she have a follow-up mammogram and ultrasound six months later. She had both tests performed as scheduled and now had another breast abnormality detected. She saw the surgeon who recommended that she have a biopsy of the left breast. She started to worry upon hearing she required another biopsy: "Well, like I said, the first one it didn't really affect me at all. It didn't bother me [she had been

reassured by surgeon it was a cyst]. This one is nerve racking” (Donna, Interview 1, 266). She received an ultrasound guided core biopsy of the left breast and the pathology report indicated there was no malignancy. The nurse from the breast clinic informed her of her results over the telephone. Donna had a follow-up mammogram and was assessed again by the surgeon who transferred her care to the primary care physician.

I met with Donna for the first time in my office a few days after her consultation with the surgeon when she learned she had another breast problem that needed to be biopsied. She appeared to be a bit nervous and she often laughed when speaking to express what was going through her mind. I sensed that part of her laughing was caused by her nervousness and it was also her way to communicate how she was feeling without becoming emotional. Donna explained that she originally searched the Internet for information about breast cancer and treatment: “Ycah, I have researched like cysts, lumps and all kinds of things. If it is cancerous, lumpectomies, yeah I have done it all” (Donna, Interview 1, 361). Donna explained that seeing pictures and having the information presented in plain language was helpful to her:

Pictures and English language, not this long word or long medical terms and scientific terms; laymen terms, something that I am going to understand. Don’t give me these long scientific terms that I don’t know what it is. That is not going to help me at all. (Donna, Interview 1, 377)

I asked Donna how often she thought about her breast problem and she replied “Hours, days, weeks, umm everyday” (Donna, Interview 1, 390). Her distress was also amplified by the press coverage on breast cancer “...Like you are trying not to think about it but you open the newspaper and there is something about breast cancer. You turn on the TV there is breast cancer.... Like I said, I don’t read the newspaper because I find

that there is something almost every day in the newspaper...” (Donna, Interview 1, 266, 394).

Donna was a single mother, who had a young son and was also a caregiver to her father who was frail and living with them. She did not speak to her father about her concerns with her pending breast biopsy because she did not want him to worry about her. Part of the distress she was experiencing was thinking about the type of treatment she would require if she was diagnosed with breast cancer. She had already discussed with her boyfriend the possibility of needing a mastectomy. He reassured her that if she required a mastectomy it would not affect their relationship.

Donna wanted to prepare her son in the event she needed to be hospitalized and he required alternate care with family or friends. She was trying to balance giving her son enough information without worrying him: “Because he is a little worry wart... he tends to really worry. So I don’t want to panic him but you know, I do want to prepare him if I do have to go to the hospital for a long period then it is not just a shock to him all of a sudden (Donna, Interview 1, 592). Her father could not provide childcare for his grandson due to his own health issues. Her son’s father worked long hours and had limited contact with the little boy. Donna had her routine “...I put him on the bus, I make his lunches, I play the games with him, I sing him the good night songs you know? Daddy doesn’t do that kind of stuff” (Donna, Interview 1, 612). When I asked Donna if she had options for his care she replied “It is a blank” (Donna, Interview 1, 622). At the second interview I followed-up with Donna about the care for her son on the day of the biopsy. She indicated that she was able to make arrangements with a neighbor who brought her son to the bus stop the morning of her biopsy. She did not required hospitalization so she

was relieved that her son was not separated from her for an extended period of time.

What I observed at the first interview was a woman who could not bear the thought of not being able to care for her son. Although she had to make childcare arrangements for the day of the biopsy, what if she did in fact have breast cancer? Would she be able to take care of her son? Nobody could replace her as a mom. At that point those thoughts were overwhelming and she could not think of a plan. Thankfully, Donna did not have breast cancer.

Donna kept herself very busy the week leading up to her biopsy. When I asked her what she found useful to help her cope she indicated being in the presence of her son and friends:

...just playing with my son, walking and being with friends more. I found that I wanted to be around them more, because usually they have a busy life, I have got a busy life; we just talked on the phone. But for that week, I wanted to be around people more.... Just to have somebody there to talk to me about something else. Like I would be at home cleaning and you are still thinking 'okay another two weeks to go'. But if you are with friends or somebody, you are talking about all sorts of different things and that was a big help. (Donna, Interview 1, 400, 404)

What was not helpful to Donna is when some friends tried to provide a false reassurance by saying that she was going to be fine:

How can I say this, they reassure that 'oh, it is nothing,' they're like 'oh, you are young don't worry about it'. But in a way that is not what I want to hear. Like it is like they are just kind of pushing it aside. I wanna hear that you are gonna be okay or you know, if it turns out to be something, then I will be there for you kind of thing. (Donna, Interview 1, 526)

When I met with Donna for the second interview, she reported that her boyfriend accompanied her the day of her ultrasound guided breast biopsy. The procedure went well and she had a quick recovery. She explained that the whole experience with the breast cancer investigation had changed how she thinks about her own health. She had

done periodic breast exams in the past however she was now committed to examining her breasts more often: “I check them [breast] more regularly than I used to.... Like it wasn’t a regular thing but now I am doing it” (Donna, Interview 2, 104, 180). Donna also made the decision to stop smoking which she partly attributed to her breast cancer investigation:

I am quitting smoking.... Like I have wanted to quit and again procrastination and you know, the last time I quit I didn’t really have the incentive. Like my son was pushing me, so that was [an incentive]. But it just wasn’t enough to push me to do it.... And this I guess, cancer, smoking, not good, no. Plus I am getting older. (Donna, Interview 2, 108, 144,148)

She explained how difficult it was to wait for the pathology results and how it prompted her to become a bit more proactive with things she had been putting off:

...But that whole week [waiting for results] was, it was rough. Like you have your ups and downs and your mind is continuously thinking, but I kept busy. The good thing that came out of it was that I used to be a bad procrastinator and now, even that whole week, I didn’t put things off because I thought ‘what if?’ So now, even now I am practicing don’t ‘put things off’. (Donna, Interview 2, 68)

Donna did not report any lingering distress related to her breast cancer investigation after learning she was breast cancer free.

5.2.1.5 Brenda. Brenda discovered a lump in her left breast and three weeks later she noticed that her nipple had retracted. She followed through seeing her primary care physician who could feel a breast lump while doing a clinical breast exam. Brenda proceeded to have bilateral mammograms and bilateral breast ultrasounds and the report did not identify concerns for a potential malignancy. She contacted her primary care physician’s office to schedule a follow-up appointment for her results to be informed by the secretary that everything was normal and she did not need to return to see the primary care physician. Brenda was not comfortable with this approach; she waited a week before

calling back to book an appointment with her primary care physician. She was referred for a second ultrasound at which time three nodules were detected and a core biopsy was recommended. Brenda was referred to the breast assessment clinic for a surgical consultation and an ultrasound guided core biopsy was recommended. She had the procedure and the pathology report indicated there was no malignancy. The nurse from the clinic contacted Brenda to inform her of the results and Brenda saw the surgeon in a follow-up visit who recommended that she have an excision biopsy of the area where there was thickening in the left breast tissue. She had a lumpectomy and the pathology report was negative for malignancy. The nurse contacted Brenda by telephone to give her the results. Brenda was eventually discharged from the breast clinic with follow-up breast health recommendations through her primary care physician.

When I met with Brenda in my office for the first time, she identified that her distress was related to the fact that she did not know what the future held for her. She was disappointed with the amount of time it had taken her to be referred for a surgical consultation. The need to advocate for further investigations was causing her distress. She had heard campaigns on television that promoted early breast cancer detection and she wondered what early detection meant for her given she had already waited over two months to be referred to a surgeon. Was she at risk of having advanced breast cancer if the investigation took too long? She was not sure what early detection meant:

Well, you know what I find is when they say early detection and I am just thinking 'well what is early detection'? I don't know what early detection is. They talk about it and it is like 'well is early detection', you know, cause I noticed it [breast abnormality] in February, would March have been early detection? I don't know. I just find when you hear about it on TV or they are always saying early detection and it is I don't know what early detection means. (Brenda, Interview 1, 456)

It was her impression that she spent less time thinking about her breast problem now that she had met with the surgeon and that her procedure was scheduled:

I spent more time before I saw [the surgeon], that was when, you know, the unknown and I sort of, you know, you spend too much time I think, thinking about it. Then after I saw her, and I read all the information, I really try not to think negatively. (Brenda, Interview I, 372)

Brenda said that prior to seeing the surgeon, she often touched her breast where she could feel a lump "I probably did breast exams ten times a day just to make sure that it was still there and then I am thinking 'they are saying, you know, is it changing?' Well then I am thinking, 'Well is it sore'? Well sure it is sore because I am checking it so often it is sore now" (Brenda, Interview I, 708).

Brenda was not able to speak to her husband about her worries of being diagnosed with breast cancer. When I asked her in the first interview if she had spoken to her husband about how he felt in regards to the biopsy she replied "No I am not there yet" (Brenda, Interview I, 548). In her second interview she explained that she preferred limiting the amount of time she talked about her breast cancer investigation:

I think the most helpful thing is not talking about it too much other than that. My husband doesn't really bring it up unless I bring it up. He sort of sits back and waits for me to say something. So that is kind of helpful because I think sometimes he never knows, you know, what to say or in case he says something that I don't like. (Brenda, Interview 2, 624)

Brenda provided factual information to her teenage son about the need for her to have a breast biopsy however she did not want this issue becoming the focus of discussions at home. She selected only a few people to share with them what she was going through because she did not want people to ask her about her health in front of her son. She was trying to protect her son from worrying about her:

So we just sort of tried to, you know, talk about it nonchalantly and you know, and that is why I didn't mention it in public when he was with me because people's reactions' would have affected him maybe.... So things like that. It would be different if I was just with my husband but when my son was there we wouldn't.... No we didn't discuss it openly because of people's reactions. It would have frightened him. (Focus Group, Non Cancer, 85, 89, 93)

When Brenda was informed that she required a lumpectomy after her ultrasound guided core biopsy, she decided to tell her son about the procedure because she knew she would have to restrict her activities:

So of course I had to tell him something was up, obviously after... when the lump was removed, so I just told him that I had a lump and that I was getting it removed and you know it would be sort of, there would be no wrestling for a week with me or you know that kind of stuff and that is about it. I didn't really say too much more than that (Brenda, Interview 2, 604).

Prior to her biopsy, Brenda wanted to speak to another woman who had been through a similar experience however she did not know anyone. She decided to approach a colleague at work whose wife was diagnosed with breast cancer: "There is one person at work whose wife had breast cancer four years ago and so I went to him and you know, got some information from him and of course he said 'you can call my wife whenever you want' so I did get information from him" (Brenda, Interview 1, 308). Brenda knew this lady would become a resource person to her if she was diagnosed with breast cancer.

When I met with Brenda for the second interview, she reported receiving an ultrasound guided core biopsy followed by a lumpectomy a few weeks later and she found both procedures tolerable. Brenda required medical attention for another chronic health issue and her mother often accompanied her for medical appointments. Brenda informed her mother that she required an ultrasound guided breast biopsy and her mother insisted on accompanying her on the day of the procedure. However Brenda did not want

her mother to see her in a vulnerable state or give her the impression there was something seriously wrong. She opted not to have her mother sit with her while she applied ice packs to her breast after the biopsy. Again it was her way of protecting her mother from worrying:

...When I went for that hour after with the ice packs, the girl said to me 'do you want me to go get your mom?' and I said 'no, no, don't get her', because I was lying in a bed with the blankets and the hospital gown and the ice packs and I just thought, no leave her in the waiting room and she won't have to see me like this and you know?... Cause then you know, I think she would have thought that I was, I don't want to say sicker than I really am or, but to that effect you know? (Brenda, Interview 2, 568, 576)

Brenda reported she had a quick recovery from the ultrasound guided core biopsy and a longer recovery period for her lumpectomy. When I first interviewed Brenda, she was not concerned about what her breast would look like after the biopsy however she had concerns at the second interview. Her nipple was inverted since the discovery of the breast problem and the surgeon had informed her of the possibility that it may stay inverted after the lumpectomy. "...It kind of bothers me a bit right now, but I might get over it.... But size wise and shape wise, it filled back out. It filled in.... I am trying not to, it could be worse things, I keep thinking, but it does kind of bothers me a little bit" (Brenda, Interview 2, 200, 204, 232).

Now that Brenda had completed her breast cancer investigation, she was resolved to becoming more breast aware however she was having a difficult time touching her breasts since her lumpectomy "I will do it [examine her breasts] but I purposely have not done it since the surgery really because I don't want to find another lump right now, but definitely I know" (Brenda, Interview 2, 416). When I asked her if she was still concerned about the breast problem she hesitated and replied:

Yeah, probably, you know I will make sure I will be getting mammograms yearly or bi-yearly.... Because now it is possible, you know? Whereas before, I wouldn't have, I mean I thought it was possible but I didn't really, just because there is no history.... But now it is like, yeah, it could happen. In two years I could find another one or a real one [lesion that is cancerous]. (Brenda, Interview 2, 460, 464, 468)

It did not stop her from encouraging her friends to regularly examine their breasts. She had purchased a keychain from the Canadian Cancer Society that has the sizes of the different breast lumps a woman may feel. She was showing her friends what to look for when examining their breasts. It was her way of educating other women about becoming breast aware. She laughed when she said:

I did feel that I have to tell everybody I know how to do it, you know what I mean? And that people don't want to hear that! So I have been educating everybody at work right who sees my key chain. But it is just a little thing that I can do... At first they don't know what it is right? They just think that it is a little gadget... I can see people going 'like enough information'... It is just a little link you know... Because I never thought about it either. I never read posters or that sort of information (Brenda, Interview 2, 416, 788, 792, 800, 808).

It had taken seven months for Brenda's breast problem to be resolved. She was concerned with the amount of time it had taken for her to be referred to a surgeon. She planned to follow-up with her primary care physician "...My family doctor, she is new to me, I have only had her for a year, so you know, I have some things that I need to speak to her about" (Brenda, Interview 2, 658). Brenda also believed that information on breast health and the breast cancer investigation process should be available in the primary care physician's office.

5.2.1.6 Kate. Kate received bilateral breast reductions and followed through with getting bilateral mammograms six months later as recommended by the plastic surgeon to establish a baseline. She was recalled for special views for both breasts and a right breast

ultrasound showed a nodule in her right breast. She was referred by her primary care physician to the breast assessment clinic to be seen by a surgeon. The surgeon assessed that the nodule was not a high risk for malignancy and she provided the option of evaluating again in six months with another ultrasound or doing an ultrasound guided core biopsy for a definitive diagnosis. Kate originally chose to wait six months however when she and her husband drove home, she changed her mind: "Initially I chose the ultrasound and then when we were driving home, because [my husband] knows me, he said 'you are going to make yourself sick all summer,' so I called and changed my mind" (Kate, Interview 1, 171).

Kate had her ultrasound guided core biopsy of the right breast and the pathology report was negative for malignancy. Kate learned her results from the nurse in the breast assessment clinic who called to inform her she did not have breast cancer. The surgeon saw her for a follow-up appointment and recommended that Kate have bilateral mammograms in one year with follow-up with her primary care physician.

I met with Kate in her home prior to her ultrasound guided core biopsy. She was very kind and made me feel welcomed in her home. We sat at her dining room table to talk about her pending breast biopsy. She was experiencing distress thinking she may be diagnosed with breast cancer. She often thought about her breast problem during the course of the day: "Lots, probably too much that's me, probably three quarters of the day (Kate, Interview 1, 378, 390). Kate described feeling nervous since seeing the surgeon "I have like those butterflies all the time..." (Kate, Interview 1, 523). Her primary care physician had informed her that she did not have breast cancer however the surgeon could not provide her with the same guarantee until she had the pathology results of the biopsy.

Kate pointed to her leg that was moving up and down very fast. She explained that she used to have this symptom of her leg moving up and down at a really fast pace all the time over 10 years ago when she found herself feeling anxious: "And that is starting again, my status is new. My friend used to say just put a new battery in your leg today" (Kate, Interview 1, 727). Kate had made the decision to postpone a test she was planning to take with a friend related to work because she was feeling so anxious. She was concerned that she would not have the ability to concentrate and complete the test.

Kate explained it had been a long journey getting her bilateral breast reduction and she was finally at a place where she was pleased with the appearance and size of her breasts. She was worried about the cosmetic results of a breast biopsy and if she would be left with an indentation in her breast. At her consultation with the surgeon, she became aware that she could have breast cancer even though the surgeon had reassured her that she had a low risk of being diagnosed with the disease based on clinical findings. When I asked her what she was most worried about, she indicated "Well, if I have to lose a breast. That is probably it" (Kate, Interview 1, 427). Kate also had beautiful long hair and she worried about losing her hair if she required chemotherapy "I don't like the thought of having to lose my hair. I mean that is, you know, vain, but yeah just what if" (Kate, Interview 1, 398).

Kate described having a large circle of family and friends and a husband who were all very supportive. She had a good relationship with the people she worked with:

...we are very close at the office anyway. We are a small group so I am not like their boss, we are kind of like all equal.... Like the friends that I have, like I can talk to them about anything, there is nothing that I can't, you know, talk about. So it is not a difficulty for me to find people to, you know, talk with." (Kate, Interview 1, 287, 295)

Kate identified it was not helpful when people tried to provide false reassurance that things were going to be fine and she should not worry. She felt like her breast cancer investigation was not taken seriously which made her feel like she was over exaggerating her situation:

...a lot of people sort of just do the 'oh well, you know it is just routine', it is just kind of 'don't worry about it' type thing. That is not helpful because it is me and if I want to worry about it I have a right to worry about it; so that happens a lot. Not with everybody but with a lot of people; [they say] 'oh yeah, I know so and so had it done and it was fine' and basically people telling me not to worry. I don't find it helpful. (Kate, Interview 1, 451)

Kate identified that what she needed was a person who could listen to her. She gave the example of her mother who lived out of town and kept in contact by telephone: "but my mother is very good because she sits and listens for hours. So she is good to talk to" (Kate Interview 1, 587). She spoke with her husband "My husband was very good. He was like if you want to talk about it that is great and if you don't then you know" (Kate Interview 2, 77). Kate also had a friend diagnosed with breast cancer which made it possible for her to ask questions. She explained why that was important:

I mean my friend at work isn't really eager to talk about it. She will though and she will answer questions... You want to know what it was like and what happened and you know. Like I said to her 'do they cut you'? I didn't know, that was what I didn't know; because I thought it was just a needle so they wouldn't need to cut you at all but they do. So when you are going, so it helps with the anxiety a little bit, and I am one of those people that I don't like the unknown. So if I am going into a situation for the first time and I haven't done this before, it is not my comfort zone. (Kate, Interview 2, 317)

Kate's husband accompanied her the day of the biopsy. She reported not feeling any discomfort with the procedure and having a quick recovery. Kate reflected on her experience and identified the waiting period to receive her biopsy results as the most

distressing time in her breast cancer investigation: “I tried to work a lot and tried not to think about it as much as I could you know (Kate, Interview 2, 73)? She was pleased when the nurse called to inform her she did not have breast cancer:

They phoned me actually. I was not supposed to go in until after the long weekend in May, I think it was. And the lady [nurse] from the [breast assessment clinic] phoned me on the Friday to let me know so that I wasn't worried about it over the weekend which I thought was very nice of them to do... I did not have to wait until I went to my scheduled appointment. (Kate, Interview 2, 61)

Her immediate reaction after learning the good news was to call her husband and her mother. Kate had good support from family and friends to help her cope with her breast cancer investigation. However she also identified it was important to have professional help available if necessary. She knew that if she would have been diagnosed with breast cancer, she would have accessed professional services to help cope with the diagnosis: “And I know that I would, if the outcome would have been different, I would have for sure” (Kate, Interview 2, 301). Kate did not report any lingering distress after her breast biopsy.

5.2.1.7 Emily. Emily was in her late 30's when she was originally diagnosed and treated for breast cancer. Now in her early 40's, she received a bilateral mammogram and a left breast ultrasound as part of her yearly follow-up surveillance post breast cancer treatment. An abnormality was detected on ultrasound and the radiologist recommended an ultrasound guided core biopsy of the left breast. The nurse from the cancer centre contacted Emily to inquire if she had a follow-up appointment with the surgeon which she did:

So what happens there is, that I have a week of head spinning and going through every single scenario. Yes it is cancer. Yes I need, this time I am going to need a mastectomy. Now I need two mastectomies. Now I need chemo again. Now I

need, I know I am not going to need radiation because I can't, so that is the only for sure I have. Everything else is in limbo. (Interview 1, Emily, 160)

Emily wondered if she had been naïve in her belief system of imagining living a life cancer free:

So everything else that happened after that second lumpectomy was just in case [adjuvant treatment]. Like it was just extra so I did not even, I have not even thought in my head that it was going to come back. Even going for the yearly tests and seeing the oncologist. Like the follow-ups and everything; I was never expecting that they were going to find something, I don't know. I don't know if that is keeping your head in the sand or whether it is a defense mechanism or, I don't know. (Emily, Interview 1, p. 430)

She was assessed by her surgeon in the breast assessment clinic who concurred with the recommendation of the radiologist. She had an ultrasound guided core biopsy of the left breast and the pathology report confirmed there was no evidence of malignancy. Emily was re-assessed by the surgeon who recommended that she have a breast MRI given the density of the breast tissue. Breast MRI was not available in Sudbury at the time, and Emily was referred to another health centre that is approximately a 3.5 hour drive from home. The MRI report was negative for a breast malignancy and the surgeon recommended that she have repeat bilateral breast ultrasounds in six months.

When I met with Emily for the first interview she explained that she worked in health care and that she had a difficult time focusing on her work the day she met with the surgeon. She was second guessing herself for decisions she was making and she consulted with her colleague several times during the day to ensure that she was not making any mistakes: "On that Friday I was having a hard time. I actually phoned [my colleague], we both work on Fridays... and I had to call her a couple of times with patients that I was not really sure of" (Emily, Interview 1, 502).

Emily received a lumpectomy the first time she was treated for breast cancer. Part of her distress now was the possibility of requiring a mastectomy if she was diagnosed with a breast cancer recurrence. She questioned if she had made the right decision the first time by choosing a lumpectomy with radiation therapy. She explained that she did not know how she was going to cope with making the decision of having bilateral mastectomies; she preferred that the recommendation came from the surgeon:

Yeah, and if it had to be recommended [bilateral mastectomies] well then the choice is not mine and if that is the best route then that takes a bit of pressure off cause I am not making the decision. Yes, you can do all the reading and say well okay, it is just a breast, it is not part of your functioning ability to live but it is all the psychological baggage that I did not have to deal with the first time. I mean my decision to have a lumpectomy, vanity or not, and then I am feeling guilty. Maybe I should have, you know, had a mastectomy the first time. Would I be in this place now? So that is why I think I needed to read. Go back and see the current statistics. Is it in my head that she said [the surgeon] that it was the same [mastectomy or lumpectomy with radiation] either way? No, it is really true. (Emily, Interview 1, 450)

Emily described going to a pharmacy and requesting to see a breast prosthetic. She was trying to rationalize how wearing a breast prosthetic was the same as having your own breast:

So I felt better after that day. I just wanted to be aware of what is there.... I still do not have to like the idea but then thought well okay, do you wear a bra everyday? Yes. So what is the difference, if you are wearing a bra that you have an extra insert in? You know? So then you kind of simplify that and it is okay and your life goes on for that day. The next day you spin and you think "I don't want that scar. I don't want that appearance, then you are, I don't know whatever..." (Emily, Interview 1, 518, 522)

She also read information about breast reconstruction questioning if she would be a candidate, given her past history of radiation therapy which affected the texture of the skin.

She identified, like most of the other participants, that the information received from the breast assessment clinic was useful to prepare her for the biopsy; she explained it was important to receive information verbally by a health care professional with follow-up written information. It was difficult for women to retain information in emotionally charged situations therefore having the information in writing was useful to reference afterwards:

I mean they are so good at the breast health program. They make sure that they tell you again; when they say something they will tell you first; they will tell you again and they send you home with a paper. Like something that you can read.... Like I said, that phone call I can't tell you what else she said [initial call from her nurse in the Cancer Centre]. You hear one thing and your brain shuts off and you don't hear the rest. (Emily, Interview 1, 250, 254)

Emily was married and her husband provided a lot of practical assistance in the home such as doing the laundry, grocery shopping and doing home repairs. It was her impression that her husband coped best by keeping busy: "...We are renovating the laundry room now. I am telling you, that laundry room is going to be done in a week the way he is working at it now. That is how he copes and that is okay" (Emily, Interview 1, 284). Emily recognized that her husband could not provide her with the emotional support she required; she confided in women who were close to her: "I have good support in a lot of places. I have sister-in-laws, sisters and friends who know what to say or not say. They are good listeners, put it that way. They do not try and fix things. Nothing against my husband who wants to fix things to make it all better" (Emily, Interview 1, 338). Her husband accompanied her to her first surgical consultation:

Yeah, my husband came with me. That was a big deal for him. He asked 'do you want me to come? I will come if you want me to come?' And he is not that kind of guy. So I don't mean that in a bad way, it is just sitting and waiting and not

knowing and there is nothing he can do about it, that is very hard for him. (Emily, Interview 1, 262)

Emily had a friend who had received an ultrasound guided core biopsy in the past and this friend planned to accompany Emily the day of her procedure:

She [friend] actually had the procedure two months ago. I have never had a needle core; like I have not had the ultrasound thing so she said 'oh well I will just come and sit with you. She works in the building so it is easy for her to come. I am going to take her up on the offer. (Emily, Interview 1, 312)

It was comforting to Emily to know she was supported by a friend who had been through a similar experience.

Emily was concerned about the possibility being off work if she was diagnosed with breast cancer and how it would negatively impact the program where she worked. Her co-worker reassured her not to worry about work and her manager also reassured her that they would find a solution: "My manager too she said 'we are not even going to, you tell me when you know, then we will figure out what needs to happen'... Yeah everybody is telling me, they are reigning me in... which is good so that I am not out here somewhere, spinning is a good word" (Emily, Interview 1, 711, 715, 719).

Emily required an ultrasound guided core biopsy and stated at the first interview she was not worried about the procedure. When I asked her about her experience with the biopsy at the second interview, she described the procedure as 'brutal'. She also spoke to the lack of privacy and her vulnerability of feeling exposed as she recovered from the procedure. She recalled having to undress from the waist up when she received radiation treatment for her original breast cancer diagnosis and she learned to accept it over time. Many years had now passed and the act of exposing her chest for a medical procedure

was foreign to her again. It made her feel uncomfortable to be lying on a stretcher in a hallway with only a sheet covering her chest:

Anyway, after, they recover you in the hallway which is very unfortunate that you can't be in an area that is a little more private. That was, you were lying there, I felt very exposed, although I was covered, you are still lying with nothing on except a sheet and you have people waiting for CT scans no more than two feet away from you. That was a bit, and yes I had been through my treatment when you go for radiation, you are used to stripping from the waist up you know, you kind of get a little bit used to that, but it had been a while so anyway.... I had a girlfriend with me so she kind of stood at the stretcher, you know, she was kind of a buffer. (Emily, Interview 2, 50, 54)

Emily was relieved to know she did not have recurrent breast cancer however the whole experience made her realize that breast cancer is a chronic disease. In the past, she never worried about going for follow mammograms or blood tests. She now felt that every test would be a reminder of her vulnerability of potentially being diagnosed with breast again:

...I always did the follow-ups [after her first diagnosis with breast cancer] and I will still do what I am told that way, I don't think it will change. I think it has changed more in my head. You know, with going for blood work or something, where in the past it was just a monitor, now I get to think, thanks to all this, that there might be something there, which is kind of too bad. But that is probably a more realistic way of being. It's just that I don't like to have to think it is going to be in the background all the time. But it is, it's a chronic illness and you know, that's how it has changed my focus I think." (Emily, Interview 2, 122)

Emily was still questioning if she had made the right decision of having a lumpectomy versus a mastectomy the first time she was diagnosed with breast cancer. She questioned if the density of her breast tissue and the radiation she received to the breast made it more difficult to detect a recurrence of breast cancer. She was suggesting that the three month investigation which had taken a physical and emotional toll could have been avoided if she had originally chosen a mastectomy. It is almost like she felt embarrassed for

bringing too much attention to her through this breast cancer investigation and she just wanted to move on:

...I am not an easy study, I know that and I think part maybe I feel that the diagnosis for me is a bit of my own fault, this is going to sound bizarre. Because I'm very dense [breast tissue], it probably would be a lot easier if I had a mastectomy at the very beginning because it is almost like, because I don't have good diagnostic breasts to manage, it is why it took that long. I think for other women who are not you know, I've had radiation that causes scarring, that causes other issues that other woman wouldn't have... (Emily, Interview 2, 86)

I sensed from Emily that she just wanted to put the whole experience of her breast cancer investigation behind her:

I walked in the weekend to end breast cancer, the 60 km walk in Toronto. When I walked through the finish line, I, I, that was the end. I think that chapter is closed even though it may not be closed, the whole everything leading up I just want to move on to something else. I've had enough of the breast cancer, everything, enough pink, enough... (Emily, Interview 2, 82)

Although Emily was previously diagnosed with breast cancer, her distress was similar to the other young women going through a breast cancer investigation for the first time. She had concerns about body image issues, specifically losing her breast if she was diagnosed with a recurrence. She experienced discomfort with the procedure that she did not anticipate. It was important to surround herself with women friends for emotional connectivity and to reach out to a friend who had been through a similar procedure. The other young women in the study realized through their breast cancer investigation that they were not immune to becoming seriously ill whereas Emily realized that she was not immune to becoming seriously ill again.

5.2.1.8 Jennifer. Jennifer was concerned about a change in the skin at the surface of her left breast however she did not have a primary care physician. Her colleague who is a physician referred her to a surgeon. The surgeon did not find any abnormality in the

left breast however she had access to Jennifer's previous mammogram report of four years earlier where a biopsy was recommended for the right breast. Jennifer explained that her primary care physician closed his practice and unfortunately there was no follow-up from this report. The surgeon recommended a follow-up bilateral mammogram and ultrasound which Jennifer received. She was recalled for special views and a biopsy of the right breast was recommended. Jennifer received a needle localization followed by excisional biopsy through day surgery. Her pathology report was negative for breast cancer and she learned the good news from the nurse who called her from the breast assessment clinic. Jennifer was scheduled for a follow-up appointment with the surgeon when I met with her at the second interview.

I met with Jennifer in my office a few days after it was confirmed that she required a breast biopsy. She was very kind and open to sharing her experience. I sensed she was sad yet she used humor at different times in the interview, keeping emotions balanced. She was scheduled for needle localization with excisional biopsy and part of her distress was related to worrying about the appearance of her breast after the biopsy. She also wondered if she would need a mastectomy if she had breast cancer. Jennifer expected to have a scar after her biopsy and the surgeon explained that she could have an indentation in her breast where the lump would be removed. Jennifer was able to joke with her boyfriend about how her breast could potentially look after surgery. Although he was supportive of her, she realized that it was a new relationship and she did not want to lose the intimacy they shared as a couple.

Part of Jennifer's distress was wondering if she was at greater risk for having breast cancer given she should have received a breast biopsy four years earlier:

The left breast is fine. So I went four years ago, had that [mammogram with recommendation for biopsy right breast] but nobody ever followed-up with me because like I said, my family doctor was not there [had closed his practice] so I just sort of went my own way until I discovered this little thing on my left [breast].... I was not aware at that point that there was any kind of issue at all. The other sort of sub plot that is going on here is the fact that I am really angry about the fact that I could have been walking around for four years with something very seriously wrong. (Jennifer, Interview 1, 73, 77)

She was learning to be her own advocate when it came to her health. She explained that after being recalled for special views, she was pro-active in contacting the surgeon's office, where she was originally seen, to get her results. She ran into some confusion with the secretary informing her that she had to call the breast assessment clinic. When she called the clinic, there was no record of her being seen in clinic because she had seen the surgeon in the office, however a nurse coordinated the care so that the surgeon would see her for her results in the breast assessment clinic:

...So I ended up calling back the [breast assessment clinic] and I spoke with [the nurse] and I became very emotional and I said "look, I am just trying to find out". So she asked me what my name was and I told her and I started crying and I thought of for goodness sake, get it together.... But yeah, I had no idea what was happening and so she was very sweet and she said 'I am going to call there right now and I will straighten this out' and sure enough, two minutes later she called back and she said 'they know where you belong now and here is the deal.' (Jennifer, Interview 1, 213, 217)

These experiences taught Jennifer that she had to be an advocate for herself recognizing that the health care system is not without flaws.

Jennifer was also experiencing distress anticipating the procedure. She required a needle localization that was a two step procedure at two different hospital sites because of hospital construction. She required traveling to one hospital site to have the radiologist insert a needle to localize the area of concern in the breast and then travel to another hospital where the surgeon would perform the lumpectomy. She described feeling

'terrified' about the whole process. She wondered if the wire would catch her clothes once inserted in her breast while she traveled to the other hospital site for the lumpectomy. The thought of being awake for the procedure made her anxious. She wanted to maintain a brave front so she did not disclose to the nurse that she was afraid of getting this procedure done. She minimized what she felt by rationalizing that other women had more aggressive procedures done:

I spoke to [the nurse] a little bit but bear in mind too when I was told this a couple of Thursday's ago it was, you know, you are sort of sitting in there in shock and I did not really have much of a chance to express those kinds of things and I certainly don't want to appear like a suck. I mean I know in the grand scheme of things this procedure is not, like I have a friend who had inflammatory breast cancer and she had a mastectomy so I know that, you know, it could be a lot worse but it is still what is preoccupying me. (Jennifer, Interview 1, 161)

Jennifer, who was single, could not afford to be without an income for too long; she wondered how a diagnosis of breast cancer would impact her lifestyle and found this uncertainty to be a source of distress. She anticipated needing a period of recovery after her needle localization and lumpectomy. She planned to take two days off work and her employer was permitting her to work from home for two days which she appreciated: "Like I am going to be working from home. Like Wednesday and that day I am not at all [working], but on Thursday and Friday I will be working by phone and email" (Jennifer, Interview 1, 343).

Jennifer's parents were deceased and her brother was her only sibling. She was also in a new relationship with her boyfriend. When I asked her if the men in her life were supportive she replied:

Yeah they have, but they are guys right? I mean they just don't get it. Men are so prone to say 'it is going to be okay' and sometimes you want to hear that but sometimes that is the last thing that you want because it is almost like a dismissive

kind of thing and even though they don't mean it that way, it comes across like 'that oh, it will be okay'. (Jennifer, Interview 1, 307)

Jennifer had a friend who received treatment for breast cancer and who was a wonderful source of support. Talking to this friend normalized her own experience with a breast cancer investigation.

I met with Jennifer after she was informed she did not have breast cancer. When I asked her at the second interview about her experience with the biopsy she sighed and then she laughed explaining:

Well it was horrible. I found it to be, I don't know how to explain it, I was nervous, I was a little scared but I had trouble just with the x-factor of the whole thing. Like the actual procedure when they were inserting the needle I just about passed out. I became very light headed and my voice sounded distant and all of those kinds of things. It is just for me, not that I could see what was going on, but I could feel that. So the nurse in there was wonderful and the doctor was wonderful and they got me through it. Then when I went over to the other site to get the actual biopsy done, my brother was with me and we went and we had a little bit of time and that kind of stuff but it was so hard to be conscious of what was in my breast and all the things that were going in my head. (Jennifer, Interview 2, 25)

Jennifer associated her fear of medical procedures to the fact that she was relatively in good health and had never been seriously ill therefore, she was not sure of what to expect; this caused her to imagine the potential discomfort and pain she would experience during the procedure. She planned to have her brother stay with her the first night she returned from the hospital however it was not necessary as she felt well enough to stay alone. He stayed in contact with her by telephone and he assisted with tasks that required lifting. She reported needing two to three weeks to recover from her breast biopsy.

Jennifer waited longer than the other women to learn the results of her pathology report. The longer she waited the more she thought there was something wrong. She

made several calls to the clinic until the nurse finally called to inform her that she did not have breast cancer. She was so excited by the news that she kept the recording of the message: "I play it every once in a while because it was such a good thing to hear..." (Jennifer, Interview 2, 201

Jennifer was relieved to learn that she did not have breast cancer. She expected to see the surgeon two days after her second interview with me. She was interested to understand if she was still at risk for developing breast cancer. She planned to request annual mammography. Her experience with a breast abnormality made her realize that she had to be more proactive on following through with taking care of her health.

5.2.1.9 Genevieve. Genevieve was diagnosed and treated for breast cancer three years earlier. She went for a mammogram as part of her annual routine follow-up. She was recalled for special views and ultrasound of the right breast which showed a breast abnormality. She met with her medical oncologist who reviewed the report of the radiologist and he reassured Genevieve and her husband that he did not believe it was a malignant lesion however he referred her to the breast assessment clinic for a surgical opinion. Genevieve had a very positive outlook: "I can't spend my energy worried about something that I don't know yet. Once I know whether I am cancer free or that it is tested positive for cancer, then I need to spend my energy making the right decisions to ensure my health" (Genevieve, Interview 1, 466). Genevieve received an ultrasound guided core biopsy and the pathology report confirmed there was no malignancy. The nurse at the breast clinic contacted Genevieve by telephone to inform her of the results. Genevieve received another right breast ultrasound and was re-assessed by the surgeon. She was to

continue with her routine follow-up care with the surgeon and the oncologist on a yearly basis.

I met with Genevieve in my office a few days after she learned that she required an ultrasound guided core biopsy. She was pleasant, soft spoken and calm. Genevieve's presentation was different than the other women. The oncologist and surgeon had reassured her that she probably did not have a breast cancer recurrence however the biopsy was required to rule out malignancy. She was aware of the risk and she trusted the opinions of her physicians whom she knew for several years now.

Genevieve went through breast reconstruction after treatment for breast cancer and she was concerned that the biopsy could potentially damage her breast implant. She found it odd that she was not worried so much about the removal of the lesion but instead she was preoccupied with the appearance of her breast:

Yes I do worry about it. Like I mentioned before, I have had my reconstruction phase completed, because of my prior experiences, both of my breasts were affected so there is an implant on the side of the area of concern. There is a risk that my implant gets damaged. So, I need to investigate what will happen now, like if it does get damaged, like what other avenue. So it sounds kind of silly that I am not worried about the lump so much, but I know that it will be removed.
(Genevieve, Interview 1, 490)

The appearance of her breast was important to her given her previous mastectomy.

Genevieve recalled feeling like a 'freak of nature' when waking up after her mastectomy the first time she was diagnosed with breast cancer with the tubes underneath her armpit. She described having lost her femininity when her hair started to grow after chemotherapy and she only had one breast:

Because I felt extremely masculine, no matter how much I colored it [her hair] or tried to shave it, I still felt like a boy. So and then at that time I was only starting with my reconstruction phase so you know, you still have one side that was flat

and the other side was dimpled [from previous biopsy] and it was like... a lot. (Genevieve, Interview 1, 861)

She was confident that the pathology result of her biopsy was going to be negative yet it did not stop her from thinking that if she had a recurrence, and the disease spread, she could die. When I asked her if she was able to express her worries to someone she stated: "Yes, and actually I have had a very deep discussion with my sister that if it should come back then you know, I will deal with it then and if it is at the point where I become like stage terminal, I am fine with that. I am not afraid of it" (Genevieve, Interview 1, 638). Genevieve reassured her family that she would "continue fighting very hard" (Genevieve, Interview 1, 630) if she had a relapse. However, it was her perception, based on her own experience of having been treated for breast cancer that a person diagnosed with terminal cancer would accept death as their health deteriorates:

I truly understand it. Because there was a lot of days where I wasn't ready to get out of the bathtub, where it would have just been easier to sink under the water, because it requires a lot of energy. Even just to take a bath that day, a lot of work. So I can understand people and what they are feeling at the time, and I am not afraid of it [dying]. (Genevieve, Interview 1, 714)

Genevieve's husband provided her with a lot of support. He looked up information on the Internet and sent it to her:

Actually, with my growth, he [husband] is the one that did the research on the Internet.... Because he wanted to know and he forwarded it to me on my computer and that was his way of helping me.... I found it helpful not just information wise, but I found it helpful that he was really interested...(Genevieve, Interview 1, 684, 692, 696)

When I met with Genevieve for her second interview, she smiled telling me she did not have breast cancer "Everything was clear" (Genevieve, Interview 2, 170). She spoke of how relieved she was when she received the call from the nurse informing her of

the good news: "But I had also received a phone call from [the nurse] in [the breast assessment clinic], and she told me the good news. So that helped alleviate even more tension..." (Genevieve, Interview 2, 174, 178). She reported minimal discomfort with the procedure and a quick recovery:

"I did have bruising. I was pretty dark and even my nipple bruised...It lasted for a good week and a half, my bruising. So, it was not uncomfortable. I could still wear regular clothing. I didn't require any pain medication and it did not show through any of my bras or my shirts so nobody else knew. (Genevieve, Interview 2, 150, 158)

When I met with Genevieve for the first interview she and her husband were postponing making plans for the summer not knowing if she would be in treatment again for breast cancer. Once she received confirmation that she did not have breast cancer, she and her husband made plans for their summer vacation. She knew that in a year, she would again require mammograms that could lead to a cycle of repeated investigations and possibly a diagnosis of cancer. Her hope was that over time, there would be less 'scares' when going for her annual mammograms:

So I think you know, still knowing that I am still at risk of a recurrence is not a bad way of thinking but I am okay until next year now. Like I will have fun for the rest of my time and I am not going to worry about anything until next March.... So we will take it one step at a time and then I would like to think that eventually as I continue to go through my mammograms that I will have some consecutive years – no scares....To build my confidence.... That the chaos will stop with the medical appointments and the investigations. (Genevieve, Interview 2, 1173, 1177, 1181, 1185)

Genevieve learned early in the breast cancer investigation that she probably did not have breast cancer. Yet she still lived with the tension of possibly being diagnosed with the disease until learning her results. Genevieve had experienced body image issues in the past with her own diagnosis of breast cancer that the other young women in the

study feared if they were diagnosed and required treatment. Similar to the other younger women, Genevieve wanted to preserve the appearance of her breast and was concerned that the biopsy could affect the breast implant she received as part of her breast reconstruction after breast cancer.

5.2.2 Women Diagnosed with Breast Cancer

5.2.2.1 Vicky. Vicky,¹⁶ who lived in a community one hour outside of Sudbury, found a lump in her left breast. She waited a few weeks thinking the lump was related to her menstrual cycle. When the lump did not go away, she saw her primary care physician. He performed a clinical breast exam and informed her that it was a lump of fat and that she should not worry. She felt reassured at first and then a few days later, she called his office again to request a mammogram: “I was happy with that. However two days later, I was not satisfied. I called for a mammogram and he told me no, then I called the breast screening program in Sudbury” (Vicky, Interview 1, 100). She was informed that the program was for women 50 years of age and over. She then contacted the breast screening program in her own community; the receptionist provided her with the same information as Sudbury however she suggested to Vicky to go to the Emergency Department and request a mammogram. Vicky followed through on this recommendation and had a mammogram; she was recalled for special views a week later. Vicky explained that when she was recalled for the special views she realized something was wrong and she became very worried: “Well she told me, ‘if we call you back don’t panic because we do it often; it does not mean that something is wrong’. Right there it started; I started to

¹⁶ Vicky was the only participant who requested to do her individual interviews in French. Her French quotes were translated to English by the researcher who is bilingual.

panic” (Vicky, Interview 1, 116). Her primary care physician contacted her and he requested that she come to the office. He informed her that the mammogram report indicated a highly suspicious lesion for breast cancer. Vicky became very anxious: “Really my anxiety started when I saw my primary care physician because he told me that there was a good chance it was cancer. Right there, it was like ‘Oh my God’” (Vicky, Interview 1, 433). The primary care physician referred Vicky to the breast assessment clinic in Sudbury for a surgical consultation. She saw the surgeon who recommended a needle core localization of the left breast with excisional core biopsy. Vicky had the procedure done on an out-patient basis and the pathology report was positive for breast cancer. She later had a mastectomy with sentinel lymph node dissection followed by chemotherapy.

I met with Vicky in my office after she learned she required a breast biopsy for a highly suspicious breast lesion. She never cried yet I could feel her tension as she described what the past few weeks had been like for her. Vicky explained that thinking about her breast problem was the first thing that came to her mind when she woke up in the morning. She made reference to having “small anxiety attacks” (Interview 1, Vicky, 833) during the day ever since she had met with her primary care physician for the mammography results that were highly suspicious for cancer. When I asked her what happened when she had these attacks she explained: “Everything shakes inside. I hurt, hurt, hurt, it passes.... I take long breaths, I take a walk, I talk to myself, I sit by myself, I say ‘I’m going to be ok’, it passes” (Vicky, Interview 1, 841, 845). She also reported losing interest in daily activities “It seems like I have lost interest; at home, I don’t even feel like making supper. I don’t want to be home (Vicky, Interview 1, 393). Vicky

indicated that her primary care physician had prescribed medication to help her relax. She took it once and did not like the feeling she experienced with it, so she did not take the medication again.

Vicky was experiencing distress over how she would look if she required treatment for breast cancer. At the first interview, she was not concerned about what her breast would look like after the biopsy or if she required a mastectomy. She just wanted the breast tissue removed as soon as possible. Part of her distress was thinking about the treatment she may require and being afraid of losing her hair if she took chemotherapy: "I am more worried about losing my hair" (Vicky, Interview 1, 389).

When Vicky went to her first appointment at the breast assessment clinic, it was difficult for her to comprehend all the information that was provided to her: "I received a lot [information], however it is like I told you, I am so traumatized. I don't hear half of what they are saying to me. However, they have been super good" (Vicky, Interview 1, 183). In the first consultation Vicky described having confidence in her surgeon who was factual and spoke of different case scenarios and actions that could be taken depending on the biopsy results. Vicky felt comfortable calling the breast assessment clinic to clarify information and she actually returned to see the nurses for a second time to get clarification about her procedure. Vicky explained that everything unfolded quickly once she was referred to the breast clinic "From there, in Sudbury, it went very fast. Like one week after, I saw the specialist, and the second week after, I am having surgery on Friday" (Vicky, Interview 1, 136). The trust she developed with the nurses and surgeon at the initial consultation permitted her to go back to the clinic and ask further questions when necessary.

Vicky described her husband as being present and supportive however they did not talk about her pending lumpectomy “My husband, his reaction, he doesn’t talk about it, but he is very positive, everything is going to be fine” (Vicky, Interview 1, 258).

Vicky explained that she had a difficult time staying in the house “I know it is crazy, but I feel better if I go somewhere. Yes if I am out of the house I feel better” (Vicky, Interview 1, 397). She gave the example that on a Sunday morning she decided to go shopping so her husband drove her to Toronto for the day which is a four hour drive one way. She laughed as she told the story however it was her way to explain that she could count on her husband to do things with her to get her mind off surgery although they did not engage in conversation about the seriousness of the situation.

Like the other women, Vicky confided in her women family members and friends. She also found it helpful talking to two women she knew, one woman in her 30’s and one woman in her 40’s, who were diagnosed with breast cancer and had a mastectomy. When I asked her what type of information she asked them, she said “the size of their lump, the procedures they went through and their symptoms...and how they felt emotionally and they both were like me” (Vicky, Interview 1, 817). She stated that after talking with these women and friends she felt more optimistic: “Yes, it helps a lot because when I speak to them it seems I am more positive” (Vicky, Interview 1, 349).

I met with Vicky for the second interview after she was diagnosed with breast cancer. She was calmer than at the first interview although she was still experiencing distress over treatment decisions and body image issues. She explained that she had received a needle localization with lumpectomy. She was scheduled to see the surgeon approximately three weeks after her surgery. Her incision was draining so she made an

appointment with her primary care physician approximately two weeks into her recovery to have the incision assessed. Alone, Vicky learned from her primary care physician that she had breast cancer. When Vicky returned to see the surgeon a week later, it was recommended that she undergo a mastectomy based on the pathology report. The surgeon explained to her and her husband that there was a possibility that there could be more cancer in the breast tissue however it was not guaranteed. It was up to Vicky to decide if she wanted the breast removed. Her husband thought she should have the mastectomy: "For him, it was like 'do what you want, if it will save your life, have it taken off' (Vicky, Interview 2, 409). Vicky agreed to have a mastectomy which was done two weeks later: "...they injected me with dye for my lymph nodes...in the morning. I was operated at 4 pm in the afternoon and at 6 pm I was in my car driving home" (Vicky, Interview 2, 134). Vicky spoke about how difficult it was to wait all day for surgery: "...I was in my little gown and I was waiting my turn, I just wanted to run, escape. I had to go through with it, but I didn't want to, you know" (Vicky, Interview 2, 146)?" In terms of her recovery, she reported discomfort underneath her arm: "The only discomfort I had and is still there a bit is when they went for the lymph nodes. It is all numb, but that is all" (Vicky, Interview 2, 233).

When I met with Vicky for the second interview, she already had her first consultations with the radiation and medical oncologists at the cancer centre. She was pleased to learn that she did not require radiation therapy however she did require chemotherapy. The medical oncologist offered four cycles of chemotherapy or she could participate in a clinical trial. Her tumor was sent to the United States for further analysis which meant that Vicky had to wait to learn which treatment she would or would not

receive. She already had a picc-line in her arm for chemotherapy and went to the hospital on a weekly basis to have the picc-line assessed "...it has been three weeks I have the picc line in my arm and it is infected..." (Vicky, Interview 2, 669). Waiting for the outcome of the clinical trial was taking an emotional toll on Vicky: "...It's like I have this large lump [in her stomach], it goes away if I talk to myself, but I have a lot of anxiety when I have an appointment here or if someone calls me from here... It is the only thing, if I can know, it will be better for sure" (Vicky, Interview 2, 597).

Vicky identified that it was difficult for her to be making treatment decisions about mastectomy and further chemotherapy without a medical background. She was expecting the physicians to tell her what to do; she wondered if she was making the right decisions. She explained that she was waiting to hear about her status to qualify for the clinical trial when the nurse called her and asked her if she wanted to start her chemotherapy. This confused Vicky as she was not sure what to do: "I said 'Well what does the doctor recommend?' and she said 'He recommends you wait' I said 'Should I wait' and she said 'Well, he thinks yes' I said 'Ok, I'll wait' like you know?" (Vicky, Interview 2, 269).

Vicky immediately called her husband, mother and friends after her primary care physician informed her she had breast cancer. She described them as being positive and supportive. Her teenage son accompanied her to one of her initial appointments at the cancer centre as she wanted him to understand where she was going for treatment: "We talked to the nurse and the nurse said in front of him, that the chances of the cancer coming back were low and that they had taken it all" (Vicky, Interview 2, 457). Her son did not ask her any further questions after the appointment. Vicky also sought support

from breast cancer survivors she knew who have been through treatment. Talking to these women gave her hope that she would also survive breast cancer. She consulted a counselor in the Supportive Care Program however the person did not speak French and Vicky did not return for further appointments: "I was not comfortable" (Vicky, Interview 2, 773). She was unaware that she could request to see a Francophone counselor and the person booking the appointment forgot to inform her of this option.

Now that she knew she required chemotherapy, Vicky was petrified at the thought of losing her hair "I think that the hair is going to be worse [than mastectomy]" (Vicky, Interview 2, 198). The loss of hair symbolized a person that was seriously ill and Vicky did not want to be seen that way. She resided in a small community and she did not want to bring attention to herself: "...it is more noticeable, and I don't like it. I live in a small town and what I don't like is that everybody knows each other. Like when someone meets you 'ah poor you'... it never stops" (Vicky, Interview 2, 202).

Vicky was the first participant I interviewed that was diagnosed with breast cancer. Her struggle to access diagnostic services for her breast abnormality was unfortunately a story shared by other young women in the study. The young women who participated in the focus groups insisted that women need timely access to diagnostic services regardless of their age.

5.2.2.2 Amanda. Amanda described her breasts as being lumpy and sore. She had received a lumpectomy on her right breast seven years earlier for a benign lesion. She noticed a lump in her left breast that she reported to her primary care physician. She was instructed to reduce her caffeine intake and to have it checked again. Her son, who was a toddler, became ill requiring several medical appointments. Amanda did not pursue

having her breast problem assessed again until several months later. She was sent for bilateral mammograms and a highly suspicious lesion was detected in the left breast; the radiologist recommended a surgical consultation. Amanda became upset the day the secretary called to inform her that her primary care physician wanted to see her after the weekend. Amanda wanted to know immediately what she was dealing with:

Then I had a phone call the day after [after her mammogram] from my doctor's secretary saying that she wanted to see me on Monday. I got a little upset cause I said well did you get the results back? So that is worrisome. So then the secretary called me back and she said 'yeah' and she said 'go see her at the clinic'. So I went right away to the walk in clinic where she is and from there we got things rolling which was good because I got my appointment today. (Amanda, Interview 1, 123)

Her primary care physician referred Amanda to the breast assessment clinic for a surgical opinion. She saw the surgeon who performed a fine needle aspiration (FNA) and a core biopsy. The pathology report indicated that both results for the FNA and core biopsy were positive for breast carcinoma. She initially had a lumpectomy however based on the pathology report, the margins were not clear and Amanda proceeded to have a mastectomy followed by chemotherapy.

When I met with Amanda in her home for the first interview, she was scheduled to see the surgeon for her initial consultation on the same day. She was very emotional when I met with her and she explained "See I haven't talked about it much so that is why I am upset" (Amanda, Interview 1, 265). Her husband and mother knew she had an appointment with a surgeon and she had informed one of her sisters the night before about her appointment. Although Amanda was very worried about her breast problem, she tried to minimize the situation to reassure her mother she was going to be fine:

“Yeah, but with my mom I didn’t get upset because like I said, my mom is a worrier. So I try not to get her worried so I just said ‘I am sure it is nothing they are just trying to be cautious’. Like I said, I don’t really tell people because I don’t like the people close to me to worry for nothing”. (Amanda, Interview 1, 285)

Amanda was the participant in the study with the youngest child. Her distress was related to the possibility of being diagnosed with breast cancer and not being able to care for him the way she wanted to:

“I am not so much thinking about my life; I am just thinking that I have a son. A young son and I am thinking like, it would be really terrible to suddenly be sick and you know, not be able to give him the same kind of care and do things and you know”. (Amanda, Interview 1, 293)

She anticipated needing the assistance of her family to take care of him if she became ill. She had difficulty getting family members to baby-sit because her parents and in-laws were older and she was not comfortable leaving her son with a new babysitter.

Amanda was also experiencing distress over the fact that she had delayed following through seeing her primary care physician for the breast abnormality she reported eight months earlier: “I kind of put myself on the backburner and I shouldn’t have and then I just went in again and she said “well let’s send you for a mammogram and get it checked out” (Amanda, Interview 1, 111). She blamed herself for not being aggressive enough to request a mammogram at the initial appointment: “...Well I did go to the doctor but I wish I had kind of pushed it a bit more for a mammogram like maybe earlier” (Amanda, Interview 1, 201). She was concerned that her disease could be more advanced given the delay. She was also upset with her primary care physician for not sending her for further diagnostic tests. Amanda explained why her physician was concerned about sending her for a mammogram:

...My physician just kept saying 'you don't have a history of it in your family' and you know, she said she doesn't usually send women my age for a mammogram and 'this is already your second one now and that is'. It is not like my mother had it. (Amanda, Interview 1, 163)

Amanda was planning to cope with her breast cancer investigation by keeping herself busy. She had recently resumed part-time work: "So working helps because you don't have time to think. You are moving around a lot and then when I get home I am tired and I just go right to bed..." (Amanda, Interview 1, 362). She was anticipating working her shifts while she waited for her biopsy results "Yeah, like I said, it hasn't been, it has only been a few days but the week to come or the week that I am waiting for my results, I will probably have to keep really busy" (Amanda, Interview 1, 374).

I met with Amanda in her home for the second interview after she had started chemotherapy. She was teary at times speaking about everything she had been through with her diagnosis of breast cancer and how it was impacting her life and yet there were moments when we laughed. She started by explaining how she learned on her own of the high probability she would be diagnosed with breast cancer:

When I went for my biopsy I was by myself because I told [my husband] not to bother, like I said I'm not going to get any results so there is no sense. It's just in and out basically but I kind of asked her [the surgeon] you know, and she said I think it is [cancer], you know and she said the radiologist that took the mammogram said they think it is and she said you know there is a slight chance it's not, you know, but they don't know for sure but there is a pretty good chance that it is, so I don't want to sugar coat it or make you think everything is fine. So that was hard. (Amanda, Interview 2, 454)

Four days after Amanda had a fine needle aspirate, she and her husband were informed by the surgeon that she had breast cancer. She originally consented to have a lumpectomy and go through the surgery but based on the pathology report, she consented to have a mastectomy.

Both surgeries were done as out-patient procedures. Her mastectomy was scheduled for a time later in the day compared to the time of her lumpectomy. She found the later time difficult because she had been fasting since the night before. She actually experienced more pain with her lumpectomy due to the incisions in the axilla for removal of lymph nodes. Amanda was guarded about her prognosis, understanding that although there was no proof that the disease had spread beyond her lymph nodes, it did not mean there were no cancer cells in her body:

So even with the chemotherapy and you know people go 'oh well it's great they got all of it, you're going to be fine'. I'm like 'well you know, because there was just one lymph node you don't want to assume everything is fine'. Another book I read, it was really clinical, maybe I shouldn't have read it but they said even if the bone scan and the liver scan shows nothing, the tumor could be so small it doesn't show but then that is in the back of your mind.... Don't think everything is hunky-dory because then everyone says you have to be optimistic it's like wow, yeh, but when you're too optimistic it really hurts when you get the bad news.... It's a bit of a rollercoaster for sure. (Amanda, Interview, 2, 466, 470, 474)

Amanda saw the oncologist one week after learning her pathology report from the surgeon and she started her chemotherapy the following week. When I met with her, she had completed her first cycle of chemotherapy which she found manageable:

I thought it would be worse. The nurses are all great and they are very you know, comforting. They can make you calm and it wasn't that bad. I was sick for two days where I had a really bad headache and I vomited a couple of times you know? I just felt you know, and by the fourth day I felt good, I just felt a little tired and then by the fifth day I felt kind of like myself again. And then ever since then I just kept getting better you know. I just thought I'd be sick for the whole month. I don't know why, you know? But I guess they really changed the drugs or I know he gave me some anti-nausea drugs in my chemotherapy, so that helped a lot I think. (Amanda, Interview 2, 210)

Amanda was caught between wanting to share information with her family yet not overwhelming them with information all at once, especially after she learned her diagnosis. She explained that her father was out of country when she learned she had

breast cancer and she decided not to fully share her news with him until he returned home:

My father was out of town, he was out of the country so I waited until he came home. Like I told him I had to get some surgery and they were going to do a lumpectomy or whatever but everything was fine. I kind of sugar coated it for my dad and then I said when he gets home I'll tell him you know? (Amanda, Interview 2, 478)

Her mother and siblings gathered at her mother's home while she and her husband went to the clinic appointment and they all learned about her diagnosis at the same time:

Well I told my mother right away and my sisters because they were all waiting at my mom's house. My mom was watching my son and my sisters are great. They couldn't sit at home. They had to be there for when I got the results. So we were all at my mom's and we just had a big cry and then we started laughing. We just all dealt with it together so that was good and [my partner] was there too. (Amanda, Interview 2, 478)

She was very fortunate to be supported by family and friends while undergoing treatment. They brought food based on her schedule for chemotherapy; they accompanied her for treatment, while others babysat her son.

Her son was too young to understand what was happening to his mother however Amanda and her partner explained to him that he had to be careful with mommy's arm:

When I first came home with my first surgery, [my partner] was just paranoid that he [their son] was just going to grab the tube or pull it or hurt me somehow because he's very rough and tumble so I just lifted up my shirt and I showed him the tube, it was all bandaged up, but I just showed him the tube that was hanging there and said that mommy had a booboo like that and he started backing up and going 'booboo, booboo' and then after my second surgery, as soon as he saw the tube, he went 'booboo'...(Amanda, Interview 2, 530)

I asked Amanda how she coped with the loss of her breast. She explained that it was very difficult to go through the lumpectomy where there was such a good cosmetic result and then going through with the mastectomy. It was difficult to fathom that there

was something wrong with the breast yet knowing that the cancer was inside the breast tissue and it needed to be removed. It also meant having to recover twice from surgery:

You know I just healed nicely, I was able to lift my son again and was able to do my activities again and then I had to start from square one so that was the hardest you know. Harder than just losing the breast was just the 'ok, I have to recoup all over again', but I know when I actually got home and had to deal with it, I thought I would deal badly with it but actually was fine once it was done because I just felt, I was telling my mother, I said, you know there is cancer in there. I said it would be better if the breast didn't look nice, if it was black and blue and you know, and it could actually look ugly and say just get rid of it, you know?... But it's all inside so you don't see it so I had to just think that way, that there is disease there. Once I was home, I dealt with it ok I think, you know? (Amanda, Interview 2, 50)

Amanda indicated that she prepared herself for the mastectomy by looking at pictures in books which served to be helpful. She gently wept explaining how difficult it was to show her scar to her partner for the first time. For her, the loss of her breast resulted in losing her femininity and sense of confidence however getting a breast prosthesis helped her adjust to the appearance of her new body:

It felt a little strange at first because you looked down and you look like a boy on one side...I got my prosthetic because you have to wait until you are healed totally which was hard so I waited almost five weeks... but then once I got that it's weird how it changed my mood totally.... When I went to get the prosthetic we tried on all these different sizes and you know, I found one and it's 'oh my god' it looks just like my whole breast when I had it on. I even jumped up and down and it even jiggled [laughing]. (Amanda, Interview 2, 370, 374)

Breast reconstruction was not an option for Amanda who was just recovering from two surgeries. She realized that her thoughts on breast reconstruction could change in the future at which point in time she would reconsider her decision. For now, both she and her partner were comfortable with her mastectomy and she did not feel it was necessary to pursue further surgery in the future that could potentially place her at risk for infection.

Amanda had just started to lose her hair when I meet with her: "I cut it very, very short, and I just started to lose it. They said I would lose it in four to ten days and I had my treatment... and I just started losing it two days ago" (Amanda, Interview 2, 226). She purchased wigs that were nice however she did not feel like herself when wearing the hair prosthesis: "You know, I'm shedding like a dog basically and I have wigs. I bought a couple of nice wigs and they look neat on and everything but I just, it's not the same...Like even when I put one on, I just feel like I'm playing dress up, you know?" (Amanda, Interview 2, 238). It was harder for her to lose her hair than her breast given that hair loss is so visible to the outside world: "Like can I really go outside with this and not feel self-conscious you know? But yet, that's the hardest part. I think that's harder than losing the breast because like I said, it's hidden, no one sees it and you can really disguise it well, you know" (Amanda, Interview 2, 238)? Amanda was trying to downplay her hair loss by comparing herself with other people who face greater challenges. Although difficult, she was learning to cope with her hair loss, something she could not have imagined in the past: "So that's all part of it and I just try and keep optimistic and say that there are people that are worse off, it's hair, it will grow back, you know? Yeah, it's funny how it changes as you go along" (Amanda, Interview 2, 242).

Amanda was guarded about her future and not sure how effective the treatments would be, so she did not permit herself to plan beyond a year:

...I've been given some bad news, you know, you kind of deal with it and I try not to think about the future...I was worried very much about [my son] and now I'm just thinking well there are no guarantees in life no matter what. No one knows how long your going to be here so stop always thinking about 'am I going to be here for' I try not and think that way because there are no guarantees anyways so why stress yourself out about the future, you know so I'm just going to be living by the month basically. We made plans for our wedding next year but that's as far

as it goes. I'm not going like five years down the road or ten years we're going to do this and like I don't even let [my partner] talk like that because lets just deal with the moment you know? (Amanda, Interview 2, 642)

Amanda explained that it was the small things that made a difference for how she coped "It's little things that make you happy and you just do a lot of it; go see a movie" (Amanda, Interview 2, 410). She was a bit more spontaneous with activities that brought her joy instead of putting them off to do later. Part of the distress she experienced was related to the change in the family income while she received treatment: "...financially it's a little hard because you know, you only have the one income and so you can't do everything you want to do, you know" (Amanda, Interview 2, 566)?

Amanda wanted to join the focus group for women diagnosed with breast cancer however she was unable to attend the day the group met because she was unwell due to treatment.

5.2.2.3 Kathy. Kathy had a medical procedure performed and took blood thinners to prevent blood clotting. Three days later, she developed pain in her right side that radiated underneath her armpit. Concerned that she may have a blood clot, she made an appointment with her primary care physician to have it assessed. By this time, both she and her primary care physician could feel a lump in her right breast and right armpit. He proceeded to refer Kathy for an ultrasound, mammogram and chest X-ray. The ultrasound was suspicious for malignancy and she was referred to the breast assessment clinic for a surgical consultation. The surgeon performed a fine needle aspiration and core biopsy during the surgical consultation. The pathology report confirmed invasive breast carcinoma. She underwent a right sentinel node biopsy with frozen section followed by

right lumpectomy and axillary node dissection. She required adjuvant chemotherapy and radiation therapy.

I met with Kathy for the first time in my office prior to her appointment with the surgeon. She was kind and appeared to feel comfortable asking me questions as we went through the interview such as what had brought me to work in the field of psychosocial oncology. There were moments when she cried gently yet she wanted to continue with the interview. Kathy was not sure what she was dealing with in terms of her breast abnormality because her primary care physician indicated to her that the clinical presentation was different from his past experiences with breast abnormalities:

Umm, it has confused me... You know because, I do feel something that is different and you know; I think I would be okay knowing, well I will just go for an examination and I am quite fine with that part of it. You know what has me a little bit stressed is the timing and just that message from the doctor. So I am anxious to find out a bit more today. (Kathy, Interview 1, 182, 186)

Kathy lived with a medical condition limiting her physical activities most of her adult life. After receiving successful corrective surgery, she believed this was her chance to live a full productive life. Kathy was disappointed that she now had this new health problem. Although she was still young, the anticipation of living a full productive life was on hold again. Kathy wiped the tears off her face as she explained:

You know I remember coming back and telling the kids 'hey yeah I don't have to take medications, I can play hockey this winter' and my oldest daughter said 'you know this is what we need to celebrate, people have'. My parents had their 50th anniversary in August and we had a celebration and she said 'now this is what we need to celebrate'. So you know, it was a reason to get together with family and we didn't have that opportunity because within three days I had something else. (Kathy, Interview 1, 402)

She kept touching her breast to see if the lump was changing: "...I do find myself checking every night to see if it is still there..." (Kathy, Interview 1, 262).

Kathy informed her husband, her sister, her mother and her oldest daughter and a colleague at work of her surgical consultation however she did not share with them what was on her mind and what she was feeling. She had a dear friend who had recently died from cancer and she was missing her. Kathy wondered what the future held for her if she was diagnosed with breast cancer. She cried explaining:

You are probably the first person and probably the only person at this time that I would speak openly to because, it is premature for one [not knowing if she had breast cancer], and that it is really I think in my case to do with, I am probably more sensitive and more emotional because of my cycle. But also, missing a friend and just sort of being excited to have that sense of relief that one thing finally resolved [medical condition]. But those are not things that you, I don't know, like maybe friends or my husband, they know that but that is not something that I would necessarily talk about. (Kathy, Interview 1, 270)

She did not want people to worry about her so she kept busy pretending that nothing was wrong:

...So you know, and I do, I am the type of person who you know, my mom is older. I do not want others to worry but they do naturally. So in every case because you don't know, so the easiest thing is just to, you know, it doesn't exist and everything is fine and then they are fine. (Kathy, Interview 1, 262)

Her partner was planning to accompany her for the surgical consultation. When I asked her what his reaction was to her finding the lump she indicated "Umm, my husband is a very positive person so, and very supportive. He dropped me off and he took the afternoon off to spend the afternoon with me, so.... He is busy, but I don't know if supportive is the word but he is there. He is present. He is always there like you know? (Kathy, Interview 1, 278, 286). She described her partner as being proactive especially when it came to her health and he wanted her to make inquiries. Kathy felt a bit overwhelmed as she preferred to deal with one issue at a time:

Like the first day, when I went home and said ‘okay the next step is, I have to see a surgeon’. Well he was already beyond that. Beyond the surgeon, ‘well what else’ you know ‘what are the other options’. I said ‘well I need to deal with this first. Let me just see the surgeon and then we will deal with the rest’. So he is way ahead and he seems to have lots of research, and I think that he has learned through loss of family and you know? (Kathy Interview 1, 378)

At our second interview Kathy explained that her partner was with her when she learned she had breast cancer which came as a shock to both of them. They were both overwhelmed by the news and the treatment decisions Kathy was required to make while learning new medical language. While Kathy and her partner were taking in the information about her diagnosis and the treatment options that were available to her, she was also thinking about how she was going to tell her mother about her diagnosis:

“...when I did get the news, the only thing that was going through my head was, how do I tell my mother? She has always been, she worries and that was the hardest thing” (Kathy, Interview 2, 79). She asked the nurse how to inform her mother and children about the diagnosis. The nurse encouraged her to speak to what she knew about her treatment for now; the first step was to get through the surgery and that is exactly what Kathy did:

I told my mom the results; I think she was expecting to hear everything is fine and I said ‘no, everything is not fine. I will need to have surgery in two weeks’. That is all I said. She didn’t respond. My oldest daughter asked as well, how did my doctor’s visit go, I had told her and I said that right now, all I know is that I need to have surgery and we will go from there... (Kathy, Interview 2, 83)

Her partner was also helpful to identify with Kathy’s mother, the type of support Kathy needed:

...I left the house for about a half an hour to go for a walk and I think that [my partner] talked with my mom and said to her ‘you know, right now the most important thing is for Kathy to be around positive energy and that is the only thing that we can offer and that is very, very important to all of us’. He was concerned that she might drag things down and get depressed by things, which I don’t deal with very well to begin with. I need to be up. So I think he talked to her and it

made a world of difference because since then, my mother who was not feeling well two months ago, who was having heart palpitations and anxiety, has become this strong, driven, positive person... (Kathy, Interview 2, 83)

Kathy was referred to the cancer centre for an opinion about chemotherapy and radiation therapy. She explained how difficult it was to walk through the doors of the cancer centre on the first day; a very simple gesture which caused distress. Once in the cancer centre, the mystery was over and she thought that more people should walk through the doors to address any preconceived negative thoughts they may have about the facility:

...The hardest thing is to come into the cancer centre because we had never been here and so many people I have asked at work 'have you ever been to the cancer centre' 'No'. So I say, 'you are going to come with me one day' because that is the hardest thing...It is easier when you know what to expect and the service here has been wonderful. (Kathy, Interview 2, 215)

Kathy required nursing care in the home for approximately three weeks after her lumpectomy to monitor the amount of drainage caused from the lymph node dissection. She identified she could have used the visit of a professional to provide her with the emotional support she required during that time. Her partner assumed a good part of the responsibilities in the home that left him physically drained at night when Kathy wanted to talk. She could have used more support during this time. It was her impression that her teenage daughter understood she had cancer although it was not explicitly discussed with her. Her younger daughter was not particularly interested in talking about her mother's illness.

Kathy was pleased with the appearance of her breast post lumpectomy. What she worried about was losing her hair; the loss of hair symbolized for her a person with cancer who was very sick and she did not want to look or be sick. She found support

from other women who have received treatment for breast cancer. One woman was able to describe her own experience of hair loss which Kathy found very helpful:

I have three peers I guess who have been through it. One who is extremely positive.... She knew I saw [the surgeon], she called and never gave me too much information although I think through her own experience she knew the types of questions, I find myself had but didn't have the gut to ask. So about three days after my surgery she said 'I bet you are curious as to when you will lose your hair'? And I was, that is the only thing I kept thinking about was I can handle the medication, I can handle the you know, the balance of finances and children and all of that, I can't handle the idea of my whole image will change and how will I deal with that. How will I know where to go buy these things [wigs/scarves] or how will I know how to put them on. (Kathy, Interview 2, 169, 173)

The breast cancer survivor talked to her about the Look Good Feel Better Program and how she could access the program; this program teaches women how to apply make-up and wear scarves when going through chemotherapy to help women feel better about their appearance. Kathy was planning to attend the program.

Kathy found her own breast lump and she wanted other women to become breast aware:

Well you know, the first thing when I was diagnosed, I know that every friend or woman that I spoke to said 'do you do self-examination'.... So every woman that I spoke to admitted not knowing how to do a self-breast examination or not doing it at all. And anyone that thought they did, all did it with their finger tips which from what I know, you should be using the palm of your hand and that is what worked for me. So I thought the first thing I am going to do when I get better is I am going to have all these people to my house.... I am amazed that they don't know how to do it. (Kathy, Interview 2, 351, 359, 367)

Kathy was fully supportive about having young women learn breast awareness starting in high school.

5.2.2.4 Chantal. Chantal discovered a lump in her right breast two years earlier. Her primary care physician sent her for a mammogram and ultrasound which showed she had a cyst that appeared to be benign; no further assessment was taken although Chantal

continued to report to him that the lump was still present and growing. Chantal developed back problems and requested a consultation with a plastic surgeon for consideration of having bilateral breast reductions. When the plastic surgeon examined her breasts, he recommended that she return to her primary care physician for further investigations. Her primary care physician referred her for a mammogram and ultrasound and the radiologist made a recommendation for an urgent biopsy. She was referred to the breast assessment clinic to be assessed by a surgeon.

The surgeon performed a breast core biopsy during Chantal's first appointment at the breast clinic and unfortunately the pathology report was positive for invasive carcinoma. Chantal and her husband were informed of the diagnosis by the surgeon at a follow-up appointment. The surgeon recommended that she have a consultation with a medical oncologist for consideration of chemotherapy prior to performing surgery with the goal of decreasing the size of the tumor. Chantal received neoadjuvant chemotherapy followed by a right modified radical mastectomy and radiation therapy.

I met with Chantal in her home for both interviews where she invited me to sit in her kitchen. She was apologetic about the appearance of her home explaining they just had a flood. The stress of the flood was another layer of distress she experienced on top of this breast problem. She was concerned about the delay it had taken to be referred for further investigations. Chantal was upset with her primary care physician and she regretted trusting his clinical judgment:

I wish that my family doctor would have insisted that I go in every few months or something to have it checked. I just went by his word and you know, he said it was a cyst and not to worry and so I didn't. But had he checked it on a regular basis it might not be as large or as far gone as it could be now. (Chantal, Interview 1, 203)

When Chantal went for her consultation in the breast clinic, she sensed something was terribly wrong based on how the surgeon and nurse spoke to her. When I ask her if she had a good understanding of her medical circumstances, she replied:

Yeah I think so. I really don't know what they can give me now. You know, you don't want to panic somebody and give them too much information but at the same time, it is funny. It is just the look on people's faces. Like even Dr. [surgeon] and her nurse when they came in and it was like very somber and you know, 'are you ok?' And it is like they couldn't give me enough, they couldn't do enough for me and it kind of makes you suspicious. You know, they know something that they can't say because they don't have all the results yet they know. You can see it in their faces.... I mean everybody is nice but it is just the kind of nice, you know? (Chantal, Interview 1, 223, 227)

Chantal had a core biopsy performed by the surgeon during her first consultation in clinic. They explained the core biopsy procedure to her however it did not exactly go as planned:

They were going to freeze me and then they were going to put the needle in; that [the needle] goes in and takes the sample, a piece, and that there won't be any pain, I won't feel anything; I will just hear that loud pop. So the first time that is exactly what happened. I heard the pop but I did not feel anything. The second time I heard the pop, I felt it and it hurt.... So then she tried to put pressure on it cause I asked her if it was bleeding cause I feel liquid running down the sides and she said a little bit. So she was trying to put pressure on it but that was not helping. Because I remember pushing up with my feet trying to get away from her but knowing I couldn't you know.... I was crying but the pain was what brought on the cry and everything else. I could not stop it. (Chantal, Interview 1, 231, 253, 423)

Chantal knew from her consultation with the surgeon that there was a high probability she would be diagnosed with breast cancer. Although she intellectually knew this information, she was trying to live the rest of her week breast cancer free but she admitted feeling nervous:

Umm, I don't know. I don't know if I can explain it. I get a little nauseous and just you know, tend to want to cry and things like that. I don't know. Myself, like

I said, it is not me inside. I was not nervous at all but everybody else is starting to give you that sad look and you know. It is like I have already been given my results and I haven't yet, not until Friday... (Chantal, Interview 1, 309)

She equated kind gestures with the possibility that her life was about to change. She noticed that her husband was more attentive to her since her breast cancer investigation: "He has been a little nicer? He is always nice though, he is super. He is a really a great guy. He has been a little bit more loving, a little bit more caring and it is all of that that makes me nervous" (Chantal, Interview 1, 305). Chantal equated the additional attention she received from her husband to the possibility of her having breast cancer which upset her. She preferred people continue treating her the same way they usually did until she knew for sure she had breast cancer.

When I met with Chantal for the second interview, she recalled how she learned her diagnosis of breast cancer. She described feeling anxious as she waited to see the surgeon and despite her gut feeling that she knew she had breast cancer, there was still the shock of learning the news. Her husband was eventually invited to join her:

They did finally go get him and they brought him in and they did most of the talking because I was hyperventilating and I was walking back and forth and just going 'Oh my god, oh my god, oh my god'. You know it's just like ... I kept hearing her say it over and over again and then my husband says 'well how are we going to fix it' and they said 'we have to do a mastectomy' and I wasn't sure if I knew what that meant. I knew what it meant but I wasn't you know, and they said they had to remove the breast and it's like 'oh my god, oh my god no' you know, I was flipping out. I did a lot of crying but when I went outside and that sun hit me it just changed my mood completely. (Chantal, Interview 2, 252)

The treatment plan recommended to Chantal by the surgeon and the medical oncologist was for her to receive chemotherapy to shrink the tumor before she underwent surgery for a mastectomy, than followed by radiation therapy. Chantal agreed to the treatment again

describing how difficult it was for her to hear the potential side effects she may experience with chemotherapy:

...But when I started chemo, again they give you all the side effects and that's pretty scary so of course it got me into crying fits again going 'oh my god, I'm going to have sores in my mouth, my fingernails are going to turn yellow and crack and I'm going to get sick, I'm going to lose my hair you know' it's all very scary but I've been very fortunate... (Chantal, Interview 2, 92)

Chantal was managing well with the chemotherapy except for some pain she had due to the medication she was taking:

...except with this new medication that I have, they changed my chemo and it causes a lot of pain in my joints and I'm getting that, so when we go for walks or whatever, its like a traveling pain and it hits really hard and when it hits, my legs will just buckle or whatever and I'll get it in my knee and then the next thing you know, I'm getting it in my eardrum and I'll just hang onto my ear. But it stays for a couple of seconds and then it's gone. (Chantal, Interview 2, 180)

She also reported symptoms of being more forgetful "I have a very short term memory with chemo brain. I've always found that I've had, as I get older, my memory had been bad, yes this is worse (Chantal, Interview 2, 485). Chantal was anticipating getting radiation treatment after her surgery which she feared:

Yes, see radiation scares me because I've heard horror stories. But then again I've heard horror stories about chemo and I breezed right through it but then I get people saying 'yes well if chemo is easy on you then radiation is going to be hard on you and if chemo is hard than radiation is going to be easy on you'. I'm just going to have to wait until I get there.... But I hear about people getting burned and stuff and that's what scares me. But who knows, we'll see when I get there. (Chantal, Interview 2, 646, 651)

Chantal was trying to move forward with her treatments in a positive way while still feeling resentful. She was angry at her primary care physician for not referring her earlier for a biopsy. The distress she identified at the first interview in relation to her delay to be sent for further investigations was still present once she was diagnosed with breast cancer.

Chantal explained how difficult it was to inform her family that she had breast cancer. She knew that she had to share the bad news with her family when she returned home. She and her husband decided to go for a walk in the park to process the information they just received and also provide some time for Chantal to compose herself. They eventually went home and Chantal started the difficult process of informing her family she had breast cancer. Her two daughters had different reactions to their mother's news:

My oldest one was not as accepting as my youngest... I haven't seen her cry yet [younger daughter] and she keeps telling me, 'mom, mom you'll be fine' and [older daughter] she cries constantly, every time she looks at me. She couldn't even look at me after I had my head shaved and it's [younger daughter] she is the one that shaved it, so they handled it very differently. (Chantal, Interview 2, 132)

It was Chantal's impression that her daughters were coping better with her diagnosis because she was tolerating her treatments well.

Chantal was well supported by family and friends making it easier to cope with her diagnosis of breast cancer. She coped with her hair loss knowing she was fully supported by her husband who also had a good sense of humor: "...I think about how you are inside and the people that love you, love you for who you are and not whether you have hair or not and that's why I can walk around without my wig in front of my husband and he rubs my head, and I'll rub his and you know, he loves me for me" (Chantal, Interview 2, 321). She made reference to speaking with other women who had breast cancer or other types of cancers which she found comforting. She was not interested in attending a peer lead support group however she could see the benefits of such groups for women to be connected with other women and feel understood. When talking with women diagnosed with cancer, it permitted her to talk about subjects that her family

would not feel comfortable discussing or understand her need to talk about certain matters such as the possibility of dying.

When I asked Chantal to summarize what had been the most difficult thing to cope with so far she replied “It’s going to be losing the breast to surgery I think, yes. That’s the part that is scaring me the most. That and the radiation is scaring me but yes, I think it’s going to be the surgery” (Chantal, Interview 2, 437). Losing her breast weighed heavily on her mind. It was difficult for her to articulate what it meant to her. She was not identifying concerns with body image; it was grieving the loss of a part of herself, who she was as a person: “I don’t know why because it’s just part of me; it’s not the sexual part of you know, how I’m going to look or anything like that. It’s just a part of me; it’s like cut off my hand and I don’t know” (Chantal, Interview 2, 445). Chantal was not concerned about how she would look with one breast knowing her husband would be there to support her. She could accept living without her breast if it meant being alive:

It doesn’t really mean anything, it’s just a breast, you know? I mean, it bothers me; I know I’m going to cry because it’s my body but as far as he’s concerned, it doesn’t bother him... and of course he’s going to have a reaction too. He could say it doesn’t bother him... but I know when the time comes, he’s going to have a reaction to it but he’ll get over it just like I will. We don’t have a choice; worse things can happen. (Chantal, Interview 2, 188, 192)

Chantal was considering having a prophylactic mastectomy of the other breast followed by breast reconstruction once her treatments were over “that’s in a year, they don’t do any reconstruction for a year” (Chantal, Interview 2, 473). The surgeon advised against a prophylactic mastectomy however Chantal admitted she was distracted at the time of the conversation and she wanted to re-visit the issue with her surgeon “...I was not really

paying attention at the time you know, and I didn't ask a lot of the questions that I have now" (Chantal, Interview 2, 453).

In terms of her future, Chantal was informed by her medical oncologist that she was at a higher risk for the cancer to return. Chantal knew there were no guarantees she would survive breast cancer. She was choosing to do activities that brought her pleasure and that she could schedule around her treatments. She planned to go camping with her family before she had her mastectomy: "My surgery is coming... so we have now until then where we are going to go camping with my family, my sister and stuff we're going to go for the long weekend... and just sit back and relax and catch some big fish" (Chantal, Interview 2, 236).

Chantal identified at the first interview the financial burden the family would experience if she was unable to work during treatment for breast cancer. When I asked Chantal about these financial concerns at the second interview she stated that they were still present and some projects had been placed on hold:

Well that's still there. Except as you know, we had that flood so we just put a hold on the house and my husband did whatever work could be done and as you can see... But that's going to wait until I see if I get back on my feet you know, I'm still working part time (Chantal, Interview 2, 152).

Her oncologist recommended that she not work while receiving chemotherapy because she was at risk of developing infections however it did not stop Chantal from working. She justified working by explaining that she was feeling well and she preferred keeping busy not thinking about her illness. When I ask her if the oncologist knew that she was working she replied:

No, I can't just sit around here. I'd go out of my mind. If I was sick or something, I'd have somebody here most of the time keeping me company but I

feel fine and you know, I'm sitting here alone during the day I'd go coo coo [if not working]. I always thought that would be nice but you know, now that I have it [time], it's not so great, boring. (Chantal, Interview 2, 168)

For Chantal working part-time meant that she continued to contribute financially to the household income although she was placing her health at risk. For her, the ability to work meant that she was not "too sick" although she was at high risk for developing an infection. Her work also served as distraction so she did not have to think about her diagnosis of breast cancer that was potentially life threatening.

5.2.2.5 Louise. Louise remembered on her 17th birthday her mother being diagnosed with breast cancer that prompted Louise to start practicing monthly breast self-examinations as a young adult woman. She was now undergoing her own breast cancer investigation for a lump she discovered while rolling in bed and scratching herself. This lump was not there when she had examined her breasts the previous month. Louise told her husband that she found a lump and proceeded to go to work. She admitted that the finding of the breast lump was constantly on her mind from that moment on "I went to work, foolishly, because I was no good" (Louise, Interview 1, 135). She did not have a primary care physician so her husband went to the local family health team clinic and asked if a nurse practitioner could assess her. Louise credited the fact that it was breast cancer awareness week in the clinic which prompted immediate action. She was able to speak with a nurse responsible for the breast campaign in the clinic and Louise explained to the nurse that she had found a lump which was a new finding. This nurse in turn consulted with the primary care physician who initiated a referral to the breast assessment clinic on behalf of Louise who lived one hour away from Sudbury.

Louise proceeded to have bilateral mammograms with a right breast ultrasound at which time a right breast lesion was detected highly suspicious for malignancy. She saw the surgeon who proceeded to do a core biopsy and the pathology report indicated that she had invasive breast cancer. She underwent surgery for a modified radical mastectomy and required chemotherapy.

I met with Louise in my office after her initial consultation with the surgeon. She explained that she lived with the belief that one day she would get breast cancer because of her mother's diagnosis with the illness. Although she held this belief, it did not minimize the impact it had on her when faced with the possibility she may have the disease. She found herself in tears many times during the day, what she referred to as "little mini melt down":

Like yeah, this is not a total foreign concept to me. I think if I sort of did not know what to expect or you know, if I had never been faced with it, I think I would be scared. But because, you know, I have the history in my family and I have been through it with my mother and I have been through it with a friend and that I am just a person who tends to sort of, until I know what I am dealing with, I will have my little mini melt down, but until I know exactly what I am dealing with I do not try to work myself up about stuff. (Louise, Interview 1, 223)

The distress she experienced with the breast finding was balanced with the support she received from her family, friends, the health care team and her employer. She was trying to stay calm until she knew definitely if she had cancer or not. She spoke openly about her fears with her husband and one of her best friends. She needed the affection of her husband to get her through the waiting period for results:

...But right now I am sort of like lets find out what I am dealing with first before I sort of panic. Like I said, I have had my meltdowns. Like I will be sitting in the chair and I am thinking ah, and then the tears will flow. But sometimes I just need that hug from my husband. That has been the thing right now that I really kind of needed more. Just that hug to say, well you know, we will deal with it when we

know what we are dealing with; that has been I think the biggest support, just knowing that he is there. I don't know what I would do if I did not have him. (Louise, Interview 1, 303)

Louise's daughter was away on a school trip when Louise found her breast lump. She was happy to have a bit of time to get over the initial shock of finding the breast abnormality and understanding the next steps before speaking with her daughter. She knew she had to tell her daughter what was happening with the breast cancer investigation but she did not want to appear upset in front of her daughter:

Well my daughter is very smart. She basically knows everything. I cannot hide stuff from her. She is just one of those kids. The nice thing that did happen is that she was... on a school trip when I found it. So it was very nice to be able to get over the initial shock of finding, have something under my belt before she got home, so that we could say 'okay, this is it'. I let her get home, have a sleep and then said 'well we have got to talk about something; this is what is coming up this week'. So it was really helpful to have that sort of not have to have her see the initial shock that I was going through. Like that it was there, but she knows everything. (Louise, Interview 1, 401)

Louise had a good relationship with her health care team that was also helpful as part of coping with a difficult situation:

Actually surprisingly, I was very comfortable. I really like Dr. [surgeon]. She is just sort of quiet. She is kind of quiet, yet self-assured, yet soothing and you know...She did not really bombard me with a lot of stuff. It was kind of like this and that. Like we have to look at this and then you know we can't really do this until we know what we are dealing with. So I did not get bombarded with a lot of stuff right away and I think that was kind of good. I think it is going to be really different this coming Friday (Louise, Interview 1, 505).

Louise was the principle income earner in the family and part of her distress was worrying about how the family was going to manage financially. They had budgeted for short term emergencies however if she was diagnosed with breast cancer, she anticipated not being able to work and not having a paycheck for several months. She had disability

benefits however she was not sure what type of income she would receive and for how long:

...I was talking to my boss about it and he is really not sure what is covered in it. Like I mean I have got RRSP's I could draw from and stuff like that. But that is a worry. Like I do not want to have to go there; I have got a brother who is, he is not well off, but he is single, and he has a very high income and like he said you know, if I need help he will help me and stuff like that. It is just the idea, I do not like the idea of having to borrow from somebody if I don't have too. I do have a line of credit so there is that, except that I am one of these people, I do not like to owe money. (Louise, Interview 1, 359)

At the second interview Louise described how she was accompanied by her husband at the follow-up appointment when the surgeon confirmed her breast cancer diagnosis:

Well she sat me down and basically said that it was positive and I said 'I know', I knew it was going to be and I had my cry, you know, like it was just, she kind of confirmed what I suspected. So like I mean with the family history and everything, it wasn't, it was a shock and yet it wasn't a shock. (Louise, Interview 2, 56)

She required a wide excision of the breast because of the location of the tumors which meant that a good cosmetic result was not achievable through surgery. Louise consented to have a mastectomy that was scheduled less than two weeks later. She was admitted overnight in hospital because she lived one hour away from the hospital and it took her several hours to wake-up from the surgery. It was incomprehensible to Louise how a serious surgery, such as a mastectomy, could be done as an out-patient procedure:

... I was really dopey waking up and my surgery was later in the day and it is considered a day surgery which really astounds me, considered a day surgery. But we chose to stay in overnight which was probably a good idea because I was pretty dopey and incoherent and I had a lot of problems making any sense waking-up and that and it was not until like about 11 o'clock at night that I kind of 'ok, I'm awake now'. So not being from Sudbury, it was a better idea, but it just floors me and anybody I mentioned to, you know, about being considered a day surgery now, it just, it just floors them. (Louise, Interview 2, 128)

When I met with Louise, she had already started her chemotherapy and expected needing radiation therapy based on her conversation with the radiation oncologist. The worse side effect she was experiencing from chemotherapy was fatigue that made her more emotional than usual.

Louise's friend received treatment for breast cancer in the past. Louise felt comfortable asking her questions about the side effects from treatment which helped normalize her own experience. Her friend had a lumpectomy that was less disfiguring than having a mastectomy. Her friend was frank with Louise asking her how she felt about the loss of her breast:

...like one day, when we were comparing scars and she looked at me and it just floored her, like she didn't realize how disfiguring really it is, you know; and she says 'how do you deal with that' and I said 'you just do'. It's there, it's your life you know, and I'm sure the cancers [Louise made reference to cancer in the plural as she had more than one tumor in the breast] gone. (Louise, Interview 2, 476)

The ease of the conversation between these two women diagnosed with breast cancer was different than a conversation with other people. Louise explained that some people avoided her not knowing what to say to her which hurt her feelings "But just the fact that people don't know what to say to you, like I'd rather them stand there, and 'slub' something in front of me than avoid me... That is the worst thing" (Louise, Interview 2, 548, 552).

Louise made reference to not having a choice about getting a mastectomy if it meant saving her life: "it was kind of like "we're getting rid of it [cancer in the breast], this has to be done, we're getting rid of it because this means the rest of my life" (Louise, Interview 2, 160). Louise felt she coped better with the loss of her breast because she

knew what to expect having seen the mastectomy scar of her mother. She was comfortable with her own mastectomy scar however she was not pleased with the appearance of her body with the breast missing. She described having excessive skin underneath her armpit that was visible through her clothes:

The one thing I found that sucked about it [the mastectomy] was clothes and until you can start wearing a mastectomy block [breast prosthesis] and like that right now [pointing under her arm pit] that's what sucks and just the idea that things have shifted and I've got pouches where, like the fact that I've lost the breast doesn't bother me, it's this pouch down here bothers me because my clothes look like crap. This pouch under here bothers me because it like, I'm conscious that it's there. (Louise, Interview 2, 297)

She was leaving her options open for breast reconstruction once she had completed her treatments. She was also considering having a prophylactic mastectomy because of the family history of breast cancer. She believed that she would have a better cosmetic result having both breasts removed. Regardless if she had breast reconstruction or if she proceeded to have a prophylactic mastectomy, she wanted both sides of her chest to be similar in appearance "...every time you go to get dressed you are thinking it would be nice if they matched" (Louise, Interview 2, 358).

Louise was having a hard time adjusting to not working: "...like you know, I'm just not used to sitting at home doing nothing. I'm not that type of a person and that bugs the crap out of me. It's inconvenient and being at home so much" (Louise, Interview 2, 700). Her income was reduced while on treatment and the family was experiencing financial distress. Her parents were supplementing her Sick Employment Insurance (SEI) premiums because it was not enough income to support her family. After 15 weeks of SEI, she planned to apply for long term disability benefits through her employer however

she wondered how people coped when they did not have these types of benefits or the assistance from relatives:

...You know maybe there should be something in there that ok, you're not going to be cured in 15 weeks, you know, and stuff like that, and usually after the 15 weeks is where long term programs kick in, but I'm lucky, but what about a person who doesn't have that long term?.. They're really screwed. Like I said, I'm lucky; I'm in a position where I have parents that can help me (Louise, Interview 2, 621, 625).

Louise found her own breast lump because she had been practicing breast self-examinations since the age of 17 when her mother was diagnosed with breast cancer. She knew that women are at risk of developing this disease and the best way to guard against advanced breast cancer is to know how to detect it early. She could not explain why she developed breast cancer but she was finding purpose in her own story by educating other women about the importance of checking their breasts:

Like the one thing you can't answer is why this did happen to me. But the one thing I think, the reason it has happened is just kind of like, I've got girlfriends that have never checked themselves, and you know, it's kind of like 'I've been checking since age 17, this can happen. Look, I've been doing this, it can happen. You have to do this'. And it's kind of like every time somebody will say 'how did you find it?' and I'll go through my story and it's kind of, the purpose of this happening, is I'm going to become the poster child for self-examination because I've been doing it since I was 17 years old and it just goes to show you. (Louise, Interview 2, 276)

She wanted to utilize her own story of detecting her breast lump that led to her diagnosis of breast cancer, to teach other women to become breast aware. She was a supporter of having high school curriculum address breast awareness with girls so that it would become routine practice for young women to check their breasts.

5.3 Summary

A total of 18 women were recruited for the study and 14 young women agreed to participate. The young women's stories were described in this chapter to understand their journey with a breast cancer investigation and diagnosis. The young women experienced a wide range of distress in relation to their physical, emotional, psychological, practical and informational needs at different points in time in their journey with a breast cancer investigation and diagnosis.

The purpose of the next chapter is to present the in-depth analysis of the different themes found across the stories of each participant, highlighting the commonalities and differences of the various stories of the young women and their experience with distress going through a breast cancer investigation and diagnosis.

Chapter 6: Data Analysis

This chapter introduces the reader to the different themes found across the stories of participants described in chapter five based on a greater in-depth analysis to describe how distress was experienced by younger women undergoing a breast cancer investigation and diagnosis – the commonalities and differences. A summary of the themes are found in Figure 6.1

Figure 6.1 Themes from Data Analysis

The Unexpected: Finding a Breast Problem and the Beginning of Anticipatory Illness

Loss of Innocence

The Vulnerability of Living with the Unknown

The Constant Worry

Increased Awareness About Breast Cancer

The Sacrifice: Life Before Body Image

Facing the Possibility of Death

The Financial Strain

The Being in Being a Patient

The Need for Information

Intuitive Trust

The Procedure: Body and Soul

Mobilizing Support While Caring for Others

Protecting Family and Friends

Internal Support from Family and Friends

External Support

-The Importance of Work

-Seeking Support from the Health

Care Team

The Journey From the Other Side – I Don't Have Breast Cancer

The Call

The Recovery

The Appearance of the Breast Post Biopsy

Health and Life Through a Different Lens

The Journey from the Other Side – I Have Breast Cancer

Learning the News and Making Treatment Decisions

Telling Family and Friends

Surgery and Recovery and More Treatment Ahead

A Modified Self, a Modified Way of Living

Experiencing Life Differently

Living with the Financial Impact

6.1 The Unexpected: Finding a Breast Problem and the Beginning of Anticipatory Illness

I was taking a shower
I just kind of felt it
I kind of panicked

6.1.1 Loss of Innocence

These women's finding of a breast problem differed in many ways yet the common thread found in their stories was the shock and disappointment they felt with the realization they could be seriously ill. The belief of being young and living a healthy productive life was challenged. Some women expressed they had been relatively healthy all their lives so this was their first encounter with the health care system for a potential life threatening issue. There was the realization that life is fragile and they were not immune to becoming seriously ill. Other women's reactions were more guarded because they were reassured by a physician they probably did not have breast cancer however they still experienced distress until they received confirmation they did not have breast cancer.

The shock of finding a breast lump is illustrated by Joan:

Well it was in March. In the middle of March and I was sick. I had like a strep throat I think. So I was already sick. I was taking a shower and I just kind of felt it [lump in breast]. It was kind of big so, then I kind of panicked. So then I went back into my room after and I was just kind of looking it up on the Internet and I found information on cysts. I didn't know that cyst could exist in your breast so, and then yeah. The next morning I had a doctor's appointment anyway and so I told my mom and she told the family doctor. (Joan, Interview 1, 87)

Jennifer, who worked in health care, saw people every day that were ill. She now realized that she could be one of those persons:

It is very real and when you have had your health your whole life and I try to practice what I preach and I tell people to appreciate each day because our health is the most precious gift and you know yourself, working in this hospital and you see cases where your heart just breaks everyday and you think they are, they are

by the grace of God and now you are wondering “okay, well now it is me” so it is a bit more personal. (Jennifer, Interview 1, 169)

For the women who participated in the focus groups, they explained that breast cancer is not a disease usually associated with younger women so the possibility of being diagnosed with the disease was unexpected: “I think that the first thing is that nobody expects it. I think that is the difference. You don’t think, you think that you are too young or you know, that you are not there yet, to have to deal with this...” (Brenda, NBC Focus Group, 47). It was their impression that perhaps older women would possibly have thought about breast cancer and considered treatment choices such as having a lumpectomy versus a mastectomy if ever diagnosed with the disease whereas those types of considerations do not enter younger women’s minds.

6.1.2. The Vulnerability of Living with the Unknown

6.1.2.1 The Constant Worry. The majority of the women reported they were worried about being diagnosed with breast cancer and the worrying started from the time they learned about their breast problem. For some women, the intensity of the worrying was worse prior to seeing the surgeon although worrying was never completely eliminated until receiving their biopsy results. For others, the worry carried through from the time they learned about their breast problem to the time they learned their diagnosis. When I met with the women, I tried to get a sense of how much time they spend thinking about their breast problem. They shared that it was always on their mind even the women who were reassured that they probably did not have breast cancer. As the women went through their day to day activities, they often paused unexpectedly to reflect

on how breast cancer could possibly change their life. Jennifer gave an example about how much time she had spent thinking of her breast problem:

Ah, good question. I would say probably 80% of my time and then it is always there because it is getting to be spring now and even just something simple as going shopping and looking like at a really cool dress and I am thinking 'am I going to be able to wear something like that'? So it infiltrates when you least expect it, I have been finding. So even though I am trying, like I really tried hard yesterday, you know with Easter dinner with my brother and we had my [friend] come up and that kind of stuff so we had a nice enough time but I am just not with it. Like I don't feel like participating in the conversations and at one point they toasted to good health and I thought 'ah, you know just enough already' so I find that I am thinking, it is 80% but it is probably closer to 90%. (Jennifer, Interview 1, 237)

The worrying took a toll on the women as some of them reported they could not concentrate, others had difficulty sleeping, others described their anxiety using words such as having 'butterflies' and feeling 'shaky'. Joan gave the example of having difficulty concentrating in school:

Yeah. Especially at first, because you know, I went to the doctor and he checked things out and he said you have to get a mammogram for that. So I thought you know, it is not something that will go away on its own. So before my ultrasound, like between the doctor's visit and the ultrasound, I was worried about like how will they do the ultrasound and like will they tell me right away and everything. So like you know, during classes I would just you know, your mind wonders and it would wonder over there and it would wonder over and then like, if it was bad, like if I do have cancer, I will have to get treatment for a year and like I will miss school for a year and everything so. (Joan, Interview 1, 308)

Louise already had difficulty sleeping so the discovery of her breast lump added to her worries: "...I know the first couple of nights after I found the lump I was up pacing the house. You know it is just, I guess I know it is bothering me because I am not, I am sleeping, even less" (Louise, Interview 1, 331). Genevieve's reaction to her breast biopsy was different compared to the other women at the first interview. She was reassured by the physicians involved in her care that she probably did not have a breast cancer

recurrence but a biopsy was required to confirm there was no carcinoma. Her outlook on life was also different since her previous diagnosis of breast cancer:

My belief is that today is the day that has been given to you as a present and that is how it should be treated, as a present. I can't do anything about yesterday, it is gone. If I have learned anything, and allowed tomorrow, that is great but tomorrow is not promised to anybody. So I live everyday for what it is... (Genevieve, Interview 1, 702).

The exacerbation of symptoms of distress appeared to differ between the participants. Nonetheless, all participants were not at ease until they had the results of their breast biopsy. Jennifer was able to articulate what many women expressed about living with the unknown, is it cancer or not:

...it is mainly just the anxiety and the fear of the unknown and I can't remember who said it but the pre-diagnosis stage is the most stressful stage. I believe it because it could be anything. It could be anything from fabulous news to devastating news and because we are human, we just go back and forth and we grasp onto the hope on the one hand and fear on the other. So, it is really just that. (Jennifer, Interview 1, 453)

6.1.2.2 Increased Awareness About Breast Cancer. The women became increasingly sensitive to the media coverage about breast cancer once they discovered their own breast abnormality. The constant reminder of breast cancer contributed to the anxiety they experienced. For Brenda, her anxiety peaked while waiting for her pathology results and information on breast cancer through the media only heightened her anxiety:

Like I did find, and I wrote it down [in her journal] that as soon as I started to go through this, it seemed that everywhere I looked there was breast cancer, everywhere.... I can't go a day without seeing it and I don't recall seeing it two months ago, ever. So maybe that is just that I didn't take any of this information in, you know, and then everything, you know, I couldn't go a day without seeing a poster or some reminder while I am still waiting for my results. (Brenda, Interview 2, 756, 760)

The women were supersensitive to the media coverage on breast cancer because it created awareness about their potential faith, which was being diagnosed with breast cancer. This constant reminder through the media was compounded with another reminder – the physical presence of the breast abnormality.

The women who could actually feel the breast lump kept touching the area during the day. The act of touching the breast emerged from disbelief that they could actually have breast cancer; was this lump actually there, was it changing, was it cancer? It was a way to reaffirm that the lump was real and so was the threat of having breast cancer.

Louise often touched her breast and was unaware until her husband pointed it out to her:

...my husband would look over and say 'you know if you keep rubbing it, it won't go away'. I did not even realize that I was rubbing it...the one thing I am finding is that I am very conscious now that there is something there, more so than anything. When I did not know it was there like three weeks ago, I just did not realize it, you know. But then the last couple of weeks I am very aware that there is something there that is not supposed to be there. I am conscious of it. (Louise, Interview 1, 339)

Unlike the other women in the study, Vicky could not look at or touch the affected breast. She was repulsed by the thought that there could be cancer in her breast and she wanted the lump gone as soon as possible: "One thing I have not said yet is that when I take my shower, I don't even, I don't even want to look at it. It's like yuck, I don't want to touch it, I don't, it is bizarre but that is what happens (Vicky, Interview 1, 750).

6.1.3 The Sacrifice: Life Before Body Image

All 14 women were prepared to undergo a breast biopsy to determine whether or not they had cancer. Some women worried about the actual biopsy and how it could change the appearance of their breast. Some women also thought about potentially having breast cancer and possibly requiring a mastectomy. Other women anticipated

needing chemotherapy and were concerned about losing their hair. The distress was related to how they would feel about their femininity and body if their appearance was altered, how it would impact on their intimate relationships and how other people would perceive them; these issues were at the core of how they identified as young women. They were almost apologetic when speaking about these concerns as they did not want to imply that the value of their appearance was more important than the value of their life. There was this undertone of feeling guilty for raising the issue yet it was important to them. At times I sensed that they thought I would judge them if they verbalized worries about their appearance based on the tone of their voice and the hesitation and pauses before they spoke. For example, during the first interview Brenda was not concerned about what her breast would look like after the biopsy however she was afraid to lose her hair if she required chemotherapy: "Well, yeah it is like, well you know, I don't want to admit it, but one of the first things is you know, am I going to lose all my hair" (Brenda, Interview 1, 400)? Jennifer wondered how her relationship with her boyfriend would be affected if the appearance of her breast was altered:

I know where it is going to be [location of biopsy] but I do not know how it is going to look. I question what I am going to feel like when I look in the mirror and those kinds of things. I am in a relationship that is newish and it is a very good physical relationship and so I am concerned about what I am going to look like afterwards... (Interview 1, Jennifer, 249)

Donna was reassured by her boyfriend that if she required a mastectomy it would not affect their relationship however she was still concerned about the impact of a mastectomy on her general appearance. She laughed explaining:

I don't like my body but I find that my breasts, I know it sounds silly, but are proportioned so it makes me look proportioned equally... Because you know, I do have bigger hips so I find that my breasts are a fair size so I find that it kind of

proportions me and I look proportioned... I don't know (Donna, Interview 1, 434, 438, 442).

Amanda also anticipated requiring a mastectomy if diagnosed with breast cancer. She was prepared to lose her breast if it meant living but the implications of that medical decision would still be devastating:

Like I know people who have gone through it and like I think if they have to do something drastic, I am not sure how I would handle it emotionally. I am just thinking like self-esteem. But then you think if they have to do a mastectomy or whatever, as long as you can have a life, I mean that is the most important thing of course but... I am young and you know, it is part of being a woman. Like you can't, it seems superficial to think that way, but you know it is part of who you are (Amanda, Interview 1, 273, 277).

The women knew that a diagnosis of breast cancer meant receiving treatment that would alter their appearance; some side effects temporarily, with the loss of hair and some side effects more permanent with the loss of a breast. Anticipating how their bodies would look like was a source of distress. They were hesitant to speak about their fears of an altered appearance, concerned they would be judged for placing attention on how they would look instead of being concerned about living.

6.1.4 Facing the Possibility of Death

Most women made reference to the possibility of dying if they were diagnosed with breast cancer. These discussions occurred at different points in time starting with the first interview. Some participants spoke about death when I asked about spirituality. They had either thought about their own mortality or about the possibility of the cancer spreading and eventually taking their life. Vicky knew that her mammogram report was highly suspicious for breast cancer. She had encountered delays with her diagnosis and she was concerned that the cancer was spreading. She kept wondering if she was going to

die “If I knew it was cancer and that I would live, I would be ok, I would be ok. But it’s the unknown, will I live, that is the biggest thing” (Vicky, Interview 1, 293). Distress was triggered when they thought about death and wondered if there is an afterlife. These types of reflections raised existential issues they had not necessarily dealt with before. Joan giggled as she explained to me: “Well you know, cause you are all worried so I started thinking about death and everything. I got really stressed out too. So then I started looking up like what happens after you die. Just cause, I don’t know why” (Joan, Interview 1, 612). They were also concerned for their loved ones especially the women who had children. It was unconceivable for these women to imagine not raising their children or not being present to witness their children’s lifetime milestones: “Like I was told that I could not have children [despite this information, Louise and her husband had a daughter]. Well you know I want to see my daughter grow up. I want to dance at my daughter’s wedding and that” (Louise, Interview 1, 347).

6.1.5 The Financial Strain

The women who were single, or whose income was necessary to support the household expenses verbalized serious concerns about how they would manage financially if diagnosed with breast cancer. Jennifer anticipated financial distress if she was unable to work as a result of being diagnosed with breast cancer and receiving treatment:

...I am concerned too if it is breast cancer, how am I going to work? Like will I be able to because I am the person that supports me and I do need to pay my rent and all. I like to travel and all of those kinds of things so I have quite a nice little lifestyle going for myself and I have worked hard to get here so, I am afraid that, that could be taken away... (Jennifer, Interview 1, 253)

Chantal also experienced distress over the thought of being diagnosed with breast cancer and not having the ability to contribute to the family income. She was self-employed and had no disability insurance. Her family relied on her income to pay half of the household expenses. She was concerned about the burden placed on her husband if she could not work:

...He [my husband] could not carry this house by himself. I have always taken care of certain bills and the kids' needs' and groceries and he takes care of his end. His end just takes him right to the line. Which is okay, so then I take the other side. But without my side, he cannot do it all and that is what scares me. (Chantal, Interview 1, 353)

There was a sense of desperation as Chantal spoke about the potential long term impact of a breast cancer diagnosis on the family income. At one point in the interview she became very upset explaining that it was not worth surviving breast cancer if the family lost 'everything' in the process:

I still make a payment on my car, another year and a half for that so if I am not working, I cannot make that payment; he cannot make that payment...So things like that and then only to find out that I am going to survive this in the long run but then we have lost everything because of that interruption in our lives. That is what bothers me. I would hate to lose everything for nothing. It almost makes me angry. It almost makes me say 'I may as well not be here, if you are going to put me through this, then take me and don't bring me back and make our lives worse. (Chantal, Interview 1, 487)

The possibility of being diagnosed with breast cancer, and not having the ability to cope financially, was recognized by participants in the focus groups as an important issue to be highlighted in the results of the study even though financial distress was not a concern of every women interviewed.

6.2 The 'Being' in Being a Patient

I could feel that it was growing
I went back to him
I told him but he did not seem too concerned
So I wasn't concerned

6.2.1 The Need for Information

The women wanted access to information immediately after finding their breast lump or being told there was an abnormality on mammogram or ultrasound. Most women identified that the more they understood about what was happening to them, the better they could cope. As Genevieve explained, "Knowledge is power, very powerful" (Interview 1, 332). The women or their family members often searched the Internet to find information about breast abnormalities and breast cancer. The participants were touched by the gesture of family members trying to access information on their behalf. They interpreted the act as demonstrating that the family member cared and wanted to understand what the women were going through. Chantal was not interested in searching the Internet herself however her teenage daughter did while Chantal waited for the results of her breast biopsy "She [daughter] said she was looking about cancer and she said 'mom if they catch it at Stage I, II or III', she said 'you will be okay'. I thought it was really cute. But I don't use the Internet myself" (Chantal, Interview 1, 277).

For some women, getting information from the Internet was helpful, for others, they found the information to be overwhelming. For example, Jennifer searched the Internet to find information about the biopsy procedure. In her case, she visualized what the procedure would be like based on the graphics she saw on the computer screen which caused her more anxiety:

One of the things that I did was that of course you go online and you search about you know, calcifications and stuff and the needle biopsy and all that stuff and I probably should not have done that. But, I like to have as much information about things that I can and again it just made me think 'oh my goodness, I don't know if I can do this.' (Jennifer, Interview 1, 173)

Some women identified they preferred to receive information from their health care team like Brenda who was concerned that she may find inaccurate information on the Internet and was not certain what she should be looking for:

Just reading the information that she gave me [surgeon]. Because it is very, you know, they don't try to make light of it [surgeon and nurse]... I mean there are Internet sites that were on the pamphlet that she gave me that are fine but if you were to go out and just do a Google search, there is just too much wrong information out there. So really try to stay away from Internet stuff (Brenda, Interview 1, 700, 704).

Emily searched the Internet for information about breast cancer recurrence however all the information she found could not provide her with the answer she was looking for; she wanted to know if she was cancer free:

...She [surgeon] could not feel it so we are going to have to go to ultrasound guided biopsy because I can't feel anything. And well what does that mean? Is that a good thing that she can't feel it or is it a bad thing that she can't feel it. I don't know? I don't know enough about it. I of course, got on the Internet and done all kinds of reading but you know, I want something that says 'if you have a non-palpable breast tumor post lumpectomy that is a very good sign, it means nothing, relax and move on'. Of course you are not going to find that. (Emily, Interview 1, 182)

Access to information was revisited again during the focus groups. It was recommended that more information should be available on breast health and breast diagnostic procedures in primary care physicians' offices. As Brenda explained:

Well I think for me when I got there [breast clinic], I was given all of these handouts with useful information and probably some of them I could have been given at the family physician's office just to read. Some of them were quite helpful. So I thought if I had those to read earlier I might not have had so many worries. (Brenda, NBC Focus Group, 483)

The women were confirming that having access to accurate information in a timely manner to help them understand the medical presentation of their breast problem, the process involved in the investigation and the various diagnostic procedures available was helpful to diminish distress. They felt more empowered having this information to understand what was happening to them and have the ability to take the appropriate steps to resolve their health issue.

6.2.2 Intuitive Trust

Having a breast abnormality meant that the women were dependent on the health care system to resolve their health issue. The women who found their own breast lump immediately sought medical attention. The women whose breast problems were detected by a health care professional or a mammogram wanted immediate actions taken to resolve their health issue. Part of the process was to learn to develop trust with their health care professionals. Although the women relied on the knowledge of the health care team to guide them through a breast cancer investigation and diagnosis, they also relied on their “intuition” or “gut” to make decisions when action taken or inaction did not feel right for their circumstances. The women expressed anger and disappointment either at themselves or their primary care physician when their diagnosis was delayed; anger at themselves for not pushing to get further investigations and anger at the primary care physician for not ordering further diagnostic tests. They were concerned about the potential ramifications of having their diagnosis delayed and the possibility that if they had cancer it was spreading. One example was Vicky who saw her primary care physician for a breast lump. He reassured her that the lump was benign and that she did

not require further medical intervention however she was not comfortable with this approach. She explained: "I was happy with that. However two days later, I was not satisfied. I called [primary care physician office] for a mammogram and he told me no, then I called the breast screening program in Sudbury" (Vicky, Interview 1, 100). Vicky eventually went to the emergency department in her community to get a mammogram. Her primary care physician received the results that were highly suspicious for breast cancer. When she saw him for the results he asked her how she had managed to get a mammogram. She said "I told him the truth. He said to me 'I don't like sending young women for a mammogram because it can cause cancer' (Vicky, Interview 1, 136). A person from the office later informed Vicky that the primary care physician felt terrible about the mistake he had made and it affected his confidence for making clinical decisions in the days after her appointment with him. Vicky accepted his clinical error and was prepared to keep him as her primary care physician.

The women developed trust with the health care professionals involved in their breast cancer investigation based on the relationship they had with them. Although the medical encounters were brief, the women developed trust based on the knowledge demonstrated by the health care professionals, how they interacted with them and how they communicated:

Well seeing [the surgeon] the other day helped because I know that she is a specialist and she was really happy, really cheerful. Like some doctors are really like you know, and she gave me all of these pamphlets, showed me how to do a self-exam and she told me about the biopsies so we got actual information. So that helped me...But getting the actual information helped me a lot from a specialist doctor. (Joan, Interview 1, 536)

Brenda, who waited two months to be referred to a surgeon to have her breast abnormality further investigated, felt confident in the care she was receiving after her initial surgical consultation. She trusted her surgeon to treat her effectively and with compassion if she was diagnosed with breast cancer:

I did feel that the day I came out, after seeing [the surgeon], I felt like really good. After I left her office, I was really put at ease and you know I felt even if it is cancer, I still feel, I really liked the way she spoke and she was so confident and so I felt good that way.... So I just found that having all of the information was reassuring. I left here and I felt good even if it was, you know [cancer] I would be in good care. And even [the nurse] was you know, she was a big help too. Very confident and they would deal with it. (Brenda, Interview 1, 288, 408)

The women recognized the staff and surgeons in the breast clinic to be the experts on breast care which gave them confidence that their breast problem was being well managed.

6.2.3 The Procedure: Body and Soul

The possibility of having breast cancer was real for all of these women. Many of them spent a great amount of time thinking about it which took an emotional and psychological toll as described earlier. However the other layer of worrying that many of these women had was related to the actual breast biopsy procedure; would it hurt would there be complications and how long would it take to recover. The women who received a fine needle aspirate or a core biopsy at the first surgical consultation had little time to think about it; they were coached through the procedure by the surgeon and nurse. The other procedures required a second appointment which meant more time for the women to think about the procedure. The women did not always recall the details of the information they were provided with at the breast clinic about process and what to expect;

they indicated they had to review the written materials received and/or call the breast clinic again.

Going through the procedure affected every part of the women's existence in that moment. The physical discomfort, awareness of the physical surroundings and how the health care team interacted with them all played on their psyche. Some women had difficult experiences with the biopsy procedure such as Emily who required an ultrasound guided core biopsy. She was not worried about the actual biopsy at the first interview, but when asked about the biopsy at the second interview, she explained the following:

So then when the physician started with the biopsy it was like trying to thread shoe leather. It was very dense, extremely dense was what the report said after and he had to drill his way over to the lump, punch pull it out, punch pull it out, and when you are laying on the side of the table and he is pressing with all his might on, you know, I'm 'is it normally like this, is it always like this?' it was awful. Not really pain but just, I was watching the screen. I didn't want to see what he was doing behind me coming at me with this gun (Emily, Interview 2, 50).

Other women were almost in a state of disbelief about being discharged home soon after the procedure. It seemed like there was a dichotomy between the 'the routine procedure' and the complexity of the lived experience of a breast cancer investigation. Brenda received an ultrasound guided core biopsy followed by a lumpectomy several weeks later. She was expecting a longer recovery time at the hospital as she thought a lumpectomy was more invasive than an ultrasound guided core biopsy however it was the opposite. She compared both procedures starting with the ultrasound guided core biopsy:

After everything was over, I had ice packs and then I went into the recovery area for about an hour and a half with ice packs and checking which I thought was all very normal and then went home. It was a little bit of discomfort maybe after the freezing wore off but nothing, you know, just minor... But then if I move along to when I actually had the lump removed and then when that was over it was like, 'okay, well get dressed, see ya'. I just thought, hmm for the biopsy I was like an

hour and a half with ice packs and then for the big one, it was just like 'well okay, well get dressed and go have a cup of coffee and away you go.' (Brenda, Interview 2, 73, 77)

The biopsies the women underwent also symbolized the seriousness of the situation; the procedure brought to reality the possibility they could be very ill. Jennifer, who had less than a favorable experience with her needled localization and excisional biopsy, explained:

...it is more just the idea of what is happening to you and the fact that you know you are really there, your breast is really in this machine, this is really happening, it just becomes real and you know all of these things that you imagine in your head are now actually happening to you. It is a very, you have got a complete loss of control at that point because up until then you still feel, well I felt that I could still maintain some kind of you know control and everything was normal... but once you get in there it is like okay this is really happening. (Jennifer, Interview 2, 45)

6.3 Mobilizing Support While Caring for Others

I live with him
I am close to him
I have talked to him about it
I find I am reassuring him

6.3.1 Protecting Family and Friends

The 14 women found the means to cope despite the high level of anxiety and fear they experienced from the time they became aware of their breast problem to the time they learned their diagnosis. However while listening to these women describing the emotional and psychological toll the breast cancer investigation had taken on them, it became apparent how they were also focused on protecting the people they loved and cared for. They walked a fine line between balancing their needs while meeting the needs of other family members. They did not want other people to worry unnecessarily so they were selective with the people they chose to disclose what they were going through or

they tried to delay sharing the information about their breast cancer investigation as much as they could:

Like I didn't tell; well I told my mother and I just told my sister last night. I don't like to worry people ahead of time. Like until I know myself, it is like why put, like I am worried, so why put that worry on someone else and then it might be fine and they have worried for two weeks for nothing you know? I tend to hold things back from the people around me which might not be good; I am not sure because it kinda makes it a little bit harder on yourself. (Amanda, Interview 1, 257)

The women who had children always had the children's best interests at heart; they did not want the children to feel their burden or worry about them. Vicky shared with her son and daughter that she had a breast lump that needed to be removed surgically and that once the tissue was analyzed, the results would provide information about the need for more medication to heal. Vicky was under the impression that her daughter did not really understand what her mother was going through and after speaking with her son, he did not talk to her about it again. Vicky, who was anticipating a diagnosis of breast cancer, felt guilty that her children were going to have a mother who was ill: "I don't want to, I feel bad, like I feel bad for my children. How can I make them go through this, but it is not my fault. I feel bad for them" (Vicky, Interview 1, 309).

6.3.2 Internal Support from Family and Friends

All the women described having support from their spouses, partners or boyfriends. The support came in various forms such as providing emotional support, accompanying the women to their medical appointments, supporting the women's medical decisions or assisting with practical tasks. When the men's work schedules conflicted with the women's medical appointments, family members or friends were available to drive and accompany the women. However most of the men accompanied

the women the day they received the biopsy results from the surgeon. Joan, a teenager, had her mother go with her at every appointment. The women turned to their women family members and friends for emotional connectivity. This support network permitted the women to seek assistance from various individuals at different times; knowing when to protect as described earlier (see 6.3.1), knowing when to lean and knowing who to lean on.

Jennifer's brother accompanied her for the biopsy procedure because she had to travel between two health care facilities for the biopsy. Jennifer found her brother to be very supportive. However she found there was a level of connectivity that was missing perhaps due to gender differences or his inability to truly appreciate the fears she was experiencing about body image issues. He did not appear to understand the level of distress she was experiencing in terms of having part of her breast removed and not knowing what awaited her in the future:

...Like he [her brother] said to me the other day 'Jennifer it is almost over' meaning that the date is getting closer. And I thought, hmm it is not almost over for me, I still have to go through it, and I still have to wait to see what it is, I still have to look at what my breast is going to look like and incorporate that into my vision of myself and you know, how I go on; not how I go on as a woman, as a sexual person all of those things will be affected so it is just the beginning as far as I am concerned. (Jennifer, Interview 1, 355)

She confided in her friend who was treated for breast cancer and this friend could validate the range of emotions and concerns Jennifer was experiencing. The support she received from this friend was making a difference for how she was coping with the investigation:

So I think that a lot of women deal with it in you know, a way that really affects their self-esteem and until you go through it, and you talk with somebody, you realize that all of the thoughts that you are having, none of them are irrational and none of them are fair, none of them are unfair, it is just the process and you see

that you are not crazy for feeling all of the things that you feel because so and so has gone through almost the exact same experience. (Jennifer, Interview 2, 181)

Brenda was hoping to speak to a woman who had been through a breast cancer investigation and treatment for breast cancer however she did not really know anyone: "...I don't want to say I would like to know more people, but you know I would like to speak to more people who have dealt with it... But unfortunately I don't have too many people that I know, close, to speak to about it. Well gone through the same thing...(Brenda, Interview 1, 516). It was important for her to make a connection with a person who could share her experience without withholding information and who would not dismiss what she was feeling:

I think because I guess people who have been through it you know, they usually have some like pretty good things to say or you know, they will tell you what happens and they don't try and fluff it up or say 'oh you are gonna be going, don't worry about it'. Because you still worry about it, so they don't say things like that. (Brenda, Interview 1, 516/520/524).

Emily had a good social support network and learned that people react differently in these situations. She knew whom she could count on for support and whom to avoid:

I had another sister that was not [supportive], and after I got a negative comment from her I did not share with her anymore because I had surrounded myself with people who I knew would be supportive. Yeh and you know, I think a lot was their 'yes we know you are upset' they were just there without trying to give me advice or tell me what to do. (Emily, Interview 2, 214)

The support received from family, friends and women who had been through a similar experience appeared to ease the distress the women were experiencing with their breast cancer investigation. They appreciated all forms of support received however they appeared to feel most validated and supported in their experience when people listened to them, showed empathy and permitted the women to have frank discussions about their

fears and worries without dismissing them by making a false promise that everything was going to be fine.

6.3.3 External Support

6.3.3.1 The Importance of Work. Despite all the worries the women experienced with pending breast biopsies and other medical appointments, it was important for them to attempt to maintain a daily routine. The ability to continue working was very important for the women who were employed. Some of them could not afford to lose income as previously described (6.1.5). Working was also a diversion from their breast cancer investigation and represented normalcy, having health and the ability to work. The support received from their workplace such as accommodation for time off or the ability of flex time provided a sense of relief during a very stressful time.

Vicky continued to work despite learning she was likely to be diagnosed with breast cancer. Her primary care physician had provided her with a medical note to support her absence from work however Vicky wanted to work “Because ever since I have known, I have not stopped working, I work anyways. I have a note from my primary care physician but I did not take it” (Vicky, Interview 1, 401). It was her way of having some control over a situation that felt out of control. She was fighting feelings of depression by keeping busy “I am very depressed, I just want to go to bed.... Yes, it helps me to work, yes” (Vicky, Interview 1, 481, 489). Louise confided in her boss that she was in the midst of a breast cancer investigation. It was a busy time of year for their workplace. Her boss provided her with the option to work her shifts based on what was best for her. Louise was very impressed with the support she received from him:

...Like he said 'you know if you do not feel like facing the office' he said 'just come in' or he said 'if you just want to come in the evening when nobody is here and putter away cause I know you will go nuts if you sit at home and don't do nothing'.... I have a boss who again, he lets me, just lets me be at work. I think if I had a boss that all of a sudden said 'well you know maybe you should be at home until you know what you are dealing with' and stuff like that, I think that would kill me. I think that is one thing... I would be a mess if I was sitting at home all the time just thinking. (Louise, Interview 1, 367, 577)

Louise's ability to work flexible hours provided her with some relief from always thinking about her breast problem.

6.3.3.2 Seeking Support from the Health Care Team. The women spoke highly of the nurses who were managing their care at the breast clinic. They appreciated that the nurses recognized they were potentially anxious about their breast cancer investigation. Amanda spoke about the first call she received from her nurse and how appreciative she was when the nurse asked her how she was coping emotionally:

[The nurse] called me back to kind of go through things with me and she even asked me about my emotions, like how my stress level and on a scale from 1-10 like 10 not being able to sleep, so I thought that was nice and then she had called me back just to tell me what I would be going through basically or what they would be doing, because I wasn't sure. (Amanda, Interview 1, 446)

However, what became apparent during the interviews was that the young women did not expect the nurses and the surgeons to address their emotional concerns in any depth:

...they are not there to get you through the process...I mean and again, it is just reality of the healthcare system but if they took the kind of time to meet everyone's emotional needs in there, they would only be seeing one patient a day. You are a mess when you go in there; there are no two ways about it. But as far what they did, they did what they could but you are still scared which is why it is really important to have the family support and that sort of outing network that you know. (Jennifer, Interview 2, 229)

Kathy, who was diagnosed with breast cancer, echoed the same thought during the focus group about not expecting physicians to spend time addressing emotional well being: "it's

still important to be addressed but I don't know that I would expect my oncologist or my family doctor or those people" (Kathy, BC Focus Group, 556).

Very few women sought professional help to deal with their anxiety except for Jennifer who requested to meet with a social worker from the Supportive Care Program prior to her breast biopsy. I asked her how helpful it was to meet with this professional and she replied:

"being able to talk to somebody who was not emotionally involved in my situation.... You know you want to rely on friends and stuff but every once in a while you just need somebody to tell you who sees folks that are going through it all the time that you are not crazy. That it is perfectly normal and that it is ok to feel what you are feeling." (Jennifer, Interview 2, 233, 237)

The concept of screening for distress was discussed as part of the focus groups. The women identified that it would be easier to indicate on paper how you feel than to have a conversation with a person who you perceive is not there to address your emotional issues. Brenda explained:

That is probably a good way to do it. Somebody would be more open to fill out a questionnaire I think than if the person doing the mammography said 'how do you feel'? 'Oh well, I am fine'? But if I filled out a questionnaire I might be more open to say 'yeah, I am terrified'. (Brenda, BB Focus Group, 693)

Joan agreed with Brenda by saying: "It is probably easier to write it rather than say it out loud to someone. I don't know if it is that you don't want to admit it or if it just easier to I don't know, write it on paper but it might be" (Joan, BB Focus Group, 695). It was also important for the women to have a choice to receive further services:

You know even if someone at mammography said to me: "ah, you have scored like here so maybe you should," you know, "speak with somebody" and still you now make it my option. Maybe speak to somebody on the phone or speak to somebody personally. I might have called. I might have looked further for more information. (Brenda, BB Focus Group, 715)

The women also raised the issue on not being certain about what services they required; they felt comfortable to contact me as part of the research study and express how they were feeling however they were not sure how to go about getting professional assistance even if they had read information about services available: “I don’t know that I really truly understand all this supportive care facility. What it has to offer or who is available. I think if I knew, like I know I can contact you if it’s part of the study” (Kathy, BC Focus Group, 666). Kathy’s comment highlighted how it can be challenging for people diagnosed with cancer to understand how supportive care services can help them adapt and cope with a new diagnosis of cancer when they have never reached out for these services in the past. If people do not understand the scope of practice of professionals who have the skills to support them in their cancer journey, chances are they will not access the services.

6.4 The Journey from the Other Side – I Don’t Have Breast Cancer

I am not worried for the moment
I am worried for the future
I am not sitting here dwelling on what is going to happen
I guess I want to understand what my chances are of getting breast cancer in the future
I know how important it is for early detection now

6.4.1 The Call

There were nine women who received biopsy results indicating that they had a benign breast lesion. They all received a telephone call from the nurse at the breast assessment clinic to let them know the good news prior to their follow-up appointment with the surgeon. There was a process established at the breast assessment clinic at the time the study was conducted where nurses working with the surgeons called women at home about their negative biopsy results prior to their appointment in clinic. The women

were not aware that this call would be made if their breast biopsy result was benign. All the women indicated they were relieved to get this call as it diminished the amount of time they experienced distress: "Everything was clear, but I had also received a phone call from [the nurse] in [the breast assessment clinic], and she told me the good news. So that helped alleviate even more tension"... (Genevieve, Interview 2, 170, 174, 178).

Jennifer kept calling the clinic to learn her results prior to her appointment with the surgeon however they were not available. She believed that no news was bad news. On the eve of her appointment she received a call from the nurse informing her she did not have breast cancer and her follow-up appointment with the surgeon was being rescheduled to a later date. Jennifer saved the voicemail of the nurse on her telephone explaining "I play it every once and a while because it was such a good thing to hear..." (Jennifer, Interview 2, 201).

Upon receiving the call from the nurse in the breast assessment clinic, all the women reported reaching out immediately to family and friends to let them know the good news. There was a sense of relief and realization that they could now move forward with life. Jennifer shared her good news with her brother upon receiving the nurse's message on her voice mail at home:

I called him [her brother] immediately and there was nobody else in the world that I wanted to see and I went over to his place, we had a couple of beers and we just felt this huge you know [relief]... We are all we have. Neither of us had any kids. We both you know, our parents are gone. We have lots of good friends and family but as far as immediate, it is just [my brother] and I. So the thought of one of us being like, that was almost too much to bear. (Jennifer, Interview 2, 201)

Emily shared the good news with her family including her two sons who could now move forward with life knowing their mother was healthy: "...when we got the positive news,

negative results, they've turned the page, like that it's ok, that was then, and now we don't have to worry about that and we can move on..." (Emily, Interview 2, 206).

6.4.2 The Recovery

The women who had a fine needle aspirate or a core biopsy appeared to recover quickly. They reported some bruising of the breast or no bruising at all. Kate who had an ultrasound guided core biopsy explained "I had no bruising, no scar, I had absolutely nothing" (Kate, Interview 2, 57). The women who had an excisional breast biopsy or lumpectomy required one to two weeks of recovery time before returning to their normal activities of daily living. It was an inconvenience that required some planning in advance especially if the women had children and needed to make arrangements to assist with their care.

Joan delayed starting her summer job by a few weeks while she recovered from her lumpectomy. She took pain medication for two days after the procedure; she was instructed not to get the bandage wet and to limit her daily activities:

I just had to watch my arm and not put too much weight on it, like carry things with this arm [pointing to right arm]...I couldn't drive for two weeks because I couldn't hold the wheel like this [gestured arms up holding a wheel]. You know just little things like that. It was just a little harder to do because I am right handed so you know... (Joan, Interview 2, 142)

Melanie lived alone with her husband so she was able to adjust her routine for two to three weeks while she recovered from her lumpectomy:

I just had to reduce activity but like I could tell, like you could tell when you were doing too much and I just stopped.... Like I couldn't like, I didn't vacuum or anything for a week which drove me nuts.... Because I know I found it difficult like even the first two days, doing dishes and stuff, like it was sore...I started doing them (dishes) and then walking the dogs, I think I waited a week or a week and a half because they are big and my gardening I waited three weeks, four

weeks. I think I waited a month before I started that. (Melanie, Interview 2, 145, 501, 509)

She wondered how women with children managed:

...One thing I wondered about is if people have children, how do they do it? Like it must be very difficult, cause I could kind of, like I just have dogs and [my husband]. I don't have a lot to worry about... Like he [my husband] was there to lift, but if you have children it must be very difficult. (Melanie, Interview 2, 433, 437)

Mona had three children and her mother stayed with the family while Mona recovered from the surgery and the infection she developed at the wound site. Mona explained to her children that she would not be able to lift them, especially her youngest son:

Well I told them, I told them before, I said 'I am not going to be able to like lift you' like my youngest 'I am not going to lift you up for a little while, a couple of weeks or so. Because sometimes like if am sitting on the chair I will say come here and I will lift him up, but you know... (Mona, Interview 2, 320).

Brenda, who had ultrasound guided core biopsy followed by a lumpectomy, made arrangements to be on light duty for work:

...I had this done on a Friday and then of course Friday I was okay because I was still like frozen for a good part of the day. But Saturday and Sunday I was a little sore. I couldn't reach and stuff like that. For work, I did go on light duty for the week after because I do a lot of heavy lifting and stuff, physical, so just to be safe. (Brenda, Interview 2, 276)

These women who had open biopsies, considered minor procedures, still required one to three weeks to recover physically therefore needing to plan for daily routines at home and around work schedules.

6.4.3 The Appearance of the Breast Post Biopsy

Four of the five women who had lumpectomies with a benign pathology result commented on the appearance of the breast post biopsy. There was acknowledgment that the appearance of the breast was different however they could accept the cosmetic result. Joan was comfortable with the appearance of her breast after her lumpectomy. It had not really occurred to her prior to the lumpectomy that her breast could look different:

I wasn't told that I would have any change in appearance so I never really thought about it. Afterwards, I didn't really see a really big change so. I wasn't told that I would have an indent or anything. Maybe a slight change in the shape but not really. (Joan, NBC Focus Group, 269)

She explained that young women are not focused on the appearance of the breast prior to biopsy; perhaps it is something they think about after the procedure:

...I was thinking that you might be told these things [appearance of breast changing] before [biopsy] but at that point, the one thing you care about the most is getting through it and then you can worry about it, you know other things. So I don't know if I want to say that it is psychological... (Joan, NBC Focus Group, 297)

The women diagnosed with breast cancer confirmed this finding: "You want to do anything just to save your life. Give me all the chemo that you want because I just want to live. Take the breast whatever, do whatever you know that needs to be done" (Vicky, BB Focus Group, 128). "At that moment, you just want to live; nothing else is crossing your mind at that point" (Kathy, BB, Focus Group, 130). This information helped provide insight about why some women had a different view about the appearance of their breast from the first interview (prior to biopsy) to the second interview (post diagnosis and treatment). The initial decision for accepting diagnostic procedures and/or

treatments, focused on the priority to save life. The reality of that decision came later when the women coped with the appearance of their breast after the biopsy.

Jennifer revealed that it was difficult emotionally and physically to take the bandage off her breast after her lumpectomy:

... So I was standing in my bathroom and I am single and I did not have anybody to help me and it was an awful thing to try and get this bandage off because it just took so long. It was very emotional because there underneath is your breast as it is now. You know it is not the one that I have had for the last 43 years. It is just there. So it was a very emotional experience but I was certainly glad to get that big grandma bandage off... (Jennifer, Interview 2, 49)

The appearance of her breast has changed, however she was satisfied with the cosmetic result: "...now that all that swelling has gone down, there is a little bit of an indentation but it is more like a thumbprint. It is still not great, I mean it does not look the same as it did, but it is not as terrible as I imagined it might be" (Jennifer, Interview 2, 81). Mona had no concerns about what her breast would look like after her lumpectomy, however at the second interview she had concerns about the scar and wondered if the color would fade over time:

... I am worried about the mark there [touching the upper part of her breast], if it is ever going to fade or go away. I have talked to a girl that my husband works with. She had it done twice. She said that one she had done when she was 18 and the scar is just a little white line now but she has another one that she says is still like a bright red and it had been, I think she said seven or eight years now. So I am kind of like, is it going to fade at least? Like I don't know; I am going to ask the doctor that, ask her if there is something what we could put on it to maybe kind of lighten it up or something (Mona, Interview 2, 200).

Brenda was not concerned about the appearance of her breast at the first interview prior to biopsy however she had concerns at the second interview. Her nipple was inverted since the discovery of the breast problem and the surgeon had informed her that her nipple may stay inverted after the lumpectomy. "...It kind of bothers me a bit right now, but I might

get over it.... But size wise and shape wise, it filled back out. It filled in.... I am trying not to, it could be worse things, I keep thinking, but it does kind of bothers me a little bit” (Brenda, Interview 2, 200,204, 232).

6.4.4 Health and Life Through a Different Lens

Going through a breast cancer investigation made these women realize the need to be more forthright about managing their health issues. It should not be assumed that feeling well automatically means that you are in good health. Many of these women were taught by the surgeon in the breast clinic how to do an accurate breast examination which they had never been taught before. There was a commitment to becoming more breast aware and there was discussion during the individual interviews and focus groups about how younger women should be taught to become breast aware as part of the high school curriculum. Some of these women discussed the role of mammography as a screening tool realizing that not all breast lesions could be detected by doing breast self-examinations or from having a clinical breast exam performed by a health care professional. The women were prepared to share their own stories about having been through a breast cancer investigation if it helped other women become proactive with their own health issues. This experience had left them appreciative of being spared a breast cancer diagnosis with the realization that there could be a next time.

Jennifer was relieved learning that she did not have breast cancer. She was expecting to see the surgeon two days after her second interview with me. She was interested to learn if she was still at risk for developing breast cancer. She planned to request annual mammography:

I am not worried for the moment, but I am worried for the future. I am not sitting here dwelling on what is going to happen a year from now because nobody has control over any of that stuff but I guess I want to understand what my chances are of getting breast cancer in the future. Would it be specifically in this one or does the same thing apply to the left breast and all of those kinds of things. So I mean I have made up my mind that mammograms will now become an annual event and I will not ever say 'oh, I am going to go, I will just let it ride'. I now know how important it is for early detection now. I mean this is what has happened and the fact that breast self-examination also is not enough, because this is not something that could not have been felt. It was only detected with the mammogram and the ultrasound, then finally the biopsy to the diagnosis. (Jennifer, Interview 2, 129).

Her experience with a breast abnormality made her realize that she had to be more proactive on following through with other health screening practices:

...I have made an appointment to go in and get a physical because I have not had one. I mean my blood pressure is fine and I take good care of myself but you know, I am in my forties and I have got a history of heart disease [in family]. I have gone for a colonoscopy about a month ago. So that was fine, but that was my second one, so I am much more resolved to getting back on track and taking better care. I am just not assuming that I am healthy because I feel good. (Jennifer, Interview 2, 137)

Jennifer's experience with a breast cancer investigation made her reflect and realize that she could have been diagnosed with breast cancer:

...I find myself at the oddest times just sort of getting very emotional about it and I try to put it in perspective by you know, saying 'it is not the worse case scenario' but it still happened to me and it lets you know how very vulnerable that you are...it puts a different slant on it because you know what it feels like to be going through those tests, and being poked and prodded and being terrified lying in the hallway and not knowing what is going to happen to you. (Jennifer, Interview 2, 101)

She was prepared to share her story with others to encourage them to be proactive about their health:

So yeah, it has convinced me that I am going to be paying attention to my breast health and my other health. Not that I didn't before, but more so and not that I want to become you know this pest with all my friends and talking to them and saying "go, go, go", but you know, when the opportunity does come up, I am

more than willing to let them know my story because you know it can happen to anybody. (Jennifer, Interview 2, 101)

Joan was the first woman to be interviewed prior to biopsy and she raised the issue of young women becoming breast aware through school curriculum. I was able to ask other women in the individual interviews what their thoughts were on this issue. Many shared that they had never been taught to examine their breasts or encouraged to become breast aware and agreed that it was a good idea. The topic of teaching women about breast health starting in high school was discussed again in the focus groups. The six women agreed that breast health awareness should start at a young age “Yes, it’s a good thing definitely” (Vicky, BC, Focus Group, 514). It was suggested that messages about breast health should be repeated over time and it should not be limited to one class. Brenda explained: “if you were being taught this [breast health awareness] even once or twice per year, every year through high school, you are going to retain some of that information” (Brenda, NBC, FG, 363). Joan agreed “Yeah I think it is important that they teach it twice a year or every year” (Joan, NBC, Focus Group, 365).

6.5 The Journey from the Other Side – I Have Breast Cancer

I’m high risk for death
I don’t feel that I’m going to die
I think I’m going to beat it
I feel like I’m going to beat it you know
I’m planning what’s going to happen after
I’m only human
I can’t guess what is going to happen
I just have to take it day by day and hope and pray that I’m going to be ok

6.1 Learning the News and Making Treatment Decisions

Five women accompanied by their husband/partner were informed by the surgeon they had breast cancer except for one participant who was alone when her primary care physician informed her she had breast cancer. When the women were informed of their diagnosis, the news still came as a shock even though they suspected they would be diagnosed with the disease. One example is Chantal who was very anxious on the day she was waiting to see the surgeon and became overwhelmed with emotions when she learned her diagnosis:

... I remember I was sitting in the waiting room with my husband just a bundle of nerves, my stomach was doing flips and everything and when they called my name I thought I was going to jump out of my skin. And they didn't let him [her husband] in and I was surprised by that because I thought he could come in with me but I guess they want a one on one to tell me by myself and I knew, I knew but when you hear those words.... When she said it's cancer I broke down right there and then I was, you couldn't even talk to me I wasn't there anymore. (Chantal, Interview 2, 248)

In the midst of the chaos, the women and their partners needed to learn new medical terms, understand treatment protocols and make treatment decisions that would affect the rest of their lives. Kathy was accompanied by her partner when she learned she had breast cancer. The diagnosis came as a shock to both of them and they were both overwhelmed by the news and the treatment decisions Kathy was facing: "...I must tell you, so you go there and you are not expecting to hear anything and she tells you 'well it is cancer' Then the decision immediately is do you want lumpectomy or mastectomy" (Kathy, Interview 2, 51)? The language was new to both of them and they had to ask many questions for clarification:

Once I sort of had a few minutes to sort of pull myself together again, she gave me a lot of information and a lot of what I had never heard before. So, I was very confused at that moment.... A lot to take in and a lot also, the terminology was not something that I have heard before so I had to ask 'like what exactly does that

mean'? Anyways, I did get the gist of everything when we spoke and I tried to pay as much attention as I could and ask as many questions. My partner, who came with me, was very anxious and I think probably even more devastated than I was at that point. So because he was so anxious, he was cutting her off and asking questions and so I was getting even more distracted so, she basically said 'just hold off until I am done and then ask'. (Kathy, Interview 2, 15, 19)

The wait times continued to be a source of distress for these women. Once their decision was made about surgery, they had to wait for the full pathology analysis before further decisions could be made about chemotherapy and/or radiation therapy. The wait time for that pathology report seemed to take forever as their lives stayed in limbo not knowing what would happen in the weeks and months ahead:

...Like I said, my biggest complaint was just the waiting game. That was the hardest for me. Especially the three weeks after the surgery. Those three weeks waiting for your pathology. I found that was really tough, really, really tough. They are telling you to be optimistic and keep positive thoughts but after, by the third week, you're just like 'I have to know what I'm dealing with'. (Amanda, Interview 2, 526)

Unfortunately decisions made about treatment sometimes had to be revisited which became another source of distress for the women. Amanda initially underwent a lumpectomy however her pathology report indicated that she had aggressive disease and required a mastectomy. This news meant a second surgery with another recovery period and reconciling that the breast must be removed:

...those results showed that it was cancer and so with my surgeon, we decided on lumpectomy because she said you know there is no sense getting a mastectomy. It doesn't really increase my chance that much to warrant it and so I thought it was a good decision and we decided on that and when I went back for my pathology report, that's when it showed indeed the cancer was aggressive. It had spread into one lymph node and there was also like pre-cancer starting so she, we both decided that mastectomy would be the next step because of my age as well (Amanda, Interview 2, 30).

The surgeon encouraged Amanda to stay positive at her initial consultation although there was a high probability she had breast cancer. Amanda tried to be positive however it seemed to her that the news kept getting worse with every appointment. First being diagnosed with breast cancer, secondly receiving a lumpectomy and later learning she required a mastectomy because of aggressive disease:

I was on my own [first appointment for biopsy], then she said to keep a positive attitude. I'm like ok. But when you keep a positive attitude, you go back and don't get good news you're like oh nuts, you know. Same thing when she did my lumpectomy and when I got the bandages off, my breast looked perfect. There wasn't even a bump or a dip or you know. I went wow, she did such an awesome job and I was so happy because I thought I was going to be disfigured... So then I was really happy and optimistic and when I went back in and I said 'I was kind of happy that you did a great job' and then she tells me she has to take it all off and I thought ok I maybe shouldn't be so optimistic anymore you know? Maybe I should just be kind of waiting for bad news, you know? (Amanda, Interview 2, 458)

Once the women made a treatment decision and followed through with it, they often revisited their decision wondering if they had made the correct choice for treatment in the first place. For example, it was recommended that Vicky have a mastectomy based on the pathology report from her lumpectomy. As the pathology report from her subsequent mastectomy indicated no further cancer in the breast tissue, it appeared in hindsight that the mastectomy may not have been necessary. Vicky explained how she felt afterwards "Now it seems, since I know there was nothing there, I have regrets, but I can't think like that" (Vicky, Interview 2, 293). On the other hand, Kathy chose a lumpectomy with radiation therapy but she was now wondering if she had made the right decision. She was young and she wondered if she was at higher risk of the cancer returning in the breast. She shared with the women in the focus group how she doubted her decision to have a lumpectomy:

Maybe you need to hear this too because you both have mastectomies and you're biggest thing is there is something missing. Well I didn't opt for that; I went for the lumpectomy. The doctors said "you know if you want to do that that's fine" but I live the other fear that maybe I should have done that [opt for mastectomy] you know? So there is never a balance, there's never, you know, whether it's a physical thing that you find you're missing something or there is always another side and mine is "maybe I would have been better off" but then in the back of my mind I always have this fear that maybe I didn't chose the right option you know? (Kathy, BB Focus Group, 68)

The original delays to diagnosis identified by the women at the first interview continued to be a source of distress as they wondered what impact it had on the future. Chantal, delayed approximately two years to have her breast lump further investigated, required neoadjuvant chemotherapy to shrink the tumor before the breast could be removed. She learned she was at higher risk for a recurrence and could possibly die. While dealing with her anger for having been diagnosed later, she was trying to stay optimistic:

If I would have had a biopsy even at the six month period when I went in and said that it was growing, if I would have had my biopsy, then I wouldn't be in this position. Now I sound angry, yes I am a little angry...because I have to go through a lot and I could die. [The Oncologist] told me I'm high risk and I said 'what do you mean, I already have cancer'. He said 'you are high risk for recurrence and you are high risk for death'.... So yes I am angry, but I can't think about that, I can't think about that, I have to think about the positive and get through this. (Chantal, Interview 2, 313, 317)

Learning the cancer diagnosis meant couples had to make life changing decisions that were not expected. Distress was experienced with the realization that dreams held for the future would now be abandoned. This was true for Kathy and her partner who had talked about having children. Kathy wanted to explain the impact her cancer diagnosis had on him however it was too emotional for her to speak. She found it easier to read from her journal:

He was devastated. We had talked prior to my diagnosis about maybe having a child together, with somebody that has been in my life for the last three years. He does not have kids of his own. So when he says 'you have cancer' it wasn't 'you have cancer', it was 'you are not going to have a family', I think. Whereas I personally I was focused on 'I need to get better', to him it was we can't have a family. Even though I have two children that he is great with, everybody wants to have their own kids, I think and the more I look into it and the more I try to understand the devastation, the devastation is much more weighted than mine...(Kathy, Interview 2, 255)

The thought of having a child was no longer feasible for Kathy because she was in her early 40's and not certain what the future held for her:

...But now that I have to put it off for two years, well I am not sure that I can handle that and I am not sure that another child and raising a child and the idea of recurrence of cancer is the right thing to do. I don't know how, like how much, I am not sure at this point. (Kathy, Interview 2, 299)

Learning their diagnosis of breast cancer meant that these women had no choice but to confront the fears they identified in the first interview about anticipating illness and requiring treatment for breast cancer. However one of the immediate challenges they faced upon learning their diagnosis was telling family and friends. It was also a time to gather support as they realized they could not get through their breast cancer journey alone.

6.5.2 Telling Family and Friends

After receiving their results, the women left the clinic knowing their lives had changed forever and that their illness would impact the lives of others. They faced the daunting task of telling loved ones they had breast cancer. Caught in crisis, the instinct was still to protect the children, family members and friends to the best of their abilities under the difficult circumstances. At the same time, they knew they would require support to get through the next weeks and months as they went through treatment.

The women tried to regain composure before telling family and friends however saying the words “I have cancer” were emotionally difficult and often brought tears:

But coming home... and telling my family was hard; to pick up the phone and because my mother, family my sister, everybody is waiting to get my phone call and they said ‘call me as soon as you find out’, which I didn’t do because I couldn’t deal with it myself. I couldn’t say the word without starting to cry so I knew I couldn’t get on the phone and start telling them because they’d be crying and I’d be crying and nothing would come out. So when I thought I had myself pulled together a bit a couple of hours later that’s when I called my mom; it didn’t help though, you just say, and I said ‘so... so yes mom I have cancer’. Oh my god, you know and then you start crying all over again. (Chantal, Interview 2, 128)

All the women diagnosed with breast cancer had children that ranged in age from 1 to 23 years. They all had their own ways of preparing their children for the treatments they would receive for breast cancer. Some women provided factual information that was appropriate for the age of the children and they involved them in medical appointments if it was appropriate. Having the children involved helped to increase their understanding about what their mother was going through and it was also comforting for the women to have the child present:

The one thing I wanted was to see my daughter when I woke-up, because that was one thing, so we had somebody drive her in after school, because she would have been bored silly, you know. So I remember, the one thing I do remember is waking-up in my room after surgery, I saw her face and went back to sleep” (Louise, Interview 2, 168).

The women shared information about their diagnosis and treatment with the children over time as they learned to accept their diagnosis. Initially, it was difficult to internalize the news that they had breast cancer. It was a life experience that felt surreal:

When I left the doctor’s office, I went to the office and I told my boss that I had breast cancer. I said that term, but you need to know where I am at. It was almost like I was talking about somebody else. It was not me. I said it like it like it was ‘we are going to a movie and having popcorn’. So no, it took me a long time and

I don't think I have really told anybody until, I have never come out and told the kids, not even my oldest daughter, that it is cancer. But we talk about the cancer centre. We talk about you know, what I said is 'what was in the tumor was not good and therefore we have to figure out how far it spread and the chemo and radiation will prevent.... I don't want to hurt them, I don't want them to panic and you know? (Kathy, Interview 2, 87, 91)

The women knew they needed the support of their family and friends to get through treatment. Family and/or friends drove and accompanied them to medical appointments and people often delivered meals to their homes while the women were undergoing treatment. The women realized early that other people coped better with their situation if they permitted them to provide support and assistance:

...my friend feels like she hasn't done anything. She keeps feeling like she had to do something because she said I haven't asked her to baby-sit. She works nights... So I think she actually feels left out a bit like she hasn't done anything so I'm taking her to my chemotherapy treatment. So umm, I have to realize that the action actually makes people feel good... (Amanda, Interview 2, 578)

There was also a greater burden placed on the husbands/partners to become more involved with the household chores which sometimes left little time for the couple to connect and support each other emotionally:

...I found because I needed my partner to help with the everyday chores that now I knew what it was like to be married to a wife. It kind of reminded me of myself when you get home and you have dinner to make and you have like everything programmed and you know, then by the time the kids go to bed you are tired to talk.... All of sudden I knew what that felt like because he was too tired to talk to me at ten o'clock. So I felt lonely, probably for a couple of weeks... (Kathy, Interview 149, 153)

Their need to speak to other women who went through a similar experience continued from the first interview when the women did not know their diagnosis. They found comfort in the ability to have frank discussions with women who had been treated

for breast cancer about topics that they could not necessarily broach with other family members. They felt safe and understood when speaking:

...I told her I had cancer and so she's been in contact with me, constantly calling me every week to see how I'm doing and stuff but we were talking the other day and so she says 'so, have you pictured yourself in a casket yet'? And I went 'Yes I have as a matter of fact'. She goes 'yes me too, I knew what I was going to wear' and we laughed about it because it's just something that you automatically, your brain will start thinking like that. Even if you're thinking positive, you can't help it because you have cancer. You have cancer and there is always that chance that you are going to die, you know? So she says, 'have you picked out who is getting your jewelry yet'? I said 'yes'. But we can laugh about it whereas if I said that to my mother she'd be going 'oh my God Chantal, don't talk like that, don't talk like that'. So it's nice that way that you have somebody who understands exactly what you're going through. So I understand about these groups and everything and that's what it's all there for. (Chantal, Interview 2, 606)

Talking to women who were survivors of breast cancer also provided hope to the women that they would also survive: "Yes it helps, because you see you are not alone. Especially the one who was 34 years old, it has been seven years and she is still here. Speaking with her helps me a lot..." (Vicky, Interview 2, 521).

The journey of women learning their diagnosis of breast cancer and having to tell the news to their families and friends was a highly emotional time. They had to face the fears they identified prior to diagnosis and embark on the long road to treatment and recovery that meant going through more physical and emotional distress.

6.5.3 Surgery and Recovery and More Treatment Ahead

Similar to the theme 'body and soul' describing the experiences of the women with their breast biopsy where all senses and emotions were heightened, the women diagnosed with breast cancer were also experiencing their treatment "body and soul". They were making treatment decisions to give them the best odds for living; nevertheless, on the actual day of the treatment procedure, they experienced distress realizing their

lives were about to change. Vicky who had a lumpectomy and was now having a mastectomy explained: "...I was in my little gown and I was waiting my turn, I just wanted to run, escape. I had to go through with it, but I didn't want to, you know" (Vicky, Interview 2, 146)? The women required sentinel lymph node testing to determine if the disease had spread. Therefore waking-up from surgery with tubes inserted in the armpit signaled the beginning of the waiting period to learn if the cancer had spread:

...When I got into recovery and I woke up and I realized that I had the drainage tube and at that point I knew, I had a panic attack, a major anxiety attack.... Because you know that was like 'oh no, now it has spread and how far has it gone.... Like so I started to shiver to a point where I could feel myself not being able to compose myself again. I asked the nurse 'can you stay a minute because I can't relax and she couldn't because she just had a patient that came to recovery. She was good though, she put a heater, another blanket and a blower on me and from the heat I calmed down within a few minutes. But I know that if there was a moment that I could have changed something, I would have liked to have had someone there in recovery with me. (Kathy, Interview 2, 59, 63, 67)

When I met with the women at the second interview they were about to start or were just starting their chemotherapy. They were able to manage the physical side effects from treatment that included nausea, constipation, muscle aches, memory loss and fatigue. When the physical symptoms were more pronounced it affected their emotional well being: "...I'm so tired, I get up, walk to the bathroom and back and I'm tired...I think that's what tends to bring it on more like I tend to have more pity parties since I've been on the chemo" (Louise, Interview 2, 386).

There was a recovery period with surgery and for each cycle of chemotherapy however there was also the psychological recovery of dealing with an altered body and finding one's identity as a 'cancer patient'.

6.5.4 A 'Modified' Self, a 'Modified' Way of Living

The treatment for breast cancer had a great impact on these women's appearance; some side effects were temporary such as the loss of hair and some changes were permanent with the loss of the breast. What was not visible to the eye was how treatment affected the women's self-esteem and how they felt about their bodies. They expressed concern about how society would perceive them: "...I feel embarrassed.... I think it's because I'm young. I think if I was older, I wouldn't have felt this way but I'm very embarrassed about it.... I'm afraid people are going to look at me in a different way" (Vicky, BC Focus Group, 34, 40, 44). The sacrifice of the appearance was a trade-off for a chance to live: "I probably generally didn't have much choice you know. I mean I did have choice but I thought for my son and you know, I want to be around so at that point you're just "whatever" what I really need to do, you know" (Amanda, Interview 2, 46)? The women who participated in the focus groups spoke about how difficult it was adjusting to their new body even though they knew they had made the right decision:

...I was standing in front of the mirror and I was having a really hard time and I was looking; I was having a good cry, I was having a really good pity party and was looking at it and my husband came in and he said "what's wrong"? and I said "I am so disfigured, I just look awful". He looks at me and he comes over and he says "you're not disfigured, your modified". So my new philosophy is "I'm not disfigured for life, I'm modified to live". You know, I'm changed, I'm definitely changed but because of this modification I'm going to live. But it's hard, I know how you feel like". (Louise, BC, Focus Group, 60)

Initially the women were comfortable with their treatment decisions however over time it was difficult to accept some of the physical changes challenging their femininity. Vicky initially felt relieved she had the mastectomy because she knew the cancer was gone however the loss of the breast was starting to bother her: "Like for my

breast, it did not traumatize me at the beginning. I was relieved, you know, that it was gone, there was nothing left, but now, it is starting to bother me..." (Vicky, Interview 2, 198). She had shown the bandage to her husband but she could not show him the scar. Vicky could not look at herself when undressed: "I would not have thought that it would be that bad [the mastectomy], it bugs me. It's not bad when I am dressed but when I take my clothes off, when I wash or something like that". (Vicky, Interview 2, 637) She had purchased a breast prosthesis and slept with her bra and breast prosthesis at night "Like I sleep with my bra and all...I have trouble with this [mastectomy]" (Vicky, Interview 2, 449). She also had lost her desire to be intimate with her husband:

...Like right now, it does not interest me [being intimate with husband]. I think it is because I am not completely relaxed yet. I am better than before, but I am not there yet. That bothers me too. I don't know why, but it bothers me, it doesn't bother him, but I don't feel comfortable (Vicky, Interview 2, 629).

For some women it appeared that the distress associated with the loss of the breast could be better managed knowing the husband/partner was supporting the decision of the woman having a mastectomy:

...He's been really supportive. I think some men would be a little scared but he looks past that so it was an easy decision that way because I didn't have to worry about him looking at me differently or you know, I didn't have to worry about that at all. That was never coming into my head. It was more just about myself. (Amanda, Interview 2, 102)

Despite the support of the partner, it was still difficult to reveal the scar of the mastectomy:

"...it took me about almost a week, no actually more than a week, before I could show my partner. I had to be ok with it first and the more you look at yourself in the mirror you know, and I just made sure I did my hair-up, wore nice clothes. Like get out of your pajamas". (Amanda, Interview 2, 370)

These women were making further choices about prophylactic mastectomies to decrease their chances of having a breast cancer recurrence: "one of the considerations is actually having the other side done, a prophylactic mastectomy on the other side because of the family history..." (Louise, Interview 2, 329). Breast reconstruction was an option after mastectomy however it was a personal choice that women indicated they would make over time. For example, Amanda was content with her breast prosthesis and breast reconstruction was not an option for her:

Why would I put myself through another surgery, you know, where you can risk getting infection, you know? Who would it be for, because you know, I've got my prosthetic and it looks fine so I'm thinking, who would it be for? ...If I couldn't deal with it properly but I dealt with it ok. Like for me, it was just, no that's not even an option. Because I always had it in the back of my mind that yeh, ok I say that now but maybe a couple of years from now, it might really start to bother me you know? I think if I was single it might bother me you know, but because my partner is totally cool with it, I would be thinking, who would I be doing it for... (Amanda, Interview 2, 286).

Although hair loss was temporary, the women dread losing their hair not only because of their appearance but also because it symbolized a person who was seriously ill and they did not want to identify with that persona. Kathy was pleased with the appearance of her breast post lumpectomy. What she worried about was losing her hair once she started chemotherapy. She observed what other people looked like when going through the cancer centre and she wondered how she would look and feel once she lost her hair:

...The incision was underneath, there is no change, it is more about no eyebrows, no eyelashes... The upcoming chemotherapy, that has got me feeling; then I find myself passing people thinking they are not that bad, their color is good and I think I am just worried that, that is when I will look sick, I don't want to be sick, I don't want to feel sick, does that make sense? (Kathy, Interview 2, 275)

The actual loss of hair was a poignant moment for the women who now saw themselves as a cancer patient:

I cried for about 15 minutes when my stepmother was here and she had asked me, this was a couple of weeks after chemo, if I was losing my hair yet and I said 'no, not at all'. I went like this [gesturing her hand over her head, pretending to pull on her hair], and I had a handful of hair. I said 'oh my god', I did it again and I kept doing it and it was just coming out so I started crying and I think not that I was losing my hair, but this is real because the chemo wasn't making me sick. (Chantal, Interview 1, 96)

Some women coped by having fun with an unfortunate situation. Chantal proceeded to have her daughter cut her hair:

So I guess the hair falling out is just the reality. Oh my god, this is real, you know? So a couple of days after that it was falling out so much I couldn't wash it or anything so my sixteen year old daughter went downstairs with me... so I let her buzz me. She gave me a Mohawk; we took pictures and when she did the zip down the centre of the hair, so I had horns... You have to try to lighten it up a bit (104, 112).

Distress surrounding the change in appearance was present prior to biopsy when the women were not aware of their diagnosis but could anticipate that if they became ill their appearance would change. They had to face their worse fears about these changes when diagnosed with breast cancer.

6.5.5 Experiencing Life Differently

A diagnosis of breast cancer meant a shift in how the women approached life. Being ill meant adjusting to the different roles they played in life in order to balance their family and/or work responsibilities with their own health care needs:

...what's compounded just in the last year too with all this going on, I've got two elderly parents so besides looking after myself, I've had to look after elderly parents as well as a teenage daughter, so you know; it's been like a dynamic of shuffling. I guess I'm kind of that sandwich group you know, and so I've had to kind of pull all these, being a younger woman, I've had to sort of learn to look

after myself as well as look after others and kind of like 'how do I get through this a little bit' you know?' (Louise, BC Focus Group, 32)

The women found themselves planning short term goals because they were not sure what would happen after treatment:

...Now I don't feel that I'm going to die. I think I'm going to beat it. I feel like I'm going to beat it, you know, because I'm planning what's going to happen after. But in reality who knows, I'm only human like everybody else and there are a lot of woman who have died from breast cancer and there are more that haven't so I just have to, I can't guess what's going to happen. I just have to take it day by day and hope and pray that I'm going to be ok. (Chantal, Interview 2, 638)

They found pleasure in simple things such as spending time with family, being more spontaneous and not putting off doing things in the future:

... I've really just been hanging out with my family a lot more and we are doing more spontaneous things now. Like a spontaneous party or you know, where as before I'd be 'we should really do this' and it just would never happen were as now, I'm just trying to just at the last minute say 'hey everyone come to my house and we'll have a little get together' you know. It just changes your outlook a bit that's for sure. You don't put things off you know? Even my partner and I were just, you know, things that we said we were going to do well we are starting to get them going now, you know, like we have already planned a trip for the summer and we are going around my treatment which helps too I find. (Amanda, Interview 2, 410)

There was an appreciation for being alive and wanting to use their personal stories to teach other women about breast awareness. This sentiment was very similar to the women who were not diagnosed with breast cancer:

Well you know, the first thing when I was diagnosed, I know that every friend or woman that I spoke to said 'do you do self-examination'.... So every woman that I spoke to admitted not knowing how to do a self-breast examination or not doing it at all. And anyone that thought they did, all did it with their finger tips which from what I know, you should be using the palm of your hand and that is what worked for me. So I thought the first thing I am going to do when I get better is I am going to have all these people to my house.... I am amazed that they don't know how to do it (Kathy, Interview 2, 351, 359, 367).

These women's perspective on life had changed however what had not changed was how they continued to care for other people in their lives. They were prepared to share their stories if it meant helping someone else.

The financial impact of a breast cancer diagnosis was difficult for these women whose income was necessary to pay household expenses. There were additional costs that came with a breast cancer diagnosis and family members often provided assistance recognizing the financial burden placed on the women:

And then the little things, like I had to buy a bathing suit with the pocket like a special bathing suit and then I had to buy the prosthetic you can't wear it in the chlorine or salt water so umm I had to buy another special swimsuit so that was a couple of hundred dollars...it adds up and anything that's specialized seems to be very expensive... I have some cousins and their mother collected a little bit of money for me too, so it all helps... (Amanda, Interview 2, 594).

Chantal, who was self-employed, identified at the first interview the financial burden the family would experience if she was unable to work during treatment for breast cancer. She decided to work despite the advice of her oncologist who was concerned that she was at high risk for developing an infection while undergoing chemotherapy: "I'm not supposed to work. They don't want me to work because of the field I'm in... I could get infection and there we go, but that hasn't happened yet" (Chantal, Interview 2, 16). Louise on the other hand was not self-employed but she was the sole income earner for the family. She applied for Sick Employment Insurance which was not enough income to support her family. Her parents were supplementing her income: "...Like I've been lucky, my parents have come through and have given me some money because like EI is giving me \$762.00 every two weeks and it's just, like that is not much" (Louise, Interview 2, 588). Work was not only important in terms of income but it was also part

of how women identified their role within the family unit and society. Work for these women symbolized their independence, their ability to support their family and it also symbolized their ability to lead productive lives “I went back to work after two months of chemo, a month and a half. I want to be so normal again” (Vicky, BB Focus Group, 212).

6.6 Summary

The purpose of this chapter was to present the various themes found across the different stories and highlight different experiences of distress of women newly diagnosis with breast cancer. Three themes were identified with sub-themes: (1) The Unexpected: Finding of a Breast Problem and the Beginning of Anticipatory Illness—Loss of Innocence, The Vulnerability of Living with the Unknown, The Being in Being a Patient and Mobilizing Support While Caring for Others (2) The Journey From the Other Side—I don’t have Breast Cancer (3) The Journey From the Other Side— I have Breast Cancer. The following chapter reviews the different themes in relation to commonalities and differences found in the study findings compared to findings in the literature and highlights findings that are unique to this study.

Chapter 7: Discussion

The purpose of this study was to provide a forum for younger women to describe their experiences with distress representing their standpoints of going through a breast cancer investigation and diagnosis for a breast detected abnormality. The knowledge gained from the participants can enhance our current limited understanding of this experience in the cancer trajectory. This knowledge also provides impetus to re-evaluate how health care services are organized for younger women presenting with a breast problem.

What is most revealing from the findings is how early distress developed in the breast cancer investigation process, a finding which has not been documented qualitatively before in a prospective manner. The results of the study showed that distress was exacerbated and prolonged when women did not have their breast symptoms taken seriously and/or referred for further investigations in a timely manner. Distress was also experienced when health care services were not offered from a person-centred perspective for timely access to information, access to support services and access to coordinated medical care. The possibility of a cancer diagnosis continued to elicit fear during the breast cancer investigation where women could anticipate possibly losing their life and suffering from several short term and long term side effects from treatment. Some of these anticipated challenges became a reality for the women diagnosed with breast cancer who entered into treatment. The findings also showed how women were protective of their loved ones to minimize distress caused by a breast cancer investigation and diagnosis while they attempted themselves to find the support needed to help them cope. The process of undergoing a breast cancer investigation brought awareness to the

importance of breast health practices and wanting to educate other women in becoming proactive for taking care of their breast health. Let us now look at each theme revealed from the findings of the study that support these observations.

7.1 Discovering a Breast Lump and Anticipating Illness

The theme anticipatory illness emerged from the stories the women shared about the discovery of their breast problem. To our knowledge, this finding has not been reported in other studies describing wait times to a breast cancer diagnosis in younger women. The term ‘anticipatory’ depicts a woman visualizing herself in the future with an illness – breast cancer; and the potential losses she predicts for herself if diagnosed with the illness. Jacobsen (1993) referred to the term anticipatory anxiety based on measuring anxiety and nervousness in women going through chemotherapy. For this study, the term anticipatory illness had a broader definition capturing the emotional, psychological and practical issues women dealt with upon finding their breast abnormality. The novelty of this prospective qualitative study is that women described their distress as they were going through their breast cancer investigation and diagnosis. The study design permitted the testimonies of the women to unveil a sequence of concerns they experienced and losses they contemplate as they waited for their fate to be determined through the breast cancer investigation.

Rosedale and Fu (2010) referred to the term loss of innocence to describe the theme of ‘losing pre-cancer being’ in a group of 13 breast cancer survivors interviewed 1 to 18 years after being diagnosed with breast cancer. The term was meant to describe concerns the women expressed about the changes in their lives and never having the ability to return to life as it was known to them prior to breast cancer treatment (Rosedale

& Fu, 2010). Our study was undertaken much earlier in the cancer trajectory with young women not yet knowing their diagnosis. Loss of innocence in our study speaks to the unpredictability of life and how the young women were caught off guard to face a potential life threatening illness. They realized they could be seriously ill thus the thought of being young, healthy and invincible was shattered. As the women explained in the focus groups, they were too young to be thinking about breast cancer; they were busy building their careers, raising their families and sometimes being a caregiver to elderly parents. Our findings seem to suggest that the loss of innocence starts with the detection of a breast problem.

The vulnerability of living with the unknown is a theme that captured the psychological, emotional, and physical distress experienced by the women while they waited for their diagnosis and anticipated the potential ramifications of the disease on their life. Many studies have identified the waiting period to diagnosis as being psychologically challenging for women undergoing a breast cancer investigation (Chappy, 2004; Demir et al., 2008; Lebel et al., 2003; Liao, et al., 2007; O'Mahony, 2001; Schnur et al., 2008; Seckel & Birney, 1996). A finding that is unique to this prospective research project is that the women could identify when distress was most prevalent in the waiting period. A sense of panic overcame the women as soon as they became aware they had a breast problem. For the women who found their lump, there was the urgency to seek immediate medical attention. The women who learned they had a breast detected abnormality through mammography wanted to know immediately what the next steps entailed. Once the women met with the specialists, they felt reassured that something was going to be done. Although distress was always present and difficult, the

women adapted to the situation once they knew they were on their way to finding out if the lump was breast cancer or not.

The anxiety peaked again while the women waited for pathology results after the biopsy. The women wanted to know immediately what the results showed. For the women diagnosed with breast cancer, anxiety peaked again while the women waited to confirm the type of treatment they would receive. In essence, these women appeared prepared to do anything to save their life so they agreed to a breast biopsy and any other treatment that followed. This finding of women wanting to immediately proceed to the next step is similar to the findings found by Fitch et al., (2008) who retrospectively interviewed women three to four years after their diagnosis of breast cancer. The authors reported the theme 'everything depends on acting now' to reflect the urgency the women felt to move forward with treatment as a means to save their life (Fitch et al., 2008). The finding of our study suggests that the sense of urgency for younger women starts when the breast problem is detected with peaks and valleys – urgency seems to reappear at critical points.

The constant worry that women experienced was exhibited through various symptoms such as lack of concentration, difficulty sleeping, feeling anxious, and losing interest in life. Our study does not quantify the levels of distress the women identified. However it is interesting that Lebel et al. (2003) reported that 30% of the women in their study had levels of depression that reached clinical significance prior to biopsy. Schnur et al. (2008) also demonstrated that women undergoing a breast biopsy had levels of mood disturbance similar to women starting chemotherapy. What we can postulate from our study is that the constant interplay between worrying thoughts and fear, compounded

with the wait times created a state of unsettledness for the women prior to diagnosis and especially for those women diagnosed with breast cancer who waited to learn what treatments they would require.

The women had a heightened sensitivity to media coverage on breast cancer as it served as a constant reminder they could be diagnosed with the disease. The awareness about the “pink ribbon” continued with the women diagnosed with breast cancer. This finding is different than the finding found by Dunn and Steginga (2000) where women reported feeling marginalized by breast cancer campaigns that targeted women over the age of 50. In our study, the media coverage on breast cancer provoked feelings of fear and anxiety about the possibility of being diagnosed with breast cancer. There was less preoccupation about the content of what was being promoted through media. The majority of the women in Dunn’s and Steginga’s (2002) study completed surveys and participated in focus groups post treatment for breast cancer. Perhaps they had more time to reflect on this issue compared to the women in our study who were just becoming sensitized to the media coverage and who were preoccupied with moving forward with their breast cancer investigation. Our finding still speaks to how media coverage on breast cancer, with reference to the “pink ribbon” for fundraising campaigns and other campaigns meant to educate and support women about breast health and breast cancer, may have a negative impact on women who are going through diagnosis and treatment. Further research is required to confirm this finding and to understand how the content of media campaigns may impact young women positively or negatively.

The awareness of breast cancer through the media was compounded with the awareness of the abnormality in the breast tissue. The women who had breast lumps

found themselves touching the area several times during the day out of disbelief that they were possibly facing a diagnosis of breast cancer. The act of touching the breast was a way to confirm the lump was present and verify if the shape of the lump was changing. Yet one woman was unable to touch her breast or even look at it knowing the possibility there was cancer in her breast and she wanted it removed as soon as possible. To our knowledge the finding of touching the breast repeatedly or not wanting to touch the breast while waiting for breast biopsy, has not been reported in other studies. Again this finding speaks to the need for shorter wait times to diagnosis to diminish the amount of time women experience distress. Clinicians should also be aware of this behavior to validate women who report it.

Prospective studies conducted with women prior to breast biopsy are mostly quantitative depicting the level of anxiety women experience without necessarily describing if the women are concerned about their personal appearance pre and post breast biopsy or in the event they are diagnosed with breast cancer (Lebel et al., 2003; Liao et al., 2007; Schnur et al., 2008; Seckel & Birney, 1996; Stanton & Snider, 1993). The women in our study described how they anticipated their appearance changing if they received treatment for breast cancer and some women also wondered if the breast biopsy itself would permanently change the appearance of the breast. There was hesitancy on their part to even speak about these concerns afraid to be perceived as vain for worrying about their appearance when their life was potentially at risk. Issues about body image were not necessarily raised unless asked by the researcher in this study. The single women wondered how the appearance of the breast would impact their relationship with a boyfriend. Some women were also worried about the biopsy and how it could affect the

cosmetic result achieved through breast reduction or breast reconstruction surgery they previously received. Some women feared losing their breast if they were diagnosed with breast cancer and some women were already thinking about having bilateral mastectomies to prevent cancer recurrence. The women also anticipated needing chemotherapy if diagnosed with breast cancer and they were afraid to lose their hair.

The documentation of the finding of preoccupation with body image issues prior to a breast biopsy is unique to this study. Younger women's concerns with body image issues are identified in studies when women were interviewed after treatment for breast cancer (Coyne & Borbasi, 2006; Elmir et al., 2010; Gould, 2001; McMahon, 2001). Our prospective study confirms the importance of addressing body image issues early in the breast cancer investigation as young women have concerns. Health care professionals have a responsibility to engage young women in discussions about these issues as a means to validate and normalize their concerns and/or to dispel concerns that may not be applicable to them. Surgeons and/or radiologists should explain to young women the impact of a breast biopsy on the appearance of the breast as part of the informed consent process so that women clearly understand the potential change in appearance of the breast with or without a breast cancer diagnosis.

The women spoke about death when the subject of spirituality was raised although spirituality was not identified as a coping strategy. This study finding is unlike the one found in Benedict's (1994) study where some women relinquished the problem to a higher power as a means to cope. The finding is perhaps attributed to the difference in age where the participants in Benedict's (1994) study were older (mean age 52) compared to the participants in this study (mean age 41); perhaps younger women rely less on their

faith as a coping mechanism. The finding may also be attributed to our small sample. Nonetheless, the women spoke openly about death and how they were afraid to die if diagnosed with breast cancer. The finding of fearing death as a result of a breast cancer diagnosis is reported in retrospective studies conducted with women who have the disease (Fitch et al., 2008; O'Mahony, 2001). Our study suggests that the thought of dying starts immediately upon finding a breast abnormality prior to diagnosis.

7.2 When Young Women Assume the New Role of 'Patient'

While anticipating the possibility of being diagnosed with breast cancer, these young women also entered the world of health care as patients. The 'being' in being a patient speaks to the vulnerability of the unknown and the inability to resolve one's health issue without relying on people who have specialized knowledge and skills. Yet there is also the quick learning curve required to become informed on matters of breast health and breast cancer and acquire the sense and/or knowledge of when to become an advocate for your own care.

The women identified coping better with their situation if they were well informed, as one participant said 'knowledge is power'. The availability of information on breast health and/or breast cancer was scarce in the offices of primary care physicians. The women received verbal and written information about their diagnostic procedures and how to examine their breasts once they had their consultation at the breast clinic. Most of the women accessed information on the Internet or they had family members access information for them. This is a similar finding to a study conducted with women receiving chemotherapy for breast cancer who identified the Internet as the most frequently used mass media source especially by younger women (Cowan & Hoskins,

2007). In our study, the women identified it was overwhelming to receive too much information all at once. The women preferred to receive verbal information directly from a health care professional followed-up with written information. This finding concurs with the finding of a previous study where women waiting for breast cancer surgery identified surgeons as their preferred source for obtaining information (O'Leary, Estabrooks, Olson & Cummings, 2007).

The women relied on intuitive trust to sense if a different action was required to deal with their breast abnormality. Five of the 14 women who participated in this study experienced delays to a definitive diagnosis as their symptoms were not fully investigated. Three of the five women were eventually diagnosed with breast cancer and the two other women were diagnosed with a benign breast lesion. The longest delays to diagnosis were eight months and two years for two of the women diagnosed with breast cancer. It is also interesting to note that all five women diagnosed with breast cancer found their breast lump. The finding that women experience problems having breast symptoms taken seriously has previously been reported in the literature (Fitch et al., 2008; McMahon, 2001).

It is important to acknowledge that the diagnostic work-up for breast cancer in women is more complex. Younger women tend to have lumpier and denser breast tissue compared to older women, making it more difficult to detect cancerous lesions (Afzelius et al., 1994). However it appears that delays to diagnosis in our study may have been related to other issues identified in the literature such as: system inadequacies (Weingart et al., 2009); primary care physicians not coordinating the necessary diagnostic tests in a timely fashion (Afzelius et al., 1994; Caplan, et al., 1996); knowledge gaps on the part of

some clinicians to effectively management breast symptoms (Nekhlyudov et al., 2008) and/or; making the mistake of using the “wait and see approach” instead of pursuing a breast cancer investigation to arrive at a definitive diagnosis (Tartter et al., 1998). The common reasons linked to delays to diagnosis in our study were that some primary care physicians were reluctant to send young women for mammograms; they did not believe these women were at risk for developing breast cancer because of their age, or because they had no family history of breast cancer, or and they did not want to expose them to radiation through mammography. Although it is unknown if earlier detection may have provided a better clinical outcome, the women worried about the cancer returning and possibly having a shorter life expectancy.

What needs to be further explored is how public policy about organized breast screening programs is shaping our thinking of breast health practices and how it impacts younger women’s access to breast health services. This raises the issue of the “blanket effect” from breast screening program policies that target women between the ages of 50 to 74 for mammography screening. The key message conveyed by these programs is that breast cancer affects older women and they should receive regular screening. There is the possibility that the policy around breast screening becomes the filter from which people make interpretations; ‘if you are young, you are not at risk and you do not require regular screening’. Messaging relayed from the policy does not make the distinction between a screening mammogram and a diagnostic mammogram. There are no key messages in the public domain that explain to young women that if you have a breast problem, regardless of age, seek medical attention. All physicians should be familiar with clinical guidelines that recommend the investigation of breast lumps regardless of a woman’s age. A simple

change in how we promote breast screening and how we communicate information to the public could potentially assist young women presenting with a breast problem about the need to have their breast symptom(s) investigated instead of being ignored as it currently happens to some young women.

A finding that was surprising is the amount of worrying and anxiety the women experienced related to the actual breast biopsy procedure, especially the women who required an open biopsy. Perhaps the prospective qualitative inquiry permitted the women to verbalize their fears about up-coming procedures whereas women participating in quantitative prospective studies (Lebel et al., 2003; Liao et al., 2007, 2008; Schnur et al., 2008) may not have the opportunity to explicitly express their concerns about breast biopsy. Perhaps the finding in our study is also specific to young women given the other studies on breast biopsy and distress were conducted with women of all ages (Andrykowski et al., 2002; Benedict et al., 1994; Chappy, 2004; Demir et al., 2008; Lebel et al., 2003; Liao et al., 2008; MacFarlane & Sony, 1992; Schnur et al., 2008; Seckel & Birney, 1996; Stanton & Snider, 1993). For the women in our study, their senses and emotions were heightened as they went through diagnostic and treatment procedures. They identified concerns about being awake and aware when the incision was going to be made on the breast, the possibility of experiencing pain and/or discomfort and complications during the procedure (e.g. allergic reaction). When it came to actually going through the procedure, the reactions were different for the women regardless of the type of biopsy they required. Some women experienced very little discomfort while other women experienced a high level of discomfort and/or pain (e.g. hand held core biopsy, ultrasound guided core biopsy, open biopsy, and needle localization). The traveling

required between two hospital sites for needed localization added distress to an already unpleasant procedure.

All the women consistently reported that it was helpful when health care professionals spoke with them and coached them through the procedure. A consistent report from all the women was the surprise of learning that open biopsies and mastectomies are performed as out-patient procedures. In the past, women were admitted to hospital for several days when they underwent a breast biopsy or surgery for breast cancer. As in-patients, women received post-operative care and support from health care professionals. With the advancement of medical procedures, it is no longer necessary for women with breast cancer to be cared for in the hospital because the physical recovery can be managed in the home. However the psychosocial support from health care professionals is not available in the home. This lack of community psychosocial resources may explain in part why women's distress scores are high when they see the oncologist for the first time (Zabora et al., 2001); they do not have the opportunity to discuss with a professional their psychosocial concerns related to their new diagnosis.

7.3 Worrying About the Wellbeing of Others While Coping with a Breast Cancer Investigation

The finding in our study that women wanted to protect the people they loved while struggling to meet their own emotional needs is similar to findings reported in a study where terminally ill patients and women who were involuntarily childless, were interviewed about their life circumstances, and the disruption on their daily lives and future expectations (Exley & Letherby, 2001). The authors' findings of 'managing' the self and others is based on the premise that people facing a lifecourse disruption are

involved in emotional work that can be difficult and challenging. In their study, it was common for women to refrain from sharing their emotional feelings to protect family members; in essence they were trying to reduce any tension in order to maintain normal interactions (Exley & Letherby, 2001).

The women who participated in our study were afraid to be diagnosed with breast cancer. Some women felt overwhelmed with emotions as they thought about the potential impact a breast cancer diagnosis would have on their life and the possibility they could die. Yet in the midst of a chaotic state of uncertainty, their instinct was to protect the people they loved. Their first instinct was to protect their children. The women were often faced with making difficult decisions about how much information to share with family. They wanted to provide enough information for the children to understand that their mother was experiencing without alarming them.

The women's instinct to protect was also extended to family members and friends. They sometimes withheld information from loved ones until after the women learned the biopsy result because they did not want their loved ones to worry unnecessarily. Some women in the study cried when they met with the researcher at the first interview admitting they had barely spoken to anyone about what they were going through. The research interview was not a counselling interview yet it provided the opportunity for the women to tell their story and express what they were feeling and thinking in a safe environment without burdening a person they cared for.

The women wanted to protect their family members and friends while balancing their own needs for emotional and practical support early in the breast cancer investigation. They confided in their partners who were present and supportive by

attending medical appointments, supporting medical decisions the women made, and assisting with practical tasks in the home. However the women often turned to women friends for emotional connectivity and understanding. They were selective in terms of who they disclosed information to about their breast cancer investigation. However they reached out to women who they thought could help them. It seemed that these women friends knew how to listen without offering advice; providing gentle reassurance that regardless of the results they would be there to assist and support. They also provided a pleasant distraction so that the conversation was not always focused on the breast cancer investigation. The women could talk about other subjects related to their work, their home and/or social life. Family members should be coached by health care professionals to understand the emotional needs of women undergoing a breast cancer investigation and how best to support them.

Another study finding is that in the time period prior to their biopsy result the women wanted to speak to other women who had been through a breast cancer investigation or who had been diagnosed with breast cancer. To our knowledge, the need to seek information from other women in the same circumstance is not reported in the literature for studies conducted in the timeframe prior to diagnosis. Snyder and Pearse (2010) report results of a retrospective qualitative study where 70 young women survivors of breast cancer were interviewed on average three years post diagnosis. In order to cope, many of these women reported they relied on experiential support defined by the authors "as a relationship with someone who has gone through a similar illness and can help provide firsthand information, insight, and even hope" (Snyder & Pearse, 2010). Experiential support can be provided by relatives, friends or someone from the

community (Snyder & Pearse, 2010). Women in our study were able to gain experiential support by reaching out to women they knew in their support network. The women were curious and felt comfortable asking their questions; it was also comforting to speak to someone who had been through a similar experience. The women diagnosed with breast cancer kept in contact with these women as they entered treatment. Experiential support prior to a breast cancer investigation may help alleviate distress and should be further explored by organizations and local peer support programs who offer this type of service for women already diagnosed with breast cancer.

Work was important to these women from the perspective of keeping busy and not having to think continuously about their upcoming breast biopsy and pathology results. The support received from their workplace to work flexible hours in order to attend medical appointments was greatly appreciated. Working also symbolized health and normalcy. The finding of working as a diversion from the breast cancer investigation is in keeping with the findings of Benedict et al., (1994) where staying mentally occupied was a coping strategy to deal with breast biopsy. The only cautionary note from the findings of our study is that some women reported feeling highly anxious and unable to concentrate at times. Work assignments may need to be modified to ensure the safety of the employee and others pending the work environment.

The women appreciated the support received from the health care team especially the nurses in the breast clinic. Although they were experiencing distress with their breast cancer investigation, they did not expect the surgeons and nurses to spend time with them to resolve their emotional distress. Hence it was important for women to have access to professionals who had the appropriate knowledge and skills to deal with these types of

issues. It was also important to provide women with information about the type of services available and how they could access them. The women supported the concept of screening for distress during the breast cancer investigation and diagnosis where they could write their concerns. They explained that identifying personal concerns on paper is perhaps easier than expressing them verbally to a healthcare professional along with the choice of receiving further supportive care services if necessary. The current recommended tool in Canada to screen cancer patients for distress is the Edmonton Symptom Assessment System scale (CPAC, 2009) that screens for many physical symptoms that women going through a breast cancer investigation may not experience. The Canadian Problem Checklist (see Appendix A), also endorsed as a distress screening tool (CPAC, 2009), has items that can be changed to suit the population to be screened making it perhaps more appropriate. More research is required in this area to understand which tools may be most appropriate and effective to facilitate a conversation with younger women about their distress during a breast cancer investigation and diagnosis.

7.4 Young Women Learning they Do Not Have Breast Cancer

We know that the wait time from biopsy to the time learning your diagnosis causes distress for women who are anxiously waiting to learn their pathology results (O'Mahoney, 2001). The women in our study reported distress while waiting to learn their diagnosis that took approximately one to three weeks after their procedure except for one woman who received her results six weeks later. This finding highlights how important it is to have a quick turnaround time from biopsy to pathology results that inform women of their results to minimize distress.

There were no indications from the women about having lingering distress issues related to their breast cancer investigation at the second interview. This finding was further confirmed by the three women who participated in the focus group six to nine months after their breast biopsy results. This finding is different from the results Andrykowski et al. (2002) reported in their study who found that women identified breast cancer specific distress up to eight months after their benign breast biopsy result. This discrepancy is perhaps due to the different research designs and data collection methods of both studies. Our qualitative study focused on interviewing women prior to biopsy and immediately after biopsy to permit women to describe distress as they went through a breast cancer investigation. Andrykowski et al. (2002) measured distress over time, with the time period beginning after breast biopsy up to eight months. This may explain the difference in findings.

The women who had open biopsies required a longer recovery time compared to the women who had a fine needle aspirate or an ultrasound guided core biopsy. The women reported one to two weeks of recovery time before resuming their full activities. MacFarlane & Sony (1992) conducted their study specifically with women scheduled to have an excisional biopsy. They reported that women experienced pain at the surgical site and soreness of the arm on the same side as the breast surgery (MacFarlane & Sony, 1992). These symptoms were similar to the symptoms reported by the women in our study. Their symptoms required them to rely on family members to assist with practical tasks or make arrangements at work if heavy lifting was involved. The women who had children also relied on family members and friends to provide child care. The physical limitations during the recovery period, highlights the importance of health care

professionals providing education to younger women about diagnostic procedures. These women need to understand the physical limitations they can expect after a breast biopsy so that they can anticipate their needs in the home and at work and proactively plan for their recovery.

The women who had excisional breast biopsies reported more concerns with the appearance of the breast after their biopsy compared to the women who had needle core biopsies. This finding underscores the importance of administering the least invasive procedures to arrive at a definitive diagnosis when the clinical presentation warrants such an approach. The opportunity to ask women about their expectations for the appearance of the breast pre and post biopsy was unique to our study. Women reported body image issues with an excisional breast biopsy when asked retrospectively about their experience with the procedure (MacFarlane & Sony, 1992). In our study, some women were not concerned about the cosmetic result of the breast prior to their biopsy however they had concerns about the appearance of the breast after the biopsy. This finding highlights the need for surgeons and radiologists to explain the impact of the breast biopsy on the appearance of the breast so that women are fully informed and know what to expect.

The experience of going through a breast cancer investigation changed the women's outlook on life; they were grateful for not having breast cancer and were motivated not to "put off what can be done now". The two women previously diagnosed with breast cancer wanted to put this 'scare of recurrence' behind them yet they knew this experience could repeat again at their next annual check-up. The women were committed to taking better care of their overall health; one woman wanted to stop smoking, other women were booking medical tests they had put off.

They spoke about becoming breast aware and educating other family members and friends on the importance of knowing the texture of your own breast tissue. The majority of the women in this study agreed that breast health awareness should start in high school for women to grow up knowing their breast tissue and feel comfortable checking their breasts. The term “breast aware” is new language in the breast cancer discourse meant to replace the language on routine breast self-examination. For the past 50 years women have been encouraged to routinely exam their breasts after their menstrual cycle using a regimented method for physically and visually examining their breasts (Eyre, Lange & Morris, 2002). Breast cancer activists argue that breast self-examination empowers women to be in touch with their bodies (Batt, 1994; Learner, 2001). In 2001, the recommendations for doing routine breast self-examinations were challenged in Canada when a scientific panel found there was no evidence to support the assumption that routine practice of breast self-examinations reduced mortality rates from breast cancer. The panel actually found the practice of breast self-examinations to be harmful as it increases the number of physician visits and increases the number of biopsies for benign breast lesions (Baxter, 2001). The United States Preventive Service Task Force reached the same conclusions (NCI, 2009). The practice of doing regular breast self-examinations is no longer supported in North America. Women are encouraged to become familiar with their breasts at a young age and to touch their breasts at different times during the month (Love & Lindsey, 2005). The danger with saying that breast self-examinations are no longer recommended is that women do not familiarize themselves with their breast tissue to know what is normal and abnormal. For younger women being breast aware is the only form of secondary prevention available to them.

The women in this study strongly advocated for education that teaches young women to become breast aware starting in high school.

7.5 Young Women Learn They Have Breast Cancer

The women learned their diagnosis of breast cancer at their follow-up appointment with the surgeon except for one woman who was informed by her primary care physician that she had breast cancer. The women identified they were emotionally overwhelmed learning their diagnosis making it difficult to make immediate treatment decisions. They instantly needed to learn medical terminology that seems like a foreign language. They were provided with treatment options which at times felt overwhelming as the women were not sure if they were making the correct decision for themselves. For example, one woman, who initially had a lumpectomy and then a mastectomy, wondered if she made the right decision to undergo a mastectomy after her pathology report showed there was no residual disease in the breast tissue. In another case, a woman, who had a lumpectomy followed by radiation treatment, wondered if she should have proceeded with mastectomy to reduce her chances of recurrence. This sense of uncertainty about treatment decision-making was also reported by another woman previously treated for breast cancer and who was now going through another breast cancer investigation. She luckily did not have a breast cancer recurrence however the emotional toll placed on her and her family made her wonder if the investigation could have been avoided if she had chosen a mastectomy the first time. A recent study revealed that breast cancer survivors experience regrets about choices they made for treatment five years earlier (Fernandes-Taylor & Bloom, 2011). Our study findings suggest that young women may start experiencing regret about treatment choices early in the cancer journey which leads to the

same conclusions advanced by Fernandes-Taylor and Bloom (2011); women may require psychosocial care to address decision making about treatment issues and that good communication between physician and patient is essential.

The women disclosing their diagnosis to loved ones was a poignant moment; people cried while often using humor to cope with a very difficult situation. The women gradually shared information about their diagnosis of breast cancer with their children and some women included them in the visits to the cancer centre. The women felt guilty that their children may have a different childhood because of their mother going through breast cancer treatment. This finding is similar to Connell et al., (2006) where the young women in the study were concerned about the impact of their breast cancer diagnosis on the well-being of the children.

The impact of a breast cancer diagnosis on the family unit and the importance of social support as a mediator for coping with illness is well documented in the literature (Northhouse, 1988; 1990; Northhouse, Cracchiolo-Caraway & Pappas Appel, 1991). In our study, the women soon realized they could not get through the psychological and physical impact of treatment without the support of their families. The women quickly learned that involving family members and friends with their care not only helped them but it also helped their loved ones cope with their diagnosis; people felt better when they could assist with practical tasks. The women also knew they had to rely on family and friends to assist with the care of the children and help maintain a routine in the household while they were in treatment. This finding emphasizes the importance of the health care team to assess the social network available to women at time of diagnosis and to link them with the appropriate resources.

The women who required two surgeries, lumpectomy followed by mastectomy, found the recovery physically and emotionally challenging. Surgical recommendations for breast cancer treatment were made once a cancer diagnosis was confirmed through biopsy. Breast conserving surgery followed by radiation therapy is the standard treatment offered to women today since the long-term mortality rates are comparable to the rates of women who receive a mastectomy (Fisher et al., 2002). It is estimated that 30% of all breast cancers are unsuitable for breast-conserving surgery and mastectomy is required for medical reasons (Harmer, 2011). For our study, the women requiring both procedures meant they had physical limitations for a longer period of time that impacted on their activities of daily living. The psychological impact stemmed from originally being able to keep their breast with the first surgery with a good cosmetic result and then mourning the loss of the breast with the mastectomy.

The women were sent home to recover physically from their breast surgery. A nurse may have visited in the home for wound care however other support services were not in place to provide the psychosocial support. The range of motion of the arm was affected from the surgery and the women reported having pain in the armpit. The symptoms of distress the women exhibited while waiting for their diagnosis such as feelings of anxiety and insomnia, were also present while they waited to start their treatment after surgery. Once the women started their chemotherapy they reported symptoms of fatigue, nausea, and forgetfulness that are often reported in the literature for women undergoing chemotherapy (Lennan & Klein née McCoy, 2011). Again these findings underscore the importance of screening young women for distress to ensure

effective symptom management and to facilitate access to psychosocial services to help them resolve their distress.

Body image and sexuality changes were concerns raised by the women diagnosed with breast cancer that concur with similar findings of other studies (Coyne & Borbasi, 2006; Elmir et al., 2010; Gould, 2001; McMahon, 2001). Most of the media coverage on breast cancer portray women as courageous with a message that life is normal after treatment (Batt, 1994). Audre Lorde, (1980) was an African American lesbian poet who recounted her own experience with breast cancer and spoke against the use of breast prosthesis after mastectomy. In her view, it encourages women to be nostalgic instead of focusing on the future. It does not permit women to openly mourn their loss inferring they are guilty for having done something wrong. It encourages women to focus their energies on the cosmetic appearance instead of paying attention to more important issues of living with whatever time there is left. To mask a mastectomy with a prosthesis “reinforce[s] our own isolation and invisibility from each other, as well as the false complacency of a society which would rather not face the results of its own insanities” (Lorde, 1980). Other feminists, such as Kathy Davis (1999) have held the view that cosmetic surgery represents “one of the more pernicious horrors inflicted by the medical system upon women’s bodies” (p. 455). However her work with women who were deciding to have plastic surgery or had already received plastic surgery brought her to conclude that cosmetic surgery was a complex dilemma that encapsulates all in one: problem and solution with symptom of oppression and act of empowerment (Davis, 1999). She recognized that some women’s suffering with their appearance made cosmetic surgery an acceptable action not to be avoided at all costs and feminists should

not perceive women who receive such procedures as misguided or deluded victims (Davis, 1999).

In our study the anticipation prior to breast biopsy of what can possibly happen to one's appearance for the treatment of breast cancer became real after five women learned they had breast cancer. The theme "a modified self, a modified way of living" encapsulates the transition from loss of self-image and femininity to a renewed sense of meaning for life. The women had no choice but to accept the side effects of treatment, some temporary such as hair loss, others permanent like the loss of a breast in exchange for living. They contemplated decisions about prophylactic mastectomy, breast reconstruction and breast prosthesis trying to improve their chances to live longer while at the same time trying to feel whole again as women. It was not so much about masking their trauma to make it invisible to society but to cope with their loss since their current body no longer felt or looked the way they were. A health care model for women based on feminist principles supports that women be informed of their choices with explanations for benefits and risks, taking into consideration individual situations and setting aside the provider's biases (Andrist, 1997).

A diagnosis of breast cancer changed the women's perspectives for moving forward with life. Their roles as mothers, daughters, wives and workers had to be balanced with their new role of being a patient and learning to meet their health care needs. The women took pleasure in the simple treasures of life such as spending time with family and they were more guarded about planning long term goals. Despite the challenges they faced with the side effects from treatment and a future that was not promised, the women wanted to help other women. They were committed to telling their

stories to make other women breast aware. This finding is in keeping with results of the study by Abrashoff Schutte, (1996) who found that women report they want to help other women diagnosed with breast cancer as part of their own breast cancer recovery.

Through their experiences with a breast cancer investigation and diagnosis, younger women are poised to bring greater awareness about the needs of younger women on matters of breast health and cancer treatment.

The women who were the sole income earners or whose income was necessary to support the family unit were concerned that they could not manage financially if diagnosed with breast cancer. Unfortunately this fear about financial concerns prior to diagnosis became a reality for three of the five women diagnosed with breast cancer. One woman continued to work during chemotherapy despite the advice of her medical oncologist placing her at risk for a life threatening infection. One woman could not support her family with the income she received from Sick Employment Insurance (SEI) every two weeks and her elderly parents assisted by supplementing her income. The other woman could not work long enough after her maternity leave to qualify for SEI. Family and friends collected money to assist her with the purchases of a breast prosthesis and swimsuits.

The financial concerns the women identified in our study were in keeping with findings found in other qualitative studies conducted with women where the burden of managing financially while ill becomes a source of distress (Coyne & Borbasi, 2006; Gould et al., 2001). A Canadian survey with 446 breast cancer survivors with 97% of the participants representing the working age group between 18 and 64 years, provided information about the financial challenges met when a wage earner becomes ill (CB CN,

2010). The study results indicated that 15 weeks of Employment Insurance premiums, paid for sick leave, fell short of meeting the needs of women undergoing treatment for breast cancer that averaged 38 weeks in duration (Canadian Breast Cancer Network (CBCN), 2010). The findings of this study showed that the average decline in household income was \$12,000 or 10% of the family income (CBCN, 2010). Another study finding is that women reported that the stress associated with the worry about finances was sometimes worse than having the disease (CBCN, 2010). The findings from this study suggested that the social safety net assumed to protect Canadians during time of illness is not sufficient to meet the needs of people diagnosed with cancer (CBCN, 2010). The findings in our study highlight the need for health care professionals to screen young women for this potential source of distress at time of diagnosis to ensure they are referred to social workers who can assist women in accessing appropriate financial resources in a timely way. There is also a role for social workers to identify the resource gaps and advocate for improved financial resources for people diagnosed with cancer.

7.6 Chapter Summary

The purpose of this chapter was to present the different themes that emerged from the data analysis based on the stories shared by the young women undergoing a breast cancer investigation and diagnosis in relation to findings in the literature. Our findings suggest that young women start anticipating becoming seriously ill from the time they identify a breast abnormality and they worry about having a shorter lifespan if diagnosed with breast cancer. For the women who have children, they worry about their children growing up without a mother and they feel sadness thinking they may be robbed of the opportunity to see their children grow-up if they die from their disease. While prepared

to do anything to save their life, they worry about losing their breast if they require a mastectomy and losing their hair if they need chemotherapy. Young women who require an invasive breast biopsy procedure worry about the procedure and the impact it will have on their recovery. The longer they wait to learn their diagnosis, the longer they experience distress. The women's distress is exhibited through various psychological and physical symptoms and the constant messaging in the media about breast cancer only serves to remind them of a potential destiny they want to escape from. While trying to shield their children and family from worrying about them, they also recognize their need for support to help them cope with the distress experienced with the breast cancer investigation.

The young women with a benign breast biopsy result do not appear to experience prolonged distress after their diagnosis, however there is the realization they are not immune to becoming seriously ill in the future. There is a commitment to become more breast health aware and generally pay more attention to taking care of their overall health. For the young women diagnosed with breast cancer, they are now confronted with the realities they feared prior to diagnosis. There is the physical recovery of going through surgery and chemotherapy while adapting to a modified way of living – a new body, a new self. Financial distress is also experienced by the young women who contribute to or are responsible for paying household expenses. The young women who experience prolonged wait times to be referred for further diagnostic tests question if they are at greater risk for recurrence leaving them angry. It appears that the young women do not want to be a burden to their family and friends however they realize they need to rely on their support network to help them through treatment.

The recommendations made by the young women to improve the experiences of younger women undergoing a breast cancer investigation and to improve the overall health of women are: (1) ensure young women have access to the proper diagnostic tests when presenting with a breast abnormality; (2) make information on breast health and/or breast cancer available in the offices of primary care physicians; (3) screen younger women for distress during the breast cancer investigation/diagnosis and ensure that clinical pathways are in place for them to access professional and peer support services if necessary; (4) introduce the concept of breast health awareness as part of high school curriculum for younger women to become more informed at an early age about taking care of their breast health.

In Chapter 8 you will find conclusions addressing how the findings relate to the five research questions and an overview of the limitations of the study and the clinical implications.

Chapter 8: Conclusions

From a feminist perspective, breast cancer is about the personal and the political (Boehmer, 2000). The breast cancer movement evolved in the 1970s and 1980s in the United States (Boehmer, 2000) and in Canada in the 1990's, (Batt, 1994) using women's personal stories as a political platform to raise awareness and take action as a result of the dissatisfaction with the medical system and how society was silencing women's suffering with breast cancer (Batt, 1994). This study was meant to understand distress from the personal perspective of young women undergoing a breast cancer investigation. Understanding the personal served two purposes: (1) to improve a woman centred approach to health care to support young women who experience distress with a breast cancer investigation and; (2) to understand the social, economic and political factors that surround the process of a breast cancer investigation for younger women to move towards a political platform for change when it comes to their breast health.

To our knowledge, a prospective qualitative study had never been undertaken with younger women to understand their experiences with distress during a breast cancer investigation and diagnosis. The epistemological application of standpoint theory combined with applying principles of feminist participatory action research provided credence to the research findings representing younger women's experiences' with distress when undergoing a breast cancer investigation and diagnosis. The five research questions were meant to understand the personal to move towards the political.

8.1 Question 1—Addressing the Personal Experiences of Younger Women with a Breast Cancer Investigation

The first research question was about understanding how women 50 years of age and younger, not menopausal, describe their experience with distress from the time they are informed they require a breast biopsy for a breast detected abnormality to the time they learn their diagnosis. What we learned from the findings of this study is that distress starts from the moment young women perceive their breast abnormality to be a threat to their life. The threat can be related to many different issues such as the fear to die, the fear of medical procedures, the fear of short term and long term side effects from treatment that affects wellness and body image, the fear of how the illness impacts the family, and/or the fear of not being able to work and maintain financial stability during treatment for breast cancer.

Feminist health care providers have argued that the relationship between provider and patient should be one of mutual reciprocity as a means to decrease traditional physical, social and personal barriers to health care (Andrist, 1997). The experiences of the young women in this study demonstrate that there are several strategies that can be put into place to reduce distress during a breast cancer investigation to create symmetry in provider – patient relationship starting with: (1) clinical pathways and guidelines that articulate and can be implemented into the clinical practice of primary care physicians to explicitly address younger women who are not eligible to participate in breast screening programs, yet who may present with a breast abnormality and require access to proper diagnostic services in a timely fashion; (2) information about breast health, breast diagnostic tests and breast cancer being available in the offices of primary care physicians

for young women presenting with a breast abnormality; (3) health care professionals working in breast diagnostic clinics need to prepare younger women for the breast biopsy so they can understand what to expect during the procedure; coaching the young women through the procedure and if necessary provide techniques to reduce anxiety through deep breathing exercises and relaxation techniques; (4) younger women needing to understand the impact of the breast biopsy on the appearance of the breast as part of the informed consent process; (5) wait times between procedures to inform women of their results being kept to a minimum through innovative clinical pathways aimed at decreasing the amount of time distress is experienced by young women; (6) routine screening for distress being implemented at breast diagnostic clinics to ensure women who require additional support have access to services pre and post diagnosis; (7) peer support programs being in place for younger women undergoing a breast cancer investigation to share their experiences with other women who have been through a similar process and to feel validated for what they are feeling and thinking as the process unfolds; (8) family oriented education materials being available to coach loved ones on how to best support women undergoing a cancer investigation and diagnosis; (9) lay education materials being available to women to help them explain their diagnosis of breast cancer to children; (10) social workers being involved in breast diagnostic clinics to provide young women with additional support services to address their psychosocial, informational and practical needs. These steps have the potential to reduce distress by improving the personal level of care for young women going through a breast cancer investigation.

8.2 Question 2—Barriers in the health care system that contribute to distress

The second research question was to describe factors in the health care system that young women perceived contributed to their distress during the breast cancer investigation. Standpoint theories teach us that women's standpoints are not automatically recognized but they are created from both collective intellectual and political struggles (Harding, 2012). Through their distress the young women in this study came to understand the reality of undergoing a breast cancer investigation. They identified and articulated concerns about the process for younger women to access care resulting in delays to diagnosis especially the time interval for presenting with a breast problem to referral for further diagnostic procedures and/or or referral to a specialist.

As we learn through this study, some young women waited several weeks to several months to access the appropriate diagnostic services prior to being diagnosed with breast cancer. The 'being' in being a patient speaks to the need for young women to rely on other health care professionals to help them resolve their health issues. This reliance places women in a vulnerable state especially if they are not taken seriously when presenting with a breast problem. If access to diagnostic procedures is denied, it leaves young women to resort to their own intuition to pursue the matter. Delays with diagnosis elicit feelings of anger in young women leaving them wondering if they are at greater risk for a breast cancer recurrence and possibly a shorter lifespan. It appears to them that the concept of early detection is not applicable to women in their age group.

Current public health policy addresses the breast health of women between the ages of 50 to 74 who participate in organized breast screening programs. The widespread messages about screening women in this age group have potential detriments for younger

women. These messages are often interpreted by the public as meaning that younger women cannot get breast cancer (Johnson & Diskson-Swift, 2008). Unfortunately, younger women's breast symptoms may not be taken seriously and this lack of attention may lead to delayed diagnosis of a breast malignancy. Public campaigns do not distinguish between screening and diagnostic mammogram and do not provide information about the appropriateness of younger women accessing mammography or other diagnostic tests when they present with breast symptoms. We need to better understand how public health policies, for organized breast screening programs, become the filter of information for women of all ages that potentially negatively impacts women who do not meet criteria to be screened in these programs. The reality in this country is that 19% of the women diagnosed with breast cancer will be under the age of 50 and at most risk for early death (CCS, 2009). Canadian public health policy is required to clearly outline the requirements of a breast cancer investigation for younger women.

There are other points of transition in the breast cancer investigation where time delays appeared to occur and prolong distress. For instance, the time interval of being informed of the need for breast biopsy to the actual procedure for young women considered at lower risk for breast cancer. It is important to emphasize that even though these young women were considered to have a low chance of their breast lesion being cancerous, it did not necessarily translate in them experiencing less distress or no distress at all. Once they saw the specialist they were reassured yet distress was never eliminated. There was also the time interval to learn the results of the pathology reports after the biopsy and finally, the time interval to learn the pathology results after surgery for breast cancer and to learn if chemotherapy or radiation therapy was required. This raises the

question of when should women have access to their health information. With the advancement in technology, have we reached a point in time where women should have the option to access their pathology reports through their e-health record prior to seeing the specialist to discuss treatment? This raises many potential practical and ethical concerns however debates over such matters is necessary to create a system that is responsive to young women's needs.

The standpoints of young women undergoing a breast cancer investigation also include economics pertaining to service delivery and household financial stability. First, the evolution of science permits medical procedures such as open biopsies and mastectomies to be done through day surgery procedures. Out-patient procedures reduce costs to the health system because women can physically recover in their home; nursing care can be coordinated through home care programs to attend to physical needs. However services to address the emotional and sometimes practical supports required by young women to cope with their situation are not provided or coordinated in the home. The lack of attention paid to the psychosocial implications of a breast cancer surgery perpetuates binary thinking separating the physical experience "the body" from the emotional experience "the soul" of a breast cancer investigation and diagnosis. A comprehensive approach to women's care should include services encompassing the physical and psychosocial.

Secondly, the financial implications of being diagnosed with breast cancer can seriously affect the financial stability of families. For the young women who were anticipating a potential diagnosis of breast cancer, the financial impact of the diagnosis on the family income was a constant source of distress. Once they were informed they had

breast cancer, the financial burden of the diagnosis became a reality with the realization that the social safety net was not sufficient to provide financial stability during illness. The criteria to qualify for Unemployment Insurance Sick premiums and the number of weeks the benefits are available for, need to be reviewed and changes advocated for; the duration of funding should be compatible with the number of weeks spent in cancer treatment.

8.3 Question 3—Expectations for Themselves and Others

The third research question was specific to understanding how young women described expectations they had about themselves, their social environment and the health care system for resolving their distress. What we learned from this study is that young women tried to mobilize support for themselves to cope with a difficult situation while at the same time caring for others. It was a natural instinct for these young women to want to protect their families, friends and especially their children from worrying about them. They often refrained from sharing how they felt in an attempt to keep their home environment as normal as possible under difficult circumstances.

Young women confided in their husbands or partners who provided emotional support by being present for medical appointments, giving input about medical decisions and providing practical assistance in the home. Young women often found emotional connectivity with other women who they trusted to help them understand what they were going through. The nurses and surgeons in the breast diagnostic clinic were described as supportive, still the young women did not expect them to address in depth the psychosocial concerns the young women were dealing with. It may be easier for young women to indicate their psychosocial concerns on a distress screening tool with the option

to pursue speaking with a professional for further counselling. It is also important to note that these young women found a lot of comfort talking to other women who had been through a breast biopsy or who had been previously diagnosed with breast cancer.

8.4 Question 4—Resolving System Barriers

The fourth research question was aimed at understanding what young women propose for resolving system barriers. Although several of the barriers that the young women identified have already been presented with potential solutions as part of the previous questions answered, one specific recommendation made by the young women was that breast health awareness needs to be part of high school curriculum. It is important that education about becoming ‘breast aware’ be repeated over time so that it becomes part of routine healthy practices for young women going into adulthood. It is interesting to note that the five women diagnosed with breast cancer all found their own breast lump. They wanted to utilize their stories of finding their breast lump to inspire other young women to become breast aware.

8.5 Question 5—Social Workers Learn From Younger Women’s Experiences with Breast Biopsy and Diagnosis

The fifth and final research question was to understand what social workers can learn from younger women’s experiences with a breast cancer investigation and diagnosis to inform their clinical practices related to screening for distress and providing psychosocial services. The study undertaken brings to light the personal and system issues that are sources of distress during a breast cancer investigation. When combining all the gaps the young women identified in the investigational process of a breast problem, it becomes apparent that there is much work to be done to address the needs of

the 19% of young Canadian women who will be diagnosed with breast cancer every year. Social workers have a role in assisting young women to cope with the impact of a breast cancer investigation and diagnosis and to become involved in addressing the barriers identified in the health care system.

The findings of this study confirm that social workers need to be part of interdisciplinary teams of breast diagnostic clinics supporting a feminist model of care aimed at achieving symmetry in provider-patient relationship. Social workers can assist diagnostic clinics to determine the type of distress screening tools that can be utilized to assist young women in identifying their psychosocial concerns pre and post diagnosis. They can assist with the development of clinical pathways for referrals to social workers and other professionals based on what is identified on the screening tool(s). They can play a role in developing the educational lay materials that will help young women navigate a breast cancer investigation and diagnosis. Social workers working in oncology have the professional values, training and expertise to provide the therapeutic interventions younger women may require to cope with a breast cancer investigation and diagnosis. The goal is not to psychopathologize the experience but to ensure the appropriate supports systems are in place for young women to move forward feeling empowered and in control of their situation.

Although the research question did not address the role of social work and policy, the findings of this study underscore the need for social work praxis to improve the health and psychosocial wellbeing of younger women diagnosed with breast cancer. Social workers can play a key role in developing knowledge translation strategies to educate policy makers about the impact of missed and delayed diagnoses in younger women who

present with breast abnormalities. They can also increase primary care physicians' awareness of the distress experienced by young women who present with breast problems and the importance of timely referral. Part of the knowledge translation strategy is to disseminate findings about the psychosocial impact a breast cancer investigation and diagnosis has on younger women and the psychosocial ramifications of prolonged wait times. Social workers can start articulating a strategy to address the financial gaps that exist in our social safety net to support people diagnosed with cancer. Finally, social workers should be initiating or/and aligning themselves with a movement to create a primary and secondary prevention strategy for younger women's breast health in Canada.

8.6 Limitations of the Study

One of the limitations of this study was the inability to recruit a larger number of participants; this was a potential known challenge prior to pursuing the project. The previous number of breast cancer cases affecting younger women referred to the breast assessment clinic was higher in previous years; the cases were lower for the year the study was conducted. The impact of this limitation was manifested in the inability to fully explore some issues that are usually identified as sources of distress for younger women diagnosed with breast cancer such as fertility. It is interesting to note that none of the young women discussed concerns about fertility prior to their breast biopsy and the issue of fertility was not an issue identified by the five young women diagnosed with breast cancer who all had children. The smaller number of participants also meant that we could not draw any conclusions about socio-cultural factors related to a breast cancer investigation.

The lag time to recruit participants into the study impacted the timeline for scheduling the two focus groups. There was concern that the women would lose interest in the study because too many months had lapsed from the time of the second interview to conducting the focus group. Hence two women not diagnosed with breast cancer were recruited after the focus group was held. There was also a four month delay in scheduling the focus group because of unforeseen circumstances. Despite these setbacks, the focus groups were extremely useful for facilitating young women to come together as a collective and share through conversation their experiences and thoughts about a breast cancer diagnosis.

8.7 Clinical, Policy and Research Recommendations

Principles of Feminist Participatory Action Research were applied to this study using the model of Reid (2004) who explains that action in such projects can be at the individual or collective unit. The actions for change in this study were more at the individual level. Many women made a commitment to become more breast health aware, share their stories with other women to encourage early detection of breast cancer and become more proactive in taking care of their own health. The process of going through a breast cancer investigation caused young women to re-evaluate life with a commitment to better self-care. Health care professionals should use this opportunity to promote healthy lifestyles and direct women to the necessary community resources to help them achieve their goals (e.g. quit smoking). Policy needs to be developed in Canada to articulate a primary and secondary breast cancer prevention strategy targeting younger women so there can be consistent messaging about breast health practices. This will require further research and collaboration at different levels of government.

The ability to bring the collective of women together to initiate action at the structural level based on the findings of the study was not possible. Women were offered the opportunity to become involved but there was not a lot of interest expressed after the focus groups were held. I attempted twice to elicit participation from women who expressed interest in becoming more involved in the dissemination of results. One young woman diagnosed with breast cancer was asked if she wanted to co-present a poster on the study at a conference for young women diagnosed with breast cancer; she was grateful for the invitation however she declined explaining it was too early for her after her own diagnosis. One young woman was asked if she wanted to become a representative on a patient advisory council and she also declined indicating she was interested but she still needed more time to recover. One young woman offered to be contacted if she could assist other young women going through a breast cancer investigation process and diagnosis. The ability of young women to be involved in action oriented strategies for social change may vary pending their emotional and physical recovery.

As an insider/outsider researcher to this study, I am able to take the findings for the purpose of informing and improving the breast health of other women. Parallel to this study, I was fortunate to secure a large two year grant from the Canadian Breast Cancer Foundation-Ontario Chapter in collaboration with the Breast Action Coalition Sudbury, the Circle of Strength Sudbury Breast Cancer Support Group and other colleagues from the cancer centre to mount a large campaign to improve women's access to breast health and breast cancer information (Mayer, 2008). One of the initiatives was to launch a large public campaign that aired on television reaching over one million adults. We elicited the

input of women and men of all ages to provide feedback on the visuals of the campaign so that it would appeal to people of all ages. We also had direct input from other young women survivors of breast cancer from breast coalitions in the Northeast. The campaign was extremely successful from the feedback received in the evaluations. We used the visuals of the campaign to develop a breast health passport to be given to women accessing the breast diagnostic clinic. Once I heard the young women in this study speak to the lack of information in primary care physicians' offices on matters of breast health and breast diagnostics, the initiative was changed to include a massive mail out to primary care physicians. Over 14,000 passports were mailed to primary care physicians' offices explaining the rationale for the passport, and its usefulness for women of all ages. We also incorporated other promotional materials so women could access the revised website www.breastnorth.info. Again this initiative was extremely successful with primary care physicians' offices calling for more supplies. A similar mail out is planned for October 2013.

A presentation by a representative from Wellspring was also organized. The presenter provided information on how to access financial resources; this person also reviewed the advocacy initiatives that are in place to improve the financial safety net for people diagnosed with cancer. The audience included over 30 social workers across the Northeast working with people diagnosed with cancer.

I was also fortunate to secure three years of funding to implement Screening for Distress, the 6th Vital Sign, at 14 Community Oncology Clinic Network sites where people across Northeastern Ontario receive chemotherapy closer to home (Mayer & Damore-Petingola, 2011). The knowledge gained from this initiative will be applied in

implementing screening for distress in the breast assessment clinic and to improve access to psychosocial care. The findings from the study have been presented to staff in the breast diagnostic clinic as a means to improve communication between health care professionals and women of all ages as they go through the program. My commitment to improving younger women's experience with a breast cancer diagnosis is firm and the findings from this study will continue to shape how we approach distress at this stage of the cancer journey. The dissemination of results will raise awareness to the political platform necessary for how we approach younger women's breast health through public policy.

Finally, some findings in this study call for further research: (1) the young women who participated in this study reported distress about health care decision making and later questioned if they had made the correct choice for their treatment leaving them with lingering doubts and possibly regret. This finding requires further research to understand the role of health care professional – patient communication in decision making about treatment choices and the role of psychosocial support in the decision making process to reduce distress. (2) Young women reported distress over media coverage of 'Pink Ribbon' campaigns that for them served as a constant reminder about the possibility of being diagnosed with breast cancer. This finding requires further research to explore how the content of breast cancer media campaigns can impact young women positively or negatively.

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Appendix A – Edmonton Symptom Assessment System Scale (ESAS) and the Canadian Problem Checklist

Date of Completion: _____ Time: _____

Hospital Location: Name of Community

Patient Missed ☐

Patient Refused to Complete ☐

Completed by:

- ☐ Patient
☐ Family
☐ Health Professional
☐ Assisted by family or

Edmonton Symptom Assessment System (ESAS):

Please circle the number that best describes:

No pain	0	1	2	3	4	5	6	7	8	9	10	Worst possible pain
Not tired	0	1	2	3	4	5	6	7	8	9	10	Worst possible tiredness
Not nauseated	0	1	2	3	4	5	6	7	8	9	10	Worst possible nausea
Not depressed	0	1	2	3	4	5	6	7	8	9	10	Worst possible depression
Not anxious	0	1	2	3	4	5	6	7	8	9	10	Worst possible anxiety
Not drowsy	0	1	2	3	4	5	6	7	8	9	10	Worst possible drowsiness
Best appetite	0	1	2	3	4	5	6	7	8	9	10	Worst possible appetite
Best feeling of wellbeing	0	1	2	3	4	5	6	7	8	9	10	Worst possible feeling of wellbeing
No shortness of breath	0	1	2	3	4	5	6	7	8	9	10	Worst possible shortness of breath
Other problem	0	1	2	3	4	5	6	7	8	9	10	

Canadian Problem Checklist:

Please check all of the following items that have been a concern or problem for you in the past week including today:

Emotional:

☐ Fears/Worries

☐ Sadness

☐ Frustration/Anger

☐ Changes in appearance

☐ Intimacy/Sexuality

Practical:

☐ Work/School

☐ Finances

☐ Getting to and from appointments

☐ Accommodation

☐ Legal

☐ Childcare

Informational:

☐ Understanding my illness and/or treatment

☐ Talking with the health care team

☐ Making treatment decisions

☐ Knowing about available resources

☐ Awareness of traditional healing practices

Spiritual:

☐ Meaning/Purpose of life

☐ Faith

Social/Family:

☐ Feeling a burden to others

☐ Worry about family/friends

☐ Feeling alone

Physical:

☐ Concentration/Memory

☐ Sleep

☐ Weight

Other: _____

Adapted from CPAC-Implementing Screening for Distress, the 6th Vital Sign, 2009

Appendix B – Consent Form (English and French)



Regional Cancer Program

Programme régional de cancérologie

a Cancer Care Ontario partner
Un partenaire d'Action Cancer Ontario

CONSENT FORM

Study Title: Younger Women's Experiences with Distress at Time of Breast Biopsy and Diagnosis

Researcher: Carole Mayer, M.S.W., R.S.W., PhD. Candidate
Supportive Care Program, Regional Cancer Program,
Hôpital régional de Sudbury Regional Hospital

The purpose of this study is to have a better understanding of the experiences of women who have a breast problem that needs to be investigated and diagnosed. Women who have a breast problem, who are under the age of 50, and who are pre-menopausal and require a breast biopsy are being asked to participate in this study. The results will provide information that can inform health care professionals about the type of care and support younger women need during the investigation and diagnosis of a breast problem. I understand that this study is also be part of Carole Mayer's dissertation for her PhD. in Social Work, through Memorial University of Newfoundland.

I know that my participation in this study is strictly voluntary. I will be contacted to do one interview before and one interview two weeks after my breast biopsy. I understand that the interviews will take approximately 1 to 1 ½ hours and they will be tape recorded and transcribed by a professional who has signed an oath of confidentiality. I will have the option of choosing where I want the interview to take place; in my home or at the hospital. I also have the option of doing the interview in English or French.

I will also be invited to participate in a group interview, often called a focus group, at least three months after my second interview; one group for women who have been diagnosed with breast cancer and the other group for women who have not been diagnosed with breast cancer. That group interview will take approximately 2 hours and it will also be tape recorded and transcribed. I understand the audio tapes of all interviews will be stored in a protected office in the Regional Cancer Program and destroyed after seven years.

During the course of the study I will be given a journal to record my thoughts and feelings that I may choose to share with the researcher. My role in this study is to answer questions based on my experiences and personal knowledge.

I understand that this type of research, called participatory action research, is different in the sense that I may choose to join the researcher and other participants in the study, to become more involved in other aspects of the study if I wish to do so, but I understand that I don't need to. I have the right to withdraw from the study at any time, without penalty or affecting my care in anyway.

I understand that the researcher, Carole Mayer, will review my health record to collect information about my breast problem, the type of tests and treatments that are being recommended by my health care team.

I may find it upsetting to talk about some aspects of my experience with this investigation and diagnosis. I understand that I can refuse to answer any questions and /or ask the researcher to take a break or stop the interview at any time. I have been given a pamphlet outlining the services provided by the Supportive Care Program at the Regional Cancer Program of the Hôpital régional de Sudbury Regional Hospital and understand that I may contact their services if I experience any distress related to this study.

I understand that all reasonable measures will be taken by the researcher to protect my privacy. All the information learned about me will be kept strictly confidential. Neither my name nor any other information will be used that could identify me. I understand that the data and findings of the study will be published and /or presented at meetings of health care providers who are interested in this type of study.

I also understand that the researcher may not be able to protect my privacy if I participate with other women in the focus group or if I decide to share with others my role in the research.

Optional:

If you agree with this statement please circle yes, if you don't agree please circle no:

I also give permission to the researcher to show parts of my interview transcripts to other researchers and students for the sole purpose of teaching them how to analyze data collected from interviews. Part of the audio tapes may also be used for these purposes. I have been assured that no personal identifiers will be kept in the transcripts or audio tapes for these teaching purposes.

I agree-Yes I don't agree-No

My Rights as a Research Participant

The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University of Newfoundland. If I have ethical concerns about the research (such as the way I have been treated or my rights as a participant), I may contact the Chairperson of ICEHR at icehr@mun.ca or by telephone at

709-737-8368. I may also contact Carole Mayer's Supervisor, Dr. Ross Klein at 709-737-8147.

Please note that because you are a patient at the Hôpital régional de Sudbury Regional Hospital, Sudbury Regional Breast Health Program, you also have the option to speak to someone local. If you wish to speak to a neutral individual who is not involved in the study at all and who will answer any questions about your rights as a research participant or about ethical issues related to this study, you may contact the following hospital based person, "the Senior Manager Responsible for Research in the Administration" located at the Hôpital régional de Sudbury Regional Hospital, 41 Ramsey Lake Road, Sudbury Ontario P3E 5J1 (Telephone: 705-523-7113).

I have been provided with an information form about this study. I am satisfied that all my questions have been answered about the study. I agree to participate in this study and I have received a copy of this consent form.

Signed: _____

Date: _____

Witnessed: _____

Date: _____



Regional Cancer Program

Programme régional de cancérologie

a Cancer Care Ontario partner
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FORMULAIRE DE CONSENTEMENT

Titre de l'étude : L'expérience des jeunes femmes avec la détresse au moment de la biopsie du sein et du diagnostic

Chercheuse : Carole Mayer, M.Serv.soc., TSI, candidate au doctorat
Programme des soins de soutien, Programme régional de cancérologie, Hôpital régional de Sudbury Regional Hospital

Cette étude a pour but de mieux comprendre les expériences des femmes ayant un problème au sein qui doit être examiné et diagnostiqué. Pour participer à cette étude, ces femmes doivent être âgées de moins de 50 ans, ne pas être ménopausées et être obligées d'avoir une biopsie du sein. Les résultats fourniront des renseignements qui éclaireront les professionnels de la santé sur le type de soins et de soutien dont les jeunes femmes ont besoin pendant les examens et le diagnostic d'un problème au sein. Je comprends que cette étude fait aussi partie des travaux de thèse de doctorat en service social que Carole Mayer prépare à la Memorial University à Terre-Neuve.

Je sais que ma participation à cette étude est strictement volontaire. On communiquera avec moi pour fixer un entretien avant la biopsie du sein et un autre deux semaines après. Je comprends que les entretiens dureront d'une heure à une heure et demie, qu'ils seront enregistrés et transcrits par une professionnelle qui a signé un serment de confidentialité. Je pourrai choisir si l'entretien se déroulera chez moi ou à l'hôpital et en français ou en anglais.

Je serai aussi invitée à participer à un entretien collectif, souvent appelé « groupe de discussion », au moins trois mois après mon deuxième entretien. Il aura lieu avec d'autres femmes qui soit ont eu un diagnostic bénin ou un diagnostic du cancer du sein. Cet entretien collectif durera environ deux heures et sera aussi enregistré et transcrit. Je comprends que les bandes audio de tous les entretiens seront entreposées pendant sept ans dans un bureau sécurisé du Programme régional de cancérologie puis seront détruites à la fin de cette période.

Pendant l'étude, je devrai consigner dans un journal les pensées et les sentiments que je désire partager avec la chercheuse. Dans cette étude, mon rôle consistera à répondre à des questions en me basant sur mes expériences et mes connaissances personnelles.

Je comprends que ce type d'étude, appelée « recherche-action participative », est différent des autres en ce sens que je peux me joindre à la chercheuse et à d'autres sujets de recherche pour participer à d'autres aspects de l'étude si je le désire, mais je sais que je

n'y suis nullement obligée. J'ai le droit de me retirer de l'étude n'importe quand sans risquer de pénalité et sans conséquence pour mes soins.

Je comprends que la chercheuse, Carole Mayer, examinera mon dossier médical afin de recueillir des renseignements sur mon problème ainsi que sur les types d'examens et de traitements recommandés par mon équipe de soins.

Je peux trouver bouleversant de parler de certains aspects de mon expérience concernant les examens et le diagnostic. Je comprends que je peux refuser de répondre à des questions, demander à la chercheuse de faire une pause ou d'arrêter l'entretien n'importe quand. On m'a remis un dépliant indiquant les services fournis par le Programme des soins de soutien du Programme régional de cancérologie de l'Hôpital régional de Sudbury Regional Hospital et je comprends que je peux y recourir si cette étude me bouleverse.

Je comprends que la chercheuse prendra toutes les mesures raisonnables pour protéger mes renseignements personnels. Tous les renseignements me concernant demeureront strictement confidentiels. Ni mon nom ni d'autres renseignements identificatoires ne seront utilisés. Je comprends que les données et les résultats de l'étude seront publiés et/ou présentés à des réunions de fournisseurs de soins qui s'intéressent à ce type d'étude.

Je comprends aussi que la chercheuse ne pourra peut-être pas protéger mes renseignements personnels si je participe au groupe de discussion avec d'autres femmes ou si je décide d'indiquer à d'autres personnes le rôle que je joue dans cette étude.

Facultatif

Veuillez encercler « Oui » si vous acceptez la déclaration ci-dessous, et « Non » si vous ne l'acceptez pas.

J'autorise aussi la chercheuse à montrer des parties des transcriptions de mes entretiens à d'autres chercheurs et à des étudiants dans le seul but de leur enseigner comment analyser des données recueillies lors d'entretiens. Des parties des enregistrements audio peuvent aussi être utilisées dans ce but. On m'a assurée qu'aucun élément identificatoire ne figurera dans les transcriptions et les bandes audio utilisées pour l'enseignement.

J'accepte – Oui

Je n'accepte pas – Non

Mes droits comme participante à cette recherche

Le comité interdisciplinaire de l'éthique de la recherche sur des sujets humains de la Memorial University de Terre-Neuve a approuvé la proposition de cette étude. Si j'ai des préoccupations d'ordre éthique au sujet de l'étude (comme la façon dont j'ai été traitée ou mes droits en tant que participante à l'étude), je peux communiquer avec le président du comité par courrier électronique, à icehr@mun.ca ou par téléphone, au 709 737-8368. Je peux aussi communiquer avec le superviseur de Carole Mayer, le professeur Ross Klein, au 709 737-8147.

Étant donné que vous êtes une patiente du Programme régional de santé du sein de Sudbury de l'Hôpital régional de Sudbury Regional Hospital, vous pouvez parler à quelqu'un de la localité. Si vous souhaitez parler à une personne neutre qui n'est pas associée à cette étude et qui pourra répondre à vos questions relativement à vos droits à titre de participante à une étude de recherche ou à des questions d'ordre éthique liées à cette étude, vous pouvez communiquer avec la personne-ressource suivante à l'hôpital, le gestionnaire principal responsable de la recherche, Administration, au 705 523-7113 [à l'Hôpital régional de Sudbury Regional Hospital, 41, chemin du lac Ramsey, Sudbury (Ontario) P3E 5J1].

J'ai reçu une feuille de renseignements sur cette étude. J'ai obtenu une réponse satisfaisante à toutes mes questions au sujet de l'étude. J'accepte de participer à cette étude et j'ai reçu une copie de ce formulaire de consentement.

Signature : _____

Date :

Témoin : _____

Date : ____



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**Information Sheet for the Study:
Younger Women's Experiences with Distress
at Time of Breast Biopsy and Diagnosis**

My Name is Carole Mayer, and I am a researcher who works in the Supportive Care Oncology Research Unit, Regional Cancer Program of the Hôpital régional de Sudbury Regional Hospital. I am currently doing my PhD. in Social Work at Memorial University in Newfoundland. The study you are being asked to participate in is part of my dissertation for completing my PhD.

My interest is to learn more about the experiences of younger women who require tests to diagnose a breast problem. The women being asked to participate in the study are under the age of 50, are pre-menopausal and require a breast biopsy for their breast problem. The results of the study will be useful for health care professionals who work with younger women who have breast problems, to understand the experience and how services should be organized to meet their needs.

I am asking you to meet with me for one interview before and one interview after your biopsy. I will also invite you to participate in a group interview 3 months or more after the second interview; one group for women who have been diagnosed with breast cancer and the other group for women who have not been diagnosed with breast cancer. You will also have the choice to participate in other aspects of the study. This type of study is referred to as participatory action research. It is different from traditional research because you as a participant can become a co-researcher. For instance, I will ask you for your opinion about the results I have found after my interviews with you to make sure my interpretations are correct. You may wish to make a recommendation on the types of questions I should be asking other participants. You may be interested in joining me and other participants to present or/and publish results. What is important for you to know is that you don't need to become more involved but that option is available to you if you are interested. You have the right to withdraw from the study at any time, without penalty or affecting your care in anyway.

You should also know that I am being supervised for this research. I am also working with an advisory committee made up of health care professionals and women who have undergone a breast investigation to ensure that the processes I am following for the study are appropriate. I have also conducted this type of research in the past and I have experience in conducting research interviews.

Please read the consent form very carefully before agreeing to participate in the study. If you have any further questions do not hesitate to contact me at 705-522-6237 ext. 2700.

My Rights as a Research Participant

The proposal for this research has been approved by the Interdisciplinary Committee on Ethics in Human Research at Memorial University of Newfoundland. If I have ethical concerns about the research (such as the way I have been treated or my rights as a participant), I may contact the Chairperson of ICEHR at icehr@mun.ca or by telephone at 709-737-8368. I may also contact Carole Mayer's Supervisor, Dr. Ross Klein at 709-737-8147.

Please note that because you are a patient at the Hôpital régional de Sudbury Regional Hospital, Sudbury Regional Breast Health Program, you also have the option to speak to someone local. If you wish to speak to a neutral individual who is not involved in the study at all and who will answer any questions about your rights as a research participant or about ethical issues related to this study, you may contact the following hospital based person, "the Senior Manager Responsible for Research in the Administration" located at the Hôpital régional de Sudbury Regional Hospital, 41 Ramsey Lake Road, Sudbury Ontario P3E 5J1 (Telephone: 705-523-7113).



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**Feuille de renseignements sur l'étude :
L'expérience des jeunes femmes avec la détresse au moment
de la biopsie du sein et du diagnostic**

Je m'appelle Carole Mayer. Je suis chercheuse à l'Unité de recherche en soins de soutien oncologiques du Programme régional de cancérologie à l'Hôpital régional de Sudbury Regional Hospital. Je prépare actuellement mon doctorat en service social à la Memorial University à Terre-Neuve. L'étude à laquelle je vous demande de participer fait partie de mes travaux de thèse de doctorat.

Je désire me renseigner sur l'expérience des jeunes femmes qui doivent subir des examens afin de diagnostiquer un problème au sein. Les femmes sollicitées sont âgées de moins de 50 ans, ne sont pas ménopausées et doivent subir une biopsie du sein. Les résultats de l'étude seront utiles aux professionnels de la santé qui travaillent avec de jeunes femmes ayant des problèmes au sein pour comprendre leur expérience et comment les services pourraient être organisés afin de répondre à leurs besoins.

Je vous demande de me rencontrer une fois avant la biopsie et une autre fois après puis de participer à un entretien collectif trois mois ou plus après le deuxième entretien. L'entretien collectif aura lieu avec d'autres femmes soit qui ont eu un diagnostic bénin ou un diagnostic du cancer du sein. Vous aurez aussi la possibilité de participer à d'autres aspects de l'étude. Ce type d'étude s'appelle « recherche-action participative ». La différence entre cette étude et les études traditionnelles est que les participants peuvent devenir des collaborateurs. Par exemple, je vous demanderai votre avis sur les conclusions que je tirerai de mon entretien avec vous afin de vérifier que mes interprétations sont correctes. Vous voudrez peut-être recommander des types de questions à poser à d'autres participantes. Vous serez peut-être intéressée à vous joindre à moi et à d'autres participantes pour présenter et/ou publier les résultats. Il est important que vous compreniez que vous n'êtes pas obligée de participer à tous ces aspects mais que l'option vous est offerte si vous le désirez. Vous avez le droit de vous retirer de cette étude n'importe quand sans risquer de pénalité et sans aucune conséquence pour vos soins.

Vous devriez aussi savoir que j'effectue cette étude sous supervision. Afin d'avoir l'assurance que le processus suivi dans cette étude est approprié, je travaille aussi avec un comité consultatif constitué de professionnels de la santé et de femmes qui ont subi des examens des seins. De plus, j'ai déjà effectué ce type d'étude par le passé et j'ai de l'expérience dans la conduite d'entretiens connexes.

Veillez lire très soigneusement le formulaire de consentement avant d'accepter de participer à l'étude. Si vous avez d'autres questions, n'hésitez pas à communiquer avec moi au 705 522-6237, poste 2700.

Mes droits comme participante à cette recherche

Le comité interdisciplinaire de l'éthique de la recherche sur des sujets humains de la Memorial University de Terre-Neuve a approuvé la proposition de cette étude. Si j'ai des préoccupations d'ordre éthique au sujet de l'étude (comme la façon dont j'ai été traitée ou mes droits en tant que participante à l'étude), je peux communiquer avec le président du comité par courrier électronique, à icehr@mun.ca ou par téléphone, au 709 737-8368. Je peux aussi communiquer avec le superviseur de Carole Mayer, le professeur Ross Klein, au 709 737-8147.

Étant donné que vous êtes une patiente du Programme régional de santé du sein de Sudbury de l'Hôpital régional de Sudbury Regional Hospital, vous pouvez parler à quelqu'un de la localité. Si vous souhaitez parler à une personne neutre qui n'est pas associée à cette étude et qui pourra répondre à vos questions relativement à vos droits à titre de participante à une étude de recherche ou à des questions d'ordre éthique liées à cette étude, vous pouvez communiquer avec la personne-ressource suivante à l'hôpital, le gestionnaire principal responsable de la recherche, Administration, au 705 523-7113 [à l'Hôpital régional de Sudbury Regional Hospital, 41, chemin du lac Ramsey, Sudbury (Ontario) P3E 5J1].

Appendix C – Consent to Release Name



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Consent Form to Release Name

It is my understanding that there is a research study looking at the experience of younger women who require a breast biopsy and diagnosis for a breast problem. In signing this consent form, I give permission to the Health Care Team to forward my name to the researcher, Carole Mayer who will explain the study before I decide if I want to participate in the study.

Signature of Patient/Legal Guardian

Date(day/month/year)

Signature of Witness

Date(day/month/year)



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Formulaire de consentement à la divulgation du nom

Je comprends qu'il existe une étude portant sur l'expérience de jeunes femmes qui doivent subir une biopsie du sein et avoir un diagnostic. En signant ce formulaire de consentement, j'autorise l'équipe de soins à transmettre mon nom à la chercheuse, Carole Mayer, qui m'expliquera l'étude avant que je prenne une décision sur ma participation.

Signature – patiente/tuteur légal

Date (jour-mois-année)

Signature – témoin

Date (jour-mois-année)

Appendix D – Interview Guides



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Interview Guide

-Introduction

-Consent Obtain

-Give guidelines for how interview will be conducted (e.g. interview will be tape recorded, may ask to stop interview at any time, may ask to repeat question, may refuse to answer question etc.)

-Complete part of demographic questionnaire with participant

Prompt Questions:

Physical:

- Can you tell me when you learned you had a breast problem?
- Have you experienced a breast problem in the past? What happened?
- What tests have you received for the current problem?
- What has been your experience with these tests?
- What is your understanding of the problem?
- What are the next steps?
- Is there anything you wish could have been done differently so far?

Information:

- Do you think you have a good understanding of your breast problem and what needs to happen next?
- Have you received enough information? From whom?
- Is the information appropriate for your age?
- What resources (pamphlets, booklets etc.) have you received? What is your preference?
- How helpful were they?
- Were they in your language of preference?
- Do you surf the web, or go on the internet to get information about your breast problem? If no, do you plan to?

Emotional/Psychological:

- How much time have you spent thinking about this breast problem?

- Can you describe for me what is on your mind at this time? What are you feeling? What are you most worried about?
- Have you worried about breast health issues in the past?
- What things have you done that help to make you feel better about your situation? What is least helpful?

Social:

- Can you tell me more about yourself and your family?
- Who knows that you have a breast problem?
 - Family?
 - Co-workers?
 - Friends?
- What support have you received?
- What have you found most helpful?
- Can you tell me who the members of your health care team are?
- How would you describe your relationship with your health care team?
- What have you shared with them about how you are feeling?
- How easy is it for you to share with them what you are experiencing?
- Do you feel that your emotional needs have been met? If something could be changed in your relationship with them, what would it be?

Spiritual:

- Do you consider yourself to be a spiritual person?
- Has your spirituality helped you cope with this breast problem?
- If yes, how?

Practical:

- Have you needed to make special arrangements to attend medical appointments for childcare? For work?
- How have you managed? What resources are available to you?
- Have you needed to incur expenses because of these appointments? Have these expenses placed a burden on your budget?

If you could summarize, what has been the most difficult for you at this time? What has been more helpful?

Eliciting information not pre-defined.

- Is there anything that we have not talked about that you would like to share with me? Is there anything else you would like to add?
- I'm going to be asking these questions to other women in a similar situation, would you change any questions?
- Add any questions?

Is there anything you want to add prior to finishing our interview?



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Guide d'entretien

-Introduction

-Obtenir le consentement

-Indiquer comment l'entretien se déroulera (p. ex., l'entretien sera enregistré; la personne peut mettre fin à l'entretien en tout temps, demander qu'on lui répète la question, refuser de répondre à des questions, etc.)

-Remplir la section sur la démographie avec la participante

Questions

Aspect physique

- Quand avez-vous appris que vous aviez un problème au sein?
- Avez-vous déjà eu un problème au sein auparavant? Que s'est-il passé?
- Quels examens avez-vous subis pour le problème actuel?
- Quelle a été votre expérience avec ces examens?
- Que savez-vous de ce problème?
- Quelles sont les prochaines étapes?
- Est-ce que quelque chose aurait dû être fait différemment jusqu'à présent?

Information

- Croyez-vous bien comprendre le problème et ce qui doit se passer ensuite?
- Avez-vous reçu assez d'informations? De qui?
- Ces informations sont-elles appropriées pour votre âge?
- Quelle documentation (dépliants, livrets, etc.) avez-vous reçue? Que préférez-vous?
- Cette documentation était-elle utile?
- La documentation était-elle disponible dans votre langue de préférence?
- Consultez-vous Internet pour obtenir des renseignements sur votre problème au sein? Sinon, envisagez-vous de le faire?

Aspect émotionnel et psychologique

- Pendant combien de temps ce problème vous a-t-il préoccupée?
- Pouvez-vous me dire à quoi vous pensez dans ces moments-là? Que ressentez-vous? Qu'est-ce qui vous inquiète le plus?
- Avez-vous eu peur d'avoir des problèmes de santé au sein par le passé?
- Quelles mesures avez-vous prises pour vous rassurer? Qu'est-ce qui a été le moins utile?

Aspect social

- Pouvez-vous me parler de vous et de votre famille?
- Qui sait que vous avez un problème au sein?
 - Famille?
 - Collègues de travail?
 - Amis/Amies?
- Quel soutien avez-vous reçu?
- Qu'est-ce qui a été le plus utile?
- Qui sont les membres de votre équipe de soins?
- Comment décririez-vous votre relation avec votre équipe de soins?
- Lui avez-vous fait part de vos sentiments?
- Vous est-il facile de lui parler de ce que vous ressentez?
- Estimez-vous avoir obtenu le soutien émotionnel dont vous avez besoin? Si vous pouviez changer quelque chose dans votre relation avec l'équipe, que changeriez-vous?

Aspect spirituel

- Vous considérez-vous comme une personne spirituelle?
- Votre spiritualité vous a-t-elle aidée à faire face à ce problème de sein?
- Si oui, comment?

Aspect pratique

- A-t-il été nécessaire de faire des arrangements spéciaux pour aller à des rendez-vous médicaux (p. ex., faire garder les enfants, pour le travail)?
- Comment vous êtes-vous arrangée? Sur quelles ressources pouvez-vous compter?
- Avez-vous eu des dépenses liées à ces rendez-vous? Ont-elles été lourdes pour votre budget?

Si vous pouviez résumer la situation, qu'est-ce qui a été le plus difficile pour vous?
Qu'est-ce qui vous a le plus aidée?

Invitation à fournir des renseignements non définis à l'avance

- Y a-t-il des points que nous n'avons pas abordés et dont vous aimeriez me parler? Désirez-vous ajouter autre chose?
- Je poserai ces questions à d'autres femmes qui sont dans une situation semblable à la vôtre, changeriez-vous certaines questions?
- Ajouteriez-vous des questions?

Voulez-vous ajouter autre chose avant de terminer notre entretien?



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Interview Number 2 Guide

-Introduction

-Inquire if they brought their journal

Prompt Questions:

-Physical:

- What was your experience with the breast biopsy?
- What were the results?
- How has your recovery been? Is it what you expected?
- What are the next steps?
- Do you feel comfortable with the next steps?
- Is there anything you wish could have been done differently so far?
- Will this experience have changed how you care about your health (physical, emotional etc) Will it have changed how you care about your breast health?

Information:

- Looking back, do you feel you were well prepared for your breast biopsy?
- Had you received enough information?
- (If applicable) You had done some research on your own, was the information you found helpful?

Emotional/Psychological:

- Are you still worried about this breast problem? or
- Now that you have been diagnosed with breast cancer....
- Can you describe for me what is on your mind at this time? What are you feeling?
- Are there any concerns with body image; sexuality?
- What things have you done that were helpful to cope with this situation? What was the least helpful?
- Would you consider seeking professional help?

Social:

- What support have you received?
- What have you found most helpful?
- How would you describe your relationship with your health care team now?
- What have you shared with them about how you are feeling?
- How easy is it for you to share with them what you are experiencing?

- Do you feel that your emotional needs have been met? If something could be changed in your relationship with them, what would it be?

Spiritual:

- Since we last spoke, has spirituality been part of your experience with breast biopsy?

Practical:

- Have you needed to make special arrangements at home?
- How have you managed? What resources are available to you?
- Have you needed to incur expenses? Have these expenses placed a burden on your budget?

If you could summarize, what has been the most difficult for you throughout this experience so far? What has been the most helpful?

From a systems perspective, is there anything you think needs to change?

Eliciting information not pre-defined.

- Is there anything that we have not talked about that you would like to share with me? Is there anything else you would like to add?
- I'm going to be asking these questions to other women in a similar situation, would you change any questions?
- Add any questions?

Is there anything you want to add prior to finishing our interview?

Review summary of data analysis so far

Review focus group, any questions she feels could be asked for the group?



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Guide : entrevue n° 2

-Introduction

-Demander aux patientes si elles ont apporté leur journal personnel.

Questions d'amorce

Aspects physiques:

- Qu'avez-vous vécu concernant la biopsie mammaire?
- Quels ont été les résultats?
- Comment votre rétablissement s'est-il passé? Est-ce à quoi vous vous attendiez?
- Quelles sont les prochaines étapes?
- Êtes-vous à l'aise en pensant aux prochaines étapes?
- Jusqu'à maintenant, auriez-vous aimé que certaines choses soient faites différemment?
- Cette expérience a-t-elle modifié votre façon de prendre soin de votre santé (physique, émotionnelle, etc.)? Changera-t-elle votre façon de prendre soin de vos seins?

Information:

- En rétrospective, croyez-vous que vous étiez bien préparée pour subir une biopsie mammaire?
- Avez-vous obtenu assez d'information?
- (le cas échéant) - Si vous avez fait des recherches, les renseignements que vous avez trouvés ont-ils été utiles?

Aspects émotionnels et psychologiques :

- Ce trouble au sein vous préoccupe-t-il toujours? ou
- Maintenant que vous avez reçu un diagnostic de cancer du sein...
- Pouvez-vous expliquer ce à quoi vous pensez en ce moment? Que ressentez-vous?
- Avez-vous des préoccupations concernant votre image corporelle ou sexualité?
- Qu'avez-vous fait d'utile pour faire face à la situation? Qu'est-ce qui a été le moins utile?
- Seriez-vous prête à obtenir de l'aide professionnelle?

Aspects sociaux:

- Quel soutien avez-vous reçu?
- Qu'avez-vous trouvé le plus utile?

- Comment décririez-vous votre présente relation avec votre équipe de soins de santé?
- Qu'avez-vous partagé avec l'équipe au sujet de vos sentiments?
- Dans quelle mesure est-ce facile pour vous d'échanger avec l'équipe sur ce que vous vivez?
- Selon vous, vos besoins émotionnels ont-ils été comblés? Quels aspects changeriez-vous par rapport à votre relation avec l'équipe de soins de santé?

Aspects spirituels:

- Depuis notre dernière conversation, la spiritualité a-t-elle fait partie de votre expérience concernant la biopsie mammaire?

Aspects pratiques:

- Avez-vous eu besoin de prendre des dispositions particulières à la maison?
- Comment avez-vous affronté la situation? Quelles sont les ressources à votre disposition?
- Avez-vous dû engager des dépenses? Si oui, ont-elles été un fardeau pour vous?

En résumé, tout au long de cette expérience, jusqu'à maintenant, quels ont été les aspects les plus difficiles? Qu'est-ce qui vous a aidé le plus?

Du point de vue des systèmes, croyez-vous que quelque chose doit changer?

Obtention de renseignements non prédéfinis :

- Y a-t-il des aspects dont vous n'avez pas parlé et dont vous aimeriez me faire part? Aimeriez-vous ajouter autre chose?
- Je poserai ces questions à d'autres femmes vivant une situation semblable. Changeriez-vous des questions?
- Ajouteriez-vous des questions?

Voulez-vous ajouter quelque chose avant la fin de l'entrevue?

Passer en revue le résumé de l'analyse des données jusqu'à maintenant.

Passer en revue le groupe de discussion et toute question qu'on pourrait, selon elle, poser au nom du groupe.

Appendix E – Definitions of Breast Biopsies

Fine Needle Aspirate (FNA) is a test that can be used to determine if the lump is solid or cystic (Burnstein, Harris & Morrow, 2011, p. 1407). Using a syringe with a very thin needle the physician will place the needle into the breast lump to draw out fluid and/or breast cells. If fluid is aspirated and the lump disappears it is most likely a benign breast cyst (Olivotto, 2006). If the lump is solid, breast cells will be collected and sent for cytologic pathology results.

A Core Needle Biopsy (CNB) involves a hand held device often referred to as a biopsy gun (Almeida & Barry, 2010). The physician inserts the needle in the breast lesion and a core of tissue is removed; several specimens may be taken and are sent for histologic pathology results. The needle used for CNB has a larger diameter that removes more tissue but not an entire lump (Almeida & Barry, 2010, p. 177). A CNB allows evaluation of architectural and cellular characteristics and is more likely to provide a definitive diagnosis compared to FNA (Jardines et al., 2010, p. 163).

Stereotactic core biopsies are utilized for the management of non-palpable breast lesions (Jardines et al., 2010, p. 164). This test is often used to biopsy very small calcium deposits in the breast or other areas that cannot be done with an ultrasound (Fretwell & Lee, 2011). Using stereotaxis (advance imaging tools), tissue is acquired using automated core needles or directional vacuum-assisted biopsy probes. Tissue collected is sent for pathological examination (Jardines et al., 2010, p. 164).

Ultrasound guided core biopsy, also used for the management of non-palpable lesions, involves using a hand held device to insert a needle into the breast with the aid of an

ultrasound. A small core of tissue is then removed and examined pathologically (Jardines et al., 2010, p. 164).

A surgical biopsy involves removing part (incisional biopsy) or all (excisional biopsy) of the breast lump (Jardines et al., 2010, p. 163). When an excisional biopsy is done a small rim of the normal breast tissue is also removed with the lump (Olivotto, 2006). This procedure is done using a local or general anesthetic. The purpose of this procedure is to establish the histologic diagnosis of breast cancer (Harmer, 2011). Percutaneous procedures such as stereotactic core biopsies and ultrasound guided core biopsies are preferred over surgical biopsies as they are quicker, less expensive and less invasive (Jardines et al., 2010, p. 164).

Surgical biopsy-needle localization is used when the abnormal area is small and cannot be palpated and the location is marked with a fine wire by a radiologist (Harmer, 2011). It is done prior to surgery with the aid of an x-ray or ultrasound imaging. The radiologist will freeze the area and then a needle is inserted. The position of the needle is confirmed on x-rays. When the needle is in the right location, a fine wire is passed through the middle of the needle. The needle is taken out and the wire is left in place until the woman's surgery. The lump or affected area is then removed by the surgeon including a rim of healthy breast tissue. An x-ray of the specimen is taken to confirm that the affected area has been removed by comparing it with the first x-ray (Harmer, 2011). If the results are negative for breast cancer, the woman may have a repeat mammogram in a few months to ensure the area of concern is no longer showing any tissue abnormality (Love & Lindsey, 2005). When a biopsy result reveals a cancer diagnosis the surgeon will make further recommendations for treatment.

Appendix F – Demographic Information Form



Regional Cancer Program

Programme régional de cancérologie

a Cancer Care Ontario partner
Un partenaire d'Action Cancer Ontario

Demographic/Medical Form

Younger Women's Experiences with Distress at Time of Breast Biopsy and Diagnosis
Demographic & Medical Information Form

Demographic Information (completed in first interview with participants):

Date data collected:

Name:

Address:

Phone Number:

Date of Birth:

Age:

Education:

- ☐ Elementary
- ☐ Some Secondary
- ☐ Completed Secondary
- ☐ College
- ☐ University

Relationship Status:

- ☐ Single
- ☐ Married
- ☐ Common law
- ☐ Divorced

Number of Children:

- ☐ Male
- ☐ Age(s)

Female:

Age(s)

First Language:

Second Language:

Cultural background:

Occupation:

Are you the main income earner? Yes No

Medical Information Confirmed in the Medical Record (some of these tests may not be applicable pending the breast problem identified)

Problem in right breast: Yes No

Problem in left breast: Yes No

Date when breast problem was confirmed by a health care physician:

Date of referral to surgeon:

Date of referral to first appointment:

Date of mammogram (s):

☐ Right breast

Radiology Result:

☐ Left breast:

Radiology Result:

Date of breast ultrasound (s):

☐ Right breast

Radiology Result:

☐ Left breast:

Radiology Result:

Date of fine needle aspirate

☐ Right breast

Pathology Result:

☐ Left breast:

Pathology Result:

Date of biopsy (hand held device)

☐ Right breast

Pathology Result:

☐ Left breast:

Pathology Result:

Date of needle localization (s):

☐ Right breast

Pathology Result:

☐ Left breast:

Pathology Result:

Date of ultrasound guided needle biopsy:

☐ Right breast

Pathology Result:

☐ Left breast:

Pathology Results:

Date of open biopsy:

☐ Right breast

Pathology Result:

☐ Left breast:

Pathology Result:

Date of lumpectomy (specify type):

☐ Right breast

Pathology Result:

☐ Left breast:

Pathology Result:

Date of mastectomy (specify type):

☐ Right breast

Pathology Result:

☐ Left breast:

Pathology Result:

Sentinel node biopsy:

☐ Right breast # of lymph nodes

Pathology Result:

☐ Left breast # of lymph nodes

Pathology Result:

Lymph node dissection:

☐ Right breast # lymph nodes:

Pathology Result:

☐ Left breast: # lymph nodes:

Pathology Result:

Diagnosis of breast cancer:

- Stage I
- Stage II
- Stage III
- Stage IV

Treatment recommendations:

- Chemotherapy and course of treatment (specify type):
 - Date started:
- Kind of hormonal therapy and course of treatment (specify type):
 - Date started:
- Kind of radiation therapy and course of treatment (specify type):
 - Date started:

Other medical health conditions:

Appendix G – Interview Guide for the Focus Groups

Younger Women's Experience with Distress at Time of Breast Biopsy and Diagnosis Non Breast Cancer Diagnosis

Introductions

- Remind women research consent still applies
 - Respecting confidentiality-group discussion
 - Limitations of confidentiality by revealing identity in focus group
 - Group will last approximately two hours
 - Purpose of group this evening, what we will do
 - Taping, transcript
 - No right or wrong answer
 - Participate as you feel comfortable
 - Where are washrooms located
 - Let women introduce themselves
1. What do you think are the issues younger women face while undergoing a breast cancer investigation compared to older women?
 2. Question arising from data analysis: do women have (psychological) difficulty examining the breast where the biopsy was performed?
 3. How comfortable were you being presented with choices and having to make decisions about the opting for a medical procedure vs. declining or opting between two different medical procedures?
 4. Review Systems issues and get feedback
 - a. These are the items that were identified as system issues at first interview with all the women and at second interview with the women who had a benign finding. If these issues could be resolved, what would it look like?
 - b. Is there anything missing?
 - c. What would be the most three important issues for you? (Provide stickers)
 5. When should women be screened to assess their emotional needs? What role should social workers/psychologists have to address these needs?
 6. Is there a role for volunteers who have been through a breast cancer investigation? Breast Cancer Survivor vs. Woman with a Benign Finding?
 7. Review draft summary of themes and get feedback
 8. Inquire regarding interest to participate in other parts of the study

Next steps and thank you for participating

Younger Women's Experience with Distress at Time of Breast Biopsy and Diagnosis Breast Cancer Diagnosis

Introductions

- Remind women research consent still applies
- Respecting confidentiality-group discussion
- Limitations of confidentiality by revealing identity in focus group
- Group will last approximately two hours
- Purpose of group this evening, what we will do
- Taping, transcript
- No right or wrong answer
- Participate as you feel comfortable
- Where are washrooms located
- Let women introduce themselves

1. What do you think are the issues younger women face while undergoing a breast cancer investigation compared to older women?
2. How comfortable were you being presented with choices and having to make decisions about the opting for a medical procedure vs. declining or opting between two different medical procedures?
3. Question arising from data analysis: do women have (psychological) difficulty with body image issues prior to biopsy with the anticipation of a potential breast cancer diagnosis and once treatment is confirmed? What are they?
 - Is Sexuality impacted?
4. Review Systems issues and get feedback;
 - a. These are the items that were identified as system issues at first interview with all the women and at second interview with the women who had a benign finding. Are there any issues missing?
 - b. If these issues could be resolved, what would it look like?
 - c. What would be the most three important issues for you? Place the order of importance to you
5. When should women be screened to assess their emotional needs? What role should social workers/psychologists have to address these needs?
6. Is there a role for volunteers who have been through a breast cancer investigation? Breast Cancer Survivor vs. Woman with a Benign Finding?
7. Review draft summary of themes and get feedback
8. Inquire regarding interest to participate in other parts of the study

Next steps and thank you for participating

