IDENTITY REFORMULATION AMONG YOUNG WOMEN WITH BREAST CANCER

by

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Abstract

The purpose of this study was threefold; to examine the unique challenges faced among young breast cancer survivors’ self-concepts; to explore the identity reformulation process as they adjust to a new lifestyle after completing medical treatment; and to identify women’s creative problem solving solution used to mitigate any long-term distress and discontinuity between past, current and ideal selves. In-person semi-structured interviews were conducted with 10 young breast cancer survivors (aged 32-45). The results indicated that exploring women’s narratives through the identity reformulation process created an alternative approach to the four prescribed quality of life domains used to understand survivors’ overall wellbeing. The results also identified three shared domains of social location (gender, youth and health status) that intersected in women’s identity reformulation process. These findings have implications for psychosocial oncology literature, as well as clinical practice for mental health practitioners. Limitations and recommendations for areas of future research were discussed.
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CHAPTER I

INTRODUCTION

Approximately one in nine Canadian women will be diagnosed with breast cancer at some period in their lifetime (Canadian Breast Cancer Foundation, 2010). However, with significant improvements in medical treatment, more women are surviving longer. Currently, eighty eight percent of women diagnosed with breast cancer are living at least five years after their initial diagnosis (Canadian Cancer Society’s Steering Committee, 2012). Due to these increasingly strong survival rates, quality of life (QOL) related issues among breast cancer survivors have become a primary focus among scholars, health professionals, as well as patients and their families. Particularly in the last two decades, the research community has become highly attuned to various concerns impacting breast cancer survivors’ QOL including pain management and late effects of treatment, psychological and emotional distress, future orientation and goal achievement, coping adequacy, re-entry into school or work, fertility issues, relationships and sexual functioning, and fears of uncertainty due to potential recurrence of disease. Although these studies have provided valuable information for survivors’, the majority of such studies have been quantitative, focused on an older, post-menopausal sample of women, and typically adhered to one of four pre-defined QOL domains to further understand women’s overall well-being after breast cancer (Howard-Anderson et al., 2012).

Despite public perception that young women are at little to no risk of breast cancer, the reality is that they are vulnerable. In fact, breast cancer is the most commonly diagnosed cancer among women aged 20 to 49 (Canadian Cancer Society’s Steering Committee, 2012). Thewes, Girgis, and Pendlebury, (2004) argued that younger breast cancer survivors struggle with many issues that older survivors do not face including: the possibility of early menopause, pregnancy
after diagnosis, more advanced cancer at diagnosis, and higher mortality rates. These factors also led to higher rates of depression as compared to older patients.

Indeed, researchers in the past have explored the experiences of young breast cancer survivors using one of four prescribed QOL domains (physical, psychological, spiritual, social); however, exploring young women’s narratives through the identity reformulation process creates an alternative approach to understand psychosocial well-being in young breast cancer survivors. Examining the identity reformulation process after medical treatment is vital to women’s long-term well-being and global functioning (Zebrack, 2000). Specifically, the identity reformulation process examines the extent to which women have integrated their cancer experience into their self-concept; this process may also result in women experiencing a new or renewed sense of self (Zebrack, 2000). In turn, changes in the way cancer survivors see themselves in relation to the world, including their ability to carry out roles and responsibilities affect their long-term QOL and overall well-being (Zebrack, 2000). This approach suggests that a cancer diagnosis may initiate a new life path as a cancer survivor, which extends over the remainder of their lifetime and ultimately impacts all prescribed QOL domains. Moreover, at a particular life stage when young women (ages 30-45) feel indestructible and see endless possibilities for themselves, breast cancer imposes an abrupt and severe limitation on this viewpoint (Siegel, Gluhoski, & Gorey, 1999). Therefore, although identity challenges are common among cancer survivors of all ages, they are likely to be even more pronounced with a younger population.

To date, no scientific knowledge is available that reflects the lived experiences and challenges faced by young women in relation to their self-concept after breast cancer treatment. The purpose of this study is threefold: (a) to examine the unique challenges faced by young breast cancer survivors in relation to their self-concept; (b) to explore the identity reformulation process
as they adjust to a new lifestyle after completed treatment for their cancer illness; and (c) to identify women’s creative problem solving solutions used to mitigate any long-term distress and discontinuity between their past and current sense of self.

A research study following an emergent qualitative design can help shed light on the complex experience of reformulating self-identity as a young woman who has completed treatment for breast cancer. It is expected that young survivors’ narratives will reflect different themes in relation to their QOL that have already been found in older samples (such as centrality of appearance to self-image, inability to have children, or concerns with career). It is also expected that the qualitative approach may lead to new emergent themes related to identity reformulation as well as related challenges and solutions among young women breast cancer survivors. This emergent knowledge is expected to resonate with, validate, and support other young cancer survivors. Thus, this knowledge may also guide the development of a quantitative survey focusing exclusively on the needs and challenges of younger breast cancer survivors regarding identity reformulation challenges that may affect their long term QOL. In terms of clinical implications, this research may provide health care professionals, future survivors and their families with information that could be applied towards enhanced psychosocial adjustment and well-being of young breast cancer survivors. Further, this research may help expand existing specialized support services among a younger population of long-term breast cancer survivors.

LITERATURE REVIEW

Breast Cancer Survivorship in Canada

Within Canada, an average of 62 women are diagnosed with breast cancer each day (Canadian Cancer Society’s Steering Committee, 2010). Breast cancer continues to be the most
common cancer worldwide and among Canadian women, accounting for an estimated 27.7% (23, 200) of all newly diagnosed malignancies in Canada (Canadian Cancer Society’s Steering Committee, 2010). Despite recent increases in incidence rates over the last two decades, mortality rates have fallen drastically by more than 30% since its peak in 1986 (Canadian Breast Cancer Federation, 2010). In fact, the breast cancer mortality rate is currently the lowest it has ever been since 1950 with an estimated of 5, 200 women dying of breast cancer annually (Canadian Breast Cancer Foundation, 2012). This is likely a result of an increase in mammography screenings and the use of more effective adjuvant therapy following breast cancer surgery (Canadian Cancer Society’s Steering Committee, 2010). Given these significant improvements in medical treatment, more breast cancer patients are surviving longer, with 87% of women diagnosed with breast cancer living for at least five years after their initial diagnosis (Canadian Cancer Society’s Steering Committee, 2010). Due to these increasingly strong survival rates, researchers and clinicians have begun investigating long-term psychosocial adjustment in breast cancer survivors. Yet, the focus of many research studies has been based on post-menopausal samples of women aged 55 and over, who are at a very specific stage in their lives (Thewes, Meiser, Rickard & Friedlander, 2003).

Younger (≤45 years) versus Older (> 45 years) Breast Cancer Survivors

Breast cancer survivors of all ages express a diversity of physical and psychosocial sequelae following treatment. Some of the issues expressed by these women are shared mutually among younger and older survivors. This has included arm swelling, pain and sexual dysfunction (Greendale, Petersen, Zibecchi & Ganz, 2001), lower physical functioning (Ganz et al., 2002) and a high prevalence of mild to moderate depression as compared to matched controls (Ganz et
al., 2002; Mols et al., 2005). Additional side effects have included: weight gain, osteoporosis, social difficulties, anxiety, cognitive difficulties, lymphedema, as well as insurance and work problems (Ganz, 2005: Hodgkinson et al., 2007). Younger and older survivors have also reported similar needs post-treatment. These have included: emotional and practical support from family and friends, the desire to access professional counsellors, as well as learning new coping strategies to deal with fears of recurrence and manage day-to-day stress (Thewes et al., 2004).

Moreover, other studies have reported that long-term survivors of all ages generally seek reassurance that their aches, pains, level of fatigue, and other minor symptoms are normal (Gray, Fitch, Greenberg & Hampson, 1998; Thewes et al., 2004).

While many of these issues are shared amongst older and younger breast cancer survivors, past research has indicated that younger breast cancer survivors are more likely to have poor psychosocial adjustment among a diverse range of outcome measures (Siegel, Gluhoski, & Gorey, 1999). Factors influencing poorer adjustment in younger women include: lower self-view, lower rates of seeking psychiatric assistance after mastectomy, depression, anxiety, adverse impact of mastectomy on sexuality, decrease in financial well-being, changed routines and impaired relationships (Siegel et al., 1999). However, while previous studies have consistently indicated that younger survivors have worse psychosocial adjustment than an older population, many of these results were acquired via survey research conducted on samples of women with breast cancer who were approximately 50 years of age or older (Siegel, et al., 1999). As a result, these samples were unable to acquire a representative sample of younger women, which the present study defines as 30 to 45 years of age at diagnosis.

Kornblith and her colleagues (2007) highlighted critically significant difference in adjustment issues that existed between younger and older breast cancer survivors utilizing
structured questionnaires. Sixty one young breast cancer survivors aged 55 and younger (Mean = 47.9 years), who were 93% white, 78% married or partnered, 70.6% with an undergraduate degree and 57% employed were compared to 67 older breast cancer survivors aged 65 and older (Mean = 72 years), who were 94% white, 70.2% married or partnered, 68.7% with an undergraduate degree, and 62.7% retired. All survivors were interviewed by telephone at study entry and 12 months later, using a battery of measures including the Hospital Anxiety and Depression Scale (HADS), Fear of Recurrence Scale, Appearance Orientation Scale, Post Traumatic Stress Disorder Checklist-Civilian, Multi-dimensional Body-Self Relation Questionnaire and the Medical Outcome Study - Social Support Scale to assess their adjustment, physical functioning and treatment-related physical and emotional problems. With an average of 3.7 years since treatment completion, almost all survivors reported good adjustment to having had cancer; however, younger survivors reported significantly worse adaptation than older survivors on a range of QOL measures involving psychological state, cancer-related treatment, sexual problems, and requests of help for unmet needs. The researchers concluded that although many of these adjustment differences were small, the young women were more likely to have poorer physical, social and psychological adjustment as well as greater distress.

Using an in-depth qualitative design, Thewes and colleagues (2004) conducted a study identifying the shared and unique needs of young versus old survivors. Eighteen patients with early stage breast cancer who completed their hospital-based treatment six to 24 months prior to participation were recruited. Unlike the majority of other studies, which used a chronological definition of ‘younger’ and ‘older’ survivors, Thewes and her colleagues used a functional definition of age for participants. Survivors were classified as young if, at the time of diagnosis, they were either pre-menopausal or had primary-school-aged children; all women who did not
meet this criteria were considered ‘older’. The sample included nine younger women (Mean = 41 years) and nine older women (Mean = 68.8 years). Most women were married/partnered (66.7%), educated beyond high school (55%), had children (72.2%), and five women (27.8%) reported having previous psychiatric problems. The authors conducted semi-structured telephone interviews ranging from 40 minutes to an hour. The results of the study indicated that both younger and older women had on-going needs for: emotional and practical support from family and friends, access to professional counsellors, and learning of coping strategies to deal with their fears of recurrence. Although some needs were shared, younger women reported more specific needs than their older counterparts. These included the need to deal with: gynaecological and reproductive consequences of treatment, fertility issues, early-menopausal symptoms, coping with changes to sexuality, changes to their lifestyle and career, financial implications for those who are at or near the peak of their career, and the isolation that accompanies being a younger breast cancer survivor. Younger women also reported a greater need for professional support from counsellors during treatment rather than volunteers, and non-hospital based support services.

In addition to the two studies discussed, Figueiredo, Fries, and Ingram (2004) and Ganz, Rowland, Desmond, Meyerowitz and Wyatt (1998), reported older women (> 50 years) having significantly better psychosocial status than younger women (≤ 50 years). These studies also found that younger women struggled with many issues that older women did not face leading to greater psychological sequela. Wenzel et al. (1999) compared QOL between younger (≤ 50 years) and older (>50 years) women, who completed treatment for breast cancer and found that younger women reported poorer global QOL and emotional well-being, more disease specific concerns and depression as compared to the older survivors. Taken together, all these studies
demonstrated higher rates of depression and long-term distress among a younger population of breast cancer survivors.

**Young Women and Breast Cancer**

Despite public perception that young women are at little to no risk of breast cancer, the reality is that they are vulnerable. In fact, breast cancer is the most commonly diagnosed cancer among younger women (those aged 20 to 49) (Canadian Cancer Society, 2010). In 2010, 4,450 women under the age of 50 were diagnosed with breast cancer (Canadian Cancer Steering Committee, 2010).

As may already be apparent, the definition of ‘younger’ women with breast cancer is extremely variable across the research literature. While many researchers have used 50 years of age as the cutoff mark, others have chosen to use 55 or even 60 years of age. Dunn and Steginga (2000) explained that the chronological definition of age, typically used as inclusion criteria to define young breast cancer patients, is far too simplistic. These researchers argued that according to women living with breast cancer, a functional definition of ‘young’ was also needed which involved: a woman who was pre-menopausal and has had a subjective belief that she was still of a child bearing age. Therefore, while the inclusion criteria for the present study included women aged 30 to 45 at time of diagnosis, it also incorporated these additional factors for study participants.

Breast cancer treatment for young women today can include a combination of surgery, chemotherapy, radiation and/or hormone therapy. The multimodal methods of treatment used for many young breast cancer patients can improve long-term survival outcomes, but may also contribute to prolonged periods of medical intervention with associated physical and emotional sequela (Ganz et al., 1998). Consequently, over the last decade, it has been firmly established in
the literature that younger women are at an increased risk for poorer psychosocial adjustment as compared to older women (Kornblith et al., 2007; Thewes et al., 2004; Siegel et al., 1999; Mor, Malin & Allan, 1994; Vinokur, Threatt, Vinokur-Kaplan & Satariano, 1990). While a diagnosis of breast cancer to a woman at any age would constitute a severe psychological insult, for younger women who perceive themselves to be in the prime of their lives, this diagnosis can be, “an especially disorganizing event – one that is unlike anything they have ever experienced before” (Siegel et al., 1999, p. 2).

Adult developmental theorists (Erikson, 1963; Levinson, 1996) suggested that a range of developmental tasks characterize different stages of the adult life cycle. Certain developmental tasks were viewed as benchmarks of major life events such as graduation, first job, marriage, first child, empty nest, retirement, widowhood, and death (Sammarco, 2001). Traditionally, chronological age was the criterion for normalizing these roles and responsibilities assumed by individuals (Sammarco, 2001). Over the last four decades, however, these conventional stages of the adult life cycle have had some drastic alterations to the ‘criteria norms’ for young women (Sammarco, 2001). Since the baby boomers reached adulthood, predictable life tasks are no longer predictable (Sammarco, 2001). Many women have begun to postpone or eliminate certain tasks typically seen in their twenties in order to devote more attention to other avenues such as their education or careers (Sammarco, 2001). As such, it is not unusual for young women in their thirties and forties to be juggling multiple role demands on a daily basis such as completing an education, pursuing work and career development, finding a partner or deciding to stay single, being a parent with a partner, or being a single parent (Sammarco, 2001). Bloom and Kessler (1994) believed that this developmental phenomenon in younger women cause them to be particularly vulnerable to psychosocial morbidity when faced with a life threatening cancer.
diagnosis. The demands of the breast cancer diagnosis and treatment are likely to compromise a woman’s ability to manage the multiple role demands associated with her developmental life stage (Cimprich, Ronis, & Martinez-Ramos, 2002). Moreover, self-protective beliefs about themselves, their identities and the world that develop before their cancer diagnosis are fundamentally challenged for young women breast cancer survivors. At a period in time when these younger women see endless possibilities for themselves, this diagnosis imposes an abrupt and severe limitation on their current role demands and their viewpoint (Siegel et al., 1999).

**Quality of Life among Young Breast Cancer Survivors**

Initially, health professionals defined QOL as the, “complete social and psychological being: the individual’s performance of social roles, her mental acuity, her emotional states, and her sense of well-being and her relationship with others (Levine, 1987 as cited by Bloom et al., 2004, p. 148). All these life domains, as originally described by Levine, cover the extent to which a woman’s objective state, as well as her expectations and hopes for the future, are congruent with one another (Bloom et al., 2004). For instance, two women could have the same objective state of health and well-being, but their QOLs may be significantly different based on their own personalized understanding of themselves, their identities and their health. Congruency, thus, is an extremely valuable aspect needed in order to achieve positive long-term well-being.

Changes in one QOL domain can also influence perceptions in other domains. Disruptions in the physical domain, for example, are likely to affect a woman’s psychological or social well-being. Consequently, QOL can be perceived differently to different people. As such, it is generally considered that QOL is best defined from the perspective of the patient. Interestingly, QOL can also changes over time, and subsequently is dependent on age and
experience. Thus, it is generally believed that, “older people adjust their perceptions about their health while younger people hold higher expectations concerning their physical and functional status” (Bloom, 2004, p. 148). The following reviews some noteworthy contributions made to the literature on QOL and unique needs faced by younger breast cancer survivors.

In one quantitative study, Avis and Manuel (2005) described the unique QOL issues faced by young women 4 - 42 months after their breast cancer diagnosis. A total of 202 women, with stage I to III breast cancer, between the ages of 25 to 50 at diagnosis (Mean = 43.5 years), majority white (96%), with a partner (81%), with some college education (52.97%) and employed (76.62%) completed a mailed survey. Fifty six percent of women had not undergone mastectomy while the remaining did. As well, 75% reported undergoing chemotherapy and 69% reported undergoing radiation therapy. Global QOL and health-related QOL were measured by the Functional Assessment of Cancer Therapy – Breast Cancer (FACT-BC), medical history, symptoms, days of work/activity missed after diagnosis, relationships, sexual and body image problems, coping strategies and feelings of preparedness. The results indicated that general aches and pains, and unhappiness with appearance were reported by more than 70% of participants. Global QOL was rated significantly lower than a non-breast cancer sample of younger women. In general, few sociodemographic and medical factors were related to QOL. Using multivariate analyses, days of work missed immediately after diagnosis, relationships, sexual or body image problems and coping strategies were related to almost all QOL domains. Ongoing treatment, vaginal dryness, and feeling unprepared for the impact of breast cancer were related to some QOL domains.

Similarly, Bloom and her colleagues (2004) examined QOL in 185 cancer-free breast cancer survivors five years after treatment who were 50 years of age or younger (Mean = 45
years) at initial diagnosis. Majority of participants were Euro-American (69%), graduated college (56%), employed (81%) and married (65%). Of these women, half had a mastectomy (51%) while the remainder had breast conserving therapy (49%). The majority of women had some form of adjuvant therapy consisting of chemotherapy, radiation and/or Tamoxifen. Further, at the time of initial diagnosis, 17% were staged as having in situ disease, 45% had local disease and 37% had regional disease. The results indicated that five year cancer-free young breast cancer survivors enjoyed good health and improved QOL; however, researchers reported that specialized physical, social and psychological concerns should be addressed so that young survivors can continue to be resilient as they age. Interestingly, Bloom and her colleagues cited in their study that the data did not explore patients’ baseline (pre-diagnosis) psychosocial well-being due to the constraints of their quantitative approach; the authors also note the significance of baseline QOL to better understand the extent of breast cancer survivors’ psychosocial adjustment. Informed by this perspective, the present study inquired retrospectively about pre-diagnosis QOL, coping and adjustment related issues.

Siegel et al. (1999) used an instrumental qualitative design to examine age-related distress among young women with breast cancer. Fifty one breast cancer survivors, aged 35 or younger (Mean = 30.6 years), who had completed all treatment for breast cancer at least six months before the interview participated in unstructured interviews. Majority of participants were white (85%) and the remainder were black non-Hispanics. The majority were diagnosed as having stage I or II disease (59%), were married (64.7%), and had completed some post-secondary degrees after high school (79%). Both adaptational challenges and unique needs faced by these women were reported in the two hour in-depth interviews. After analyzing the narratives of all women involved in the study, six prominent themes arose from the data,
including: (1) coping with the untimelessness of the diagnosis, (2) concerns about the impact of the illness on their husbands, (3) sadness about lost opportunity for childbearing, (4) a feeling of being different and isolation, (5) uncertainty about their future, (6) concerns about their young children. These six areas of distress provided detailed information using the lived experiences of young survivors and are a reference guide to further understand the distressing issues consistently faced by young women after their breast cancer diagnosis.

Unlike Siegel and colleague’s study, Dunn and Steginga (2000) moved beyond describing the challenges faced by the women in their study. Using a multi-angled qualitative methodology, these researchers utilized focus-groups, in-depth interviews, and three rounds of iterative surveys in order to further investigate and detail the concerns of the survivors in a way that would accurately reflect their experiences. Twenty three women aged 31-47 (Mean = 37 years) were selected to take part in this study, including nine who had breast conservation therapy, 13 with a mastectomy, and one with a bilateral mastectomy. Researchers chose a self-selection method in order to gather younger breast cancer survivors. Dunn and Steginga recruited study participants with breast cancer who spontaneously identified themselves as being young. Among this sample, 87% were married and 56.2% had children of primary school aged or younger. Consistent with previous research, women identified fears about not surviving long enough to see their children grow to adulthood, issues regarding current infertility, or fear of infertility due to a possible cancer recurrence. Majority of the concerns described by women were related to their own life stage, emphasizing the challenges specific to their age group. This study added to Siegel and colleagues study by incorporating some examination of the social context and survivors’ coping strategies, in addition to describing survivors’ concerns, towards the goal of guiding the provision of supportive interventions for other survivors. Participants
emphasized the importance of peer support as well as meeting with and sharing experiences with other young women with breast cancer.

**Four Quality of Life Domains in Young Breast Cancer Survivors**

QOL is not uni-dimensional, but rather, covers a number of life domains. Currently, it is defined as having four specific domains including: physical, psychological, social and spiritual. Ferrell and Dow (1997, p. 566) defined QOL using these domains to create an ‘all-encompassing’ definition specifically for cancer survivors:

1. “Physical well-being: the control or relief of symptoms and the maintenance of function and independence
2. Psychological well-being: the attempt to maintain a sense of control in the face of life threatening illness characterized by emotional distress, altered life priorities, and fear of the unknown
3. Social well-being: the effort to deal with the impact of cancer on individuals, their roles and relationships
4. Spiritual well-being: the ability to maintain hope and derive meaning from the cancer experience which is characterized by uncertainty”

Using this ‘all-encompassing’ definition, the four QOL domains in relation to a younger population of breast cancer survivors are reviewed:

**Physical Domain.** Thewes and colleagues (2004) reported that fatigue, breast and arm pain and problems with lymphedema are the most commonly reported late physical effects of treatment for young women. Other physical problems among younger pre-menopausal women included restricted arm/shoulder movement, dryness of the throat and menstrual cycle issues. For
many women, current level of physical symptoms (fatigue, pain) were not perceived as debilitating and did not significantly affect their daily living activities. Instead, many women worried whether their symptoms were normal, and preferred to be reassured that her physical symptoms were not signs of recurrence.

Young women also discussed how gynecological late-effects of treatment impact their QOL. Common challenges among women under the age of 50 included irregular or painful periods, vaginal dryness, and loss of libido (Bloom et al., 2004). There is also consistent evidence of sexual dysfunction post treatment (Fobair, 2005; Bloom et al., 2004; Broeckel, 2002; Ganz et al., 1996; Dow et al., 1996; Olweny et al., 1993). These problems have been reported to occur regardless of treatment options (Bloom, 2004). Obesity and weight gain have also been frequently reported in studies on young women with breast cancer (Howard-Anderson, 2012). Among studies that have explored this variable, the percentage of women who reported gaining weight or being bothered by gaining weight after diagnosis ranged from 23% to 83% (Howard-Anderson, 2012).

**Psychological Domain.** Depressive symptoms (such as depressed mood, worthlessness, hopelessness, loss of sleep, psychomotor retardation, and appetite disturbances) have been commonly reported by younger breast cancer survivors (Howard-Anderson, 2012). Ganz and her colleagues (1999) found that improvements in mood and overall QOL occurred during the first year after treatment; however, no subsequent improvements were found when year 1 was compared to year 2 or year 3 follow-ups.

As well, concerns related to their future were positively associated with symptoms of depression and anxiety in younger women (Howard-Anderson, 2012). Concerns such as nervousness about medical follow-up, and self-image have also been reported (Omne-Pontent,
Holmberg & Sjoden, 1994). In one instrumental study, Bloom et al. (2004) found that even five years after diagnosis, 52% of women reported that they were generally “overly stressed, tense or anxious” and 68% had anxieties about the future. Despite these concerns that carried over long-term survivorship, women’s ratings of cancer intrusiveness and worry about the future showed a statistically significant improvement over the 5 year benchmark (Howard-Anderson, 2012).

The meaning of having children is another important aspect of QOL for many young breast cancer survivors. This concept is not only important in terms of the experience of pregnancy, child birth and mothering, but also as an investment in, and affirmation of a woman’s future (Dunn & Steginga, 2000). As such, specific concerns and worries arose particularly among survivors who identified as mothers to young children. In their qualitative study, Siegel and colleagues (1999) found that the stress faced upon these young mothers was threefold; first, mothers felt both fear and sadness that they would not live to see their children reach adulthood; second, they felt anxious about finding suitable caretakers to raise their children if the cancer were to recur and they were to become increasingly ill or die; and finally, these women struggled with the challenges of trying to minimize the daily impact of the illness on their children.

Additionally, there is fairly consistent evidence of increasing problems in sexual functioning post-treatment (Bloom et al., 2004; Ganz et al., 1996; Dow et al., 1996). These problems occur regardless of the treatment modality (Bloom et al., 2004). While sexual functioning problems are partially physiological, they are also psychological. Some research has reported that women feel rejected as many partners do not want to touch their affected breast(s). It is not surprising that self-image and intimacy problems are also frequently reported (Bloom et al., 2004; Helms et al., 2008). Additionally, emotional and practical support from their partner throughout treatment and as a survivor was fundamental to an improved QOL for this
population. However, expressed guilt surrounding the toll of their illness on their partner and their relationships was also expressed as a major concern leading to poorer QOL (Bloom et al., 2004).

**Social Domain.** Many young women reported being distressed about the impact of their breast cancer on their lifestyles and careers. Given that the majority of young women have full-time employment and are entering the peak of their careers at the time of their diagnosis, work-related issues do arise. This may include subtle discrimination in job promotions and/or being laid off because they were believed not to be able to do their work effectively (Bloom et al., 2004). Women also reported a lack of resources available to assist in work re-entry (Carter 1994).

Self-image and relationship problems are also frequently reported among these younger women. In a study conducted by Thewes et al. (2004), the authors cited an interview with one pre-menopausal woman who was not married. The woman explained herself as being a “liability” for future partners because of a potential recurrence and issues with infertility.

A significant theme documented in many studies has been a sense of isolation and feeling different from other women their age. In fact, even some women interviewed in large-scale cities indicated feeling that the support groups available to them did not cater to their unique needs and thus they did not fit in because of their young age (Thewes et al., 2004; Siegel et al, 1999). Past studies have shown feelings of isolation can occur in patient support groups where younger women could not connect with other group members as the majority of participants were older, typically in long-standing marriages, and had already raised their children. Consequently, instead of younger women regaining their sense of normality within these groups, they would feel even more isolated, uncomfortable and even depressed (Siegel et al., 1999). Feelings of isolation were
also not uncommon when socializing with friends. The difficulty of seeing friends pass through developmental milestones that were impossible for survivors was also reported to be distressing (Siegel et al., 1999).

Interestingly, younger survivors have also reported feeling marginalized in public health campaigns to promote mammography which target women over the age of 50 years. These campaigns contribute to feelings of isolation and stigma as women who are ‘too young to get breast cancer’ are not ‘normal’ based on these public health messages. Stigma perceived by young women reinforced feelings of isolation, consequently, these women are more likely to remove themselves from interacting with others by leaving jobs and social activities where these interactions could occur (Bloom et al., 2008).

**Spiritual domain.** While there is a growing interest among researchers in the spiritual well-being of cancer survivors, to date, no studies have exclusively targeted spiritual well-being in relation to young breast cancer survivors. However, research with an older sample of breast cancer survivors exists. In one study, Gall and her colleagues (2002) examined 52 women, with a mean age of 55.2, who were asked to write in their own words how religion and spiritual factors played a role in understanding and coping with their breast cancer. Researchers found that spirituality and spiritual practices had a positive role on the majority of women, including their belief in God, religious coping activities (e.g.: prayer), spiritual meaning to their illness, and social support in religious organizations. Other studies have also found that an openness to spirituality among cancer survivors can lead to post traumatic growth and a sense of life affirmation for women (Kyngas, 2000; Gall, 2002; Bloom 2004)

Breast cancer patients have reported religious faith to be an important source of support in dealing with their illness (Gall, 2002; Heim et al., 1993), and that the cancer experience itself
can lead to increased awareness of spiritual issues (Cavanaugh, 1994). Spiritual-wellbeing has also been documented to be a source of long-term adjustment for cancer survivors by maintaining self-esteem and confidence, providing a sense of meaning or purpose, giving comfort, reducing emotional distress and increasing inner peace and engendering an overall sense of hope and a positive attitude towards life (Gall, 2002; Jenkins & Pargament, 1995; Johnson & Spilka, 1991; Levin, 1994).

**Self-Concept and the Identity Reformulation Process**

From this literature review alone, it is evident that the research community has become much more attuned to various concerns that impact breast cancer survivors’ overall well-being. However, much of this research has focused on an older, post-menopausal sample of women, and typically adhered to one of four prescribed QOL domains to further understand women’s overall well-being (Howard-Anderson et al., 2012). One area of investigation absent within the plethora of QOL literature is the reformulation of young women’s identities after a breast cancer experience. While researchers have explored breast cancer survivors’ QOL using the four domains previously described, the present study aims to expand upon these four domains by suggesting that women’s breast cancer experience involves a process of identity reformulation. This process examines the extent to which women have integrated the cancer experience into their self-concept, which may also result in women experiencing a new or renewed sense of self (Zebrack, 2000). In turn, changes in the way cancer survivors see themselves in relation to the world, including their ability to carry out roles and responsibilities, affect their long-term QOL and overall well-being (Zebrack, 2002). This approach suggests that a cancer diagnosis may initiate a new life path as a cancer survivor that extends over the remainder of their lifetime and ultimately impacts all prescribed QOL domains.
Relationship between the Self and the Body: Significance of Self-Concept in Cancer Survivors

Charmaz (1995) believes that human existence essentially means embodiment and that the self is inseparable from the body. Mind and consciousness depend on being in the body; in turn, the bodily feelings affect the mind (Charmaz, 1995). However, the relationship between the body and self is challenged for those with chronic illnesses who realize that they have suffered lasting bodily changes (Charmaz, 1995). The challenge in this realization intensifies for people with chronic illnesses who previously assumed a position of control over their bodies (Charmaz, 1995). Not only do people with chronic illness experience disruption to their assumption of bodily control, but they also experience challenges to their assumption regarding embodying individualism through their bodies (Charmaz, 1995). As Victor Kestenbaum (1982) discerns, “illness threatens a person’s sense of integrity of self and body and of self and the world”. Many people who suffer from chronic illnesses find progressive losses repeatedly threaten their body and self-integrity. These individuals risk becoming socially labelled and/or self-identified exclusively by their altered bodies (Charmaz, 1995, Goffman, 1963, Bury, 1988). Moreover, Charmaz believes that people with chronic illness who are able to move beyond loss and transcend stigmatized labels are “able to define themselves as much more than their bodies and as much more than their illness” (Charmaz, 1995, p.660). Nonetheless, Charmaz (1995) clarifies that with each new and often unsuspected bodily impairment people with chronic illnesses repeatedly experience a loss of whatever unity existed between the body and self. Therefore, at each point when individuals suffer and define their loss, questions related to identity and self-concept emerge.
Defining Terminology

Although researchers have had some interest exploring identity related issues among individuals with breast cancer, no researchers have included explicit definitions of self-concept or identity in their studies. Subsequently, the present study addresses and delineates these construct as utilized in the research. The words identity and self carry a lot of colloquial meaning within Western society. ‘Identity crisis’, ‘finding one's true self’, ‘self-actualization’ are only a few phrases that reflect the popularity of these terms (Friese, 2001). Despite their popularity, these terms lack precise definitions within the realm of psychology. Richard Stevens’ (1996) edited volume entitled, Understanding the Self highlights the ambiguity of these terms. He states that researchers adhering to a social constructionist tradition, for example, “celebrate the diversity of the self through cultural influence, language and discourse” (Friese, 2001, p. 1). Conversely, biological psychologists view the self as “a subject of evolutionary processes and accentuate continuity and the universal nature of self” (Friese, 2001, p. 1). Cognitive experimentalists, in contrast, “stress the importance of social factors and the cultural context in understanding the self” (Friese, 2001, p. 1). Furthermore, the psychodynamics view the self as “less of an entity that can be assessed primarily through conscious actions. Instead, it is viewed as essentially fragmented, as something that can only be experienced partially and that may altogether just be a defensive illusion” (Friese, 2001, p.1).

Thus, amid the ambiguity, how do we differentiate constructs like self-concept and identity? Döbert, Habermas and Nunner-Winkler (1987) suggest that self-concept is a psychological construct while identity is a sociological one. As such, one could assume that scholars concerned with the self-concept could take a micro (psychological) approach while those concerned with identity view the issue from a macro (sociological) approach. However, the
distinction made between these two constructs is not so clear-cut (Friese, 2001). Friese (2001) explains that social issues are equally entangled in self-concept as issues of psychology are with identity. For example, before a person acquires a sense of identity, certain cognitive abilities must develop (Friese, 2001). Therefore, one must venture into the realm of psychology to learn something about how identity is formed (Friese, 2001). Likewise, the self-concept must find its place within sociology as it is developed through processes of socialization as well as interaction and social comparison with other people (Friese, 2001).

Given that the present study is exploring the self in relation to psycho-social-cultural variables in young women’s breast cancer experiences, both the self-concept and identity constructs will be operationally used and defined.

Self-concept is defined as a multidimensional construct that refers to an individual’s perceptions of “self” (Oyserman, 2001). It functions as a “repository of autobiographical memories, as an organizer of experience and as an emotional buffer and motivational resource” (Markus & Wurf, 1987; Oyserman, 2001, p.500). Rosenberg (1979) adds to this definition by describing it as the “totality of the individual’s thoughts and feelings with reference to himself as an object” (p.8). The individual is able to stand outside of him/herself and describe and evaluate him/herself as a detached object of observation (Poochikian-Sarkissian, 2005). Thus, Rosenberg (1979) and others (Gerrig & Phillips, 2002) highlight the evaluative, self-assessment component involved in the self-concept.

While it has long been recognized that the self is a stable and enduring structure that protects itself against change (Greenwald, 1980; Markus, 1977), in different social environments, different components of the self can also emerge (Markus & Kunda, 1986). As such, most
comprehensive theories of the self-concept recognized these two paradoxical aspects of the self. Rogers (1954) described the self-concept as organized and consistent but also fluid. Similarly, Turner (1956) characterized self-concept as “a stable set of evaluative standards but also quite variable…the picture the person has of himself or herself at any given moment”. Although different terminology is used, these researchers emphasize the central importance of the fluidity in the self-concept.

As previously articulated, components of the self rooted in socio-cultural phenomena is defined as a person’s identity. Unlike the self-concept, the construct of identity has no self-assessment component; but rather is the way “an individual defines, locates and differentiates self from others” (Charmaz, 1995). Little and colleagues (2002) add to the understanding of identity by explaining that identity is,

*the sense of personhood that places us uniquely in a social context. [It is] the sense of agency, the sense of what it is to be this willing, choosing, and acting entity, both now and in the future. Identity is the sense of being this person with attributes (i.e. gender, physique, intelligence), acquisitions (i.e. wealth, property, rank), and capabilities (work, vulnerability, reputation) which condition interactions between the person and the social system in which he or she lives. It is constructed and experienced by the person, but its experience is constructed and modified by events and associations within which the person moves. (p.171)*

**Women’s Reformulation of Self-Concept after Breast Cancer**

While changes to a woman’s self-concept may not be evident immediately upon hospital discharge, these changes are likely to manifest after treatment and may even linger years later
(Park, Zlateva & Blank, 2009). Once women are diagnosed and treated for breast cancer, their world irrevocably changes. After this experience, their values, beliefs and perceptions of themselves in relation to the world are likely to be altered and as such affect their long-term psychosocial well-being. Although young breast cancer survivors’ self-concepts are clearly an important issue needed to be addressed, to date, no research has been exclusively conducted on this topic.

Thoits’ (1991) identity theory is a useful framework to understand the identity reformulation process in breast cancer survivors. Thoits (1991) argued that extreme experiences like a breast cancer diagnosis could threaten the element of continuity in one’s sense of self, bringing about bodily and cognitive changes that challenge central values and beliefs. The cancer experience can also be disruptive causing an interruption of normal processing in a person’s self-concept formulation. Thoits further highlighted that the cancer experience could result in changes of relative importance to specific identity characteristics, which he defined as the salience identity hierarchy; as individuals reconstruct their identities after cancer, the salience of certain identity characteristics change too. Changes to this hierarchy, in turn, alter aspects of a person’s self-concept. A specific identity that may have been central to a person’s sense of self prior to their breast cancer, (e.g.: femininity, youth, career, spouse), for example, can diminish in salience in the face of cancer and be replaced by other, more salient identity characteristics.

Ultimately, when these individuals perceive themselves as not living up to their original expectations or ideals they believe they should have achieved prior to cancer, distress is likely to follow (Thoits, 1991). Post-cancer related tasks (e.g.: handling psychological reactions of self and others, maintaining a positive body image, sustaining social relationships, and dealing with constant uncertainties can be experienced as disruptive and stressful, particularly if it interrupts
women’s pre-cancer norms and expectations (Zebrack, 2000). Although the cancer experience can assault prior perceptions of the self and break down a person’s identity salience hierarchy, the cancer experience can also be viewed as an opportunity for personal growth and improved well-being, allowing for a potential reintegration of the self-concept. This process is exemplified by the comments of one survivor who stated, “for a long time now, maybe four or five years, cancer has felt like it’s been part of a quilt… one of those patches is cancer” (Zebrack, 2000, p. 238). This quote suggests that over the passage of time, her breast cancer experience was not necessarily forgotten, but rather, integrated into a larger life experience.

Not surprisingly, the reformulation of the self-concept is likely to be even more pronounced among younger women with breast cancers who have faced a disease assumed to affect an older population of women. As a young woman, breast cancer diverts her initial trajectory of normal identity formation. After her cancer treatment and subsequent physiological changes, for example, a young woman’s physical self-image is likely to change from being sexual and attractive to others to being sickly and degenerate (Little et al., 2002). Thus, issues related to her appearance may greatly impact the way she feels about herself and her feminine identity (Little et al., 2002). Beyond body-image related concerns, at a time in many young women’s lives when they feel indestructible and life is filled with endless possibilities, plans and expectations for themselves drastically change. Little and colleagues (2002) provide a short narrative from a young woman to further capture this notion. A recently married young woman always imagined herself having at least five children in the future. She and her husband had made this decision many years ago. However, after surgery and radiation for her breast cancer, she became infertile. She later explained that her cancer robbed her of this future plan, leaving her uncertain about the direction or purpose in her life. She further explained that even five years
after doctors described her as ‘cured’, she remained unsettled, insecure and unable to construct a meaningful future for herself (Little et al., 2002). Many young women in this situation have also felt lost, defeated, and even cheated out of their own trajectory (Tindle, Denver & Lilley, 2009). One survivor explained, “All of a sudden my life was on hold… I now had to watch those friends I had worked alongside getting on with their lives, happy, healthy and competing for their dream jobs…[I was] convinced I was being left behind” (Tindle, et al., 2009, p.287). While less obvious to health professionals, changes in a young person’s self-concept and identity may not be evident upon discharge; the reformulation process is likely to manifest slowly after her treatment, potentially lingering for many years later (Park, et al., 2009).

Piot-Ziegler, Sassi, Raffoul and Delaloye (2010) conducted an open qualitative reflective study focusing on the consequences of body deconstruction from mastectomy on identity in women with breast cancer. Nineteen women (aged 37-62) diagnosed with breast cancer who underwent a mastectomy participated in one semi-structured 30 to 60 minute interview, shortly before or after their surgery. Some were offered immediate breast reconstruction, while others, because of their cancer treatment, had no intentions for reconstruction. Five main themes emerged from the interviews. One major theme central to the current study was entitled, Body Deconstruction: A Challenge to the Woman’s Identity. Many of the women in this study described their mastectomies and the deconstruction of their ‘original’ bodies as a “deep identity crisis”. Specifically, seven women spoke about the impact of illness on their self-concepts and identity in relation to the changes in their appearances. One woman named Barbara, in the process of her treatment stated, “I have the impression that I am losing my true self” (p. 494). Eleven women from the study feared that they would no longer be or feel like a woman again. They expressed concerns about the challenges imposed on their gendered identity and
femininity. Some even felt that after their surgery, they would appear genderless, or worse, would transform into a “male person”. Others felt that they had stepped back into time, and returned to childhood before their physical transformation of puberty.

Many women also felt like their surgery had an impact on the symbolism of the breasts. These women felt as though their breasts were closely connected to motherhood, maternity and fertility. Four women expressed that this surgery would prevent them from becoming mothers. As well, for some women, the mastectomy induced a large discrepancy between what they believed was socially expected from a woman’s appearance and their own reality. The frequently idealized feminine images in the media as well as the attitudes of others were seen as acts of aggression, or as futile especially when compared to the severity of their illness. In sum, the researchers were able to use this study to demonstrate that a breast cancer illness can invoke a painful experience of body deconstruction and identity reformulation. Body transformations, in particular, were accompanied with experiences of modified physical, emotional, social, symbolic and relational dimensions of women’s identities.

In another critical study, Little, Paul, Jordens and Sayers (2002) conducted interviews on seven Australian women and six Australian men between 13 and 89 years of age, who had survived either colon cancer (n = 11), Hokinson’s lymphoma (n=1) or hepatoblastoma (n=1). In these interviews, participants were invited to tell their stories, beginning with the first signs of illness. Interviews lasted in between 50 to 90 minutes. Using survivors’ narratives, the researchers found four specific ways in which identity discontinuities were expressed in their self-concept after cancer. These included: (1) discontinuity due to differences between their past and future memories, (2) discontinuity due to permanent changes to their body, (3) discontinuity due to existential disruptions, particularly in relation to work, or carrying out old roles, (4)
discontinuity due to disruption in the memory of others. Interestingly, these researchers were also able to derive themes from survivors that challenged the discontinuity. These included: (1) Anchor points (ie. Work, religion, privacy) to hold on to; (2) Resuming a version of their former lives within the context of their new insights from this extreme experience. (3) Taking on the counsellor role to help others struggling with a similar disease, (4) Instilling this experience with personal meaning. Through this study, it is evident that extreme experiences like cancer leave no aspect of identity untouched (Little et al, 2002). The content, cognitions, perceptions and remembered experiences that make up the background to their thinking have changed.

Park and colleagues (2009) examine the extent to which four post-cancer identities (the patient, the person who had cancer, the victim, and the survivor) were adopted; the relation between each identity, the involvement in cancer related activities, and the relations between each identity to physical and mental well-being were explored. Using a cross-sectional questionnaire-based design, 168 young to middle aged adults who were diagnosed with cancer 1-3 years prior participated in this study. Participants reported on background variables related to their cancer diagnosis and treatment, their current cancer identification (of four), psychological functioning, cancer-related risk appraisals and coping, cancer-related activities, and mental and physical well-being. Through regression analyses, identities were shown to be explained by a combination of background variables, functioning, appraisals and coping variables. The results also indicated that a survivor identity correlated with better psychological well-being and post-traumatic growth, while a victim identity was associated with poorer well-being. Furthermore these identities were minimally correlated with one another and differentially associated with involvement in cancer-related activities.
Deimling, Bowman and Wagner (2006) specifically examined the concept of survivorship and the adoption of a survivorship identity by individuals who had been treated for cancer. The larger study was an ongoing longitudinal and qualitative study which included survivors of breast, colorectal, or prostate cancer who were at least 60 years of age at the time of the interview. Participants had been diagnosed with cancer at least five years prior to study enrollment. The data suggested that older adults (>60), who survived cancer for at least five years, identified as cancer survivors and/or as ex-patients rather than as victims or patients. Most participants also viewed being a cancer survivor as an important part of whom they were, did not seem themselves as less whole, and were not overly concerned about how others saw them. The study concluded that a survivorship orientation is associated with better mental health outcomes, and can reinforce the effects of quality medical care provided by clinicians, and overall QOL among individuals living with a history of cancer. However, it is important to highlight the problematic nature this study takes when identifying only one method of recovery towards improved QOL. It should be emphasized that while certain identity categories have shown to lead to better QOL outcomes, there cannot be one uniform approach used to help survivors during their healing journey. Given the complex backgrounds and histories of each individual dealing with their cancer diagnosis, health care professionals, family members and friends must be open minded about this complex and individualized process.

Posttraumatic Growth and the Identity Reformulation Process

While paradoxical, the notion that after suffering, individuals can gain or grow from an experience has been acknowledged for thousands of years (Tedeschi & Calhoun, 2004). This process, also known as posttraumatic growth (PTG) is defined as “positive psychological change experienced as a result of struggle with highly challenging life circumstances” (Tedeschi &
Calhoun, p. 1). It occurs when an individual disengages from previously held assumptions and reconstructs new beliefs and goals in their life (Gillies & Neimeyer, 2006). A more recent topic of investigation among breast cancer patients, PTG is critical to further understand the identity reformulation process in breast cancer survivors. Gilles and Neimeyer (2006) assert that when individuals move through the PTG process, they express a “changed sense of self” (Gilles & Neimeyer, 2006, p. 6). Subsequently, these two processes may be interrelated. While PTG does not provide a completed framework for survivor’s healing journey, it appears to be a relevant factor. According to Tedeschi and Calhoun (2004), changes to an individual’s sense of self are not directly the result of a traumatic event; rather, the trauma acts like a catalyst for change. The confrontation and struggle with the negative emotions and cognitions from the traumatic event are what bring these changes to the forefront of a person’s self-concept. After the occurrence of a traumatic event, individuals usually experience automatic and intrusive thoughts resulting in a disengagement from previous goals and schemas (Amirfarhad, 2011). However, over time, cognitive processes help individuals to reconstruct new schemas, goals, personal narratives, and meaning in their lives (Amirfarhad, 2011). Processing trauma is explained as complex and involves a combination of powerful emotional, cognitive, narrative, psychosocial, and metaphorical factors (Amirfarhad, 2011). These factors are believed to be necessary for individuals to achieve, “higher order schemas that allow for appreciation of a paradox…as they [trauma survivors] take on a life that has become surprisingly complicated beyond expectation, and painful” (Tedeschi & Calhoun, 2004, p. 15). Davis (2008) adds that while it may be obvious that individuals coping with trauma need to manage changes to their world-views, self-views, roles and relationships, the fundamental assumption about their identities “are generally understood to be conservative and resistant to change” (Davis, 2008, p. 310). Yet, Davis also
asserts that an individual’s ego is “totalitarian”, altering the individual’s past in order to maintain a coherent and benevolent view of the self (Amirfarhad, 2011). When managing identity changes, Davis highlights that change mostly occurs through a gradual alteration of world and self-views, not as a complete replacement of identity or previous viewpoints.

In a study by Davis, Wohl and Verberg (2007) on individuals who had suffered a trauma through the loss of a loved one, the researchers coded the interviews and derived three hierarchical clustering profiles from trauma survivors. As expected, participants from the first profile reported losing a part of their identity, looking for and finding some meaning, personal growth, and positive changes in their experiences (Amirfarhad, 2011). In contrast, participants from the second profile reported that they searched for meaning, tried to make sense of their trauma, but were unsuccessful (Amirfarhad, 2011). These individuals did not report any growth, but instead reported some negative changes in their life philosophy that had replaced their shattered assumptions (Amirfarhad, 2011). Interestingly, the final group of participants reported that they did not have a need to search for meaning; nevertheless they reported some personal growth particularly on the dimension of positive change in themselves (Amirfarhad, 2011). Unlike the first two profiles, the third group expressed positive change, while not experiencing any shattered world-views or self-views (Amirfarhad, 2011). This group did not look for meaning in their trauma, did not have the need to re-tell their stories, and did not report significant changes in goals, commitment or identity (Amirfarhad, 2011). As a result, Davis and colleagues demonstrate that meaning is not fundamental to identity changes or reformulating one’s self-concept. As well, the authors demonstrate that identity changes are not necessarily significant among all trauma survivors. Davis (2008) later identified an additional profile after trauma that some survivors went through called “gaining insight”. Gaining insight was described
as sustained changes in a better and deeper understanding of the self (i.e. “I know myself better now”) (Amirfarhad, 2011). Davis explains that this self-awareness may not be evident to others (including family members and health professionals) since it does not entail a change in the “core self”. Instead, it involves a change to their self-concept, or how an individual understands the core self (Davis, 2008, p. 320). Thus, by gaining insight, individuals learn to understand who they are and what they are capable of after their traumatic event (Amirfarhad, 2011).

While active coping styles and processing of positive feelings are commonly thought to be involved in PTG, this notion is not necessarily true for all trauma survivors. As has been previously stated, not all individuals heal in one unified way after a significant trauma like a cancer illness. Although PTG research has highlighted the importance of growth through positivity and active coping strategies, it is equally important to examine alternative coping strategies and creating problem solving solutions use to cope with their trauma. While positive change is expected and desired among most health care professionals for their patients, some breast cancer survivors are unable to make these ‘standardized’ changes towards growth, due to social, cultural, and/or personality issues. Therefore, by exploring young breast cancer survivors’ healing journey through a diverse spectrum of positive and negative changes to the self, the current study expands on current research with young breast cancer survivors.

**Gendered Identity in Breast Cancer Survivors**

Despite public interest and attention to breast cancer, there is a significant gap between what is portrayed as the breast cancer experience and the real life experiences of women diagnosed with this disease (Gray, Sinding & Fitch, 2001; Kasper & Ferguson, 2000). As women respond to their illness, parts of their identity tends to clash with certain social expectations about
what it means to be a women and what it means to be a breast cancer patient (Fosket, Karran & LaFia, 2000). For women, social expectations surrounding their gendered identity are deeply entrenched in the social position as a caregiver (Sulik, 2007). When a person is ill or in crisis, women frequently are expected to extend their social roles as family caregivers to provide care and social support. Because women typically take on these roles and are regularly concerned with others’ needs, they are viewed as inherently skilled at giving “good care” (Sulik, 2007). “Good care” is equated to normative feminine attributes such as empathy, emotional sensitivity, and genuine concern for others (Sulik, 2007). However, women who have experienced breast cancer must call these roles into question. When women battle a deadly disease, like breast cancer, they often must negotiate, challenge and revise their gendered identities within the societal constraints of a gendered division of labour, in which caring takes on both a “gendered and feminized meaning” (Sulik, 2007, p. 298). To manage their breast cancer, it is vital for women to be protective of their inherent gendered identity and to prioritize their own needs. Yet, these tasks to a large extent are contradictory; to prioritize their needs would require women to break away from inherent gender norms and expectations that define women as natural nurturers, placing them in the service of others. Women would need to renegotiate their ambivalence about accepting help from others and the desire to take care of themselves instead of asking for help directly. As a result, this process frequently contributes to role confusion, identity changes and identity reformulations for many women (Sulik, 2007).

In one influential study, Sulik (2007) used qualitative data from 60 intensive in-depth interviews to examine how gender influenced women’s breast cancer experience. Interviews ranged from 1-4 hours. Women in the study had a mean age of 53.6 years, where majority were white (90%), had an education beyond a bachelor’s (36.7%), had 1-2 children (56.7%) and were
in the second to fourth year of their survivorship (41.7%). Once interviews were completed, Sulik explained that prior to the cancer diagnosis, many women behaved in ways consistent to gender role expectations which included nurturing and caring for others. As a result, majority of interviewees frequently discussed not being accustomed to the self-interestedness required to cope with their illness. Sulik further stated that the narratives illustrated the salience of gender, particularly as it related to compliance with others’ needs and desires, rather than prioritizing their own. However, women repeatedly described their efforts to break from feminine norms to cope with their cancer, become more self-interested, assertive and self-reliant. If successful, these qualities have the potential to promote agency and empowerment in women. Yet, these same qualities can conflict with their nurturing, other-focused traits associated with being a female and what many women would characterize as desirable. As such, an illness like breast cancer may further intensify the gendered social scripts on women and influence their perceptions and coping strategies.

One of the most critical issues women discussed in their narratives was their need to become more individualistic. All 60 women reported that their cancer experience changed them in a number of ways including: doing things differently, being assertive, setting priorities, and establishing boundaries. This shift in perspective was believed to be a necessary coping strategy for managing QOL as a survivor. While many women did not view their breast cancer as a “blessing”, many survivors thought of themselves as transformed and “truer to themselves” (p. 303). As the researcher articulated, these women developed a new, “gender consciousness”. It is also important to recognize, however, that for some women, gender identity changes after cancer are much less significant. One survivor, Barbara explains, “I liked my life the way it was before I got sick. I was not working at some horrible job and wanting to quit, I did not have a terrible
mate, or make some great discovery when I really looked into my life” (p.304). Essentially, Barbara highlighted that the model of survivorship that requires courage and triumph, is too narrowly defined. Yet, although she rejected the cultural expectation to wear a pink ribbon of survivorship, she discussed in her interview a new sense of confidence in pursuing what was important to her, and resisting things that might have undermined her life priorities.

When coping with breast cancer as survivors, all women evaluated, negotiated, resisted and renewed their sense of self. To further understand women’s self-concept in relation to their gender identity, Sulik asked whether they “felt like the same person” after their breast cancer treatment. Majority of the responses suggested a need to develop a new sense of normality, and a new sense of self. The ease with which women redefined what they considered to be normal was tied to others’ expectations, particularly spousal expectations. In sum, women’s gendered identity is one component that shapes how breast cancer survivors reconstruct their sense of self in order to manage their needs and long-term QOL.

**The Intersection of Feminist Psychology and Women with Disabilities**

Rarely has traditional feminist psychology considered the influence and impact of disability on women’s lives (Banks, 2010). Instead, feminism has focused its attention on women’s strengths, discounting their weaknesses including those resulting from a disabling condition (Banks & Mona, 2007). However, a disability, like a cancer illness, is an identity category for a woman that she can enter at any time in her life (Garland-Thomson, 2002). Furthermore, a disability, like a cancer illness, reveals the dynamism in one’s identity, reducing the cultural belief that women’s bodies are the “unchanging anchor of identity” (Garland-Thomson, 2002, p.20). It also undermines our fantasies of a stable, enduring identity by
highlighting the fluidity of our self-concepts (Garland-Thomson, 2002). Thus, like a cancer illness, disability confirms that our identities are always in transition; it invites us to question what our identities truly depend upon as our bodies constantly change (Garland-Thomson, 2002).

Embedded in western society is a desire for physical perfection, applauding those who are sporty, good-looking and well-functioning (Barnes, 1996). Cultural messages of beauty, symmetry and wholeness are constantly reinforced and significantly impact the way we perceive ourselves and others (Thomas-Maclean, 2004). Consequently, women with disabilities become one marked and excluded group within the larger social class of women (Garland-Thomson, 2002). The privileges of normative femininity are often denied to these women (Fine & Asch, 1988). Cultural stereotypes view women with disabilities as asexual, unfit to reproduce, overly dependent and unattractive as they are generally removed from the world of femininity and womanhood (Garland-Thomson, 2002). These women often struggle to have their sexuality and rights to bear children recognized by others. As a result, disability, like a cancer illness can both intensify and minimize the cultural script of femininity for women (Garland-Thomson, 2002). Thus, what may be viewed in society as scars from mastectomies, are now expected to be surgically erased to produce unmarked and ‘normal’ bodies (Garland-Thomson, 2002).

For women with breast cancer, prosthesis and/or breast cancer reconstruction are expected within the medical community in order to create visually unobstructed bodies after surgery. By falsifying these women’s bodies to be perceived as ‘normal’ to outsiders, the goal is ultimately for these women to go unnoticed in society with their ‘deformities’ and instead to pass as one like everyone else (Garland-Thomson, 2002). But these ingrained images of disgust and fear in society cannot be countered while women remain silent and concealed about their ‘abnormalities’. As feminist have argued in the past, “silence goes hand in hand with
powerlessness” (Smith, 1980, p. vii, as cited by Wilkinson, 2001) and until women with breast cancer can freely show and tell their stories, “it will remain a solidarity ordeal, or a gateway to oppression instead of an issue to be addressed with the public” (Wilkinson, 2001, p. 273).

The notion of being silenced or powerless as a women with breast cancer is further discussed by Wilkinson (2001) who identifies two important sets of coercive discourses that have traditionally oppressed women with breast cancer. The first outlined is the discourse of concealment. While women with breast cancer are initially allowed to express distress, shocks, or horror from their illness, the time and space identified for this process is highly circumscribed (Wilkinson, 2001). Soon after her diagnosis, she must “resume her social duty, be seen to brave unpleasant treatment with courage and humour and then return to living a normal life once again” (Wilkinson, 2001, p. 270). She explains that women with breast cancer are expected by society to resume their normal obligations with no discrete signs of loss, no allowance for grief, and no acknowledgement that their world has forever changed (Wilkinson, 2001). Therefore, concealment of distress, anxiety and fear from others becomes part of the breast cancer experience. One woman described her experiences by stating, “we become very good at behaving ourselves, especially as women – we’re very good at hiding what we feel and just putting on a brave face for everybody else” (Wilkinson, 2001 p. 271). As a result, the thousands of women that undergo breast surgery each year for cancer are a completely hidden population. Furthermore, this particular discourse is reinforced by the medical and fashion industries. Within the medical community an, “absolute routine assumption” exists that after breast cancer treatment, a woman will be fitted for a prosthesis (or breast reconstruction) so that her outward appearance to the world is unchanged and no one will know she has had cancer (Wilkinson, 2001, p. 271). Within the fashion industry, post-surgical images of women’s bodies are rarely
seen in mass media, and when they are, they are usual located within a narrative of horror (Saywell, Beattie & Henderson, 2000).

The second discourse Wilkinson identified was the notion of personal blame and responsibility for their illness. Traditionally, in both medical and popular literature, women as a group, have been blamed for getting breast cancer because women’s bodies were seen as inherently diseased and prone to malfunction (Wilkinson, 2001); as individuals, women were also to blame because of their personal reproductive or lifestyle choices (e.g. oral contraceptive use, excessive drinking, smoking, too few children, delayed childbearing, etc.). Furthermore, women who resisted sex-typed feminine norms and domesticity were also portrayed as culpable (Wilkinson, 2001). Therefore, this discourse emphasizes that the responsibility of cancer derived not just from who you were, or from what you did, but also from how you thought as well.

Over the past few decades, there has been an increased emphasis in psycho-oncology literature that correlates cancer morbidity and mortality to psychological states and functioning. One ongoing message found in this literature is that individuals are to blame for contracting breast or other types of cancers because of their habitual dysfunction and/or coping styles (Wilkinson, 2001). As a result, patients are also seen as responsible for the recovery from their breast cancer by developing a ‘scientifically tested’ coping style that emphasizes positive rather than negative thoughts and attitudes (Wilkinson, 2001). However, it may also be important for many of these women to resist the notion of positive thinking (Wilkinson, 2001). Positivity as a coping style is not necessarily suited for all women (Wilkinson, 2001). Instead, other less common coping strategies may be more beneficial for some individuals, due to their worldviews, particular social contexts and life circumstances. Therefore, it is vital for these particular women to state their ‘moral oppression to positive thinking in cancer’ and instead actively resist being
placed in victim-blaming ideations (Wilkinson, 2001). Denial, isolation, victimization cannot be overcome until women are able to speak freely and candidly about their experiences as cancer survivors (Wilkinson & Kitzinger, 1993).
CHAPTER II

The Present Investigation

The present study aimed to add to the existing literature in a number of ways. First, by conducting a qualitative study that focused on the identity reformulation process in young survivors of breast cancer, the study utilized an alternative approach (in contrast to the existing four prescribed QOL domains) used to examine survivors’ psychosocial wellbeing.

Second, unlike the majority of studies explored on young breast cancer survivors, the present study explored retrospective information about women’s pre-cancer selves (as retrospective baseline information). This approach could help clarify any changes that occurred after the cancer experience.

Third, utilizing a life history approach, the study examined both current challenges and solutions described by women, while holding a critical lens to research participants’ diverse life contexts, including: the nature of their partnerships and friendships, their economic realities, or dominant values regarding women’s roles and identities. Indeed, the life history approach emphasized current challenges and solutions within the context of lifelong social experiences (Cole and Knowles, 2001). Studies conducted thus far in the field have de-emphasized situational factors, diverse social locations, and any pre-diagnosis baseline information in shaping the process of healing and the experiences of young breast cancer survivors. Adopting a life history perspective therefore allowed for a greater emphasis on the social and historical context of the phenomena under study.

Fourth, implementing a critical feminist perspective in this study served as an important theoretical lens for young breast cancer survivors, particularly among women oppressed by social and cultural experiences during their cancer experience. A critical feminist perspective
also helped examine the way breast cancer has changed their experience in relation to widely sanctioned social expectations and structures.

Fifth, by focusing on young survivors’ healing journey after treatment, the study emphasized protective factors and creative problem solving solutions, in addition risk factors and adverse challenges. To date, a paucity of research exists on young breast cancer survivors’ personal reflections on protective factors in relation to their long-term care. Thus, the present investigation included protective dimensions of the healing journey, not reflective of research studies conducted to date. By focusing on intra-individual risk factors (avoidance coping) leading to poor QOL, researchers to date, have focused on a pathological formulation of the healing journey. However, as Bloom (2008) pointed out, we must shift our focus. Rather than finding the perfect approach to “cure” a survivor from any psychosocial problems, perhaps we should examine processes of healing through the social location of survivors. In the 1998 edition of Our Bodies, Ourselves for the New Century, Yanco and Norsigian wrote, “conventional medical care, with its heavy emphasis on drugs, surgery, and crisis intervention, sometimes helps us when we are sick, but it does not always keep us healthy. To a great extent, what makes us healthy or unhealthy is how we are able to live our daily lives” (p. 29).

For many women who have just become breast cancer survivors, the healing journey is a socially and culturally located process. Respecting survivors’ own healing journey is an aspect of accepting diverse processes of healing and the multiple factors that shape these diverse processes. Western concepts of ‘cure’ may not reflect the complexity of a healing process. For example, in one woman’s narrative regarding her healing process after trauma, she articulates the problematic nature of the ‘capitalistic’ mentality of healing in the Western world, “…I find that the world is not really structured for people to heal…it’s very capitalistic. It's a capitalistic form
of healing, get over it really quick, fast, easy” (Batacharya, 2010, p.206). She argues that the openness to a healing process is far less appealing in a product-oriented consumer culture, especially if this process is difficult, time-consuming and if a desired outcome might not be guaranteed. The present investigation examined the journey of healing from survivors’ own perspectives.

The present inquiry aimed to lead to emergent knowledge that would validate and contribute to the psychosocial well-being of other young breast cancer survivors, and that would inform health and mental health practitioners supporting young breast cancer survivors in their healing journeys. This knowledge may ultimately reduce the negative long-term psychological effects of cancer and yield better QOL for women who have lived through this deadly disease.

**METHODOLOGY**

**Qualitative Research**

Qualitative approaches to research emphasize the importance of meaning individuals ascribe to their lived experiences through a very broad context (Antoniou, 2009). Generally, qualitative research is utilized when gaining novel knowledge from a unique perspective (Antoniou, 2009). To date, no research study has explored psychosocial adjustment in young breast cancer survivors by focusing on women’s sense of self after treatment. Typically, psychosocial adjustment in cancer populations have been explored using one of four pre-defined QOL domains. Moreover, a dearth of research studies exist that have investigated young women’s lived experiences as breast cancer survivors from a qualitative and in-depth perspective. In order to carry out an investigation focused on the unique challenges, needs and
coping strategies used among young breast cancer survivors within a broader social context of their lived experiences, an emergent design from a critical feminist approach was used.

Life History Approach to a Qualitative Inquiry

The goal of life history research is to utilize individuals’ lived experiences in order to construct broader contextual meaning (Coles & Knowles, 2001). As stated by Antoniou (2009), a life history approach “honours, understands, and emphasizes interpretations that individuals make of their own experiences within various contexts, including: social, cultural, political, geographical, familial, educational and religious contexts to name a few” (p.58).

Unlike more traditional forms of research that promote distance, formality, objectivity and adherence to defined relationships between the research and participant, a life history approach is different; it is guided by several distinct principles which include: relationality, mutuality, empathy, care, sensitivity and respect (Cole & Knowles, 2001). Life history researchers do not simply compile someone’s stories as if it were an objective entity that exists outside the interactions elicited in an interview; rather, it is always jointly constructed by the participant and researcher, together (Muchmore, 1999). Further, a life history approach regards the relationship between the researcher and participant as critical to the overall research quality and knowledge production of the investigation (Cole & Knowles, 2001); the approach applies a more humanistic perspective, with an importance placed on the intimacy and genuineness of the relationship developed (Antoniou, 2009). These two components of the relationship, as described by Antoniou (2009), place an emphasis on: qualities of mutual care and friendship, disclosure of respect for personal vulnerabilities and attention to relational ethics and power relations. Moreover, the researchers place fundamental importance on creating empathy in the relationship
in order to build the rapport needed to engage and elaborate on sensitive topics likely to be discussed in the interview (Coles and Knowles, 2001).

In contrast to more conventional types of research, a life history approach does not view participants as passive subjects (Antoniou, 2009). Rather, this approach uses the term ‘partnership research’ to describe the notion of mutuality and equality throughout the research process (Coles & Knowles, 2001). As such, a collaborative relationship is extremely critical to the research. Essentially, the role of the researcher is to, “preserve the meaning of the experiences and stories told” and provide, “reflections and feedback to the participant” (Antoniou, 2009, p. 59). The researcher also provides opportunities for the participant to clarify any inaccuracies or misrepresentations made while researchers collected data (Antoniou, 2009). Moreover, Cole and Knowles articulated that their task with each participant was to, “try to get as close as possible to apprehending, understanding, and rendering elements of a life as it is influenced by and intersects with pervasive and subtle forces or influences of context.” (p. 71)

Similar to other qualitative approaches, the life history approach values depth over breadth (Antoniou, 2009). This research methodology requires only a small number of participants for a more intensive exploration of their lived experiences (Antoniou, 2009). As a result, the focus of life history research is not population representativeness; instead it focuses on finding committed individuals that are willing to explore their lives in a deep and meaningful manner (Antoniou, 2009).

**Critical Feminist Theory and Situating Distress in Breast Cancer Survivors**

Most research within the biomedical, physical and even behavioural sciences is anchored rigorously in the scientific empirical method, and believes in the power of its objective truths (Sweeney, 2003). However, few researchers are aware of the historical and philosophical roots in
logical positivism and objectivity (Sweeney, 2003). Positivistic science openly explains that, “the
tasks of identifying, diagnosing and treating any disease entity is independent of and unaffected
by the social, cultural, political, or economic contexts within which both physicians and patients
may live their lives” (Sweeney, 2003, p. 76). As such, in traditional approaches to research and
diagnosis, the social context of people’s life circumstances and every day activities are stripped
away as unnecessary details in a process that “decontextualizes” their experiences (Stoppard &
McMullen, 2003). While excluding these details may create a neatly organized package of
general information for researchers, clinicians and patients, retaining this detailed information is
extraordinarily valuable, casting new light on the experience of living with a deadly disease such
as cancer. Re-contextualizing the experience of a woman who has gone through the experience
of having breast cancer enables researchers and clinicians to see her so called, “symptoms” or
“feelings of distress” beyond a pathology that requires individuals to change their specific ways
of being; but rather these symptoms or feelings of distress are seen as embedded in relationships
and a variety of social settings (Stoppard & McMullen, 2003).

Grounded in this study is the critical feminist theory, a theory which seeks to reveal
systems of privilege, transform these systems, and emancipate oppressed individuals, using
gender as the key category of analysis (Breitkreuz, 2005). By making visible previously invisible
female experiences, the critical feminist theory is effectively able to, “correct both the invisibility
and distortion of [the] female experience” while going through the painful experience of living
political, social, cultural, sexist and racist factors intersect in the field of breast cancer and this
should be recognized and incorporated into research surrounding the disease. Subsequently, the
critical feminist theory serves as a potentially validating theoretical lens for young breast cancer
survivors who are consistently oppressed by social, cultural and religious experiences while going through this deeply unpleasant experience. The need to focus on women’s lives grounded in their daily experiences and their language is fundamental to creating significant improvement in the overall long-term wellbeing of young breast cancer survivors (Stoppard & McMullen, 2003). In a narrative by a young woman named Evelyn struggling with her clinical depression and frustrated with the conventional medical approaches to research that she experienced, she passionately asked, “....have you really, really been down to our level? Do you know how we live? How we feel? Because so much of [what we are told] is way up in the clouds, and just doesn’t apply to us.” (Stoppard & McMullen, 2003, p. 139) As emphasized by Evelyn, research grounded in the lived experiences of this specific population is critical in order to provide more meaningful and adequate support.

When Stoppard and McMullen (2003) explored the lives of clinically depressed women, grounded in their cultural and social contexts, they found that this distressed group of women consistently discussed cultural standards of being a good wife and/or mother, beliefs that they should not express anger or sadness in certain ways, beliefs that they should always feel happy and fulfilled when becoming a mother, beliefs that they should keep strong for the sake of others, beliefs that they should work from dawn to dusk, beliefs that they should take care of everyone and everything, beliefs that they should strive for perfection, beliefs that they should be able to have children and work outside the home, and beliefs that they should be self-sufficient, self-reliant and independent. These types of societal prescriptions have an alarmingly powerful effect on women (Stoppard & McMullen, 2003). Given that many of these cultural standards are impossible to achieve, these women became even more overwhelmed and anxious, only adding to the distress they already felt.
Using a qualitative approach which emphasizes the social location of research participants is therefore fundamental to re-contextualizing the lived experiences of young survivors of breast cancer. Unlike existing conventional quantitative research that strips away social context, qualitative studies that hold a social critical feminists lens are able to highlight the context of people’s experiences by attending to the details of women’s lives (Stoppard & McMullen, 2003). Furthermore, such qualitative research can add a novel set of scientific knowledge about the meaning of being a young women with breast cancer; it further can provide a deeper understanding of their overall well-being and possible psychosocial distress by opening up questions about power, ideologies, practices of gender and social and structural inequalities in women’s lives (Stoppard & McMullen, 2003). This new scientific knowledge also has practical value, opening up other fruitful avenues towards better coping strategies and superior psychosocial adjustment for survivors. Using women’s narratives as a method to uncovering knowledge can be extraordinarily useful, revealing, “culturally embedded concepts and practices [within our dialogue] that are often not heard, precisely because they are so common place” (Stoppard & McMullen, 2003, p.34). Being more aware of the taken-for-granted forms of discourse that exist in our culture can strengthen the interpretive and critical analysis that will follow from these narratives (Stoppard & McMullen, 2003).

**Situating the Researcher’s Lived Experience**

In keeping with the traditions of qualitative research, a brief comment on my interests in this area of study is warranted.

My interest in this area stems from my previous work experiences as a research associate in a hospital for cancer patients, where I spent a great deal of time talking with patients and having them complete a set of questionnaires based on their experienced levels of distress. This
research experience revealed to me that cancer survivors had important knowledge to share that was not revealed through structured questionnaires. Their unique knowledge included creative problem solving solutions during their cancer experiences. For example, a man diagnosed with leukemia introduced himself to me as Jim (names used in the following story are not real names). As a research assistant, Jim and I had a very interesting and lengthy discussion about his life before his cancer diagnosis. About a week later, I saw Jim again with his brother. Instead of being called Jim, his brother referred to him as Alex, his middle name. When he noticed my bewildered look, he explained that the easiest way for him to cope with his cancer was to use two different names in order to separate his identity as a “normal person” and a cancer patient. Given that all of his family members already called him by his middle name, he preferred that hospital staff refer to him by his first name. This coping strategy appeared to work very well for Jim. This experience made me realize how important it is for individuals to find their own unique coping strategies to deal with their illness. I believe that this type of emergent knowledge has the potential to be extremely powerful and resonate with other cancer patients/survivors who may be struggling with their own issues of identity. Consequently, as part of this study and based on this memorable encounter, exploring creative problem solving solutions with survivors was an important area of the present study.

Another memorable experience that I had was collecting survey data from a young university student who was undergoing radiation therapy treatment. During our informal conversations, it appeared as though many of the support options and programs available to her were not specialized for her needs, but rather, for an older population. Although I was interested in finding out her perspective on the matter, the quantitative nature of the study I was involved in did not allow for me to have this conversation. In fact, I found that with many of the patients I
spoke to, the study’s lengthy survey could not capture the complexity of each person’s unique experiences. These ongoing frustrations I had with the research made the knowledge gained from the study appear to be incomplete. These experiences also shaped the emphasis in the current study on women’s lived experience from a broader, socially-oriented context.

**Research Participants**

Participants were recruited over a period of four months from diverse, urban and suburban areas in Southwestern Ontario. This location was chosen because of its convenience to the researcher and also because of its diverse population. Women with diverse ethnic and class backgrounds were recruited to ensure a wide range of cultural and social perspectives of young women living in Canada. The age range of 20-45 at diagnosis was selected as it encompassed an atypically younger population of survivors who were of childbearing age, had not reached menopause and/or had children of school age (Dunn & Steginga, 2000). The women invited to participate in this study were diagnosed with carcinoma in situ, stage I, II and III cancers only, allowing the researchers to focus on issues surrounding adjustment to their daily lives as opposed to issues about mortality that may be more apparent at a more severe stage of cancer. Furthermore, women selected for this study completed treatment at least six months since the interview. Exclusion criteria in the study included: women diagnosed with breast cancer over the age of 45, women with Stage IV cancer, women treated for breast cancer less than six months ago, and women with an English comprehension level that was less than Grade 5. Participants who met demographic criteria were invited to participate in the research process. All individuals who responded to the advertisement were able to participate. The number of women recruited for this study was determined by the criteria of saturation. As identified by Glaser and Straus (1967), saturation is defined as the point when the same themes continuously reoccur in the data with
later interviews failing to add any new information to the themes already created. Furthermore, according to these researchers, saturation is typically reached within 10 to 12 interviews. Ten interviews were conducted to reach saturation.

To illuminate the socio-cultural and medical context of the 10 women interviewed, a brief summary is provided (See Appendix H for more details). Ten women who met the inclusion criteria were interviewed for 90-130 minutes. The mean age of women at the time of breast cancer diagnosis was 37 years, ranging from 32-45. Participants’ times since completing medical treatment for breast cancer ranged from six months to 47 months. Thus, all participants were in their first five years of survivorship. All 10 women underwent surgery and adjuvant therapy. Eight of the 10 women interviewed had a mastectomy, while two received a lumpectomy. Six women were single, three women were married, and one woman was in a serious relationship with her partner. Participants’ cultural backgrounds included Canadian (2) European (3), Mediterranean (1), Caribbean (3), and East Asian (1) descent. All participants also completed at least one year of post-secondary education. Household annual income ranged from no income (on sick leave) to $100,000.

**Procedure**

This study used an emergent qualitative design with in-person semi-structured interviews (Seidman, 2006). The study explored, retrospectively, the progression participants experienced in their psychosocial adjustment following their breast cancer experiences.

To carry out this investigation, ethics approval was obtained from the Research Ethics Board at the University of Toronto. Once ethics was approved, recruitment opportunities were advertised through targeted poster (Appendix A). Breast cancer community organizations were used within the Toronto and the Greater Toronto Area including: Rethink Breast Cancer,
Caring Voices, Breast Cancer Now What, and Wellspring. A telephone and/or email screening process followed a general script (Appendix B) and ensured that all participants met the inclusion criteria and were gathered from diverse backgrounds. The screening process was also used to fully inform interested individuals regarding the nature of the study and the type of commitment needed. If the individual accepted the study, detailed contact information was collected. If the potential participant informally consented to participate in this study, then an interview time and meeting place was set over the phone/email. The formal written consent was obtained at the beginning of the first interview.

**Interview**

Upon arrival at the interview, introductions were exchanged, participants’ questions were answered and written informed consent was obtained. Participants were also provided with the opportunity to sign a request for information form indicating their interest in receiving a summary of the research results (Appendix C). All participants made this request. After consent was obtained, each participant was asked to choose a pseudonym to be used throughout the data collection, analysis, and report phases of the research project. This pseudonym ensured anonymity was maintained for each participant involved in the study.

Participants were interviewed once. Interviews ranged from 90-130 minutes in length. In each interview, guiding questions (Appendix D) were used to ensure that information pertaining to young women’s identities in the context of having been diagnosed and treated for breast cancer was covered with each participant. Three central questions raised included (1) challenges faced in relation to a changed sense of self, (2) the reformulation of identity as a cancer survivor, and (3) the creative problem solving solutions used to lessen any long term discontinuity between past and current experiences of self. These questions were explored within the contexts
of physical, psychological, social, vocational, gendered and parental life domains. Specific probes were used as needed, including: the impact of body deconstruction, motherhood, beauty and body image, sexuality, media and fashion industry, and family relationships, in relation to identity as a breast cancer survivor. Participants were further asked to explain in detail how these probed areas changed before and after their cancer experience (Seidman, 2006). The interview also explored participants’ presently lived experiences in relation to their current identities as well as the meaning they ascribed to these experiences (Seidman, 2006). Beyond the basic probes, the researcher followed participants in their discussions of their experiences, promoting, “a wide latitude of responses and richer insight” (Antoniou, 2009).

Following the completion of all the interviews, a transcriptionist was hired to transcribe all interviews. A written summary for each interview was then created, outlining each participant’s story organized in chronological order. This was emailed to each participant along with the interview transcript for their review. The purpose of the written summary was twofold: (1) to elicit feedback concerning content accuracy and (2) to provide an opportunity for participants to alter their stories and allow the researcher to ask clarifying questions about the data collected (Antoniou, 2009). Summaries and transcripts were revised based on participants feedback and clarification. Providing participants with an active role in the current study was essential to the critical feminist, qualitative approach in this research process. Overall, participants’ summaries were well-received with only minimal revisions regarding demographic information, specific treatment regimens and/or timing of significant events.

Data Analysis

In qualitative research, data analysis is an ongoing and flexible process (Antoniou, 2009). In the present study, the researcher kept ongoing field notes about her impressions, thoughts, and
key issues that presented as salient during the interviews. These notes ensured that the researcher
remained closely connected to the way her own experiences informed the interviews and data
analysis (Charmaz, 2006).

The systematic process of coding occurred once all 10 interviews were completed under
the supervision of graduate supervisor, Dr. Piran. Data analysis was conducted using QSR Nvivo
9 software, a program used to manage, organize and analyze qualitative data. The process of data
analysis began by developing a familiarity with the data. Initial category development was
created with brief descriptive codes for possible meaning in each transcript. Codes were
independently reviewed and validated by Dr. Piran (Appendix E). The constant comparison
method, a central feature of Grounded Theory methodology was used to analyze the data. During
this initial process, the data was then chunked into smaller units of meaning. At this stage of
analysis, it was important for the researcher to stay closely grounded in the data while generating
as many themes as possible from a single unit of meaning (Charmaz, 2006). The next phase of
data analysis involved deriving higher level categories using the constant comparison method
(Appendix F). In doing so, the researcher compared the relationship between lower level themes
and higher level categories. During this phase of analysis, the coding scheme was slightly revised
by adding new codes and by eliminating and re-configuring existing codes as a deeper
understanding of the data emerged. The final phase of the data analysis involved organizing the
data through hierarchical theme extraction (Seidman, 2006). This process involved comparing
categories with one another in order to facilitate a process of integration (Antoniou, 2009),
leading to a comprehensive and well-represented analysis of themes, sub-themes and categories
related to young women’s experiences as breast cancer survivors. Each category was compared
to other categories as a way to identify common processes in order to unify and integrate higher
order categories. The structure of the coding and categories was discussed and validated with Dr. Piran.

Based on the core categories, categories, themes and sub-themes that emerged from the data analysis, and results are presented accordingly.
CHAPTER III
RESULTS

Analysis of the interviews revealed that the unique challenges to these young women’s self-concept, following breast cancer treatment, related to the intersection of three shared domains of social location, specifically: gender, youth, and health status. The identity reformulation process was also explored by dissecting each of these three heightened social locations. Correspondingly, three core categories emerged in the reformulation process: 1) re-locating self in gender; 2) re-locating self in youth, and 3) re-locating self in health status. Within each of these core categories, the data uncovered prominent themes that showcased physical, social, cultural and psychological factors impacting the reformulation process and subsequently women’s psychosocial well-being. Analysis of the interviews revealed facilitative factors that young women used along their healing journeys upon completion of their breast cancer treatment. Careful attention was paid to the influence of macro-social and medical variables, such as age, ethnicity, and socioeconomic status, stage of cancer, time since completed breast cancer treatment, which each contributed to the complexity of women’s life experiences as survivors.

Unique Challenges to Young Women’s Self-Concept

The unique challenges to these young women’s self-concept after breast cancer treatment encompassed variables that related to the intersection of three domains of social locations: gender, youth, and health status. Five categories emerged as unique challenges to women’s self-concepts including: 1) betrayal of the body; 2) sexuality and dating; 3) fertility and adoption issues; 4) role changes in close relationships; and 5) disclosing a cancer identity. Nonetheless,
several women also noted that while these challenges were apparent after treatment, they were also quite fluid and amenable to change over time.

**Betrayal of the Body**

Majority of the women interviewed discussed an altered relationship with their body after a breast cancer diagnosis. Although disbelief and feelings of betrayal are common reactions among women who have received a breast cancer diagnosis, these reactions may be more enduring among younger women because of their particular life stage; younger women enter a stage in their lives where they feel physically invincible. A cancer diagnosis shatters these assumptions about their bodies, leading them to feel a sense of betrayal and distrust in their bodies.

Judy captured her sense of invincibility being shattered by her cancer diagnosis.

*...You think you’re invincible and that it will never happen to you. You think 'my god' it’s one thing if there’s some family history or anything like that, but there wasn’t. Because you’re so young you think that can’t possibly be true. So yeah, I was confident and thought I was invincible.*

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

Jessica described feeling betrayed by her body when diagnosed with breast cancer during her second pregnancy.

*I felt a bit cheated as a woman because I thought... it crossed my mind because it happened during pregnancy and I thought ‘Ugh, here I am doing what I’m supposed to do and that’s what your body does and you know, people call it your temple and that’s to...*
create and you’re so happy you’re pregnant.’ At the same time it kind of betrays you by…

having this thing grow inside of you.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Olivia described feeling betrayed by her body in relation to her career. She wanted to be able to
do more than she was capable of after her treatment.

Going back to work, the hardest thing to realize is I can’t do as much. I’m still tired. I
can’t do as much as I would like to do or as I should be able to do as a relatively young
person.

(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

Abigail identified the betrayal of her body in relation to her sense of independence.

I always thought I’m going to be independent; I’ll be able to look after myself and
manage things for a long time where I realize that’s not the case...I knew how to take
care of myself so getting sick from being perfectly healthy to Stage III was a big shock to
me and I feel that my body had betrayed me, that my body has let me down.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

Among the women who felt let down by their bodies, they also developed a sense of shame and
distrust in their bodies. When reflecting on her body’s journey before and after her cancer
diagnosis, Alexandra discussed the shame she felt as she noticed the significant physical changes
to her body.

Before being diagnosed... it was the first time I was really proud of my body. It was the
first time I felt really attractive and pretty, I guess again it was tied to turning 40 but
looking, because I was running, I thought I looked younger. I was proud of my body.

Now, I am not at all. I’m embarrassed. I’m ashamed. I’m trying to go out with my friends and stuff whenever I have the energy and I’m pretty embarrassed about the way I look.

(Alexandra, age 43, low SES, Caucasian, Stage 0, 12 months since trx)

Ultimately, several women explained that the betrayal and shame led to an inability to trust their bodies and its physical sensations.

It’s almost like me being now hyper vigilant. Like my ankle hurts, why is my ankle hurting? Is it because I’ve been on my feet for too long or is it the shoes I’m wearing? Or is it the medication? It makes me more nervous because I don’t trust myself as far as being able to tell what’s going on with my body.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

Sexuality and Dating

Sexuality. Some variability existed in the way that young women connected their breasts to their sexuality post treatment. Suzie and Olivia, two single women in the study had strong connections between their breasts and sexuality prior to their cancer experiences. Both women discussed shifts in the way they maintained these connections as survivors.

I think one of the biggest things was I was losing the breast and what that meant. How it meant physically and not having a breast and what that’s like. What that would mean sexually, down the road, the loss of a sexual part of you. Not just physically how you look in clothes but the loss of no one’s going to touch me there. That would have been
something that I would have enjoyed and that would be gone. The loss of some sort of sexual pleasure.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

...to me they’re still a part of my sexual identity, they’re still sensual entities, right? They’re important to me for that. Not in the sense of attracting another person, it’s just to me, they are important for my sexuality, not my sexuality as it relates to somebody else.

(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

After medical treatment, other women in the study developed a stronger connection between their physical appearance and breasts in order to feel like sexual women again. Kelsey, for example, decided to take control of her outward appearance and get breast reconstruction surgery.

I wanted to feel like a sexual woman and I put the emphasis on the fact that both my breasts didn’t look normal anymore, I’m going to pay for them to look good.

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Regardless of the connections formed between breasts and sexuality, several women rejected the notion of feeling physically older or different than the norm and thus less sexy after their breast cancer experience.

I feel this need to tell people ‘I’m you!’ You hear people saying that all the time that like ‘I feel like I’m 40 years old and I’m 70’. I don’t want to see myself as someone who is past her prime, you’re not really sexy anymore, the sexy people are the ones who are 22 and you’re 43 and on top of that you don’t have a breast and you’re bald.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)
However, others, like Alexandra, accepted the notion of being physically different from the norm and ultimately felt a loss of sexual identity.

*I have no, zero, sex drive. I don’t know what happened. I don’t know how to explain this but I have zero sex drive. I think part of it, I know my breasts were really super-sensitive, and actually the oncological surgeon said to me, actually because of that, that’s probably why you’re in more pain than usual because they were really sensitive. It was very much connected to my sexuality and now I have no feeling on my breasts or whatever they are….I lost a big part of my sexual identity.*

(Alexandra, age 43, low SES, Caucasian, Stage 0, 12 months since trx)

Majority of the women diagnosed with more aggressive forms of breast cancer also candidly shared that their sexuality was not a priority immediately after treatment. It took some time before women could feel that they had some sexual identity.

*Right after treatment, it wasn’t something that was at the forefront of my mind, I was living, I was happy and everything was good. I didn’t really look at even, do I feel sexy? Whereas now, I can definitely say, I do. I feel like a sexy woman. How did I progress here? I don’t really know I’m not really conscious of how that happened. If I look back I know it was not at the forefront of my mind before, whereas now I can’t say that it has fit into my consciousness.*

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

**Dating.** One area of significant concern for the single women in the study was re-immersing themselves into the dating world.
The idea of dating with this baggage, well different type of baggage. That was I think a challenging thing as a young female... Prior to the diagnosis, I was doing different things like speed dating or other things, now I’d be reluctant to do that now because, I don’t know what but probably because of the grey hair, but also it just feels different somehow. It feel like if I were to be dating that I’d be presenting a false self, not necessarily in your speed date do I think you should go oh by the way I had cancer, but it sort of feels like is that wrong to go on a speed date?

(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

Olivia, as well as the other single women interviewed had concerns about revealing her cancer experience to a potential partner. The women were unsure when would be the appropriate time to reveal this personal information. Olivia, in particular, had concerns about presenting a ‘false-self’ by keeping her cancer identity confidential; in doing so, she questioned whether she would not represent who she had become since her breast cancer experience.

The majority of single women interviewed who were less than one year since they completed medical treatment spoke about dating becoming more difficult and less opportune after their cancer experience.

I wasn’t a big dater to begin with. I would say now I’ve kind of come to the conclusion that it’s going to be even more difficult for myself. I think I view the dating situation now as being more bleak.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

... I’m so embarrassed about how [my breasts] look, I don’t think I’d show them to anybody anyway. That’s how I feel, I honestly think there’s no way I’d let anybody touch
them. I’m single right now and I’m not in a relationship but even, I couldn’t imagine if
down the road, I got into a relationship and as you can imagine, even having them
touched, it freaks me out. I don’t feel like a woman.

(Alexandra, age 43, low SES, Caucasian, Stage 0, 12 months since trx)

However, unlike the other single women who completed treatment less than one year ago, Claire
discussed a noteworthy romantic relationship she had with another cancer patient. The attention
and interest she received from her new partner helped boost her self-esteem at a faster rate than
several other women interviewed. Claire quickly began to feel more confidence in her physical
appearance.

One interesting thing that happened to me was that in the [support centre for] 20s and
30s group, the first one I went to was in March which was two weeks after treatment
finished. I ended up meeting a guy there. So, that relationship grew very slowly but it did
grow. To have another cancer survivor, as in his scars were bigger than mine kind of
thing. As in I felt very comfortable and safe with him. Again, I was not looking for a
boyfriend, for any type of relationship with a man having just been fresh out. I still had
burns on my body when I met him but I do think the relationship made sense... because
he was in my life right after it’s like I wasn’t given a chance to feel horrible about my
body. It was still something I was worried and conscious about with him but because we
took it really slow, it was 2-3 months that everything was fine. Had I not had that, right
now I would probably be horrified and extremely scared about meeting a normal guy... I
think it’s an ego-boost.

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)
The single women who completed medical treatment over one year since the interview appeared more optimistic about dating. One woman discussed her personal “progression” in her cancer journey; over time she felt she reached a state of acceptance of her body. Thus, she felt ready to take the next step forward and begin dating. Questions about potential partner’s level of acceptance of her cancer experience and her altered body were explored.

For me myself, I definitely have seen the progression. I guess it comes to where I am along that road with my acceptance. So yes, I was fine with my body but I did not know if someone else would be fine with my body. How would I approach that topic with them? How would I even start that when you’re getting to know someone? When do you start to share that? Actually, it’s been a part in my life that I haven’t gotten to that point in terms of my relationships and interacting with people, with a potential partner where I’ve had to share just yet. I’ve definitely thought about what that would look like and again, I think now because I am in a much stronger place of acceptance, my self-esteem is great, I am ready to definitely take that step. I don’t think I was as ready after treatment, just having to go through that discussion with someone and their reaction...If I happen to broach the topic with someone it’s not something that they can’t handle, then they are not the person for me. I think I had that thought process before, I just didn’t know how well I would execute it. Now I feel sure that I would be able to execute and move on without any melodrama.

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)
Fertility and Adoption

For some women, the diagnosis of breast cancer was the first time they had been forced to confront issues around fertility and the possibility of not having children.

*I think also I hadn’t really thought about… fertility. You’re forced to think about things that were not first and foremost in your mind.*

(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

Since majority of women had to face fertility issues head on, several women were forced to accept the reality of their situation; a reality without a traditional family and biological children of their own.

*I mean there was a time when I was diagnosed and better after my treatment I went through the 'oh my god, I want to share my life now that I have a life with somebody'. Children. Not somebody because I have a husband but little ones. But I dunno, it’s been so long, so many years that I'm done with waiting. I just want to move on with my life, especially after this last surgery having a clean bill of health. You know the pathology report coming back showing no cancer. I just want to close that chapter in my life and move forward. For me it doesn’t have to include children. I guess at one point the cancer did affect my decision.*

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

Abigail shifted her plans to adopt a baby to suite her current reality after her cancer experience.

*[Prior to my diagnosis,] I was thinking that I would probably go to Russia and adopt a boy since that’s more readily available in Russia from a young age. I’d be able to bring him back to Canada and have family, my own family. From what I understand having
had cancer and at my age, that would be more difficult. I guess there’s a possibility I could still become a mother if I took on an older child but that’s not really what I pictured. Even if that were the case, realistically I have to think well, what would happen if I became sick again? Whether it was a young child or a child in their pre-teens, what would my plan be? I don’t think it’s fair to expect any of my family or friends to be able to step in and I have to have that long-term picture. In the past I wouldn’t have thought about that long-term picture but with me now that is my new reality. I can’t assume that I’m going to be around in ten years.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

In contrast, Kelsey had never been interested in raising children; thus, having a prophylactic orchiectomy after her breast cancer treatment did not shift a pre-cancer identity or future plans.

I’m having my ovaries removed in a year and a half. I couldn’t care less because I don’t want children.

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Role Changes in Close Relationships

The young women interviewed consistently reported new challenges faced to their self-concept in their relationships with close others after completing medical treatment. In particular, the women described role changes that occurred as a 1) mother to young children; 2) daughter; 3) partner; 4) sister 5) friend to other young women

Mother to young children. One area of greatest concern for women who were mothers at the time of diagnosis was their children. Given the young age of their children, who were
typically toddlers or pre-adolescents at the time of diagnosis, these mothers had significant concerns for their children.

The cancer experience is one that can alter the role that mothers play in their family; it can change what young mothers are physically and emotionally capable of doing for their children.

As Jessica shares,

_Everybody says ‘you’re the CEO of the family’ and all of a sudden for the CEO to fall apart it doesn’t look very good._

(Jessica, age 39, Korean, Stage III, 10 months since trx)

All the mothers in the study came to a heightened awareness about what is most important while raising young children.

*I think a lot when I’m raising kids that we live in this time that you just want to shelter kids from anything bad. So if you think that nothing bad ever happens then everything will be okay. The opposite of bad is good. Instead of that, I’m really trying to think life experience is good. That’s what living is. It’s experiencing what life has._

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

So, I think as a parent now I have a bit, for myself, more of an urgency when it comes to teaching them things… to be a better… to be a person that will actually contribute to society in that respect. I find that now I want to create memories all the time… I always want to create memories… do special things to create a memory. Like Halloween this year was special…for Halloween I had like 22 kids over because she just loved it and she keeps talking about it. Will she remember 10 years from now? I’m not sure. I know from
now till next year this is all she’s going to talk about. And then she’ll have that happy
association so I guess, for me, that has changed.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Jessica emphasized that her outlook on parenthood has changed based on her own fear of
recurrence. She had some concerns about not having enough time to teach her children important
life lessons.

*I just want to teach them as much as I can now because you’re a bit uncertain of the
future. So some of my friends think it’s a little bit nutty. But I’m like let’s say 3-4
years... ‘Yeah, in that 3 years I have to squeeze in what most parents squeeze in, what, 25
years?*

(Jessica, age 39, Korean, Stage III, 10 months since trx)

After her cancer treatment, Elizabeth articulated that she had to redefine what it meant to be a
mother to her young child.

*If anything it’s made me reconstruct what a mother is...It’s been a real sort of struggle
on finding balance or trying to redefine the relationship and not be afraid of being alone
with my three year old. I kept thinking how am I going to entertain him? I’m sure that
some people find that regardless of history, three year olds are hard to entertain; it’s just
been an added... I developed this feeling of I can’t do it by myself. I still feel very nervous
about doing it by myself. I do it every day by myself but I can’t say I look forward to it.
Where I think I should look forward to spending time alone with my three year old. I find
it more... anxiety provoking.*

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)
Unlike the young mothers in the study, some women were focused on having their first child. Prior to her diagnosis, Judy, for example, had unsuccessfully tried in vivo fertilization to get pregnant with her first child; however, after her cancer experience, Judy realized over time that she would not have biological children of her own. This led to a shift in her perspective on motherhood and family; she explained that she was able to accept the possibility of creating an “unconventional family” for her future.

*I'm now at the point where I don't even need to go through this international adoption, it's been so many years. I'm completely fine with it. I'm sure other people would have a different outlook... We are going to have an unconventional family, just because we don't have children be it adopted or biological, we've got lots of nieces and nephews and lots of friends with kids that we'll be a great aunt and uncle.*

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

**Daughter.** After a cancer diagnosis, many women described roles change as daughters with their mothers. Shortly after Judy was diagnosed with breast cancer, her mother was diagnosed with multiple myeloma. Judy felt a responsibility to be a strong support system and caregiver for her mother, while she was going through her own medical treatment. She focused her attention on the well-being of her mother while going through her medical treatment. Judy shares her experiences,

*Well, I am an adult but I felt like I had to take over that role as the parent when my mom got so sick... I felt like the roles reversed because I had to be the strong one, I had to step up to the plate.*

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)
She also mentioned that she and her mother developed a deeper bond as a result of their shared experiences. Their closer connection helped facilitate a shift in their relationship.

*I could literally walk a mile in her shoes and she could for me. There were days when we were both having chemo treatments the same time... Now, if anything else, we are on the same playing field. I have always considered my mother like my best friend and that’s just been reinforced after everything we’ve gone through.*

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

Other women discussed having to support their mothers through their cancer journeys. Elizabeth discussed how her relationship with her mother remained stagnant during and after medical treatment. She described feeling frustration with her mother who continued to view her as a “sick person” after her illness.

*At first she would call me every day and that was fine. I sort of wanted to... vent... is not the right word but talk it out kind of thing. Her calling everyday didn’t stop. Sometimes I almost feel like I’ve been counselling her through my breast cancer more than her supporting me through it....sometimes I feel like she almost still needs to focus on the fact that I had breast cancer that I was sick... almost treats me like I am sick even though I’m not. Instead of her moving on. It’s like ‘Come with me, Mom!’*

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months sincetrx)

Some women described having some difficulty sharing their cancer experiences with their mothers, as they did not want their mothers to suffer through the pain that they were experiencing.

*[My mother] lost her husband to cancer and now her daughter had it. I made sure that I had other people to talk with. Again between the social worker, I eventually got into see*
the psychiatrist because I can’t afford to see a psychologist and now I’m seeing a 4th year resident in psychiatry but I knew not to burden my mom with too much because I didn’t want to just download everything.

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)

Partner. The women in the study who described having difficulties with their current partners prior to their illness highlighted that their cancer experience triggered a desire for more in their romantic relationships. Suzie explained that for many years, she was not completely satisfied in her marriage. Her husband was clinically depressed and as a result she felt obligated to take care of him along with her three children. She struggled to accept that her husband had rarely been a good caretaker to her children. Moreover, she felt an enormous amount of responsibility to stay in the marriage given her religious and family values. In the interview, she discussed how her cancer diagnosis catalyzed her decision to leave her husband.

We were very unhappy for a long time and wrestling with it because neither one of us wanted to be divorced, obviously. We both are very committed to marriage, the institution of marriage... So, when I got diagnosed with cancer I thought to myself if I’m staying in the marriage then I don’t want chemotherapy, I’m not doing surgeries, I’m not fighting this to live like this. When I said that out loud, my husband knew how deeply unhappy I was but also he was so deeply unhappy that he said ‘Then this is crazy, why are we doing this? We shouldn’t be together’.... And cancer feels like a wakeup call. You can’t look after everybody...So I’m like we need somebody here who is not sad, who is coping and actually likes being with the kids. That was already in me and cancer hyped it. Cancer brought them to the forefront in a more concentrated and intense awareness.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)
Similarly, another woman’s cancer experience impacted her decision to leave her romantic relationship. Once Kelsey recognized a desire to change her romantic relationship, she hoped her partner would want to make these changes with her. She discussed the difficulty she faced when dealing with a partner who was unwilling to accept new changes to their relationship.

_It wasn’t good enough for me to do the things that I had been doing. You know, you get on a routine when you’re in a relationship, we lived together, too. Some nights we’d go out for dinner, he’d watch this TV or that TV or go see these friends and I realized it wasn’t good enough. I told him I wanted change and I was bored and he thought there was nothing wrong and why can’t you be satisfied with what we have. It just all blew up into and I’m leaving sort of thing._

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Ultimately, Kelsey realized that her values did not align with his any longer and she was not willing to compromise.

_I realize that when I thought we were on the same pathway he really wasn’t and I was going to compromise to him and I realized I don’t want to compromise, I don’t need to compromise, I’ll find somebody else who wants the same things as I do._

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

In contrast, several women described a positive outcome that the cancer journey had on their romantic relationships. Jessica identified that while her relationship was tested during her cancer experience, their solid foundation kept their relationship intact.

_Oh we’ve gone through hell and back. I said to him ‘Good thing you have a good foundation.’ We have a very good foundation...so pretty much if a tornado came and_
ripped everything apart, and tore our whole house down. I said we’re so strong that we’d be building it up.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

**Sister.** Several women identified that their roles as sisters shifted after a cancer diagnosis. Olivia self-identified as the “baby” in her family. She explained that her two older sisters always treated her like a child, prior to her illness. She also admitted that she received lots of support and care from her siblings as an adult. The role as the “baby” in her family sometimes agitated her. Reflecting on her cancer experience, Olivia explained,

*I guess [my cancer experience] allowed me to be okay being the baby in the family at that point. I didn’t rebel as much about it.*

(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

While Olivia accepted her identity as “baby” of the family after her cancer experience, she also perceived her role as a sister shifting in other ways; after her cancer experiences, she took on more of the “protector role” for her two sisters.

*I do feel now there I have been more of a protector role because I have the [breast cancer] gene. I really want my sisters to get tested. It was really hard for me when the other sister, she still doesn’t want to get tested. It’s really hard to let go of that. It’s her choice to get tested and Wellspring is great as far as cancer support, they offer you three free counseling sessions with a psychologist. And the psychologist said to me, well it is her choice, it’s not yours. That’s a thing for me. I sort of want if possible to prevent anyone else in my family from having breast or ovarian cancer. So I just feel like okay, if we could just get everyone tested, we could figure that out. That’s one thing that’s changed.*
Another woman felt that her identity as a sister was altered after her cancer diagnosis. Prior to her illness, Abigail self-identified as the caretaker in her family, particularly to her elderly father who was diagnosed with terminal lung cancer; this aspect of her identity was challenged.

_I’ve had to relinquish some of that [role as caretaker] and have my sisters pick up where I have left off. I guess because my sisters probably would admit that I’m closer to my dad than they are. I know that they try to take some of the responsibility or take some of the onus off of me to help out. I don’t know if it’s as effective but I think it’s good that they are more involved, but it is hard for me to take a back seat... even like last Christmas it was a source of conflict who was going to host the Christmas day festivities. I wanted to do it even though I was still in treatment, still in radiation at that time and my sisters basically... I know that they felt that they would be helping me if they took it on, but normally Christmas is at my house and not knowing how well our dad was going to be doing it was important for me to have that routine. I insisted on it but again, I know it’s because I was sick that that became an issue._

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

**Peers (young women without cancer).** A consensus existed among the women interviewed about challenges in their relationships with their peers after their cancer experience. In particular, many women discussed the heightened sensitivity they had to other women’s breasts.

_I have to tell you I’ve never been booby envy but ever since I did lose a breast I’m a bit booby envy, I never noticed... I never looked at boobs before and then, sometimes I look_
at someone and their wearing something nice and I’m like ‘man, those are nice boobs’ and then sometimes I’m like ‘but they might betray you someday.’ [laughs]. So just take care of them and love them.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

As well, many of the women interviewed discussed a sense of isolation and feeling different from other young women because of their illness experience. Suzie discussed what it was like to go to a party with her healthy young friends after her breast cancer treatment. She was instantly categorized as the “sick person”.

_I went to this party recently and realized I hadn’t seen anybody there for about a year. The last time they saw me I was bald. The whole conversation was ‘oh my god how are you? You look so good! How are you doing?’ and I was like what are they talking about? Everybody here is thinking of me with cancer. I don’t think of myself like that anymore. That feels like a long time ago even though treatment stopped a year ago._

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

Claire articulated the isolation that she and other young breast cancer survivors felt from their peers.

_I think if you just ask random people when you hear cancer what do you think? You know, they all can relate to perhaps somebody in their life who’s had cancer. Be it a grandparent or an aunt or an uncle. They generally die. It’s something that old people get. So people in their 20s and 30s can’t relate to cancer, they don’t understand it and they think they’re like well wait a second, you’re healthy, you’ve always worked-out, you’ve always eaten well, you never smoked or any of these things that means if you can get it I can get it. They can’t relate to it at all._
While older women are more likely to know others around their age who have been diagnosed with breast cancer, this is much less common for younger women in their 30s and 40s. Claire, along with several other women in the study, explained why their connection to other young people was altered after breast cancer.

Young people have lives and they keep going where your life kind of stands still.

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)

**Disclosing Illness (Conceal vs. Reveal Cancer Identity)**

Concealing her cancer identity. Given the potential cost, avoiding the disclosure of a cancer diagnosis entirely can be a natural response to any illness. Several women felt uncomfortable revealing their cancer identity both during and after medical treatment. Their discomfort was particularly apparent when women felt that revealing their illness would alter their desired self-concept.

Abigail spoke about the extreme measures she took to avoid opportunities that would reveal her cancer identity.

During my treatment I really tried to hide ... tried not to have people know I was going through treatment. I had a wig, I went to a different church, I stopped going to the gym that I would normally go to. It’s not that I isolated myself; I see it more as I was protecting myself and I did just not want to have those conversations with people.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

Claire spoke about concealing her cancer identity.
Throughout you feel like you’re in the closet, like you’ve got this big secret kind of thing. That’s what my choice has been thus far.

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)

While Kelsey decided to share her cancer identity with her long-term partner after her treatment, she continued to struggle sharing illness-related experiences, or aspects of her self-concept that highlighted her illness.

I can’t let him see my hair. Then I feel I look sick again or I don’t feel I’m the me I’m portraying. Because we live together now... I have a game with myself that I don’t want to tell him that I’m going to do this, I’m going to do that, I’m going to see that Doctor but then I get upset when he’s taken his mother to her appointments or his daughter gets sick or something and he’s looking after her, because I never allow him to come to any of my appointments.

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Kelsey also provided an explanation for her desire to conceal her cancer identity around others.

I didn’t want people to feel sorry for me or treat me in a different way, or ask too many questions. That’s a big one too. Once you say something like that... I couldn’t explain to you every single drug I was taking and treatments I had on this and that, so for someone to keep asking me all this, I don’t have patience for that. A whole bunch of things: privacy, patience and feeling sorry for me... I think it still comes down to the same thing that I don’t want somebody to look at me like a victim.

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Kelsey was adamant throughout the interview that she did not want to be portrayed as a “victim”.

In fact, she felt that no young breast cancer survivor should be forced into a victim role. These
strong sentiments were an important reason behind her decision to conceal her cancer identity and maintain a strong sense of self.

Similarly another woman felt a need to conceal her cancer identity from others. Olivia felt that that her illness was not a significant aspect of her current identity or who she wanted to be portrayed as to others.

*If people get to know me first and think she’s one crazy, funny person who maybe you’ll never find out I had breast cancer. I don’t know if it’s necessarily concealing it’s just that I don’t necessarily want that in my identity right now.*

(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

Finally, several women spoke about the stigma that still existed with a breast cancer diagnosis. Given Judy’s personal experience of being stigmatized for her illness in her workplace, she felt it was necessary to conceal her cancer identity at her new job.

*So when I got this job, it was fairly new, I kept it from everybody and I didn't tell anybody because I wanted them to view me as a capable, competent individual who could do their job without any baggage*

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

**Revealing her cancer identity.** Alternatively, several women highlighted that they felt comfortable revealing their cancer identity to others once they had good prognoses of their illness. Their self-concepts were no longer rooted in a “sick-person” role, facing their own mortality.

*Then I came home and I was like ‘I’m cancer-free!’ All of a sudden I was telling anybody and everybody because I got the best news ever.*
(Jessica, age 39, Korean, Stage III, 10 months since trx)

*It was only when I could say to them ‘yeah I’ve got cancer but the prognosis is good for now’ that I could tell them.*

(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

Although Suzie brought up the notion of shame in identifying herself as a woman with breast cancer, she felt it was necessary to reject feelings of shame by revealing her cancer identity to others.

*There is this little bit of shame but I think if you talk about it then it’s like I don’t need to be ashamed by this. I don’t need to be embarrassed by this. I would never think that about somebody else.*

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

However, several women pointed out that they did not always have control about when their cancer identity was disclosed. Jessica shares,

*When I joined the running room there’s a nurse, and we finished the running room clinic; and afterward she kind of asked me ‘So, how did you get that?’ and I think in that profession they know that you went through something. So she just asked. That’s the only thing that I can’t conceal is the little scar.*

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Similarly, Suzie described a lack of control she faced when disclosing her cancer identity as a result of being bald from the chemotherapy. During her treatment, Suzie was uninterested in wearing wigs. As a result, she highlighted an inability to hide personal and private aspects of her life. Similar to her experience separating from her husband, she could not control being identified by others as a sick person.
To walk into the world and tell people I’ve been separated is very similar as walking into the world as bald with cancer. It’s like you can’t hide it, you can’t pretend that you’re perfect, you can’t pretend that you’re something you’re not. It’s on the stage for everybody to see... I know I am being identified by others as that older woman who has cancer as opposed to being me.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

Identity Reformulation after Breast Cancer Treatment

The young women in the study faced a vast number of challenges to their self-concept after their cancer diagnosis and medical treatment. The challenges that were most apparent in the present study were related to three aspects of social location shared by all participants: gender, youth, and health status. To further understand women’s identity reformulation process, the three intersecting social locations were analyzed separately. Three core categories that emerged in the reformulation process included: 1) re-locating self in gender; 2) re-locating self in youth; and 3) re-locating self in health status. These core categories have shaped the transformations women described in their self experience after treatment.

Re-locating Self in Gender (Embodying Femininity)

Women in the study re-located themselves in relation to their gendered identity after treatment. Further, the study found that the process of ‘re-locating self in gender’ involved two categories: 1) gender role expectations and 2) the feminine body.

Gender role expectations. Related to gender role expectations, challenges to female identity following diagnosis and treatment were associated with several women developing a
greater connection to traditional feminine roles. For other women, the process involved rejecting some traditional feminine roles.

**Maintaining Traditional Image of Femininity.** In the present study, participants addressed certain traits pervasive to the stereotypical role of women; these included a greater focus on beauty and a healthy physical appearance, as well as a need to be a caretaker to others.

Given Jessica’s desire to maintain the societal image of femininity around others, she, along with others, felt a need to conceal her altered body to maintain a ‘feminine status quo’.

*I don’t want to shock other people this much. When I do yoga, you know hot yoga they have the showers, and I would love to just hop in but I think sometimes at the back of my mind I don’t want to make other people uncomfortable.*

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Some women’s views on traditional femininity heightened after their breast cancer treatment.

*I have this silly thing now about dresses and their feminine and pretty. The most feminine is a dress. I’ve gone to the... not extremes because that’s not where I’m going but I tried hard to make myself even more feminine.*

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

To me, having two breasts is still part of a beautiful woman so I wouldn’t want to go out without my prosthesis. That’s an indication. Even at home that’s the image that I have in my mind as well. The way a woman should look. I think having gone through this experience has made me be more careful about how I present myself...

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)
As well, several women identified a difficulty confronting the dual role as a cancer patient and a caregiver for their family members.

*As a young mom you’re trying to make everybody feel like it’s going to be okay, but it’s really hard to do when you yourself are not sure what’s going to happen but you’re trying to make everything.*

(Jessica, age 39, Korean, Stage III, 10 months since trx)

*I feel I have a responsibility to reassure them that I am well... Just by showing them, if I’m okay, they’ll be okay so you try and put your best foot forward even when you’re feeling crappy. A lot of people who are looking to me for how they would be feeling if they saw me being better then they felt better about the whole experience.*

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

**Rejecting the Traditional Image of Femininity.** In response to the cancer diagnosis and treatment, several women had a strong desire to maintain society’s traditional image of femininity. In contrast, other women were more interested in rejecting this view; however, these women had already started questioning the traditional female role prior to their cancer experience. The cancer experience, thus, helped facilitate the rejection of this traditional role.

From a young age, Suzie was placed into a very traditional female role. Although she recognized the oppression that existed for women in this role, she continued to live in it.

*I ironically found myself in a very traditional marriage being a homemaker, I didn’t pursue my career I stayed home with the kids. I kind of worked on the side part-time. Always saw that as well this is my choice, no one is forcing this on me. Now that I’m*
older I think no one really put a gun to my head on that fact but certainly I was forced with, which many women even today are with the expectation that you should marry and have children.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

She overtly rejected the image of femininity, and questioned her role as a caregiver to others after her breast cancer diagnosis.

I really feel like I was a very stereotypical pleasing woman who dedicated her life to first her husband, her children, her parents, took that role on and was a sensational wife and mother. I fit that stereotype well and I think I did a really great job within that. Then I felt I was burning out without support from a partner, I felt I’m going to lose myself here, I could feel the stress of trying to do all that for somebody and trying to live with somebody with depression. And cancer feels like a wakeup call. You can’t look after everybody... I feel like I need to look after myself, I need to follow my dreams, it’s not just about dedicating your life to other people...

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

In order to reject the traditional view of femininity, several women were forced to ‘fight’, or reject their mothers’/older women’s viewpoints, who attempted to impose societal view of femininity on them.

I don’t know whether it’s you gain more of an attachment to your breasts the longer you have them. If it’s sort of the different role or identity that women had 20 years earlier when they were learning to identify themselves as a woman. My mother kept saying ‘It’s an amputation!’ To the point where my friends and I joked that I needed a war amps tag
because I was going to be an amputee. To me, it wasn’t an amputation. It’s gone bad, we’re taking it off, done.

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)

When my doctor told me I was going to go bald I was like okay that’s not an issue for me. I’m not one of those people who care about how they look. My mom was like ‘I can’t believe you’re going to lose your beautiful hair!’ and I was like oh gosh why are you being so superficial, that’s so silly.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

Majority of the women who rejected certain views of femininity also questioned their pre-conceived notion of beauty.

It’s not about what you wear, not that it ever was before but I think you’re just that much more fine with the idea that beauty is really for me, it’s the personality, it’s who we are...

(Jessica, age 39, Korean, Stage III, 10 months since trx)

I guess now that I have one breast it feels it’s so ludicrous that society is going to define beauty and I resent that... I am experimenting with this notion of is beauty just totally socially constructed? In other words, can a scar where a breast was actually be perceived as a thing of beauty?

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

Similarly, Michelle developed a less traditional, more expansive definition of beauty.
I appreciate beauty a bit more. Just really in a general sense. I look at women and see the natural beauty pouring fourth from there. Before I don’t think I was in tune to that. I think that would be the difference. Even men, people in general, I see the beauty in us… I go out to a party or even just walking down the street I seem to be more, I don’t know if it’s more general for me but I look around and I think ‘Oh wow, we’re really just all beautiful beings, we all look different, but beautiful nonetheless.’ Whereas, before it didn’t come into my consciousness. I would walk around and see people sometimes I may see someone who I view as stunning and then it would come, it would register in my consciousness. Right now, I could just be sitting in a room and looking at someone and think ‘Oh wow, they’re really beautiful.’

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

Among the women who rejected stereotypical images of femininity, some were also able to question beliefs about womanhood. Suzie in particular shared her thoughts.

What makes someone a woman? I know it’s a socially constructed idea. So, what is a woman, can you be a woman without breasts, can you be a woman without a uterus… You think of transgender people and you think of body parts and that there’s this idea that certain body parts go with certain genders. You kind of feel like am I on some scale, am I moving away from womanhood...

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

The feminine body. In addition to re-evaluating gender role expectations and traditional images of femininity after breast cancer, many women also re-formulated their femininity through their altered bodies. These women frequently spoke about the struggle to accept themselves through their altered bodies. Jessica introduced this topic stating,
The medication you’re on for five years… the side effect[s]… mine is no hair. Mine is thin so I don’t get too much hair growth. Some women gain weight. There’s a lot of it. So we not only have to go through shit and take this medication and on top of that it’s the body image, it’s so hard in our culture, I think it sucks.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

**The struggle to accept her body.** Alexandra shared her personal struggle to accept her body after breast cancer treatment due to the chronic nerve pain in her chest.

*I have nerve pain so my recovery is really slow. Because of that, I’m constantly feeling aware of my implants and I hate them. I hate them. I want them out. I’m in pain, I’m on a lot of different medications for pain which have a lot of nasty side effects. I’m absolutely exhausted, physically. Probably because of the medication but probably because I’m in pain. I’m always aware of them and I hate that feeling... ‘It seems like you’re just butchered and its gross and anyway, I find dealing with that really difficult and the self-image issues really hard.*

(Alexandra, age 43, low SES, Caucasian, Stage 0, 12 months since trx)

Abigail disclosed the difficulty she faced finding acceptance in her sense of self as a result of her altered body.

*Sometimes in my home I still felt like myself. At other times, especially if I would catch a glimpse of myself going by the mirror, it was like a reminder; even though I’m not looking at myself I still feel like a tired version of my original self. When I would catch a glimpse it would be another reminder that you’re a sick person right now... I think to some degree still feel not as whole a person as before. I do think that I might feel like I’m*
damaged goods and if I were to start a relationship, I don’t even know how... where I
would slip that in.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

In order for Judy to feel some sense of acceptance of her body, she made the decision to have
reconstructive surgery; she did not want to live any longer without two breasts.

*I had to make the decision to have reconstructive surgery because I wasn't going to live
looking the way I looked.*

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

Majority of the women who completed treatment over one year ago found some degree of
acceptance in their changed bodies.

*It’s coming from an acceptance of who I am that my body is telling my life story. That my
stretch marks are because I’ve had three children and they were huge and I’m short and
my stomach was stretched. This breast sags, yes because I’m 42 years old and I’ve had
life experiences and I breast fed. I’m really trying to accept my body and one breast.*

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

*I’ve made myself what I want... kind of like a jigsaw puzzle. I’ve made myself what I
want to portray.*

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

*After you do your mastectomy because the incision area has to heal, you can’t wear a
prosthesis, so I was walking out with just my one breast and I was fine. I think that’s
when I realized my acceptance.... it’s an acceptance. This is the way I am now and
there’s really nothing wrong with me. I’m healthy. I think what it is I focus on my many blessings and I really have so much of them. I’m a little different, we’re all unique. I think I’m in a place of acceptance and that’s the reason for my outlook.

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

**Greater effort into physical appearance.** Many women from the study had a greater desire to put more effort into their physical appearance after their illness. For many women, this led to the decision to always wear a prosthesis in public or have reconstructive surgery. Kelsey described this journey after her breast cancer treatment. By putting more effort into her body and outward appearance after her illness, she felt empowered.

*I invested that money; it was $8000 out of my pocket. I probably could have gotten some sort of help but I wanted it now, I wanted to choose the doctor and I wanted to be in control of how it was all going to be done. So I paid that money so that I could feel better and I could feel attractive and sexual again. Because I didn’t... In my own opinion now I feel that I look even better because my inside confidence and personality is so much better than it was before... [I put] more effort into not nullify what I’ve been through but to make me feel even better... I would probably have never had my breasts done I don’t know if I’d ever wear hair extensions to this length and look like this. I dig things that I might not have done before and now I feel so much better for doing them. Maybe I would have never opened that door before. I’m so happy now.*

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Similarly, Abigail decided to put more effort into her body and outward appearance.

*I think having gone through this experience has made me be more careful about how I present myself, physically. Today is not a good example but I would usually put more...*
effort into making sure that I look attractive when I go out. Whereas in the past I
wouldn’t have put as much effort or time into it. That’s been a change….It’s not so much
that I’m doing it as a disguise like I would have done when I was putting on my wig when
I was going through treatment... you can give me your attention now based on how I look
rather than giving me your attention because you want to see how she’s doing, she’s been
sick...I would say it makes me feel normal. It makes me feel that I could have been doing
way before I was sick. But now I know that I’m doing it because I was sick. It’s kind of
like... I think it’s also reassuring to the people around me that I’m going on, I’m moving
forward and that I’m doing stuff like being concerned about my appearance just like any
other person would when they’re stepping out to go to work or out... it makes me feel
more normal.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

**Connection to breasts - post surgery.** Many women in the study discussed a strong
connection between their breasts and their femininity. Several women described maintaining this
connection before and after their surgery.

*I just never had any ill feelings about my breasts. I always liked them from the time I
remember having them. I always enjoyed them sexually, like being touched. I did like
them and enjoy them being touched. I also breast fed my children, I loved breast feeding.
I didn’t have issues. A lot of my friends were like is this, it’s that, there’s no milk. I just
breast fed them... it’s always bumpy at the beginning, getting all that stuff. But I love
that. I guess I love what breasts represent. I love women. I sort of think that women are
so great and I see breasts as symbolic of that.*

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)
It comes down to my age, I went and had my breasts done because I then felt that I didn’t look feminine. My femininity and sexuality is very important to me. The way I look is very important to me.

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Several women also identified becoming even more attuned with their bodies after their breast cancer experience.

Before breast cancer, I was still someone who was quite in tune with my body. I was the one who found the lump in my breast because I used to do my regular breast self-examinations. I think now I’m a little more in tune with everything. My internals and externals. For instance, my cycle is not as regular as it once was. Before I could go by the calendar, I was very regular. Now I really have to pay attention to my body and the little signs that it’s giving me to indicate ‘Oh, yeah my cycle is going to start’ because I’m not as regular as I was.

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

Unlike the majority of women in the study, Alexandra discussed a stronger, but more negative relationship to her body post-treatment. Given that this was her second cancer experience, she was unable to receive radiation therapy; thus, she decided to have a bilateral mastectomy. The surgery caused her to have significant chronic pain and ultimately lowered her QOL. Alexandra discussed her desire to feel less connected to her body.

I am aware of my chest all the time but I would really just love to step out of my body right now and I’ve never felt like that... I wish I could just step out of it so that honestly, I could get a break from the pain.

(Alexandra, age 43, low SES, Caucasian, Stage 0, 12 months since trx)
Participants who had less of a connection between their femininity and their breasts prior to their diagnosis felt more confident in their decision to have a mastectomy.

*I wasn’t a woman who identified my femininity with my breasts. So, to me, it was a fantastic experience breast feeding my son. When I was told regardless of what you do with this affected breast, you won’t breast feed from that breast again. I thought well I don’t need it… so I might as well get rid of it and I can get reconstruction.*

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)

*To begin with I was so small, [the mastectomy] didn’t really matter, pretty much, a lot of it… I think the first thing that crossed my mind was ‘well if I have it just take it.’*

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Michelle felt it was important to distinguish her breasts as an important part of her female anatomy but not her femininity.

*My breasts represent, part of the female anatomy for sure, however I’m not less female without them. That’s how I feel about them.*

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

**Body in relation to disability.** As women transitioned from having a perfectly healthy and young body to one with a breast cancer illness, several women paralleled their cancer experiences to that of a person with a physical disability. More specifically, women identified this parallel when they felt physically different or alienated from the norm.

*Then I was bald and I was like now I think I understand how people feel who are in a wheelchair or ... like a disabled person.*”

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)
He told me right away that he would have to perform a mastectomy and that there wasn’t any way he could save the breast. I had said to him I remember ‘well, that means I’m going to be disfigured’, and he said ‘oh no’. and I was thinking how can you say no? You’re removing one whole breast.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

Although some women felt that their experiences paralleled individuals who had physical disabilities, Elizabeth clearly rejected the notion that her body was ‘mutilated’ from her mastectomy.

I really do think there is this cultural message [for women to keep their breasts] because people think of mastectomy as mutilation. I really get that sense of this horrific de-feminizing of the body, which I didn’t identify with.

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)

In sum, participants in this study re-located their sense of self through their altered gendered identity. Participants described their gendered identity reformulating in relation to their perceived gender role expectations. After their breast cancer experience, some women reported a stronger connection to stereotypical female roles; other women, who held less stereotypic views of the female role prior to their diagnosis, typically rejected traditional role expectations. Further, women’s altered bodies also shaped the way they reformulated their gendered identity. Given the unconventional changes to their bodies, many participants struggled to accept their bodies. However, the majority of women who completed medical treatment over one year since the interview felt more comfortable in their bodies. Women described changing their physical
appearance and/or shifting their definition of their gendered identity and beauty in order to find some degree of acceptance. Yet, some women still faced outward criticism and judgement on their bodies, which were perceived by others as mutilations.

**Re-locating Self in Youth**

After completing medical treatment for breast cancer, many women in our sample had difficulty reclaiming their youth. Women experienced different changes to their sense of self in relation to the course of their lives, and, in particular in relation to: a) uncontrollable shifts in their life stage, b) reformations in their career aspirations, and c) heightened differences between younger and older women with breast cancer.

**Uncontrollable Shift in Life Stage.** After their cancer journey, many women experienced a shift in their current stage of life. Alexandra spoke about feeling like “an old person”. She compared her current complaints to those that her 70 year old mother had experienced.

*I feel like a little bit of an old person. Suddenly I went from being 40 to 80. All of my issues are the same. I’m tired all of the time, I ache all the time, I’m not contributing, suddenly my body is ugly, so suddenly I feel like an old person... I listened to my mom’s complaints, I noticed and I listened to her complaints. She’s in her early 70s. She’s doing well but still she has the general complaints an elderly person would. Every time I hear them I’m like ‘those are mine’ and then I realize I’ve become an old lady.*

(Alexandra, age 43, low SES, Caucasian, Stage 0, 12 months since trx)

Similarly, Olivia shared that this uncontrollable shift in life stage has led to some “identity issues” after her cancer treatment. Prior to her diagnosis, she identified as the “baby” in her
family; now she reports that others perceive her to be the eldest sibling in her family due to her changed physical appearance.

*I’m having identity issues with that because somebody on the bus… somebody thought I was older than my sisters and they’re older than I am. That sort of threw me for a loop… Part of my problem with my hair is that it’s growing back. It’s growing back grey and white and it wasn’t like that prior to… I am looking forward to dying it in Christmas holidays because I don’t feel as young as I should, when I look at myself.*

(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

Elizabeth described her initial reaction to her mastectomy. She felt as though she reverted back to a pre-pubescent young girl.

*I remember sort of driving home and putting my hand on my chest and feeling it being like ‘I haven’t felt this since I was like ten.’*

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)

Reforming Career Aspirations. Regardless of how women put value on their careers, the participants were confident that they would live long lives achieving their career and family aspirations. However, many questioning remained related to their work-related priorities. Several women spoke about becoming less career-driven and re-focusing their lives on what seemed more important.

*My relationship to work has become even more removed… it’s not that I don’t do my best or anything like that. In terms of the level of importance I put on it… it’s probably even dropped down on the ladder a little bit more.*

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)
The only difference that I’ve noticed that it’s really only in my work life is I’m not really as driven anymore. I’m a little bit more relaxed and I was relaxed to begin with so, now it’s even more so.

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)

Jessica shared the shift she made from focusing on work and making money to becoming more present with her young children at home after her cancer experience.

Not to say that my kids weren’t important then, they were, but then my mentality was more like my work is to work so that we can do things. But the kids would have to go to daycare, they would have to be cared for. It was more about... this sounds so shallow but it was more about being able to do things. Creating memories, too but it was more about well if I work we have more money and we can do this, we can do that... It was very different focal point in a way. Now it’s more... you sacrifice a little bit more and spend more time with the kids and career will come, everything will come. In that sense it has changed. I can’t pinpoint in what way but it has, my focus is not just about getting that pay cheque. I get to walk my kid to school.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Abigail described changing the way in which she identified as a teacher.

Before I would have highly identified myself in my role as being a teacher and now its stuff that I would have addressed and would have driven me crazy I just say to myself, that’s not a battle that I think I should be wasting my time on. In that way it’s changed.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)
Many women also spoke about not feeling fulfilled by their current jobs. While their jobs provided a stable income for themselves and their loved ones, they became more interested in finding ‘meaningful’ careers that suited their needs and interests.

All of a sudden you want to do something different. You want to do something that hopefully pays okay but something that you’re more happy with and is more fulfilling in a non-stressful way. I think things have changed.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Now it’s about doing something that makes you happy, you feel gratified, fulfilled, rewarded and all that stuff.

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

As well, several of the women discussed changes in their work-related priorities.

When I went back to work, as I said my priorities changed, I’m not going to be stressed at work. I’m going to do something I love to do. I had the choice of going back into my old job of buying or I could be moved into a new assignment buying a different commodity. I didn’t want to go into a buying period because there’s a lot of stress that goes along with it. I said it’s the devil over and over it’s the devil. I don’t know. So I opted to go back to my old job.”

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

When they call me for work and they say ‘can you take this shift?’ I’m more likely to say no now. ‘I think I’m going to make plans with human beings.’
Furthermore, many women returned to work after their cancer experience with a changed outlook on their current professional career. Olivia always had some interest in becoming an oncology nurse, yet never pursued this avenue; instead, she worked as an orthopedic surgery nurse. After her cancer experience, she knew this was where she was meant to be.

*When my mom had breast cancer and I wasn’t a nurse at the time, I mentioned I went into nursing and I thought maybe I’ll go into oncology because my mom had breast cancer. Now I know that’s where I’m meant to be. I’m definitely meant to be there because I can bring that experience, both experiences of being the relative, the loved one of somebody and I can certainly bring experience of being the person having gone through treatment. Obviously everyone’s experience is different but I think that makes a big difference in just being the medical person pumping the chemo... I think I’m definitely meant to be an oncology nurse, or in oncology somehow. That would be my plan.*

Olivia also explained that her cancer experience would make her a better, more empathetic health care practitioner.

*I had a terrible allergic reaction to the chemo, one of the drugs I was on. I was itching I felt like I was being eaten alive from the inside, they had to change the chemo because I said I can’t do this anymore. They put all these drugs that were supposed to stop the itching and nothing worked. Anyway, I come back to work and one of my first patients is on this drug that’s for itching. I was like ‘I know this drug.’ We didn’t have it on the floor yet but I said we need to get this drug now because I can actually picture what he was saying. It was itchy for a different reason, it wasn’t chemo, it was a different condition. I*
was like I can get what you’re going through. Let’s get that right now. Because people think you’re itching that’s not a big deal. No, no, no. He probably thinks he’s being eaten alive right now. It’s not just itching. I think that... I was the person being like ‘itching? Stop being a baby, come on!’ I get what your itchiness is now, I know what that means. (Olivia, age 36, Jamaican, Stage II, 6 months since trx)

Similarly, Suzie identified her breast cancer experience being one vital factor that helped her become a better mental health professional.

I feel like I’ll be a better [mental health professional] having gone through something, whether that’s cancer, or divorce because if you never go through anything, it’s really difficult to relate to people in this profession but also that you can get the sense that my life is going by and I’m not living it.”

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

After some hostile work experiences with her employer during her breast cancer treatment, Claire questioned whether her pre-cancer career aspirations in human resources were right for her.

It shattered me and my ability, even in human resources. This is something I’ve been doing from day one graduation in university. I couldn’t believe that somebody with such high stature for working for a global company could react... I would say in my professional opinion that she created a hostile work environment for me after I told her I was sick... It was hard because again I thought maybe well I could use my skills in something else. Maybe I don’t want to be in human resources if that’s the way human resources people are. I thought long and hard about all that and I took a whole bunch of tests, career counselling and in every box that came up had human resources in it.
Claire, among many other women interviewed explained further how difficult it was for her to work in a hostile environment during her cancer experience.

*She was driving me crazy working there. She was putting me under so much stress I was afraid, although I had my cancer removed, I was afraid it was going to start growing because she was putting me under so much stress...It was very disheartening, I’m in human resources, my boss was the VP of human resources when we ended my contract. And she got promoted while I was off on leave before we negotiated it. So she was the senior vice president of human resources for an international bank and she treated somebody who was sick absolutely horribly. I actually now have a much better understanding and feel horrible that people who don’t know their rights and don’t know their laws, have to deal with people, bosses who are ignorant of the laws. But my boss knew the laws. It didn’t matter if I was sick, there was an expectation to put in the 10-12 hour days in between treatments.*

Other women too discussed the struggles faced when returning to work and/or to a hostile work environment.

*I really didn’t realize the amount of energy it took to do my job or just to get my job even. That’s one of the things that I would really highlight.*

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

*I was teaching (Academic Subject) when I became sick and I had been planning to go back to work in September. In June when I had informed my department head that when*
they were doing the timetable to even consider me in coming back and I didn’t go back to Geography. I went back to do courses that I’ve never taught before. When I asked numerous people, no one could explain to me why that was my timetable. I suspect it was being done well 1) maybe they weren’t thinking I was coming back or 2) they were the courses nobody else wanted and that if I did come back, those may be easier on me because they’re smaller classes, smaller number of students in them.”

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

Differences between younger and older women with breast cancer. Given the unexpectedly young age at diagnosis, several women re-located themselves in their youth by comparing their experiences to older women with breast cancer. Jessica described being located at a very different life stage than her mother-in-law who also had breast cancer. In her interview, Jessica made a downward social comparison to older woman with breast cancer as she felt fortunate to have her young children as motivators throughout her cancer experience.

She [mother-in-law] even said it was very different for her because... I’m just starting a family; the focal point is so different having to go through that. It was really nice the way she was able to understand and see my situation and feel for me...I feel for the older ones, the 50, 60 year olds because they already lived their life and their kids are already gone. The kids are the motivator you don’t have that motivation. I know I felt very lucky I got it when I did because my kids were the ones who pulled me through.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Kelsey felt strongly that unlike older women, young women with breast cancer should put a much greater focus on staying present in their current lives.
I also think with young people, you shouldn’t take yourself out of the whole world. I think that the whole cancer society says come on now you’re sick, let’s put you in the sick area, we’ll put you there for two years and then we’ll bring you back. I think young people should try to still be in. If you’re under the age of 35 you’ve got a career that’s not even fully developed, you don’t have a sexual relationship with your partner yet, you’re still working on that. I really think that you shouldn’t be leaving.

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Michelle talked about feeling silenced while interacting with older volunteers who had breast cancer as she was unable to identify herself with them.

In the very beginning, right after I went, I did my mastectomy; I was going around doing research online. I went to a [Cancer support centre] and that particular time that I went, a lot of the volunteers there were older people. In that regard I felt a little bit silenced in that I didn’t feel as if... I didn’t identify with them is what it was. They were lovely people, very nice, very supportive, it’s just I found that the people that I had been interacting with at that particular location were all older people... I couldn’t find someone that I could speak to who could share that experience with me in terms of the volunteers available to you that I knew of at that time.

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

Therefore, Michelle, along with other women in the study, felt a strong need to find other women their age that had breast cancer for support.

[The cancer support centre] have been awesome. It’s been the best experience ever because I was able to meet other women in my situation, diagnosed around the same thing, similar diagnosis, similar aged kids....As much as it sucks that there were other
people, you take comfort in knowing that other people are sharing the misery that you are because then at least you feel that you’re not the only one.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

[Cancer support centre] now has a young adult group as well so going to the young people group to be around other young people who are going through the same kind of stuff as you. Definitely helped me.

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)

In sum, participants described their youth reformulating as a result of an uncontrollable shift in life stage. The breast cancer experienced caused women to feel a significant shift in their normal life trajectory; majority of women felt their bodies had caused them to move into an older life stage. Further, participants felt strongly that their breast cancer experience reformulated their career aspirations. Work-related priorities shifted; women felt less career-driven and more family-oriented. However, given that the participants were all at a life stage where work/careers was a fundamental component of their lifestyle, participants’ also discussed work-related priorities shifting within professions. Further, women described being more interested in finding a career with more depth, meaning and/or fulfillment in their lives. Consequently, several women considered changing the direction of their career in order to suite this renewed needs. Finally, participants reported reformulating their identity as a younger person by comparing their cancer experience and life circumstances to older women with breast cancer. Given that younger women are the minority within the breast cancer community, participants identified having less common experiences to their older counterparts.
Re-locating Self in Health Status

In addition to re-locating themselves in relation to their gender and youth, many women also re-located their sense of self in relation to their health status. While not all women felt comfortable identifying themselves as a cancer survivor, all women were forced to face changes with respect to their health status. The participants described confronting their health status in relation to a) the socialization of the cancer experience, b) others’ discomfort with cancer, c) the fear of recurrence.

Socialization of the cancer experience. Several women in the present study faced considerable pressures among medical staff during treatment to maintain certain standards in relation to their femininity and youth during treatment.

Elizabeth discussed feeling polarized by the doctors with her decision to have a prophylactic mastectomy.

*I think it was because she was a woman and ironically, as much as I know doctors aren’t supposed to give you their personal opinion, she kept saying ‘You know you don’t have to have a mastectomy?’ and I said ‘I know! This is what I’m choosing’... Even being on the operating table and there was the surgeon and then her... and the resident... he did say something like ‘So this is elective, right?’ and I said ‘I guess so’ and when he examined me post-operatively he said something along those lines too, like ‘This was your decision.’ I’m like ‘Yep!’*

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)

Olivia discussed feeling like a failure because she was young, yet unable to handle her chemotherapy treatment the way she was told she could.
My oncologist had said to me, prior to my chemo, you know, because you’re young I don’t anticipate any problems, which made me some sort of failure for not being able to handle chemo….I felt like ‘Okay, what’s wrong with me? Am I a big baby?’ People apparently go to work right after, people run marathons during chemo apparently and whatever reason I can’t do these things, I think that was something that had… made me feel as a survivor as a person who went through maybe I’m not doing it right.

(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

Several women mentioned that being told by the medical community and loved ones that they should keep positive and stay strong was somewhat disheartening and unrealistic to them.

I read an article... saying this pressure on people with cancer to be positive is out of control. Regular people who don’t have cancer are not positive. And then you get slapped with cancer and you have this expectation that you have to think positive and be positive because a positive attitude might save you. These non-cancer people who know nothing about the cancer you have, nothing about your treatment are like spouting as if ‘you know, having a good attitude is the most important thing and you have a great attitude and you’ll be fine’ I find that very patronizing and I find that to be kind of offensive. I feel like we live in a world that tells you how to look and tells you how to feel ... Right now, today, in North America, this idea that you have to be happy all the time. Everybody should feel happy. If you’re not feeling happy then there’s something wrong with you and you need to go see somebody. Instead of saying, this is life, life isn’t happy all the time and it’s in accepting that, that you’ll find happiness. I feel like that was no more the case, like the extreme in this cancer case when you’re told. You’re always being told that by people who don’t have cancer, but people with cancer aren’t saying be positive, it’s
people who don’t have cancer, who don’t really know what else to say, they’ve heard this, kind of in our culture, to keep positive and they kind of gravitate to that because they don’t know what else to say... it really resonated with me...

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

At the time, honestly, I hated it. I know they meant it in the nicest way but it sounded a bit condescending like you’re strong, well that’s why you got it. And I felt like saying ‘Aw hell no, so the next person who is strong can go and get it, no thank you.’ I didn’t like it. I think it would have been a lot nicer if someone just said ‘man that sucks that you have it, do you want anything? Do you need anything? How are you doing?’

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Furthermore, several women described feeling propelled into a confined role as the “sick person”.

I felt there wasn’t space [to be] comfortable with having breast cancer it was kind of this is the box that you should be, you should be upset, a victim, to be looking like you’re dying and everybody taking care of you, and that whole role and if you didn’t tick that box and you should be 50-70 years old and I just felt that I wish there was more my kind of vision of going through it and help... or support that concept.

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

I didn't want to be treated as a sick person. The day I came home from having my first chemo treatment, we did a major renovation at the house, painting the deck. My last chemo treatment painting the exterior of my house. I didn't want anything to change.
(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

There does seem to be a vision with cancer from society, as there is with everything else. That there is a right way, a wrong way, a better way, a hierarchy of ways that you should cope. I resist being told by people that.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

**Discomfort with cancer.** While breast cancer prevention and fundraising have entered into common dialogue within North American culture, majority of participants identified a level of discomfort from others in relation to their breast cancer experience.

*Everybody feels really uncomfortable with the big C word.*

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)

*I wish someone would friggin’ write a hallmark card that knows what to say and give it to the person because honestly, nobody knows what to say.*

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Suzie mentioned that as a result of the discomfort she experienced from others, she felt obligated to comfort them during her illness.

People don’t know what the right thing to say is and what I find is mostly in these conversations that I would have with people would be comforting them.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)
Less common in our sample, Abigail discussed her own discomfort and inherent stigma she perceives with her illness. She compared her comfort level with her illness to having a physical disability.

*I tried to convince myself that I was making more out of this than I really should be, so I tried to say ‘What if you had been in an automobile accident and you lost a leg?’ Right? You wouldn’t be able to hide from people that you were missing a leg. I probably wouldn’t hesitate to tell somebody ‘yeah I lost my leg in an accident’ whereas because this was a breast, I didn’t feel the same way and I still don’t feel the same way.*

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

**Fear of recurrence.** As women re-located themselves in their current health status, many identified the fear of recurrence of their cancer as another significant concern. The fear of recurrence forced many women to re-think their future orientation.

Several women explored what it was like to live with a time constraint and a looming fear of mortality.

*I kind of feel like I’m a bag of milk with an expiry date. I only have this much time left so it doesn’t... it’s a constant reminder... Suddenly I feel like I’m an old person and also I’m doomed to get another cancer.*

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

*I think it’s hard when you’re... not given a death sentence but a time-frame almost, you feel like you’ve been giving a time-frame when you think you have your life to live then it makes it more difficult because you’re constantly living by that time-frame.*
Several women discussed their need to re-think their future orientation in relation their young children.

*As much as I really wanted to have a second baby there was certainly that ‘am I going to be fair?’ I know I’m not technically at increased risk for this to happen again, but if something did come back and I do leave my current son and now to be second child motherless… you sort of have those struggles of am I being fair.*

*(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)*

*I’m trying to live more for the now. I’m one of those people that had my whole calendar planned out. Now I just plan about a month at a time.*

*(Jessica, age 39, Korean, Stage III, 10 months since trx)*

Judy, who struggled for over a year with her own fears of recurrence decided to get a prophylactic surgery; she was ready to move forward with her life, without this constant fear.

*I just want to move on with my life, especially after this last surgery having a clean bill of health. You know the pathology report coming back showing no cancer. I just want to close that chapter in my life and move forward. For me it doesn't have to include children. I guess at one point the cancer did affect my decision.*

*(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)*

In sum, many women described their experiences with medical professionals and hospital staff impacting the way in which they reformulated their identities. Some women felt pressured by
medical professionals to behave in a certain manner, others felt pressured to carry out certain medical treatments suggested by their doctors. Several participants also disliked having their loved ones promote unrealistic expectations of remaining ‘strong’ and ‘positive’ throughout their breast cancer experience. Many women also disliked being treated as a ‘sick person’ after their treatment. Moreover, participants reported that the discomfort from loved ones about the breast cancer also facilitated the reformulation of their identity. Women felt obligated to educate and share their experiences as well as provide comfort to others. Finally, the fear of recurrence was another factor that drove women to reformulate their sense of self by reconsidering their future plans, relationship with loved ones, and connection to their cancer.

**Healing and Facilitative Conditions**

In addition to the challenges faced, and the identity reformulation process that took place after breast cancer treatment, participants also had a strong interest in sharing key factors that facilitated their healing journeys.

Jessica paralleled part of her healing journey to the stages of grief while mourning a death.

_The way I analyze having cancer was like when you mourn for a death. You’re in shock if someone dies so I was in shock when I was diagnosed then you’re sad because you miss your old self. That care-free, never worried, planned the world away. Planned my retirement away, now I can’t do that. And then you’re a bit angry. Then the whole ‘why me?’ and ‘why did this person leave me?’ I suppose. My mom lost my dad so I remember her whole... it just kind of... the way I compared myself it was like going through a whole mourning process. After I got through the anger I think you accept the fact that it_
happened and you either decide to move on or dwell and I decided to go the other way and move on and do the best I can.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Overall, the women in the present study shared a range of factors associated with their healing journeys after the diagnosis and treated of breast cancer. Specifically, these women identified facilitative factors commonly and less commonly reported in young women’s healing journeys.

**Commonly Reported Facilitative Factors in Young Women’s Healing Journeys**

The women interviewed identified factors facilitating their healing journey that are consistently reported in the literature.

**Don't sweat the small stuff.** Participants highlighted that after their cancer experience, they were less likely to be upset over small and less meaningful issues. Alexandra explained that she tried to enjoy herself more and was less likely to notice small things that used to annoy her.

*It is true that I don’t get frustrated with stupid little things the way I did before because I just don’t care because I now really realize life is short. Life is hard, too. There is unfortunately for many people, people suffer. Life is hard. I do try and enjoy myself whenever I’m physically able to. I notice I don’t get upset by the small things anymore and I just notice in my relationships with my family members, things that they do that used to annoy me, I don’t care anymore.*

(Alexandra, age 43, low SES, Caucasian, Stage 0, 12 months since trx)

Suzie shared a similar notion to Alexandra. In fact, this new philosophy to “not sweat the small stuff” made her feel empowered.
I think there’s something also about cancer that when you survive cancer, you feel a little bit kind of super powerful that things that used to bother me can’t hurt me in the way that it did before because my problems are bigger than that, or I’ve faced worse enemies than you. I guess it’s empowering in that way and that is identity changing to become more powerful than before.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

Living in the moment. Most women became less bothered by superficial factors in their lives and thus spoke about living more in the present moment. These women shared their desire to live more for the immediate future; they felt the need to do more in the time that they had available.

I guess I kind of became more at peace with the idea that there’s this life now, that’s what I’m living and it’s finite and I want to spend whatever days I have left not like anything normal, it’s not like that, it’s like living in the moment, trying to be present... We always live in the past and in the future it’s really easy to be like that and cancer kind of brings you into the present.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

I think it has made me live more for the immediate future. In the past I would have said with my family and friends the talk would be well what are you going to do when you retire? Whereas that may not be an option for me. Yes, I like to travel so it’s like I should plan, where do you want to go during Christmas break whereas in the past it was like yeah I like to travel I’m going to be travelling. Now I feel a time crunch in that I need to be doing more now.
Similarly, Michelle spoke about becoming less concerned about her distant future.

*I know before cancer I missed some things or I had chosen sometimes to do a course that was for my career rather than go on a trip. I was also more focused on preparing for retirement. You always hear ‘Oh you have to put away for your RRSPs, don’t spend’ it’s not that I’m not looking forward to a future but I know that future will be great, it will be fine, I will enjoy it and I will still be in a position to support myself. I think it’s the concern factor about the future or the distant future that has gone based on my experience.*

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

**Support from family, friends and medical staff.** Women in the study repeatedly mentioned the benefit of having supportive loved ones both during and after their treatment.

*I always made sure I had someone with me, whether it was my husband or my sister that could participate in these meetings where doctors were overloading me with information. I felt in control the whole time.*

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

Michelle also highlighted the comfort she felt from others’ concern for her well-being. Their positive words helped strengthen her self-esteem.

*I have been fortunate to be told by people, my loved ones, checking in with me, especially right after. ‘How are you feeling? Do you feel okay?’ They wanted to make sure that I was fine. And people telling me that I look great and meaning it. You can sense sincerity. They said it and they meant it and I’m sure that’s done a lot to bolster my self-esteem.*
Most women described that sharing their cancer experiences with others was therapeutic and beneficial to their healing journey.

*I had been talking to somebody from day one, every week from day one. Basically, my coping mechanism was to talk to as many people and with the resources at wellspring.*

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)

The women in long-term relationships also focused on the important role their partners played as strong support systems.

*But my husband was there and he was like my listening board. Even though he wasn’t at the beginning. He always tried to fix everything until I finally told him ‘You can’t fix me anymore! Just listen to me!’ He did, he bought a book and he did, he realized. He was also learning ways to help me which helped.*

(Jessica, age 39, Korean, Stage III, 10 months since trx)

*[My Husband] is the eternal optimist. Never letting you stay upset for very long. Just reminding me that it doesn’t matter what you physically look like, it doesn’t take away from the woman you are. He’s just… I could get emotional just talking about him. He’s amazing.*

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

Additionally, women found variable levels of support from their medical staff during treatment. Michelle discussed the wonderful medical staff she had during her treatment.
My experience was very positive, my doctors were amazing; the chemo nurses, extraordinary; it was just one extraordinary individual after another who I was fortunate enough to have on my team and to interact with. I know how blessed I am simply because I went to a conference and again, things I took for the norm because it was my experience I found out it was not the norm.

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

In contrast, other women wished their medical staff could have been more sensitive during their treatment.

When I went to get my tattoos for the radiation, the radiation technician or whatever was whistling as they were doing the procedure. To me, I found that upsetting. Whistling in my mind is like passing your time. I didn’t think it reflected on what I thought was a serious moment.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

While there were mixed opinions about the psychosocial support offered by health care professionals among participants, Claire shared what she felt would be most valuable to her while receiving support from mental health professionals.

It’s more [about the] feedback in that a) tell me more about this or leave me with a question to ponder. I’m not expecting [the psychiatrist] to give me answers to solve all my problems.

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)
Humour. Another prominent factor facilitating women’s healing journey was humour. Elizabeth emphasized her appreciation for her friends’ humour both during and after her treatment.

I have a couple close girlfriends who were really good. In that time period before diagnosis and surgery I got together with them at my family’s cottage and my one friend presented us all with tank tops that said ‘real or not, these are hot!’ [laughs] …I mean, so that kind of think… you know… certainly helped… They came out last October and did the CIBC run for the cure with me. My one friend who did the tank tops says: ‘I’m running for’ and on the back said ‘[participant’s] tata’s.’ It was so cute. I mean, that kind of think certainly helps. That’s just it. I’m focusing on the humour sort of the irony of the whole thing.

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)

Olivia stated that only once her chemotherapy treatments were complete and she received a good prognosis from her doctor, did she feel ready to return to her old, humourous self.

Now, since chemo’s done you can count on me to say inappropriate things, maybe morbid things more so now. In that sense I’m back to my old self humour-wise.

(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

Abigail mentioned the importance of using humour as a teacher with her students to deflect conversations about her changed physical appearance after cancer.

I usually try and use humor and say ‘Well, you know it’s my new look, I’m thinking of doing what you’re doing there with that… Mohawk or whatever.’ Just try to deflect it that way. I’m sure because I’ve come back to work after a long absence and physically
looking quite different. I’m sure students and staff have figured out that chemo and so forth...

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

**Maintaining a sense of control.** Several women in the study appreciated some return of control and power after their breast cancer experience. This renewed power allowed them to move forward in their lives after living without any control over themselves, their decision and their futures.

Kelsey described feeling some sense of freedom, taking control back in her life, as she returned to work.

> *It also realized my way of controlling and having power and moving my life forward, because work brings money, right? So, going back to the no body controlling me anymore and me being in control and focusing on something that’s productive. It could give me more choices and freedom.*

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Although Judy was unable to have control over her illness, she was able to feel some sense of control in her life outside of her illness, working on a major house renovation during her chemotherapy treatment.

> *The day I came home from having my first chemo treatment, we did a major renovation at the house, painting the deck. My last chemo treatment painting the exterior of my house. I didn't want anything to change. But then I'm very much in control. That's my personality.*

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)
Similarly, Jessica identified exercise and eating as ways in which she felt in control of her self and her body after her treatment.

*I do work-out quite a bit because that was the only thing I had control over. Right? Everything else I had no control over. So when the doctor said exercise is good for you, that’s one thing I could control and the eating.*

(Jessica, age 39, Korean, Stage III, 10 months since trx)

**Acceptance of Body Changes.** Participants also shared that working towards accepting themselves and their bodies was important in their healing journeys. Michelle and Suzie, for example, spoke about the importance of accepting their bodies post-treatment.

*It’s an acceptance. This is the way I am now and there’s really nothing wrong with me. I’m healthy. I think what it is is I focus on my many blessings and I really have so much of them. I’m a little different, we’re all unique. I think I’m in a place of acceptance and that’s the reason for my outlook.*

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

*You have an image of who you are and what you look like. That image you’re seeing something that’s like ‘what is that?’ it’s not what I’m used to seeing. I’m trying to take that and accept that and internalize this new image in a positive way and say that can be beautiful.*

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

Kelsey had to make her body into something that she could accept in order to heal.
“I love what I’ve done to my body so, I’m accepting of it now and I’m getting better at showing it.”

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Furthermore, in order to accept their bodily changes, many women needed to recognize that this aspect of the healing journey occurred over time. Michelle highlighted that while, she, like other young women, wanted to return to work immediately after her treatment finished, this plan would not be appropriate or helpful for her recovery. She hoped that young women who face breast cancer in the future will take the time they need to listen to themselves and their bodies before returning to certain life tasks.

I even tell the women based on my experience, take your time. If you are able to, ease yourself back into it, there isn’t any rush if you’re able to take that time. I definitely have a different outlook in terms of my drive...Before going back to work I think it’s allowing your body to heal and your mind. It is a stressful life experience, you don’t realize the impacts. Well, I know I didn’t. The long-term impact of chemo. I was really fatigued when I started back...Everyone’s experience is different. Listen to yourself. You know when you’re ready to do certain things. You’re definitely going to have well-meaning individuals saying ‘Oh, go back to work, go out and interact socially’, just try to listen to yourself. Only you know how you’re feeling. You definitely want to be moving forward and living in the present but you also want to be aware of where you’re at. Take your time.

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)
Less Commonly Reported Factors Facilitating Young Women’s Healing Journeys

In addition to the factors commonly reported in breast cancer survivors, the participants also identified less commonly reported factors that facilitated their healing journeys. Moreover, many of these factors, too, were more specialized to younger women after their breast cancer treatment. These prominent factors include: a) decentralized focus on altered body, b) support from other young women with breast cancer, c) re-defining the self-concept, d) freedom to express self; healing as an individualized process.

Decentralized focus on their altered body. The women in the study felt that decentralizing the focus on their altered bodies after treatment was beneficial to their healing journeys and psychosocial well-being. In particular, many young mothers and aspiring mothers identified children shifting their focus from their bodies after treatment.

Elizabeth, pregnant with her second child during her breast cancer diagnosis, continually spoke about moving her focus towards her soon-to-be-born child to help cope with her altered body and illness.

It wasn’t a nice clean incision. It was lumpy and swollen and kuckered, and it was ugly. I thought... regardless, onward and upward and now we can focus on having a baby and I can come back to this another time...focusing on what’s important. I’m never going to... well, not never. I’m not going to be able to wear clothes like that for a while but I get to have this incredible experience of having another baby and spend time with my family and I’m healthy.

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)
Similarly, Jessica spoke candidly about her young children being the motivating force during her cancer experience.

*I have to tell you before I forget, with children, it was the only thing that got me through it. They were my motivation... if it were just [my husband and I] and I didn’t have a kid, I would be so friggin’ depressed, I would have no one to get up to.*

(Jessica, age 39, Korean, Stage III, 10 months since trx)

Of all the participants without children of their own, Abigail and Kelsey represented the women who decentralized the focus on their altered bodies by proactively taking steps to change their bodies.

*Today is not a good example but I would usually put more effort into making sure that I look attractive when I go out. Whereas in the past I wouldn’t have put as much effort or time into it. That’s been a change.*

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

*I: So you’ve put more effort in?*

*K: Exactly... More effort in to not nullify what I’ve been through but to make me feel even better about... to me, I would probably have never had my breasts done I don’t know if I’d ever wear hair extensions to this length and look like this. I dig things that I might not have done before and now I feel so much better for doing them. Maybe I would have never opened that door before. I’m so happy now.*

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)
Support from other young women. While participants felt it was necessary to receive support from their loved ones (as mentioned above), the women interviewed also identified the instrumental role that other young women with breast cancer played in their healing journeys.

[Cancer support centre] now has a young adult group as well so, going to the young people group to be around other young people who are going through the same kind of stuff as you. Definitely helped me.

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)

It helped a lot to hear that other people were feeling the same way and undergoing the same experiences. Having the same type of reactions. I didn’t feel that I’m the only one that doesn’t want to be talking about the fact that this is my diagnosis and [its] hidden from work. To hear other people who are still working and having their treatment but still feeling the same way that they had to make it seem they were well enough makes me realize that it isn’t that odd... think it is very important to hear other people’s stories because I have been amazed by some of the other women, much younger than me as well who have had to go through the similar diagnosis and treatment and they don’t have any family around them or they newly come from another country and they just started a new job or a new relationship and they still have managed to afford... to me, personally, that’s encouraging. It makes me realize that there are other strong women out there.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

Several women also discussed supporting other young women with breast cancer as a facilitative factor. Kelsey, the primary “call person for young people with breast cancer” at a cancer support centre explained why it was important for her to take on this role.
I really felt that talking to, again, don’t take it the wrong way, but talking to someone who is 56 years old, who has children, who has a husband, is completely different than someone who is single, who still wants to be sexually attractive and doesn’t want to lose a partner or a boyfriend and… it’s completely different. Same things but maybe at a different level. Whatever their number 10 is could be my number 1 or my number 5 could be their number 2. You know what I mean? It’s a completely different way of looking at it for the same issues, kind of thing... Talking to people my own age it’s very rewarding. I was scared at first because I didn’t know if I was ready, but as soon as you get into it, it just works.

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Similarly, Michelle described how her volunteer experiences with other women who had breast cancer empowered her, and subsequently facilitated her own healing journey.

I also volunteer at an exercise program for women who are going through or who have gone through breast cancer. I find it very empowering being around those ladies and that particular organization... The organization is just filled with wonderful, positive energy and everyone is very supportive. The fact that I can help someone who is going through the same kind of disease that I went through, I find that empowering. I find it empowering to be able to help and really, all I’m doing is being there. That’s it. I’m there, I’m walking. I’m listening and that’s it, yet I’m able to have an impact. I find that empowering. I find that organization empowering in terms of the energy there and the people who work there.

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)
In contrast to the majority of the women interviewed, Claire described the difficulty she faced finding support from her friends, given that she was unemployed after her cancer treatment and many of her healthy friends “had lives to live”.

...even socially, due to my unemployment, I didn’t have a lot of money to go out so I started losing friends just because I was unemployed, so by the time I got cancer, there wasn’t all that many people left.

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)

Claire also described her personal struggle to find support groups that suited her particular needs as a young woman working at her job throughout the day. Given that she had a full-time job when diagnosed with her breast cancer, she hoped to find support groups that were available to her after work hours.

I very quickly had made lots of phone calls I think the first thing I did was talk to a social worker at [Toronto Hospital]. The only other resource I had available to me, because I was working, was Gilda’s club had their support groups in the evening, so I could go there. However, when I went there it was their wellness group which is all adults and most of them are terminal. So for me having been newly diagnosed with a non-invasive cancer being in a room full of people twice my age, well, maybe not twice my age, they’re in their late 50s-60s and some of them were dying, I mean, literally, people were going in for lung transplants. It was pretty scary I had spoken with the facilitator kind of like ‘I don’t know if this is right place for me’ but I didn’t have anything else. Nothing was available in the evenings. I was attempting to work through all of my treatment. I had a couple weeks off for my surgery but the only other resource that I had was the social worker was very flexible so that on my lunch hour we would do telephone calls or I
would go down and see her in person because I work down the street. So I think just support, resources, for younger people, a) at that time weren’t there and b) they weren’t available at different times. Wellspring had lots of programs but 99% of them are during the day. Even the ones in the night aren’t really support groups, it’s more activity-based kind of stuff. Exercise or yoga or meditation class but that’s not what you need necessarily in the beginning.

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)

The participants also discussed what types of support they would like to see in the future for young women that would better facilitate their healing journeys. Kelsey shared the importance of separating support groups based on age ranges.

*K: I would like to see more different kinds of support for younger people. For it to be separate and made aware that you have a right to feel different and, I don’t want to say stuck with older people, but that it’s... the same disease but it’s a different sub-sectional or routine you should be going through...It should be age group categorized. It would be even better if they say ‘okay this group is for people under the age of 35.’

I: Would it be for breast cancer?

*K: No, any cancer where you’re losing your hair. Because that’s what it’s for, you need to learn how to make yourself look better. Anyone in that thing who is young. There should be things geared towards if you’re at this age, that’s the whole point of why I’m at Wellspring. I’d like to see more of that.

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

Elizabeth would appreciate support groups that had a greater focus on motherhood and fertility issues.
I would love to talk to those people who had to go through the ‘Am I going to have another baby?’ you know...Yeah. Or how do you be a mom with breast cancer like that kind of thing. I suppose it’s a much smaller demographic and I don’t know if there are enough people to warrant that [in smaller towns]... It’s certainly not talked about.

(Elizabeth, age 34, middle SES, Caucasian, Stage I, 14 months since trx)

Re-defining self-concept. Majority of the women expressed some shift, either positive or negative, in their self-concept after their cancer experience. Suzie, for example, felt a significant change to her self-concept after her cancer experience and separation from her husband. She is currently at a life stage where she wants to re-define her core self, her individuality and what makes her unique.

I’m shifting in my identity. I’m becoming more of an individual, I’m searching out things who am I really without my parents, without [husband]. This cancer experience was my own, something that I didn’t share with anybody. I mean, other people were around me but it was my own. This isn’t about anybody but me....I’m thinking of a metaphor... a flower blooming despite all the pressures to be a certain way. That you’re supposed to be like a rose but when you bloom you’re a tulip. You’re trying to find your own way that’s unique, I’m trying to find my own way that’s unique to me isn’t prescribed by anybody else but me. That couldn’t be anything but right because that’s me.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

Abigail, too felt a change to her core sense of self.

I don’t see myself as the same person that I was before. Again, I try to rationalize that my sense of humor, everything else what really makes a person has stayed the same. I try to
think if this were a friend saying the things that I’m thinking, I know what I would say to that friend. You’re still you, that doesn’t really make a difference but it’s not the same thing when it is you.

(Abigail, age 47, middle SES, Italian-Canadian, Stage 3, 11 months since trx)

Likewise, Claire described experiencing a change to her self-concept. After her treatment, she decided to distance herself from her cancer identity and travel to Nicaragua. There, she said she was able to “practice” her “new self”.

That was a good experience for me, Nicaragua in general because I could practice my new self. As in I’m here in an environment where you’re never going to see these people again, so you could practice things like if you wanted to tell people or not. I didn’t tell anybody but I did, when there were only two of us, and my boyfriend was going through surgery. I did reveal that my boyfriend had cancer but not that I had cancer. I was in a safe environment in which it didn’t matter what I said about my cancer, but I could experiment it if I wanted to.

(Claire, age 40, low SES, Caucasian, Stage 0, 8 months since trx)

Prior to their diagnoses, many women described having a primary focus on others in their lives. Subsequently, after their cancer experience, several women began re-defining this component of their identity as a mother, friend, teacher, partner …etc. Many women began consciously placing more emphasis on themselves and their own needs. Reflecting upon her life experiences, Jessica realized that being selfish, “doesn’t have to be a bad word”.

Before it was all about the kids, the family, my husband, my family, my sisters, my mom and then I finally realize I only have one life to live and it’s my life. If everybody doesn’t like me I don’t care because I have my family and they love me and I just have to live for
them. My focus has so changed in that way so I find that... I decided that... selfish
sometimes isn’t a bad word, I find people associate it with a bad word but I find it
doesn’t have to be a bad word. I’m sometimes very careful to say that but I decide and I
tell my husband every time ‘I decided to be a bit more selfish and to take care of me first’
and that’s something I’ve done a lot. I’ve taken the time and effort to do more for me.
(Jessica, age 39, Korean, Stage III, 10 months since trx)

Olivia too recognized that as she continues her healing journey, she wants to start putting herself
first more often.

...prior to my diagnosis, I was focused on others. Making sure my family got along,
making sure my patients were taken care of... I could see that I was putting other people
first and I would really like to make a concerted effort to not put myself last anymore. So,
it hasn’t happened yet but I’m hoping that it’s going to start pretty soon.
(Olivia, age 36, Jamaican, Stage II, 6 months since trx)

Abigail similarly felt that since her illness, she started putting herself and her needs above her
students, family members and friends on more occasions.

My sisters will say that I’m a giver. I will think about what other people need or help out.
I don’t think of myself in that way, like what do I need and what should I be doing for
myself? That definitely has changed. I’ve backed away [from] some of the things at work
but I want to make sure that I’m exercising enough where in the past I would have said
it’s more important that I belong to this committee and do this work whereas now
somebody else can be on that committee and I’m going to go to a spin class. That’s a big
shift. I think that I ask myself when there’s a situation well what would I like to do, and
give myself permission that okay, if I want to...I don’t want to be going to [someone’s]
I'd rather stay home and see a movie, or go spend some time with my niece.

(Abigail, age 47, middle SES, Italian-Canadian, Stage III, 11 months since trx)

**Freedom to express self; healing as an individualized process.** The women interviewed were adamant that they should be able to express their genuine feelings in order to move through their healing journeys. Some participants felt that staying positive and optimistic was essential to heal. In contrast, other women were highly critical of this traditional healing approach; these women felt that they should be able to express other, less positive emotions when necessary. They wanted the freedom to express their authentic selves.

Among the women who advocated for staying positive in their healing journeys, Michelle discussed the importance of positive energy, particularly in facilitating high morale among those close to her.

*Cancer takes a toll on a lot of people, it’s really not just the person going through it it’s anyone who loves you, it takes a toll on them as well and it creates a lot of stress. Or it can create a lot of stress. I find that if you can look at the positives, lean on your loved ones if you’re fortunate enough to have them around you then you can still put out a positive energy and I think that positive energy will touch those around supporting you and instead of everyone feeling down and hopeless.*

(Michelle, age 39, middle SES, African-Canadian, Stage II, 48 months since trx)

Likewise, Judy shared,
There are other people who would approach this completely different who would expect pity and sympathy. This is the hand that I'm dealt and I'm just dealing with it in the best way possible. The positive attitude has gotten me a long long way.

(Judy, age 37, middle-upper SES, Caucasian, Stage II, 47 months since trx)

Nonetheless, other women believed they should give themselves “permission” to express their genuine emotions. They explained that there are legitimate reasons for them to feel sadness or anger; thus, they should not feel any shame or discomfort in expressing them.

...Almost giving yourself permission. You say okay tonight you can feel bad for yourself, or even tomorrow. Go ahead, feel sorry for yourself. Cry it out, do whatever but the next day let’s move on. I think giving permission to feel bad helps you. Because you think oh okay I felt bad and now it’s time to be okay. I think if I always had to be on the up and be happy, it might be too much of a stress. Finding balance.

(Jessica, age 39, Korean, Stage III, 10 months since trx)

I think people should be allowed to be however they want to be, however they’re feeling, and not be told that there’s a right way to be. In anything. About emotion, about how we should look, about how we should behave... There’s a lot of very valid valid bona fide reasons for somebody to feel down when you’re going through treatment. To rob people of that opportunity because somebody somewhere made this idea that if you’re positive somehow... I don’t know what that’s founded in, I don’t know if that’s research that’s been done that’s truly scientific research that’s shown that, but that’s a scare tactic.

(Suzie, age 43, low SES, Mediterranean, Stage II, 13 months since trx)

Kelsey explained that while the notion of positivity is useful for an average older woman with breast cancer, it is less needed among a younger population.
In my age group, you need to let someone say ‘you can be negative and upset, today, or whenever you need to take that day.’ Or sometimes because older people are more negative or less positive so that whole concept comes from the average person being negative where I think if you looked to the average young person, [they’re] positive and upbeat.

(Kelsey, age 38, low-middle SES, Jamaican, Stage III, 24 months since trx)

In sum, participants shared a variety of factors that facilitated their healing journeys after their breast cancer experience. Women reported factors that are frequently found in the psychosocial oncology literature among cancer patients and survivors. Participants highlighted the importance of: focusing less time on insignificant or meaningless aspects of their lives; living in the present moment, and being less concerned with the distant future; support from family, friends, partners and medical staff throughout the breast cancer experience; finding humour; maintaining some sense of control after treatment; taking time to accept bodily changes in order to move forward. Additionally, women reported on facilitative factors less commonly found in the current literature. Women discussed: decentralizing the focus on their altered body, and instead shifted their focus to more important aspects in their lives; giving and receiving support from other young women; redefining their self-concept after their breast cancer experience by placing a greater emphasis on themselves and their loved ones; making each woman’s healing journey an individualized process where she has the freedom to choose how to express herself.
CHAPTER IV

DISCUSSION

The objectives of the present study were threefold; to examine the unique challenges faced among young breast cancer survivors in relation to their self-concept; to explore the identity reformulation process as women adjust to a new lifestyle after their cancer illness; and to identify women’s creative problems solving solutions aimed at mitigating any long-term distress and discontinuity between their past, current and ideal selves. Retrospectively examining the life history narratives of a diverse group of women between the ages of 32-45 at diagnosis, including inquiries about their pre and post breast cancer experience, this qualitative study provides a general framework to understanding each of these objectives. Moreover, exploring young women’s narratives through the identity reformulation process created an alternative approach to the four prescribed QOL domains typically used to examine breast cancer survivors’ psychosocial wellbeing. This exploratory approach also provided a greater emphasis on women’s lived experiences, their sense of self, and personal agency. Of particular significance was the intersecting role that three domains of social location (gender, youth and health status) played in relation to the three objectives stated above. The discussion therefore commences by examining the unique challenges and the identity reformulation process in relation to these three intersecting domains. The discussion follows with an exploration of the facilitative factors which serve to foster women’s healing journeys after completing their cancer treatment. Limitations to the present study and recommendations for areas of future research are also highlighted and discussed.
Unique Challenges to Young Women’s Self-Concept

While a number of challenges faced by young breast cancer survivors in relation to the different domains of QOL have been identified in previous literature and discussed in the literature review (Siegel et al., 1999; Dunn & Steginga, 2000; Bloom et al., 2004; Avis & Manuel, 2005), this research has not focused on young women’s self-concepts after their diagnosis and treatment. The present study provided participants the opportunity to reflect on their sense of self, their lived experiences, and their personal agency before, during and after their cancer experience. Situated at the intersection of three shared domains of social location (gender: women, age: young adults, and health: cancer survivors) the women identified five prominent challenges to their self-concept after treatment: 1) betrayal by the body; 2) sexuality and dating; 3) fertility and adoption issues; 4) significant role changes, 5) disclosure of illness.

Betrayal by the Body

Given the unforeseen and lasting challenges of the cancer diagnosis and treatment to their bodies, women in the present study commonly reported feeling betrayed by, and shameful of, their bodies after their breast cancer treatment. Piot-Ziegler et al. (2010) also reported on women expressing disappointment and betrayal by their bodies as a result of developing breast cancer at an early age.

Prior to their diagnosis, as young healthy women, participants in the present study assumed a position of control over their bodies; they assumed that their bodies, their sense of self and their futures were indestructible. Indeed, Charmaz (1995) identified this as a common phenomenon among young people prior to any chronic illness. Moreover, Siegel et al. (1999) specifically reported on young women with breast cancer who described these common feeling
prior to their breast cancer diagnosis. However, previous studies tended to address only some of these components. Unique to the present investigation is the range of experiences subsumed under their sense of confidence in the body prior to their diagnosis, which included: being in control, being indestructible, feeling feminine and sexy, the possibility of future pregnancies, and having enough energy to get through a long day of work and/or family life.

As a result of a breast cancer diagnosis, these multiple assumptions were shattered. The women in the study experienced a disruption between their self experience and the changed experience of the body following diagnosis and treatment. These results are in line with those articulated by Charmaz (1995) who described that with each unsuspected alteration found in the body, people with cancer experience a loss of unity between their bodies and sense of self. This incongruence leads to disappointment and betrayal (Charmaz, 1995). Although some women who experienced disappointment and betrayal chose to hide their altered bodies from themselves and others, they could not easily hide from the uncertainty and fear that their altered bodies had come to represent. As Waskul and Riet suggest, feelings of betrayal do not end with a mastectomy; rather, it carries on, often manifesting itself in uncertainty, fear, and distrust of the body.

The present investigation suggested that the shame that several women identified in their bodies was related to their pre-cancer self experience in the context of their social world. In particular, women who retrospectively reported a stronger connection to widely sanctioned societal standards of health and beauty prior to their cancer diagnosis were more likely to hide their bodies after their cancer treatment. These women were also more concerned with the possibility of being stigmatized as a result of their illness. Further, those who feared stigmatization as a result of their altered bodies also reported experiencing stigma more often
among family members, friends and co-workers. In contrast, women who reported less of a connection to traditional societal standards of health and beauty prior to their diagnosis were better able to accept changes and feel less shame from their bodies.

Piot-Ziegler and colleagues (2010) pointed out that breast cancer confronts women with the reality of an ailing body and therefore women have no choice but to reflect upon their pre-cancer bodies. The researchers further explained that two different experiences of corporality exist after a breast cancer experience. Among women who reported taking good care of their bodies (i.e. physical activity, healthy diet, no smoking etc.) prior to their cancer experience, these past moments of caring for their body were seen as a special time, when their body was seen and touched in a positive way. When illness struck, these women felt that their bodies had betrayed them. Piot-Ziegler stated that it induces, “bitterness and feelings of unfairness” (Piot-Ziegler et al., 2010, p. 489). However, for women who reported not paying attention to or caring for their bodies (i.e.: no physical activity, or attention to healthy diet, etc.) prior to their diagnosis, “this lack of attention was then interpreted, in the context of illness, as a form of disrespect towards their bodies as well as towards themselves” (Piot-Ziegler, et al., 2010, p. 489). These women were more likely to develop feelings of guilt or regret, leading them to reflect on and/or redefine themselves (Piot-Ziegler et al., 2010).

Nonetheless, while some women in the present study felt a significant amount of betrayal, shame and guilt from their body after their breast cancer experience, others did not associate their bodies with these disruptive experiences. Interestingly, several women reported feeling a stronger connection to their bodies after their breast cancer experience. Indeed, in many ways, participants had the ability to find strength and connection to their bodies after the illness. These divergent experiences raised the questions of, first, what caused some women to feel
betrayed and others to feel closely connected to their bodies? And, second, how are some women well-adjusted after their cancer experiences, while others are not?

Using the present results, it appears that the perceived discrepancy between women’s past and future selves after the cancer experience may have led to greater long-term distress, and ultimately a greater sense of betrayal in their body. Participants who identified some degree of discontinuity between their pre and post cancer selves (i.e.: as a mother, a partner, a successful professional, an independent individual), described having difficulty making positive connections with their body and, thus, felt an enhanced sense of betrayal. In contrast, women who identified greater continuity between their pre and post-cancer selves experienced less distress and thus, less betrayal.

**Sexuality and Dating**

An important change in self-concept for the participants in this study involved the change in sexual identity. These results have been reported by other researchers. In particular, Rubin and Tanenbaum (2011) explained that sexual identity is rarely assessed and/or reported in psychosocial adjustment and QOL studies among breast cancer survivors. In an essay about Illness and Imagery, Datan’s (1989) explained that breast loss was not only a physical change to one’s body, but a removal of one’s sexual identity and attractiveness (as cited by Rubin & Tanenbaum, 2011). Datan (1989) further stated, “One is victimized not by a disease but by its cosmetic consequences: the threat of a desexualized body” (p. 185).

In the present investigation, most women viewed their breasts as important symbols of their sexuality and consequently their feminine identity; this suggests that a diagnosis of breast cancer, therefore, is more than a major health crisis for a woman. By most women, not having
breasts that fit the traditional standards of health and beauty was viewed as a threat to their perception of beauty and attractiveness, and thus, to their feminine identity, leading to significant distress. Women who identified a stronger connection to their breasts before their cancer diagnosis reported having some internal struggle reclaiming their sexual identity after treatment. Many of these women also questioned what this perceived loss in attractiveness would do to their dating and sex lives. Nonetheless, while these concerns were quite common, most participants were also adamant that over time, their sexual identity could be reclaimed as they continued to adjust to their altered bodies and renewed selves. In fact, one woman in the present study (Suzie) was so passionate about reclaiming her sexuality after her cancer experience that she decided to desensitize herself to her new body. Once a day, she would stare at her chest in a mirror and rub the area of her chest where she had had surgery in order to feel comfortable with her body and renew her perception of sexuality. Similarly, another woman (Kelsey) felt strongly that she needed to reclaim her sexuality; however, she decided to have reconstructive surgery in order to make herself look and feel more sexual than her pre-cancer self. Not only are women’s breasts a symbol of sexuality, but also physiologically connected to sexual desire. Alexandra articulated that her breasts had always been an important link to her sex drive. Consequently, physically losing the feeling in her breasts significantly impacted her overall sexual desire.

Interestingly, not all women interviewed had a strong connection to their breasts prior to their cancer experience. Several women retrospectively reported that their sense of sexuality and attractiveness was acquired through other aspects of their bodies and selves such as their height or weight. Thus, these women reported being more at ease with the decision to have a mastectomy and/or prophylactic surgery in order to remove the cancer and reduce the possibility of recurrence.
In addition to their breasts, the women in the study felt a loss of sexuality and attractiveness as a result of hair loss. Indeed, other authors have highlighted the symbolic value of hair for women across different cultures, including beauty, femininity, personal growth, maturity, and age (Helms et al., 2008). Helms and colleagues further suggested that many people view their hairstyle as an important part of their identity and appearance. These authors also described that hair loss as a result of chemotherapy has been associated with loss of sexuality, attractiveness, and individuality as well as dying (Helms, et al., 2008). In the present investigation, participants discussed the challenges of feeling sexy without hair. They often expressed that it was appropriate to wear wigs in order to portray a self-image that aligned with who they wanted to represent. However, several women struggled with the decision to wearing wigs. These women questioned whether they would be presenting a fake self, one that did not face reality. As such, some women chose not to wear wigs and, instead, shared their cancer experience with the world, hoping to portray their true selves to those around them.

Given the obvious sensitivity that exists around a woman’s altered body and self-image after the loss of her breast(s) and possibly hair, all single women interviewed had significant concerns about re-entering the dating world. Dating was identified as another prominent challenge for women. Immediately after completing treatment, most women did not feel ready to re-enter a romantic relationship. At a time when women faced significant discrepancies between their past and current selves, these women were not ready to face a prospective relationship. Commonly asked questioned by these women included: When can I tell a new partner about my illness? Can I date with this unique kind of baggage? Will anyone ever find me sexually attractive? Will someone be able to touch my chest in a sexual way? These questions were typically asked among women who continued to feel discomfort with their current sense of
self and their connection to their body. Many of these women also expressed concerns about presenting a false self to potential partners by not disclosing their cancer identity.

Interestingly, Claire’s narrative highlighted the impact that potential partners can have on enhancing one’s sense of attractiveness, sexuality and overall self-image after cancer treatment. Two weeks after completing adjuvant therapy, she met a partner who also had cancer. Claire felt an immediate impact that her partner had on her self-esteem. She felt comforted knowing that he too had gone through this painful experience. She valued him and the way in which he strengthened her sense of self and bolstered her self-esteem.

Finally, women also shared that over time, they became more accepting of their bodily changes, and consequently were ready to move forward and date new people. However, the time taken to reach this level of acceptance was variable. The results of this study also indicated that a woman’s acceptance of her altered body was also related to the level of discrepancy reported between her current and ideal selves. If her current self aligned with who she ideally hoped to be after her cancer treatment, she was more likely to accept her altered body and begin dating.

Fertility and Adoption Issues

The results of the study indicated that several women were forced to come to terms with the reality of their new life circumstances after their breast cancer treatment. Many young women in their 30s and 40s were at a life stage where they hoped to share their lives with a child. Motherhood, for several of the women, was seen as an ideal future prior to their cancer experience. However, after their cancer experience, most women faced the reality that they would not be able to get pregnant or adopt a child. Gorman, Usita, Madlensky and Pierce (2011) highlighted that although fertility issues were important to young women with breast cancer,
treatment decisions were mainly motivated by survival concerns. As such, women were left to deal with the possibility of infertility after their medical treatment was completed. Unique to the present investigation, though, was women’s exploration of having a less traditional life trajectory without future children; thus, a cancer experience for many of the women permanently diverted the trajectory of their life path and thus challenged their post-cancer self-concepts.

One participant, Judy, had a strong desire to get pregnant for the first time with her husband before her cancer experience. After many failed attempts at conceiving, she and her husband tried an in vitro fertilization (IVF) procedure. However, after this procedure, Judy was diagnosed with breast cancer. She and her doctors believed that the IVF played a direct role in her cancer diagnosis. While Judy continued to want children after her cancer experience, she came to terms with the reality of her situation; she would have a non-traditional family, one that did not involve raising biological children of her own. Similarly, Abigail, for many years had planned to adopt a baby from Russia, when she was ready. However, after her cancer experience, she realized that her new reality could not include a child. Her concerns about possible cancer recurrence caused her to change her pre-cancer life trajectory. Conversely, some participants did not have to change their life trajectory after their cancer experience. Kelsey, for example, emphasized in the interview that she had no intention to have children.

Role Changes in Close Relationships

The results from the present investigation found that the cancer experience challenged the way women interacted in their close relationships. Indeed, the tendency to re-define oneself in relation to others is common among young women (Tindle et al., 2009). Role changes among participants were related to the bio-psychosocial changes that the women experienced throughout
their cancer illness; they occurred in different domains, including their roles as mothers, daughters, and partners. Tindle and colleagues explained that women’s “system” of relationships with others can be affected by bio-psychosocial developmental changes; these changes can ultimately interact with each other, leading to a renewed sense of self.

As mothers to young children, women in the study felt an enormous responsibility to care for, raise, and teach their young children to live happy, healthy and successful lives. However, with a cancer diagnosis, this was challenged. All mothers interviewed identified the important role they played as caregivers to their child(ren). Subsequently, when their role as caregiver was challenged with a cancer experience, participants came to a heightened awareness about what was most important in raising their children. One mother, for example, felt it was important for her children to see life as an imperfect journey; she wanted to teach them that obstacles and challenging life experiences were valuable and important life lessons. Many mothers too felt a sense of urgency to impart ‘life’ lessons onto their children. Wilson (2007) reported that after any chronic illness, mothers tend to demonstrate an overwhelming desire to survive and protect their children; this represents a fundamental reformulation of their identity as a mother.

Interestingly, several mothers in the study felt their original definition of motherhood had been challenged after their cancer experience. Elizabeth, for example, felt strongly that her cancer experience allowed her to reconstruct the definition of motherhood. Prior to her illness, she believed that a mother was a nurturer, and a person responsible for taking care of all her children’s needs. However, after her cancer treatment, Elizabeth was physically less able to take on many of these self-defined tasks. Subsequently, she developed some significant anxiety being alone with her child; she felt useless around him. Her anxiety and feelings of uselessness forced her to challenge her definition of motherhood and thus made her reconstruct this role. Elizabeth’s
narrative, in particular, demonstrates women’s ability to redefine their understanding of motherhood in order to appease a part of their disrupted identity after their cancer experience. Parallel to Wilson’s (2007) findings, the results of the present study suggested the potential significance of motherhood as a key identity needed to be explored to better understand the experience of breast cancer in young women. Given the scarcity of research exploring motherhood as a key identity in relation to breast cancer, this body of work was invaluable; Wilson (2007) suggested that motherhood might represent a key source of a women’s identity. Further, Wilson stated that when other sources of identity, such as work, are undermined, the importance of maintaining key identities, such as motherhood may be accentuated.

Additionally, several women identified their role as a daughter was challenged during their cancer experience. More specifically, women described spending time consoling and counselling their mothers after their treatment. Some women felt frustrated by this new role task. Additionally, few felt their mothers continued to label them as a ‘sick person’ after their hospital treatment finished; a role that no longer suited their post-cancer treated identity. As identified in previous literature, after breast cancer, women typically desire a ‘new normal’, with little discrepancy between their perceptions and others’ perceptions of their sense of self (Sulik, 2007). Hilton (1996) further highlighted the importance women with breast cancer place on returning to ‘normal’ with family members. Hilton found that once women were ready to move forward after their illness, they wanted to return to their usual daily tasks, and deemphasize the sick role demands placed upon them by family members. As such, the views in the current study are in line with past literature. Interviewing young women brings a unique perspective emphasizing their desire to resume their normal roles in relation to their nuclear families, and their mothers in particular.
All women who had long-term partners discussed the transformative effects that occurred within their romantic relationships. Most women identified the foundation of their romantic relationships being tested during their cancer experience. Several women shared that while the cancer experience was a challenging period in their relationships, ultimately, it strengthened the bond with their partner. In fact, for these women, their cancer experience heightened the importance in maintaining a connection with their partners. In contrast, other women saw the foundation of their relationships crumble through their cancer experience. These women realized they could no longer continue in their current relationships. One disruptive type of experience was not feeling supported by partners during their cancer experience. One participant, Suzie explained in detail the process of deciding to separate from her husband after her cancer diagnosis. Her diagnosis was described as the trigger that caused her to recognize that she could not continue living her life in an unhappy marriage. Correspondingly, Holmberg, Scott, Alexy and Fife (2001) reported that partner relationships, like Suzie’s romantic relationship, that are troubled before the diagnosis typically faced challenges and negative changes within the relationship. Likewise, Walsh, Manuel and Avis (2005) also reported on young women’s romantic relationships being tested during the breast cancer experience. The researchers specifically found a range of changes within partnered relationships after a breast cancer diagnosis including: an increased closeness and intimacy with partners, communication difficulties/avoidance with partners, and separation or termination of partner.

Unique to the present study, women described a greater understanding of their needs within their romantic relationships. Thus, another common challenge discussed in the current study was having both partners willing to make changes within the relationship. After her cancer experience, Kelsey, for example, became more aware of the values that were important to her
sense of identity and overall well-being. Thus, she realized that she was less interested in compromising on certain values in her current relationship.

Another critical role change that occurred was in relation to healthy peers. Like their romantic relationships, many women in the present study found the foundation of their friendships tested during and after their cancer experience. Women felt truly blessed by the friends that took the time and effort to support them during this painful life experience. Consequently, many reported stronger connections to their friends after their illness. These women also realized who their true friends were and which friends they could rely upon. In contrast, other women in the study described feeling alienated from their healthy peers. These women believed that the alienation experienced was a result of their peers carrying some degree of discomfort and/or fear of cancer; thus, their peers had little desire to interact with them. In describing unmet needs, Holmberg and colleagues (2001), similarly reported women experiencing both negative and positive responses from their close friends. Moreover, the researchers explained that interactions with friends during this time period took on new meaning for women with breast cancer. The present study adds to this existing literature; women in the study explained that once they were diagnosed with cancer and had to put their lives on hold, their peers continued to move forward with their normal life trajectories. As such, several participants described feeling abandoned by their peers.

**Disclosing her Illness**

Disclosure represents a subjective form of telling, which brings, “one’s experiencing, feeling self into the foreground” (Charmaz, 2006, p. 159). A disclosure reveals crucial facts and feelings about the self (Charmaz, 2006). By revealing a breast cancer identity, one faces many
risks including being labeled, judged, questioned, pitied, or victimized. All of these potential risks have led women in the study to question whether they should disclose their identity as a cancer survivor. For most women, revealing their cancer identity meant acknowledging that they were weak, sick, or undesirable. Therefore an overwhelming amount of women took measures to hide their cancer identity from others; women wore wigs, put on make-up and isolated themselves from their friends and social communities. Furthermore, by revealing this cancer identity to others, these women would be admitting that their cancer experience had been absorbed into their self-concept. The cancer experience had thus helped shape their current sense of self. However, many women were uninterested in attaching their cancer identity to their current self-concept; therefore, these women did not reveal their cancer identity to others. A dearth of literature has focused on young women’s difficulty disclosing their identity as breast cancer survivors. However, Landmark and DrPolit (2002) reported that a mastectomy and the ensuring physical changes affect the overall identity of women. Their findings showed that when women’s altered body were seen as an isolated phenomenon, women experienced this as a “handicap requiring adaptation” (p. 119). As a result, this adaptation ensured that many women would detach their cancer identity from their current self-concept.

While several women were uninteresting in disclosing their cancer identity, they also inadvertently challenged their sense of self by keeping part of their life experience hidden from their social world. These women indeed identified a negative connotation around illness and and/or having breast cancer. Some women feared that this negative connotation would adversely shape their social world. For example, Kelsey felt strongly that her cancer identity would place her in a victimized role, a role that considered her weak or dependent on others. Thus, she de-emphasized her cancer identity among those close to her. After her cancer treatment, Kelsey hid
any physiological changes and follow-up medical appointments from her partner in order to ensure that her current identity was dissociated from a sick person. Similarly, when Judy began her new job after her breast cancer experience, she wanted her co-workers and employers to view her as a competent, strong and independent woman; however, she feared that if she disclosed her cancer, problems would ensue at her work and people would negatively judge her work abilities. Consequently, she decided not to tell her co-workers about her breast cancer experience. These findings may also align with the notion that social constraints such as cancerphobia and/or concerns about stigma still exist among women with breast cancer (Wilkinson & Kitzinger, 1993; Lepore & Helgeson, 1998). Women may feel uncomfortable disclosing their cancer illness, and consequently their cancer identity as a result of the prevailing negative attitudes experienced within their social world.

In contrast, other participants saw significant value in revealing their cancer identity. Once these women knew that their cancer was no longer life threatening, many women felt comfortable sharing their identity with close others. These women enjoyed sharing feelings of relief with others. Interestingly, many of these women also experienced feelings of shame and embarrassment about their diagnosis; they felt victimized or pitied by others. However, they explained that by revealing their cancer identity to others, they were ridding themselves of internal feelings of shame and stigmatization. Not only did they eradicate these feelings, but they also felt a stronger desire to spend time with others debunking myths that existed around the breast cancer experience. They desensitized family members, friends and co-workers to their illness by providing more information about their personal cancer experiences. Ucok (2005) reported in her findings that women who identified supportive social interactions and external validation, such as committed friendships, a spouse who showed understanding, intimacy and
love regardless of one’s appearance, were more likely to move beyond attachment to a prior concept of who they were, and make peace with the present experience in one’s body. Once women were able to reach a level of congruence between their self and their altered body, women in the study felt more comfortable and even empowered disclosing their breast cancer experience to others.

While some women felt empowered by choosing to reveal their cancer identity, others did not have this control when disclosing their identity. Given some of the obvious physical changes that occur from cancer (i.e. hair loss, removal of breast, scars), certain people labelled them as cancer patients without their permission. Thus, their cancer identity was not always controlled by the survivors. Subsequently, this powerlessness and unwanted labeling was distressing for survivors and challenged their sense of identity and personal agency. The uncontrollability in their cancer identity was described as disempowering for women; they felt silence and powerless by an unwanted component of their identity. Stang and Mittlemark (2010) reported on the importance of making women’s voices heard throughout the cancer experience. Having control over the dialogue that emerges from their cancer experiences caused women in the present study to feel more empowered in themselves. According to Frank (1995), “seriously ill people are wounded not just in body but in voice. They need to become storytellers in order to recover the voices that illness and its treatment often take away” (p xii).

Disclosing an identity as a cancer survivor is a significant challenge on many young women’s self-concepts. Nonetheless, the results of the present study reveal that efforts need to be made for women to feel less stigmatized or negatively labeled by their illness within their social world. This may result in the disclosure process becoming less of a challenge, and instead, an empowering one that integrates their cancer identity into their newly reformed self-concept.
Identity Reformulation Process

Cancer survivorship is embedded in identity reformulations; they result from emotional, psychological, social and physical changes that arise out of the cancer experience (Thibeault & Sabo, 2012). The identity reformulation process is a constant and compelling force that drove many women in the present study towards self-actualization (Thibeault & Sabo, 2012). In the process of gaining meaning, a renewed life trajectory was envisioned, shaped and rewritten by participants. While greater meaning and enlightenment did not always occur for participants, the women were forced to confront discrepancies between past, current, and ideal selves as a result of the cancer experience.

Of particular relevance to the present study is earlier research on chronic illness within medical sociology (Bury, 1982; Charmaz, 1991; Strauss et al., 1984; Corbin & Strauss, 1988; Anderson & Bury, 1988). Bury’s (1982) concept of biographical disruptions aligned with the current study’s findings. Biographical disruptions occur, “when the structure of daily life becomes disjointed. Activities which previously could be engaged in are more difficult or totally impossible because of the illness, and there is a discrepancy between the individuals’ definition of herself with regard to her past, present and anticipated future” (Asbring, 2001, p.313). In the present study, women’s cancer experiences brought to the forefront questions about their biographical work. The biographical work in this study included women discovering which aspects of their identity had been lost, maintained, and reshaped. This process created a partly transformed identity among young women after their cancer experiences, which the present study defined as the identity reformulation process. Thus, the present study examined the identity reformulation process by exploring biological disruption between past, present and ideal selves after women’s cancer experience. In order to mitigate these disruptions, participants described
re-locating themselves in their gender, their youth, and their health status after their cancer experience.

**Re-locating self in Gender**

As outlined in past literature (Little et al., 2002; Tindle, et al., 2009) aspects of the breast cancer experience, including the deconstruction of women’s bodies generated a deep identity crisis for women in relation to their gender schemas. A mastectomy, for example, was not portrayed simply as a surgical treatment that left superficial scars; rather, for many, a mastectomy was a life changing, potentially traumatizing experience that shook the foundation of women’s sense of self.

Women in the study expressed concerns after their surgical procedures that they no longer felt like a woman. As has been found in other studies (Piot-Ziegler et al., 2010), women feared that their cancer experience would challenge the connection to their gendered identity. Women were concerned about becoming less feminine, or even genderless. In fact, one woman expressed feelings that she had reverted back to pre-pubescent young girl after her mastectomy. Thus, in order to reduce the discrepancy between past and current selves, and consolidate their renewed gender experience, these women had to face re-locating themselves in relation to their gendered identity.

Two divergent experiences existed among women who re-located themselves in relation to their gendered identity. On the one hand, several women developed a stronger, more traditional feminine role after their cancer treatment. After the physical and psychological insults that occurred on their bodies and femininity, women felt deeply obligated to counteract the negative attributes placed on their self-concept. Thus, these women eased the anxiety felt
between their past, current and ideal feminine selves by developing an even stronger feminine role, based on stereotypical norms. These women put a greater emphasis on their physical appearance, on caregiving, and on maintaining a feminine status quo. By maintaining a feminine status quo, women were able to feel ‘normal’ and less out of sync from their young, healthy peers. These women attempted to assimilate their physically different selves to that of the ‘norm’. Paradoxically, while many women described this experience as empowering, for many, this experience also involved hiding their bodies and their distress from others. Kelsey, for example, described feeling deeply empowered by her renewed feminine identity after her treatment; yet she also had difficulty sharing medical appointments and showcasing parts of her body that identified her as a cancer patient to her partner. It was important for her to feel strong, healthy, and feminine with her partner. Henderson, Davison, Pennebaker, Gatchel, and Baum (2001) reported in their study that minimal disclosure of breast cancer-related experiences may lead to worse long-term psychosocial outcomes. Nonetheless, Kelsey and other women in the current study felt that heightening their traditional image of femininity with others, and minimizing their cancer identity, put them at ease with their altered body and renewed their feminine identity.

On the other hand, several women re-located themselves in relation to their gendered identity by rejecting the traditional image of femininity, and the feminine status quo. Rather, these women successfully redefined the meaning of womanhood, femininity and beauty in order to suite their lived experiences. This approach also meant that they had to ward off societal judgments (made mostly by their mothers and health professionals) in relation to their femininity. Similar to women who re-located their gendered identity towards a more traditional feminine role, women who rejected the traditional feminine image also felt empowered through
this process. These women reported that this process eased some of their anxiety by partially mitigating the discrepancy between their past, current, and ideal selves. According to an integrated feminist, existential perspective, Rubin and Tanenbaum (2011) explained that these two strategies may be used by women to symbolically defend against any existential anxieties within themselves and among others.

One fundamental question remains, why do some women re-locate themselves in relation to their gendered identity through adhering to stereotypic feminine norms while others prefer to defy these norms and redefine their gendered identity? As has been identified as a limitation in other studies (Howard-Anderson et al., 2012), pre-cancer biographical information, or baseline data, is rarely captured in the literature. However, the present study found that the retrospective accounts of women’s identities before their cancer experience were fundamental to clarifying this question. Specifically, the results suggested that women’s connection to traditional, hetero-normative standards of femininity prior to their cancer experience impacted their psychosocial well-being and overall self-concept as survivors. Women who had a strong connection to traditional feminine norms prior to their illness were more likely to maintain or heighten traditional images of femininity in themselves. Alternatively, women who questioned societal standards of femininity prior to their cancer experience were more likely to reject the traditional feminine image post cancer diagnosis and treatment.

Beyond gender role expectations, participants also discussed re-locating their gendered identity through their feminine body. For many women, the cancer experience induced a discrepancy between a socially expected female body and her altered body after treatment. The symbolic parts of the body linked to femininity were challenged by the illness, and subsequently challenged women’s overall gendered identity. When the discrepancy between women’s
idealized versus current images of the female body reached a significant level of impairment and distress, women struggled to accept their altered, non-traditional bodies. However, the results of the study also found that greater acceptance of women’s altered bodies commonly occurred after one year since the completed medical treatment. This may also indicate that there was an adjustment period that took place, before women were willing to accept possible changes to their body and sense of self.

The results of this study also indicate that in order to accept changes to their body, women typically reformulate their self-concept in ways that lessened the discrepancy between past and current connection to their femininity. For some women, acceptance involved reconfiguring their body to encompass a traditional feminine identity. For example, Kelsey chose to reformulate her altered body to encompass a traditional feminine identity. She spent $8000 on reconstructive surgery to make her breasts more feminine. She took the necessary steps to relieve the discrepancy she felt between her past and current selves. According to Price (1990), Kelsey’s behaviour is an indication of the body’s physical value. Price states that patients (like Kelsey) compensate for losses of their ideal body and for their present reality by accentuating their appearance. As found in the present study, some women focused on external factors in order to gain control over their life situation and keep threats towards their identity and self-image at a distance. Additionally, the present study highlighted an alternative method in which women with breast cancer compensated for the loss of their ideal body and self. For several women in the present study, acceptance occurred by reformulating their feminine identity to include an altered body. Suzie, for example, chose to reformulate her feminine identity to include her altered body; she de-sensitized herself to her changed body by watching herself rub
her chest in a mirror. This act helped her to accept that her altered breast was a new part of her renewed gendered identity.

Similar to previous literature (Garland-Thomson, 2002; Piot-Ziegler et al., 2010), the results of the study found that women identified some similarities to people with physical disabilities. Specifically, feelings of isolation, alienation and physical differences with others caused participants to feel connected to people with physical disabilities. Thomas-Maclean (2004) explained that cultural messages of beauty, symmetry and wholeness are constantly reinforced and significantly impact the way we perceive ourselves and others. Consequently, women with physical differences (physical disability or breast cancer) become marked and excluded within the larger social class of women. Interestingly though, not all women resonated with these beliefs. Two women interviewed noted that the cultural discourse linking a mastectomy to an amputation was completely out of context and unnecessary. In fact, they did not feel their bodies had been de-feminized. However, these women also reported a weaker connection between their breasts and femininity prior to their cancer experience. It is possible that these women also had a weaker connection between their bodies and the widely socially sanctioned constructs of the female body; this may have contributed to their rejection of the disability schema.

**Re-locating self in Youth**

As a result of biographical disruptions that occurred from the cancer experience, significant discrepancies between women’s identities as young people before and after their cancer experience emerged in the present investigation. These disruptions forced women to reformulate their identity in relation to their youth.
Confronting, and adjusting to an illness that strikes at a shockingly young age can be a significant hurdle (Cimprich et al., 2002; Dunn & Steginga, 2000). Dunn and Steginga explained that after young women experience breast cancer, many feel they have unfairly progressed into an older, less agile life stage; a stage typically seen in older adults. Likewise, women from the present investigation experienced symptoms they assumed they would acquire later in life such as menopause, fatigue, chronic pain, memory loss…etc. Therefore, the discrepancy between their past selves as vibrant, youthful and healthy young women with long futures ahead, and their current selves forced them to reformulate their identity as young people.

All women interviewed described an altered connection to their career aspirations and life goals. While some women passionately spoke about transforming their careers into more meaningful and valuable work, others spoke about their professions becoming less important after their treatment. These findings are in agreement with Thewes and colleagues (2004) who found that young women’s breast cancer experience altered their progress and priorities at their current profession, or reduced their level of professional ambition. Further, women in the present investigation also felt a strong urge to pursue certain life priorities that they were never able to accomplish before their cancer experience. For example, Suzie was in a traditional marriage with her husband prior to the diagnosis and had been quite unhappy in her relationship for many years. Her cancer diagnosis pushed her towards her pre-cancer life priorities which included separating from her husband and pursuing a new career path. Similarly, Olivia candidly spoke about becoming dispassionate about her job as an orthopedic surgery nurse. While she had always wanted to find more meaning in her career, and had some desire to become an oncology nursing, she stayed at her position. After her cancer experience, she knew that she could make a significant difference in the lives of her patients as an oncology nurse. Thoits (1991) explained
that the cancer experience can result in changes of relative importance to specific identity characteristics, also known as the salience identity hierarchy. As individuals like Suzie and Olivia reconstruct their identities after cancer, the salience of certain identity characteristics change too. Changes to this hierarchy, in turn, altered aspects of their self-concept.

Unfortunately, most women in the current investigation also faced hostile work environments after their cancer experience. Unlike many older survivors, the majority of the younger survivors in the study were at a particular life stage where they must return to work. In fact, several women were still interested in advancing in their given field of expertise. Yet, despite public discourse banning stigma or discrimination among individuals with chronic illnesses or disability, stigma was still apparent in the workplace. Although stigma, particularly for breast cancer, has diminished considerably in the past 30 years, it has not entirely disappeared (Rubin & Tanenbaum, 2011). Rubin and Tanenbaum pointed out that, “as the army of one-breasted women have…morphed into a sea of pink sponsored by the fashion and cosmetics industries, problems such as social and employment discrimination are left to be solved by the individual, rather than through collective action” (p. 409). Given the highly competitive job market, young employees are expected to put in a tremendous amount of time and effort in order to keep their jobs. Moreover, most employees acknowledge that they can be easily replaced if they do not work up to the standards of their employers. Thus, when young women with breast cancer in the present investigation presented physical and psychological symptoms at work, they reported being discriminated against and/or stigmatized. In fact, employment discrimination caused significant distress among participants, that some women felt forced to resign from their jobs. Claire explained that when she worked for a Human Resources department at a large corporation, she was shocked that her direct employer showed little
understanding for her illness. Claire said that she was even more surprised given that her employer was also in a similar age category. Interestingly, majority of women interviewed also reported feeling uncomfortable disclosing illness-related information to their direct employers. As a result, miscommunication between women and their employers frequently occurred. Regardless, survivors faced significant stigma in the workforce which caused considerable distress and frustration. These frustrations propelled some women to re-consider their career aspirations and goals.

While several women in the study felt greater success and meaning by re-focusing their career path, others felt success by creating more distance from their careers and career ambition. These results are in line with other researchers (Joly et al., 2000; Thewes et al., 2004). Among the samples used, these researchers found a diversity of alterations made within women’s careers ranging from resigning from their jobs to changing the complete direction of their profession. Specifically within the present investigation, mothers with young children in the study identified the importance of becoming more focused on their children and less present at work. Many women also felt less motivated to advance their careers or make money for their family. Instead, they saw their illness as a ‘wake-up call’ to refocus on being good mothers. Thus, these women reformulated their identity as a young person by de-emphasizing their work life, and placing greater emphasis on their identity as a mother.

Women also indicated some discrepancy in the way that they managed their life priorities before and after their cancer experience. Once women realized that they were not living their lives to their full potential, they changed their life goals accordingly. In order to make these changes, many women needed to feel centered in their youth. While faced with their mortality as a women with breast cancer, these women also believed that they had many more milestones and
crucial years of life to live. As a result, they were propelled to carry out life priorities that they
had put off before their cancer experience.

Finally, participants discussed how their lived experiences as young survivors greatly
differed from older breast cancer survivors. Thus, women re-located their renewed identities as
young people with unique challenges, needs and goals in relation to older women. As young
breast cancer patients, most women in the study felt different and alienated from the breast
cancer community that mainly targeted an older population of breast cancer patients. In fact,
most women reported feeling silenced in breast cancer support groups with an older breast
cancer population. Thus, feelings of alienation were widespread for younger breast cancer
survivors, occurring among their healthy peers, their co-workers and even their breast cancer
communities.

Re-locating self in Relation to Health Status

For people who survived serious illness, Roesler (2006) stated that the “meaning of life”
is frequently dominated by the power of the medical narrative (as cited in Milligan, Kearns &
Kyle, 2011). Roesler suggested that the patient’s sense of self recedes into the background and
the physician’s view of the world takes precedence (Milligan et al., 2011). The author further
explained that individuals who survive illness seek to replace themselves in their illness story;
they create illness narratives in order to reframe and reclaim the illness experience (Milligan et
al., 2011). Many of these illness narratives were reflected in stories of restitution (movement
away from and back to health), chaos (life as never improving) and quest (opportunity for
change) (Milligan et al., 2011). While some women did not create illness narrative, nor do they
consider themselves “cancer survivors” in the present study, all women face the reality that they
had lived through a life threatening illness. Consequently, women explored and re-located themselves in their renewed health status.

The socialization of the cancer experience was one avenue in which women struggled to re-locate their sense of self in their renewed health status. While most women felt they had a voice during their medical treatment with health professionals and close others, some women felt pressure to maintain a ‘normal’, healthy feminine body after treatment. Elizabeth experienced medical staff continuously questioning her decision to have prophylactic surgery. Indeed, shared decision making between patients and health care providers is advocated within the medical community (Piot-Ziegler et al., 2010). However, medical staff may compromise patients’ shared decision-making processes by communicating a belief that they know what is best for the patient. Elizabeth described in her interview feeling negatively judged by her treatment decision from medical staff.

Current medical culture allows health professionals to provide feedback and even help with some decision making in relation to patients care. Yet, medical culture also attempts to physically return women back to their “normal” feminine selves with as little disfigurement as possible; a self where women can fit into society’s mold and mask their identity as a cancer patient. Rubin and Tanenbaum (2011) referred to this medical phenomenon as ‘gender policing’. Gender policing is a form of pressure from health care providers and survivorship communities against patients with cancer to adhere to traditional feminine standards of beauty during and after treatment (Rubin & Tanenbaum, 2011). However, for many women, the idealized feminine image is not always possible to attain. In fact, by promoting this fantasy, some women try returning to a part of their identity that they can no longer attain, an identity that excludes their cancer experience. Thus, gender policing within the medical and cancer community may cause
even greater discrepancies between past, current and idealized selves. While women appreciate medical professionals’ desire to return their bodies to ‘normal’; medical discourse also needs to recognize the reality of their renewed identity in relation to their health status. Therefore, the focus among health care professionals and survivorship communities should not necessarily be to return women to an idealized healthy body (once valued prior to diagnosis), but rather, to focus on adjusting to their ‘new normal’ with a renewed sense of self. Sherman and Rosedale (2012) explained that the 'new normal’ for breast cancer survivors involves creating a new mindset for women to develop a new way of being in the world that provides opportunity for growth. The concept of a ‘new normal’ is not a new phenomenon to the breast cancer literature or survivorship communities. Nonetheless, the present study suggests that facilitating women’s adjustment to a ‘new normal’ both during and after medical treatment is necessary among medical professionals and survivorship communities.

Olivia also linked the socialization of her cancer experience to her cancer identity. Before medical treatment, Olivia was told by medical professionals that her young age would likely ensure that she had an easier time (compared to older women) during treatment. Olivia was happy to hear this news. However, when faced with her chemotherapy treatment, she struggled significantly. She explained in the interview that the medical staff had unintentionally made her feel like a complete failure during her treatments, unable to handle her treatment regimen as she was expected to. This experience caused her to dissociate from a cancer survivor identity. She described feeling weak and disempowered by the experience. Helgeson (2011) explained that when women have had a more negative view of being a breast cancer survivor, survivor centrality is more likely to signify a potential problem. Olivia chose to dissociate her illness from her identity; thereby alleviating some problematic adjustments after her cancer experience.
Within the medical community, it is also important to recognize subtle differences between public discourse of illness and survivors’ narratives. Public discourse promotes women maintain “feminine bodies” after cancer, and remain positive and strong throughout their illness (Gray, Sinding & Fitch, 2001; Kasper & Ferguson, 2000); however, survivors’ narratives in the present study described this discourse as unrealistic and problematic. Using survivors’ narratives from the present study, it was apparent that women’s lived experiences were shaped by different dimensions of their social location; social location also impacted the way in which they decided to reformulate their sense of self after their cancer illness. Nonetheless, with excessive pressure from health professionals, survivorship communities and the public, it is understandable that women may have had difficulties fitting their illness or survivorship status into their identity.

Furthermore, participants in the present study reported being placed into a traditional ‘sick person role’ after their treatment by others. This finding was in line Parsons’ (1951) research who defined the ‘sick person role’ as a, “delicate entry into attitudes and behaviours consistent with being ill and gradual loss of the role of a healthy ‘normal’ person” (as cited by Chesler, 1987, p.2). Thus, women were given this illness identity without their consent. Participants explained that this role reinforced an identity that they did not want as a weak and dependent victim of a disease. Harwood and Sparks (2003) described the stigma associated with cancer patients; once an individual becomes sick with cancer, she may experience discrimination, and be placed into a pre-defined ‘sick person role’ (Harwood & Spark, 2003). Healthy people without cancer may carry anxiety, discomfort and fear in relation to this illness, and thus desire control over their bodies and health status (Harwood & Spark, 2003). As a result, healthy individuals may also distance themselves from illnesses like breast cancer by placing a survivor into pre-defined ‘sick role’ (Harwood & Spark, 2003). This ‘sick role’ thus allows
healthy individuals to dissociate themselves from the illness. However, this dissociation can cause women with breast cancer to feel confined to a stereotypical role that they do not associate with.

Finally, many women in the current study expressed a fear of disease recurrence after their cancer treatment. This fear has been commonly cited in QOL literature (Thewes et al., 2004; Dunn & Steginga, 2000; Sammarco, 2001). Women’s fear of recurrence is sadly one way in which survivors in the present study were forced to maintain some connection to their health status and cancer survivor identity. Thus, health status can be negatively linked to women’s sense of self and ultimately this can impact women’s long-term psychosocial adjustment and well-being.

**Healing and Facilitative Conditions**

The completion of medical treatment is in many ways a welcome milestone; yet, our results showed that indeed there were great hardships, uncertainties and challenges ahead as young breast cancer survivors. As stated by Hutchinson (2011), “the aim of medicine is not just to eradicate the suffering that can be eradicated, but also to support patients in facing suffering that cannot be eradicated, and which they may be avoiding, with the hope that they can experience a greater sense of integrity and wholeness” (p.26). Health care professionals can support patients beyond the completion of treatment. They can help patients move forward towards greater connections with themselves and their loved ones.

Participants identified six common facilitative conditions used in their healing journeys that have been illustrated in previous research studies with: younger breast cancer survivors (Bloom et al., 2001; Thewes et al., 2004), non-age specific breast cancer survivors (Sadler-
Gerhardt, Reynolds, Britton & Kruse, 2010; Landmark & DrPolit, 2002; Carver et al., 1993; Stanton et al., 2002; Henderson, Gore, Davis & Condon, 2003) and other cancer populations (Kyngas et al., 2000; Steptoe, Sutcliffe, Allen & Coombes, 1991; Molassiotis, 1997). Variants of these themes including: Don’t sweat the small stuff, living in the moment, support from family, friends and medical staff, humour, acceptance of body changes, and maintaining a sense of control, have been explored and identified as important facilitative factors to women’s healing journeys.

To date, a paucity of research exists on facilitative factors associated with young breast cancer survivors’ healing journeys based on their personal reflections. One of the most frequently cited factors among young women was their desire for specialized support with other young survivors. While women appreciated the support they received from older, post-menopausal breast cancer survivors and from individuals diagnosed with other forms of cancer, the women identified support from women at a similar life stage to be highly valuable to their healing journeys. Women in the study emphasized that the camaraderie, mutuality, and shared experiences created within specialized support groups for young women facilitated growth, empowerment, and a greater desire to move forward with their lives. These specialized groups also ensured women did not feel silenced as a minority group within the cancer community. Furthermore, women in this present study were adamant that support groups targeting younger women and their needs should include issues surrounding motherhood, fertility, dating and sexuality. Interestingly, Claire highlighted that while she appreciated attending support group after her treatment, many of the specialized groups that interested her took place during the daytime, while she was at work. Given that young women are likely to return to work after their cancer experience, (yet still struggle with a range of physical and psychosocial issues), Claire felt
strongly that these specialized support groups for younger women should also occur at more convenient hours.

Another facilitative factor that young women consistently identified in the present study was moving the focus away from their altered body. While previous research has identified that breast cancer survivors cope best through approach-oriented (active) coping strategies (Stanton et al., 2002), women in the present study also identified non-approach-oriented strategies that benefitted their overall well-being. Approach-oriented coping involves strategies directed at solving or managing the distress caused by the illness (Folkman & Moskowitz, 2004). Yet, unlike previous research, many women in the study felt that it was important to re-focus on other domains of life, particularly on important relational connections. This included developing stronger relationships with children, partners, siblings, parents, and other loved ones. As indicated in other research (Henderson et al., 2003), after a breast cancer experience, women tend to develop stronger bonds in their valued relationships.

Surprisingly, a dearth of literature exists that focuses on women’s sense of self as a facilitative factor to the healing journey. While several women were satisfied with their self-concept after their illness, others described becoming confused and uncertain of themselves and their futures. At a typical life stage where young women re-define and solidify who they are, and what they want for themselves, participants in the study seemed to go through a heightened version of this process. Women often described this process as empowering, feeling more control in their lives. Furthermore, women felt they were given the opportunity to critically examine past choices made in their lives. This resulted in women recognizing the importance of putting their needs ahead of others.
Several participants felt that others (including: the medical community, the survivorship community and family members) consistently promoted a narrow-minded approach to their healing journey. This approach emphasized positivity throughout the cancer experience and pursuing active coping strategies to relieve any distress. Indeed, this approach to healing has been extensively reviewed in the literature (Faller 1999; Brown, Butow, Culjak & Dunn, 2000; Richardson, Zarnegar, Bisno & Levine, 1990). However, while several women described the benefits of this particular approach, others felt it did not capture the entirety of their experiences. Instead, participants highlighted the need to break from this uniform approach to healing in order to express natural reactions to their cancer experience, including: despair, sadness, or loss. In fact, processing and expressing all forms of emotion has been found to enhance adjustment in cancer survivors (Stanton et al., 2000). By facing the reality of their experiences, women expressed and processed the emotions that more fully represented how they felt at specific moments. Furthermore, one of the largest studies used to compare high, medium and low levels of active coping strategies among cancer patients found no association with survival outcomes after controlling for clinical and socio-demographic factors (Reynolds et al., 2000). If seminal research studies have demonstrated that active coping strategies using positivity, strength or control do not necessarily lead to better psychosocial outcomes, then why do women continue to feel pressure to heal in a way that follows this approach? Clear variability exists in the factors that facilitate younger breast cancer survivors’ healing journeys. In fact, the dynamic processes in each woman’s healing journey are varied. While one factor may be particularly advantageous to one person, other factors may be equally advantageous to another person. Thus, by describing the facilitative factors articulated by the participants, the researchers recognize that there is more than one way to achieve good psychosocial outcomes after treatment. Exploring young women’s
past, current and ideal selves and their lived experiences can provide us with a better understanding of the appropriate coping strategies needed to facilitate their healing journey. Survivors, health professionals, leaders of survivorship support groups and family members should consider taking into account the variability of women’s healing journeys, their unique challenges and their complex social locations.

**Limitations**

The present study had some limitations that should be addressed. Primarily, conducting only one interview does not determine changes of the healing journey and reformulation processes over time. In the future, researchers could examine the identity reformulation process in younger women from a prospective longitudinal perspective. This knowledge would further our understanding of the fluidity involved in survivors’ identities and healing journeys. Secondly, the size of the group of participants was relatively small and homogenous, including mostly white women, which narrowed the generalizability of these results. Therefore, future research should recruit a more diverse population of younger women. Thirdly, although participants were all 45 years of age or younger at diagnosis, the age range was still large enough that participating women were at differing life stages. In the future, reducing the age range, and adding additional exclusion criteria may ensure that women from very specific life stages are included. Finally, the time since women finished medical treatment was variable in the study; women ranged from six months to 48 months since completing their treatment. Subsequently, women in the study were at diverse stages of their identity reformulation and healing journey. In the future, researchers should consider the impact that the time since women completed medical treatment has on the identity reformulation process and long-term well-being.
Clinical Implications and Future Research

Miller and Crabtree (2000) stated that, “the purpose of research is to inform clinical practice so as to improve life” (as cited by Sadler-Gerhardt, Reynolds, Britton & Kruse, 2010, p.276). Meeting women with breast cancer and listening to their stories, it is also important to consider how mental health professionals might help improve women’s overall survivorship experiences in the future. While early stage survivorship has been heavily researched (Sadler-Gerhardt et al., 2010), much of this research has addressed physical or short-term aspects of their care based on medical models that do not consider the entirety of their experiences (Sadler-Gerhardt et al., 2010). Based on the survivors in this research study, we identified four areas where mental health practitioners can advocate for and promote better psychosocial well-being for young breast cancer survivors. These included: targeting the identity reformulation process, individualized psychosocial support, support groups with other young cancer survivors, and educating others.

Targeting the Identity Reformulation Process in Future Interventions

Exploring the identity reformulation process has proven to be an alternative approach to understanding psychosocial well-being in young breast cancer survivors. However, this approach also provides a greater emphasis on women’s lived experiences, their sense of self, and their personal agency after a breast cancer experience. As well, this approach focuses on identifying any biographical disruptions that may have occurred as a result of the cancer experience. Thus, future psychosocial interventions targeting a younger population of breast cancer survivors should consider helping women to reduce discrepancies made between their past, current, and ideal selves. These interventions may also help women find greater meaning and inspiration in their futures.
Individualized Psychosocial Support

Unlike other studies, the present study clarified the relevance of women’s social location to their healing journeys and overall well-being. More specifically, in this study, women’s connection to their femininity, their youth and their health status all impacted the way in which they adjusted to the world around them. Thus, it is important for future interventions to develop more individualized psychosocial support systems that take into account women’s unique social locations; this will provide women with more specialized and more meaningful care.

Mental health professionals are well-positioned to take a holistic approach to fostering women’s experiences of social location and personal agency. In particular, mental health professionals can facilitate an individualized healing journey that embraces women’s experiences in relation to their gender, youth, and health status. This process is not easily accomplished; however, mental health providers have the knowledge and training to empower women and move them successfully forward in their healing journey.

Support Groups with Young Breast Cancer Survivors

While programs for younger breast cancer survivors do exist, our research suggests that the healing journey should take into account younger women’s dynamic sense of self and social location. Therefore, health professionals running these programs may consider facilitating women’s experiences by developing more support groups that promote individualized healing journeys suited to their unique needs. Health professionals should also support women as they make typical transformations to their self-concept, with their loved ones, and in the world around them.

As has been identified in the presents study, many women have difficulty finding support from other young breast cancer survivors. When facing their illness alone, women’s healing
journeys can be particularly challenging. Thus, having support from other women at a similar life stage, and facing similar cancer experiences would be instrumental to women’s progress through their healing journeys. Women may be better suited to re-locate themselves when surrounded by others going through a similar process. Although less of these support groups exist, health professionals should continue to advocate for and promote groups targeting younger women.

**Educating Others**

Finally, many women struggle to accept their renewed identity after their cancer experience as a result of common societal perceptions of breast cancer. Despite public perception that stigma and discrimination no longer exist among cancer populations, unfortunately, this is not the case. Indeed, stigma and discrimination do occur as women are still blamed for, and mistreated about, their cancer diagnosis. Thus, mental health professionals can advocate for and further educate employers, family members, friends and other health professionals to lessen any discrimination. This may also include educating family members and friends on best practices to communicate with loved ones after their illness. The role of mental health professionals within the breast cancer community is fundamental to young women’s post-treatment care; there are a multitude of opportunities in which mental health professionals can continue to support younger survivors and their loved ones.

While many young women adjust well to their lives after breast cancer, this is not the case for all young breast cancer survivors. By further examining the identity reformulation process, we can continue to develop new evidence-based recommendations for young women after their cancer experience. Indeed, a breast cancer diagnosis is a devastating illness for many young women. As mental health professionals, we can provide them with more specialized and appropriate care based on their unique challenges and needs; we can confront and help mitigate
any biographical disruptions resulting from discrepancies between women’s past, current and ideal selves. Health professionals have the opportunity to better the QOL and psychosocial well-being of young women who are beginning a new chapter of their lives after a cancer illness.
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APPENDIX A

RESEARCH STUDY: YOUNG WOMEN WHO HAD BREAST CANCER NEEDED

Who are we?
Investigators at the University of Toronto/Ontario Institute for Studies in Education looking for participants to take part in a 1 hour interview for a Master’s research project under the supervision of Dr. Niva Piran.

Purpose of the study
Despite public perception that young women are at little to no risk of breast cancer, the reality is that they are vulnerable. The purpose of this study is to explore the complex yet unique experiences of living as a young breast cancer survivor.

Eligible participants:

- Women between 20 and 45 years of age
- Living in the Toronto area
- Had a Lumpectomy or Mastectomy
- Completed treatment for breast cancer at least 6 months ago
- Interested in exploring issues around sense of identity, womanhood and body image as a survivor.

Lianne at:
Phone: (416) 978-0688 or youngbreastcancersurvivors@gmail.com
APPENDIX B

TELEPHONE SCREENING GUIDE

Introduction
Hello, my name is Lianne Trachtenberg. You left a message for me indicated that you might be interested in taking part in a research project. I am conducting a study that focuses on the complex experiences of living as a young breast cancer survivor. I would like to take a few minutes to talk to you and to ask you some questions. Is this okay?

Who I am and the Purpose of the Research
First, I would like to tell you a little about who I am. I am a graduate student at the Ontario Institute for the Studies in Education at the University of Toronto. I am working towards the completion of a Master’s degree in Counselling Psychology. As part of this process I am conducting a research project to explore 10 to 15 women’s experiences as young breast cancer survivors and how this experience has influenced their sense of self today.

Limits of Confidentiality
In talking with me it is important that you understand the limits of confidentiality. Any conversation that we have is confidential. However, there are several exceptions to this including: if you indicate that you are a danger to yourself or to others, or if you disclose details about apparent, suspected or potential current child abuse. If any of these exceptions arise I would be required both legally and ethically to contact the appropriate authority whether that be emergency services, or children’s services. Do you have any questions about this?

Address any questions.

Inclusion and Exclusion Criteria
Before we go any further, I wanted to make sure that you noticed the criteria on the poster advertisement which included: 1) being between 20-45 years of age, 2) not menopausal, 3) surgery during your treatment, 4) treated for breast cancer less than 6 months ago.

Do you meet all of these criteria? If not, thank you for your interest in this study, but at this time we are not able to have you participate in this study. If they do not apply to you, then I would like to tell you more about the study if this is okay with you.

Procedure
I would like to tell you a little about the research and what would be involved in our participation. This will help you decide whether you are interested in taking part. If you were to take part in this research it would involve your participation in 1, 90 to 120 minute interviews, depending on the time you require. After the interview, you will be required to review and comment on a summary from the previous interview.

The interview sessions would be audio taped and the tapes transcribed. All information that you would provide during the interviews is kept in strict confidence. However, verbatim excerpts from the interview transcripts may be used in the publication and presentation of the research findings with you name and other identifying information changed.
Benefits and Potential Harm
In the interviews you would be asked to explore your understanding and experience living as a breast cancer survivor and how this has impacted you as a young woman.

Making your thoughts and beliefs explicit may be a personally rewarding and enlightening experience. However, it is possible that in this process may stir up feelings that are upsetting to you. Because this is a research project I would not be available to provide you with psychotherapy services, however, should the need arise I would help you connect with an appropriate mental health professional.

Questions
Do you have any questions? 
Address any questions.

After hearing about the research project are you interested in taking part in the study?

If the individual demonstrates interest in the study:
Great! We can meet either in the lobby of the Ontario Institute for Studies in Education’s (252 Bloor St. West).

What day and time work best for you?

Okay, so we are set to meeting on _____ day at _____ location at_______ time. I will call you a couple days before the meeting to confirm the date and time again. Is this okay this you?

If the individual is not interested in participating:
I appreciate you taking your time to speak to me and expressing an interest in the research project. I wish you all the best. Thank you.
I, __________________________ am interested in receiving a summary of the final research results for the study entitled, Examining the Unique Psychosocial Needs of Young Breast Cancer Survivors once it becomes available.

Email Address: __________________________

Phone Number: __________________________
APPENDIX D

Interview Guide:

• **Thank them** for agreeing to participate in the study.

• **Introduce yourself** and your interest in the study

  *a) Self:*
  
  o My name is Lianne Trachtenberg. I am a second year Master’s student in counseling psychology at U of T.

  *b) Previous Jobs*
  
  o Previous jobs working at Hospital - worked on a study explored distress in head and neck cancer patients.

  o Used surveys to ask them a variety of questions about their emotions, feelings and overall wellbeing.

  o Frustrated – my experience that cancer survivors own experienced knowledge is deeper than what the surveys captured.

  *c) Interest as Master’s student*
  
  o Over past 5 years, I’ve become increasingly interested in health psychology, particular in women’s health issues.

  o Breast cancer in young women occurs at higher rates than people realize, and interested in conducting research that helps young breast cancer survivors – now, to tell their stories, and in the future to better their long-term wellbeing.

1. What made you interested in participating in the study?
   
   • Validate their interests.

2. Ask about the history of the illness, treatment, etc. Living arrangements (all the demographics), to establish rapport.
   
   • Stage of cancer, type of treatment, living arrangement

3. What, in your mind, have been the most difficult challenges in being a young woman, breast cancer survivor?

   a) **Notice here if she is mentioning things related to any aspect of identity.** If so, highlight then that the *research aims to center on the experience of identity of being a young woman* who is a breast cancer survivor, and encourage her to keep talking about these aspects.

   b) If she does not mention any aspects related to identity, mention the central question of the study: “the experience of identity in being a young woman who is a breast cancer survivor”, and examine her response.
c) It is my understanding that identity = your sense of self in the world; your conception and expression of individuality or group affiliation. I also believe that there are different dimensions to our identities. Physical, Psychological, Spiritual, Social…etc.

4. Core probes:
   - When you think back about the period prior to your diagnosis and treatment, how would you describe your experience of yourself and identity as a young woman?
   - How do you see your experience and sense of self have changed following diagnosis and treatment?

(Here follow her description, dimension after another)

5. Main dimensions:
   A) Physical
   - When you think back about the period prior to your diagnosis and treatment, how would you describe your physical self (i.e. your body) as a young woman?
   - How do you see your physical self, (i.e. your body) has changed following diagnosis and treatment?
     - Have the physical side effects of breast cancer impacted your current identity?
     - Have you ever felt disconnected from your body as a survivor?
   - What do your breasts represent to you after your cancer experience? How has this changed?
   - What strategies have you used to move forward, or resolve these physical changes in identity
   - How have you re-created or re-constructed your sense of self

B) Psychological
   - When you think back about the period prior to your diagnosis and treatment, how would you describe the psychological side of yourself (i.e. your way of thinking, feelings towards others) as a young woman?
   - How do you see your psychological self, has changed following diagnosis and treatment?
     - Did you see any changes in self-esteem before and after your cancer experience?
     - Do you feel the need to conceal your identity as a young breast cancer survivor to others?
     - Do you feel any personal blame for your cancer?
   - What strategies have you used to move forward or resolve these changes in identity
• How have you had to re-constructed your sense of self

C) Spiritual
• When you think back about the period prior to your diagnosis and treatment, how would you describe your spiritual sense of self (i.e. beliefs about G-d, religion) as a young woman?
• How do you see your spiritual self, has changed following diagnosis and treatment?
• What strategies have you used to resolve these spiritual changes in identity

D) Social
• When you think back about the period prior to your diagnosis and treatment, how would you describe the social identity (i.e. your relationship with friends and loved ones) as a young woman?
• How do you see your social self, has changed following diagnosis and treatment?
  o Do you feel others (i.e. family members, co-workers, medical professionals, and friends) have impacted your identity as a cancer survivor?
  o Media’s impact on your identity?
    ▪ Perception of one’s appearance compared to perception of ideal woman)
• What strategies have you used to move forward or resolve these social changes in identity
• How have you re-constructed your sense of self?

E) Vocation
• When you think back about the period prior to your diagnosis and treatment, how would you describe career oriented self as a young woman?
• How do you see your career oriented self, has changed following diagnosis and treatment?
• What strategies have you used to move forward, or resolve these changes in your identity?
• How have you re-constructed your sense of self with these changes?

F) Gendered identity
• When you think back about the period prior to your diagnosis and treatment, how would you describe your sense of self as a woman?
• How do you see yourself as a woman has changed following diagnosis and treatment?
  ▪ Role changes?
  ▪ Need to become more individualistic?
- Greater focus on the self?
- What strategies have you used to move forward/resolve these changes?
- How have you re-constructed your sense of self?

G) Parental
- When you think back about the period prior to your diagnosis and treatment, how would you describe your sense identity as a parent/child?
- How has your sense of identity as a parent/child changed following diagnosis and treatment?
  - Role changes?
  - Need to become more individualistic?
  - Greater focus on the self?
- How have re-constructed your sense of self with these changes?

H) Existential shifts
- How do you think your life course has been changed due to cancer? How do you imagine now your life would have been without the cancer?
- Have you been able to find meaning after this experience?
  - Positive
  - Negative
- Do you feel as though you carry a new perspective about the world?

6. General Coping
- What strategies or solutions have you used to reduce discontinuity between these differences in yourself before and after your cancer experience?
- What strategies or solutions have you used to reduce general distress as a survivor?

7. Other Comments
- How did you feel about the emphasis on positivity and positive change needed as a breast cancer survivor?
- Impact of Social Class
- Impact of Ethnicity

- What have you learned from this journey?
- What wisdom would you pass on to other young breast cancer survivors?
- Is there anything else you’d like to add
APPENDIX E

Impact of strong female identity on cancer
- Importance of breasts
- Language used; discomfort with Cancer
- Locating self in Feminine Norms
  - Accepting others' views of the body, women, cancer
    - Amputee; Disability
    - Importance in maintaining society's image of body
      - Fear of others' perceptions
      - More effort into physical beauty
      - Shame in body
      - Inability to accept who I am
    - Lowered Self Esteem
    - Sexual woman
  - Rejecting against others' view of the body, women and cancer
    - Accepting who I am
      - Struggle to accept self
    - Fight against ignorant others
      - Freedom to express self
      - Greater understanding of beauty
      - Mother's perception
  - Questioning beliefs about womanhood
    - Feeling Fake
    - Rejection media's perspective
    - Sexuality and breasts

Maintaining sense of control
Medical Professionals and Young People
- Lack of resources to receive best care
- Socialization of Mastectomy in Medical Community
Moving forward - more to live for
- Expectations
- Wants
Returning to Normality
2) Illness vs. Health (Re-Locating Self in Health):

- Cancer Identity
  - Conceal vs. Reveal (powerlessness)
- Fear of Recurrence
- Language Used; Discomfort with Cancer
- Socialization of Mastectomy in Medical Community
  - Gender policing
- Change in Relational Connections
  - To Mother
  - To Healthy Young Adults
  - To Self
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