Illness- and Gender-Related Identity Processes and Psychosocial Well-being among Young Breast Cancer Survivors: A Mixed Method Study

by

Lianne Jill Trachtenberg

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Graduate Department of Applied Psychology and Human Development

Ontario Institute for Studies in Education

University of Toronto

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ILLNESS- AND GENDER- RELATED IDENTITY PROCESSES
AND PSYCHOSOCIAL WELL-BEING AMONG YOUNG BREAST CANCER
SURVIVORS:
A MIXED METHOD STUDY

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Department of Applied Psychology and Human Development
University of Toronto

Abstract

The purpose of the current investigation was to explore Identity Integration, defined as the reformation of post-illness identities, and its impact on psychosocial well-being among young breast cancer survivors. Two key aspects of identity were assessed: a) illness-related identity—women’s experience of themselves in relation to developing breast cancer and b) gender-related identity—women’s experience of themselves in relation to stereotypic and hegemonic gender constructions. A triangulation mixed method design was utilized to collect data on identity processes and related shifts among young breast cancer survivors. In the quantitative inquiry, 113 young women breast cancer survivors, diagnosed at age 36.25 (SD=5.89), mostly between stages I-III (93.9%) completed a measure of illness-related identity: the Impact on Self-Concept Scale (ISCS), four measures of gender-related identity: Gender Role Socialization Scale (GRSS), Objectify Body Consciousness Scale (OBCS), Mental Freedom Scale (MF), and Silencing the Self Scale (SS), as well as two measures of well-being: the Functional Assessment of Cancer Therapy-Breast (FACT-B), and the Experience of Embodiment Scale (EES). As predicted, the illness- and gender-related identity subscales were significantly correlated with both measures of well-being. In the multiple regression models, GRSS and MF significantly predicted FACT-B scores, $R^2=40.0\%$. In contrast, OBCS and MF predicted EES scores, $R^2=61\%$. In the qualitative inquiry, 12 women between the ages of 24 and
44 at diagnosis participated in one interview about identity processes and related shifts before, during, and after their breast cancer experience. Six core dimensions of women’s identity emerged in the Constructivist Grounded Theory analysis: 1) Loss and Adversity, 2) Connection to the Physical Body, 3) Social Power Related to Bodily Experiences, 4) Internalization Versus Rejection of Gender- and Illness-Related Discourses, 5) Relational Connections, and 6) Meaning and Life Goals. Related to the centrality of body experiences in these emergent themes, the results suggested that identity was intertwined with bodily experiences and was therefore referred to as ‘embodied identity’. Taken together, findings from the study highlighted a critical relationship between young women’s altered bodies, illness- and gender-related identities, and their psychosocial well-being after a breast cancer experience. Unlike previous research in psychosocial oncology, which considered identity as disconnected from the body, this study underscored the importance of examining identity through an embodied lens. Theoretical innovation and clinical implications for psychological intervention are discussed.
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Identity and Well-being in Breast Cancer Survivors

Chapter One: Introduction and Literature Review

Introduction to Breast Cancer in Canada: The Need for Further Investigation

Breast cancer continues to be the most commonly diagnosed cancer among women over the age of 20, accounting for an estimated 26% (23,800) of all newly diagnosed malignancies in Canada (Canadian Cancer Society, 2016). Over the last 25 years, breast cancer incident rates have risen by approximately 10% (Canadian Cancer Society, 2016). Despite these increases, mortality rates have fallen drastically, by almost 40% since its peak in 1986 (Canadian Cancer Society, 2016). In fact, the breast cancer mortality rate is currently the lowest it has been since 1950, with an estimated 5,000 patients dying of breast cancer annually (Canadian Cancer Society, 2016). This downward trend is believed to be the result of a combination of increased mammography screening and the use of more effective adjuvant therapies following breast cancer surgery (Chappell et al., 2012). Given these significant improvements in medical treatment, more breast cancer patients are surviving longer, with 88% of women diagnosed with breast cancer living for at least five years after their initial diagnosis (Canadian Cancer Society, 2016). Due to these increasingly strong survival rates, researchers and clinicians have taken a strong interest in the investigation of psychosocial well-being, and health-related quality of life (QOL) among breast cancer survivors. However, the focus of past research has been primarily based upon post-menopausal samples of women aged 55 and over (Thewes, Meiser, Rickard, & Friedlander, 2003). Only more recently have we begun to examine and better understand the unique and severe challenges faced by a younger population of breast cancer survivors.

Why Study Young Women with Breast Cancer?

Despite the public perception that young women are at little to no risk of breast cancer, the reality is that they are vulnerable. Breast cancer is the most commonly diagnosed cancer
among younger women ages 20 to 59 (Siegel, Naishadham, & Jemal, 2012). In 2012, the Canadian Cancer Society estimated 4,265 women under the age of 50 were diagnosed with breast cancer (Chappell et al., 2012).

As may already be apparent, the definition of young women with breast cancer varies across the literature (Trachtenberg & Piran, 2012). While many researchers have used 50 years of age as the cut-off mark, others have chosen to use age 55 or even age 60 (Trachtenberg & Piran, 2012). 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 argue that, according to women living with breast cancer, a functional definition of young, which includes a woman who is pre-menopausal and/or has a subjective belief that she is still of a child bearing age, is also needed. Therefore, the researcher in the present study assessed for these additional factors with study participants.

A vast amount of literature has been conducted on the challenges faced by survivors who have completed treatment for breast cancer; however, only more recently—within the last decade—have studies begun to emphasize the need to investigate a younger population of survivors, a population consistently found to be at an increased risk for poorer health-related QOL relative to older women (Kornblith et al., 2007; Thewes, Butow, Girgis, & Pendlebury, 2004). While many of the challenges faced by older and younger survivors are shared, past research has consistently found that young breast cancer survivors are at a greater risk of poor psychosocial adjustment among a diverse range of outcome measures (Siegel, Gluhoski, & Gorey, 1999). Factors influencing poorer adjustment in young women include: lower self-view, lower rates of seeking psychiatric assistance following a mastectomy, depression, anxiety,
adverse impact of a mastectomy on sexuality, decrease in financial well-being, changed routines, and impaired relationships (Siegel et al., 1999).

The unique challenges faced by young breast cancer survivors. Breast cancer in younger women is more likely to be fast growing, higher grade, and hormone receptor-negative (Litton & Theriault, 2010). As a result, treatment for younger 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 might also contribute to prolonged periods of medical intervention with associated physical and emotional sequelae (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 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 than older women (Kornblith et al., 2007; Mor, Allen, & Malin, 1994; Siegel et al., 1999; Thewes et al., 2004; Vinokur, Threatt, Vinokur-Kaplan, & Satariano, 1990). While a breast cancer diagnosis to a woman at any age would constitute a severe psychological insult, for younger women who perceive themselves to be at 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). The following paragraphs review some noteworthy contributions made to the literature on psychosocial adjustment and the unique needs faced by younger breast cancer survivors.

In one quantitative study, Avis, Crawford, and Manuel (2005) described the unique QOL issues faced by young women four to 42 months after their breast cancer diagnosis. A total of 202 women with Stage I to III breast cancer, between the ages of 25 and 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 (56%) of women had not
undergone a mastectomy while the remaining 44% had. 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 following 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 with a non-breast cancer-affected 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.

Siegel, Gluhoski, and Gorey (1999) used unstructured qualitative interviews 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 prior, participated in unstructured interviews. The majority of participants were white (85%) and the remainder were black non-Hispanics. The majority were diagnosed as having Stage I or Stage II breast cancer (59%), were married (64.7%), and had completed some post-secondary education (79%). Both adaptational challenges and unique needs faced by these women were reported in 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 untimeliness of the diagnosis, (2) concerns about the impact of the illness on their husbands, (3) sadness about lost opportunities for childbearing, (4) a feeling of being different
and isolated, (5) uncertainty about their futures, and (6) concerns about their young children. These six areas of distress provided detailed information regarding the lived experiences of young survivors and are a reference guide to further understanding the distressing issues consistently faced by young women following a breast cancer diagnosis.

Using a multi-method qualitative methodology, Dunn and Steginga (2000) 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 identified themselves as being young. Among this sample, 87% were married and 56.2% had children of primary school age or younger. Consistent with previous research, women identified fears about not surviving long enough to see their children grow to adulthood, and issues regarding current infertility or fear of infertility due to a possible cancer recurrence. The majority of 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’ (1999) study by incorporating some examination of the social context and survivors’ coping strategies, in addition to describing survivors’ concerns toward 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.

In addition to the self-reported QOL measures used in previous studies, which have found poor health-related QOL outcomes among a younger sample of breast cancer survivors,
Sammarco (2001) provided additional insight as to why younger women are more likely to have poorer psychosocial adjustment as survivors. Sammarco (2001) explained that traditionally, adult developmental theorists (Erikson, 1968; Gilligan, 1982; Levinson & Levinson, 1996) have suggested that chronological age was the criterion used for normalizing women’s developmental role demands and responsibilities (i.e., graduation, first job, marriage, first child, empty nest, retirement). However, over the last 40 years, these conventional stages of the adult life cycle have seen drastic alterations (Sammarco, 2001). Many young women are postponing or eliminating certain tasks once typical of their twenties—childbearing, for example—in order to devote more attention to other avenues such as their education or careers (Sammarco, 2001). As a result, it is not unusual for young women in their thirties and forties to be juggling the demands of multiple roles 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) also believed that this developmental phenomenon concerning multiple role demands caused young women to be particularly vulnerable to psychosocial morbidity when faced with a life-threatening cancer diagnosis. The unique challenges faced during a breast cancer diagnosis and treatment likely compromise a woman’s ability to manage their pre-illness role demands (Cimprich, Ronis, & Martinez-Ramos, 2002). Siegel, Gluhoski, and Gorey (1999) shed light on the severe impact that a cancer illness can have on a younger woman’s ability to manage her multiple role demands. At a period in time when younger women see endless possibilities for themselves and their futures, this diagnosis imposes an abrupt and severe limitation on their ambitions and world-views (Siegel et al., 1999). This line of research indicates that young women who deal with a breast cancer diagnosis face additional challenges
in the already taxing life of women, juggling inequitably distributed tasks in the domains of home and, often, work.

**Predictors of psychosocial adjustment in young breast cancer survivors.** As described above, the present literature on young breast cancer survivorship and health-related QOL has focused exclusively on the unique challenges survivors face; however, there is a strong need to move beyond identifying these challenges. Given that many of these young women are surviving well beyond the diagnosis and subsequent treatment of their illness, it is critical that the research community begin to focus on predictors of psychosocial adjustment following breast cancer treatment. Greater knowledge of predictors of adjustment can benefit researchers and health care practitioners who could begin to pre-emptively determine which variables would likely lead to more successful levels of adjustment among survivors.

A dearth of information currently exists in identifying predictors of positive psychosocial adjustment for post-treatment breast cancer survivors. Among the existing research that has examined predictors of adjustment within cancer survivor populations, most studies are limited by small sample sizes and/or an exclusive focus on medical variables (e.g., extent of surgery and adjuvant treatment), rather than outcomes of psychological well-being (Brezden, Phillips, Abdolell, Bunston, & Tannock, 2000; Ganz et al., 2002; Partridge, Burstein, & Winer, 2001). Additionally, the majority of such studies focus on predictors leading to poorer long-term adjustment; thus, very few researchers have targeted predictors of positive psychosocial adjustment and well-being. As a result, limited information is currently available detailing predictors that promote positive psychosocial adjustment for younger women.

Analyses of prior research (typically older samples of breast cancer survivors) suggest variables that predict long-term adjustment and well-being among breast cancer survivors.
Specifically, in a meta-analysis conducted by Mols, Vingerhoets, Coebergh, and van de Poll-Franse, (2005), they used 10 high quality, pre-selected studies conducted between 1997 and 2004. Demographic information (age, education, ethnicity, income, and employment), social factors (social support, marital status, and children living at home), psychological stress (stress, anxiety, belief that the world is controllable, and purpose) and disease variables (general health, stage of disease, years since diagnosis, health perceptions, chemotherapy, and medical condition) were investigated. Strong evidence was found for the predictive value of chemotherapy, medical condition, income, and social support for poor QOL. Past chemotherapy was a statistically significant predictor of poor QOL (Ganz et al., 2002). Women who received chemotherapy were also at risk of post-traumatic stress and thus a lower QOL experience (Amir & Ramati, 2002). Medical condition (e.g., comorbidity) also appeared as a strong predictor of QOL. A patient who suffered from other medical conditions in addition to the cancer experienced a lower QOL (Ashing-Giwa, Ganz, & Petersen, 1999; Bloom, Stewart, Chang, & Banks, 2004; Ganz et al., 2002). Another critical predictor of QOL and positive well-being is social support. Social support is the most commonly cited predictor of well-being within breast cancer literature (Bloom, 1986; Sammarco, 2001; Wortman, 1984). Research has consistently found that social support can facilitate individuals’ adjustment to stressful situations, and can moderate negative effects of stressful life events (Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Koopman, Hermanson, Diamond, Angell, & Spiegel, 1998; Parker, Baile, de Moor, & Cohen, 2003; Sammarco, 2001).

In their study of emotional versus instrumental support, Bloom and colleagues (2001) stressed the importance of social resources on well-being following a life-threatening illness less than one year post-treatment among young breast cancer survivors. The findings suggest that
emotional and instrumental support buffered the stress resulting from the diagnosis and treatment of breast cancer in 336 women less than 50 years of age. Their sample included a majority of women who were married (65%), employed (75%), had dependent children (63%), were white (70%), and had a mastectomy (51%). The results indicated that emotional support, in particular, improves women’s long-term mental well-being. In this study, even the size of the social networks (after controlling for sociodemographic and treatment-related variables) positively correlated to greater emotional and instrumental support.

Using a cross sectional design, Sammarco (2001) examined perceived social support as a predictor of QOL among young breast cancer survivors. In this study, a sample of 101 breast cancer survivors below age 50 completed the Social Support Questionnaire, Mishel Uncertainty in Illness Scale-Community Form, and Ferrans and Powers Quality of Life Index-Cancer Version. In this study, 17.3% of the variance of QOL was accounted for by perceived social support. Spouses and family members, in particular, were cited as important sources of support for women with breast cancer (Sammarco, 2001). Nonetheless, Sammarco also described that a large percent of the variance of QOL remained unexplained.

Using a prospective design, Carver, Smith, Petronis, and Antoni (2006) examined a variety of psychosocial variables that could predict positive well-being. Early-stage breast cancer patients (N=163) who provided medical, demographic, and psychosocial variables during the year after surgery completed multiple QOL measures five to 13 years later. In this study, women who were partnered when first treated reported less frequent negative feelings, more frequent positive feelings, less social avoidance, and less distress about the possibility of recurrence than women who did not have a partner at the time of treatment (Carver et al., 2006). Likewise, partnered women also reported less fatigue as well as less-frequent distress about their family’s
future (Carver et al., 2006). The results of the study focusing on the effects of partner status are conceptually consistent with other evidence that social resources predict better psychological well-being over time (Ganz et al., 2002; Helgeson, Snyder, & Seltman, 2004).

Mols, Vingerhoets, Coebergh, and Poll-Franse (2005) also found weak evidence for the predictive value of such factors as: employment status, having no children under age 18 living at home, ethnicity (Euro-American, African-American, Latino, Asian, or other), trait anxiety, state anxiety, health perceptions, life stress, the belief that the world was controllable, and purpose. These variables were investigated in only a few studies, and therefore are weak evidence as predictors. At least part-time employment and having no children under age 18 living at home predicted a greater increase in QOL (Bloom et al., 2004). Ethnicity was not a predictor of QOL (Ashing-Giwa et al., 1999). Trait anxiety, which represented a long-standing personality feature, in contrast to state anxiety was in one study the most consistent predictor of QOL (Weitzner, Meyers, Stuebing, & Saleeba, 1997). Breast cancer survivors who experienced less life stress reported a better QOL (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997). Finally, the belief that the world is controllable predicted physical functioning scores, and purpose in life predicted greater mental functioning scores (Tomich & Helgeson, 2002).

**Identity: A Novel Predictor of Psychosocial Adjustment and Well-Being**

**Defining identity.** One variable that remarkably has never been thoroughly investigated as a predictor of psychosocial adjustment or well-being is the role of identity. For more than four decades, practitioners have argued that a person’s beliefs, feelings, and expectations of the self play a fundamental role in shaping health outcomes and therefore should be a primary focus of psychological intervention (Beland, 1970; Burgess, Groth, Holmstrom, & Sgroi, 1978; Compton, 1973; Lehberger, 1973; Mitchell & Loustau, 1981; Stein, 1995). Despite this long-standing
recognition of identity in regulating health behaviours and outcomes, it has been difficult to translate this intuitive understanding of identity into an empirically supported theoretical framework used to guide psychological treatment and practice (Stein, 1995). The difficulty in establishing a foundation of knowledge in this area can be attributed to identity being a highly abstract construct that is inherently challenging to define (Bonham & Cheney, 1983; Stein, 1995). Historically, theories of identity and the self have been too general and provided little direction for the development of valid measures (Marsh & Richards, 1988; Stein, 1995; Wylie, 1979). Subsequently, the majority of such studies focused narrowly on a single, more measurable aspect of the construct such as global self-esteem. Other aspects of the self that are thought to be powerful determinants of behaviour, including beliefs about who one is today, and expectations, fears, and wishes about what one will become in the future, remain largely unexplored (Cantor, 1990; Markus & Wurf, 1987; Stein, 1995).

Some theorists with a traditional developmental perspective and a modern conceptualization of the self have promoted a deceptively straightforward point of view that every person has an identity and a self. However, troubling questions arise about the meaning of the words self and identity. The assumptions underpinning any statement about self and identity have consistently been open to challenges and opposition. For example, postmodernist writers both inside and outside of psychology have targeted the very concept of the self. Gergen and Gergen (1988) suggested that the notion of the self is just a misleading and spurious construction, “a reference without a referent.” Others, too (Markus & Nurius, 1986) have questioned whether there is one self or co-existing selves. Subsequently, the confusion and contradictory assumptions that have shaped the theoretical conceptualization of these terms over
time have resulted in a lack of unity. Thus, amid all this ambiguity, the challenge of defining and differentiating constructs such as identity and the self persist.

The language of identity is ubiquitous in contemporary social sciences, cutting across psychoanalysis, psychology, political sciences, sociology, and history (Stryker & Burke, 2000). Yet, the term identity still faces considerable variability and ambiguity both in its conceptual meaning and its theoretical role (Stryker & Burke, 2000). Even when consideration is restricted to psychology or social psychology, variation is still substantial (Stryker & Burke, 2000). Stryker and Burke (2000) stated that there are three relatively distinct uses for the term identity. Some use identity to refer to the culture of people, drawing no distinction between identity and, for example, race or ethnicity (Calhoun, 1994; Stryker & Burke, 2000). Others use identity to refer to common identification within a collective or social category, as in social identity theory (Tajfel, 1982), or in contemporary work on social movements. As such, these individuals create a common culture among participants (Snow & Oliver, 1995). Stryker and Burke (2000) add that the third option, which underlies much of the psychological research, is when identity is defined as the part of the self composed of “meanings that persons attach to the multiple roles they typically play in highly differentiated contemporary societies” (p. 284).

Little, Paul, Jordens, and Sayers (2002) provide some additional clarification on the definition of identity:

Identity… is the sense of personhood that places each of us uniquely in 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 (such as gender, physique, intelligence, endurance, health), acquisitions (such as wealth, property, rank, education, training, achievement), and capabilities (including work,
power, vulnerability, reputation, status approval), 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)

Castells (2010) further stressed that identity is “people’s source of meaning and
experience … on the basis of a cultural attribute, or a set of related cultural attributes that is
given priority over other meaning” (p. 6). Like other theorists, Castells (2010) argued that for
any given individual, there might be a plurality of identities, which can be a source of stress and
contradiction. He also argued that identity must be distinguished from role-sets. Roles (e.g.,
being a worker, a mother, a daughter, a neighbour, a hockey player, or a doctor) are defined by
norms structured by institutions and organizations within our society (Castells, 2010). While
identities can also originate from dominant institutions, an identity, unlike a role, only occurs
once an individual internalizes their roles and constructs their meaning around this
internalization (Castells, 2010). Thus, some identities can coincide with social roles—for
instance, being a mother might be an important identity for an individual at a particular period in
time; however, identities are stronger sources of meaning than roles because of the process of
self-construction and individuation that they involve (Castells, 2010).

The term self is equally necessary to define and distinguish when exploring identity.
Oyserman (2001) defines the self as a multidimensional construct that refers to an individual’s
perceptions of who they are. It functions as a “repository of autobiographical memories, as an
organizer of experience and as an emotional buffer and motivational resource” (p. 500).
Rosenberg (1979) added 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, 2006). Greene (2003) provided some additional insight, distinguishing the concepts of identity and self. She viewed the self as a more inclusive term, … encompassing all that one experiences as a person, whereas identity is that which is seen as distinctive and/or enduring about the self. The self may thus be equated with the embodied locus of individual experiences both conscious and unconscious. The self may participate in experiences which are transient and not definitional of the self’s identity even though they may have an influence upon it (Greene, 2003, p. 99).

In other words, the self may have an identity, but the identity may not have a self (Greene, 2003). Thus, Greene acknowledges that an individual’s identity can fall under a broader conceptualization of selfhood.

In sum, amidst the long-standing ambiguity that has risen with the conceptualization of identity, defining features in the context of this study are still present. First and foremost, identity is the meaning an individual attaches to the multiple roles that they typically play in a highly differentiated contemporary society. In addition, a person’s identity has the capacity to explore what they have in common as well as what differentiates them from others.

**The relationship between identity and illness.** Over the last several decades, psychosocial interest in and research on the relationship between identity and illness has flourished (Lively & Smith, 2011). Historically, the focus of research in this area has been twofold. The majority of researchers have examined the impact of the illness experience (i.e., the breast cancer experience) on identity. From this perspective, researchers typically treat identity as a function of illness, meaning they examine how one’s identity forms or changes as a result of contracting a particular illness. This approach has been most successfully represented by those
who view illness as an identity disruption (e.g., Charmaz, 1991; Karp, 1996; Trachtenberg & Piran, 2012). Alternatively, the second, understudied approach examines the impact that one’s identity has on the illness experience: Does a woman’s identity have the capacity to impact her illness experience and long-term well-being? While the field of identity and illness has grown substantially over several decades and has progressed well beyond the Parsonian framework of the *sick role* (1951), it has done so, predominantly, with the inclusion of few empirically tested studies and with vague insights into some social psychology theories of identity. The section below will outline the two primary trends of research present in the identity and health literature.

**The effects of illness on identity.** As described above, the majority of researchers studying identity and illness have taken the approach that illness creates a disruption in one’s identity—an illness alters an individual’s sense of self. This approach has focused on the negative impact of illness on the individual (Horwitz, 2002). More recently, some studies have focused on how individuals strive to maintain their sense of self in spite of their illness. Sanders, Donovan, and Dieppe (2002), for example, found that while people with osteoarthritis do talk about the disruptive effects of the condition on their daily lives, they still manage to view these symptoms as part of their day-to-day existence. Likewise, Trachtenberg and Piran (2012) found that young women who had survived the diagnosis and medical treatment of their breast cancer were able to reformulate and renew their sense of identity using three shared domains of social location (femininity, youth, and health status).

It is widely acknowledged that studies examining the effects of illness on identity had their genesis in Parsons’ (1951) theory of the sick role (Julia, 2003; Lively & Smith, 2011). Parsons’ theory hypothesized that patients assume “a set of rights and obligations that determine behaviour once they have been diagnosed with a medical condition” (Lively & Smith, 2011, p.
Based on the more popular perception that illness is a form of dysfunction, Parsons argued that patients should be “released from the obligations of other social roles and not held accountable for their actions in order to facilitate their return to health and reintegration into society” (Lively & Smith, 2011, p. 506). Subsequently, patients were expected to seek out and cooperate with competent medical professionals (Lively & Smith, 2011).

Later generations of scholars, post-Parsons’ theory, began to criticize the conceptualization of the sick role theory. First, scholars argued that he neglected the experience of those with chronic illnesses (Crossley, 1998; Lively & Smith, 2011; Radley, 1994). Second, they argued against its “overly deterministic nature” (Lively & Smith, 2011, p. 506). Third, given his view of illness as a form of deviance, Parsons was further criticized for neglecting to incorporate the physical body and its impact on the illness experience (Lively & Smith, 2011). As Lively and Smith (2011) elaborated, “it is difficult to avoid the reality that illness often brings with it physical aches and pains and limitations, and these physicalities surely impact the individuals’ sense of self, which is derived, in large part, from the reactions – real or perceived – of others” (Lively & Smith, 2011, p. 506). Finally, criticisms have also been laid on Parsons’ theory for his failure to acknowledge the agency of patients in constructing their illness experience and identities, and that patients do not simply conform to what physicians and society demand of them. As a result of these ongoing criticisms, many researchers have sought to counteract this perspective by bringing the patient’s voice alive, drawing upon patients’ own perspectives and illness narratives through qualitative methodology. However, as mentioned earlier, these studies frequently focused on the negative impact of illness, and posited identity changes in response to illness or the threat of illness.
Kathy Charmaz (1991) completed one prominent illustration of this approach in her seminal work on how individuals with chronic illness experience a loss of self. She found that those with chronic illness often faced several negative reactions and life situations—from experiencing increased social isolation to being discredited by others (Lively & Smith, 2011). In dealing with these negative reactions, people’s various identities and meanings of themselves may contradict and collide with one another, such that a loss of self in one area of their lives might also result in the loss of self in another (Lively & Smith, 2011). Someone diagnosed with breast cancer, for example, may no longer be able to fulfil her role as worker, forcing her to take a temporary if not permanent leave of absence. This role change may also result in a changed sense of overall independence. However, Charmaz explained that people could have agency in constructing their identities during and after illness. This woman diagnosed with breast cancer, for example, may redefine what it means to be a parent, a spouse, a sibling, or an employee while dealing with these changes.

*The effects of the cancer experience on psychosocial well-being and identity.* Although extremely limited empirical research exists examining the relationship between breast cancer survivors’ psychosocial well-being and identity, researchers have previously explored and theorized why this connection is critical for future investigation. In their article “Survivorship and the Discourse of Identity,” Little and colleagues (2002) asked, “Why does an extreme experience leave consequences that outlast the event itself?” Little (2002) explained that extreme experiences, like cancer, leave no aspect of an identity untouched. The physical embodied component of identity is challenged and its vulnerability accentuated (Little et al., 2002). There are also likely physical changes in the body as a result of the extreme experience, such as a loss of a breast, surgical scar(s), less or thinner hair, fatigue, and/or weight gain. These bodily
changes may also result in cognitive perceptions and remembered experiences, transforming thoughts (Little et al., 2002). Additionally, during the survivorship phase, survivors are able to review their life lived thus far and make decisions about the kind of life they want to live after this extreme experience (Little et al., 2002). Questions arise such as, “What kind of future memories do I want to construct?” (Little et al., 2002)

Little and colleagues (2002) also posited that cancer survivors are “surviving a radical challenge to continuity of identity” (p. 176). Likewise, Erik Erikson also believed that a traumatic experience, like a cancer diagnosis, could undermine a pre-established identity and ultimately lead to an identity crisis (Stevens, 2008). Additionally, Charmaz (1995) pointed out that many people who suffer from cancer find that progressive losses repeatedly threaten their body and thus their self-integrity, too. As a result of these losses and drastic life changes, Little et al. (2002) argued that cancer survivors move through a dilemma of self-creation and assimilation of cancer-related experience into their identity. The dilemma comes in part from the failure of past social discourses that have focused on survivorship (Little et al., 2002). While traditionally an acute illness created Parsons’ sick role paradigm (Parsons, 1951), to structure the expectations that privileged the actions and responses of an ill person, Little and colleagues (2002) argued that present-day cancer survivors do not have such a construct for survivorship discourse. These scholars believe that a new discourse must be built that can recognize “the adhesiveness of the extreme experiences, and the cognitive, emotional, physical and moral tensions that are part of survivorship. The survivor has no specially defined status quo, and no modes of performance that are socially validated” (Little et al., 2002, p. 176). Subsequently, survivors are left to try fitting into inadequate and dissonant paradigms (i.e., the sick role) of the ill or perhaps even of the normal (i.e., individuals who have not experienced a life-threatening illness). However,
survivorship is not suited to any of these paradigms. Little et al. (2002) state that survivorship is a category *sui generis*—a life lived through the context of new and unique knowledge (p. 176). As a result of this new and perhaps meaningful knowledge set, survivors’ tasks revolve around the assimilation of their knowledge into a “dynamic evolution of identity in a way that recognizes both the continuity of identity and the powerful forces of change inherent in extreme experience” (Little et al., 2002, p. 176-177).

*The effects of identity on the illness experience.* Although the majority of studies in this field have focused on how illness affects identity, and illness as an identity disruption, this is not to say that scholars have completely ignored how identity has the capacity to affect one’s experience of illness and adjustment as a cancer survivor. In Bury’s (1982; 1991; 2001) classic work on biographical disruption, he found that those diagnosed with rheumatoid arthritis carefully selected specific events in their earlier biographies to help make meaning out of their illness experiences (Lively & Smith, 2011). For example, one woman in his study recounted her belief that her troubles with rheumatoid arthritis began with her then seven-year-old son’s emergency appendectomy (Livey & Smith, 2011). The stress of this incident with her son, she believed, might have triggered her illness (Livey & Smith, 2011). However, Bury’s theory of biographical disruption did not develop into a more integrated concept of identity; he chose instead to focus almost entirely on the impact of particular events (Lively & Smith, 2011; Richardson, Ong, & Sim, 2006; Wilson, 2007). Building on Bury’s work, Williams (1984) proposed the concept of *narrative reconstruction*. In studying how people make sense of their illnesses, Williams found that not only did people focus on specific events in their earlier biographies; they also “weave elaborate and concise narratives incorporating these events” (Lively & Smith, 2011, p. 511). Williams posited that these narratives help to reconcile the past
and the present for the person experiencing the illness (Lively & Smith, 2011). While Williams provided a more holistic theorization of how individuals make sense of their illness through their pre-illness experiences, he, like Bury, focused primarily on the impact of specific events and did not examine how a pre-illness identity might play a role (Alaszewski, Alaszewski, & Potter, 2006; Hallowell et al., 2006; Lively & Smith, 2011).

More recently, scholars within the field of psychology and public health have begun to address the so-called buffering effect of identity (Lively & Smith, 2011). Specifically, they addressed how a strong identity might help to mitigate the impact of psychological distress (Lively & Smith, 2011). For example, a study by Wester, Vogel, Wei, and McLain (2006) found that particular aspects of racial identity attitudes in African American men helped to mediate the relationship between gender role conflict and psychological distress. Other studies have also examined how racial/ethnic identities play a role in mediating the impact of racial/ethnic discrimination on an individual’s health (Brown, Wallace Jr., & Williams, 2001; Gee, Delva, & Takeuchi, 2007). However, many of these studies limit their conceptualization of the self to the use of personality markers such as mastery, self-efficacy, or self-esteem—what Lively and Smith (2011) term as proxies of identity. Moreover, Lively and Smith (2011) believed that while these approaches have provided valuable insight into the protective nature of particular aspects of identity on the experience of illness, these one-dimensional measures only tap into a limited and fixed understanding of the self. These variable-based measures assume that the self is something inherent to the individual and is therefore asocial (Lively & Smith, 2011). This perspective, though, is at odds with social psychology theories of identity (Lively & Smith, 2011). Just as the more dominant and popular areas of investigation on examining the effects of illness on identity have failed to address the independent effects of identity on health, studies examining the effects
of identity on the illness experience have failed to consider the social, dynamic, and interdependent aspects of the self that can ameliorate and/or exacerbate the experience of illness (Lively & Smith, 2011).

**Theoretical frameworks intersecting identity and illness.** While some studies have attempted to examine the impact of identity on an individual’s experience of illness and adjustment, Lively and Smith (2011) emphasized that the majority of such studies have drawn upon only vague insights from social psychology theories, largely discounting more developed theories of identity, which posited “a more dynamic, proactive, social self that may lead individuals to make different choices regarding their health and illness and subsequently to different health outcomes” (Lively & Smith, 2011, p. 511). In an attempt to provide more clarity on the theoretical underpinning of identity in psychosocial research, identity theory will be discussed.

Various forms of identity theories have been developed. Generally speaking, identity theory (Stryker & Burke, 2000) focused on how “social structure influences individuals’ identities and behaviours, as well as the role that individuals play in sustaining both the social structure and the normative order in which they are embedded” (Lively & Smith, 2011, p. 512). From this perspective, individuals develop their identities from the social positions or roles they occupy within a social structure; ultimately, they come to derive meaning and normative behaviour from these roles (Lively & Smith, 2011). Within identity theory, social psychologists have differentiated between different types of identities. Most commonly, these identities have included role identities, although some scholars also study person identities (Stets & Burke, 2003), and social identities (Hogg, 2003). A role identity is “a set of self-meanings an individual internalizes from her position within the larger social structure” (Lively & Smith, 2011, p. 512).
Thus, individuals derive meaning about the self, their social surroundings, and their behaviour by adopting role positions (Lively & Smith, 2011). These role positions shape the individual in important ways and also tie the individual to the very social structure from which the social role originated (Lively & Smith, 2011). The present investigation will outline a specific theory of identity development called Structural Symbolic Interactionism that will ground the study in a social constructionist framework.

**Structural symbolic interactionism.** Many studies in this field (Charmaz, 1983; Karp, 1996; Sabo & Gordon, 1995; Weitz, 1991) have drawn almost exclusively from a traditional symbolic interaction framework (Blumer, 1986; Mead, 1934). In one of the earliest stages of symbolic interaction, Mead (1934) posited a reciprocal relationship between the self and society. Mead believed that the self shaped society and that in turn society shaped the self (Lively & Smith, 2011). Likewise, more modern scholars have argued for the reciprocal relationship between the public and private selves (Kelly & Millward, 2004). In his discussion on the self-concept, Rosenberg (1981) argued that the private self is a product of society as well as its own social force (Lively & Smith, 2011).

One critical premise to symbolic interactionism is that meaning is central to human life (McLeod & Lively, 2007). This basic tenet asserts that meaning shapes not only how individuals interpret particular events, others, and their environment, but also themselves (Heise, 2002; Lively & Smith, 2011). These meanings and interpretations also shape how individuals respond to events and situations, regardless of the objective reality of the event itself (Charmaz, 1980, 1991; Lively & Smith, 2011). For example, in her cancer survivor support group study, Westphal (2004) found that individuals with cancer were encouraged by group leaders and other support group members to adopt specific preferred meanings regarding their current situation. In this
particular environment, individuals were urged to view their condition as acute (instead of chronic) and to see chemotherapy as a necessary evil in their battle against illness (instead of a poison that made them tired, nauseous, and irritable) (Lively & Smith, 2011). Nonetheless, the pressures and persuasions used to promote specific meanings and interpretations not internalized by certain cancer survivors had significantly negative effects on a person’s sense of self; in these circumstances, some women described feeling like an outcast with undervalued beliefs (Lively & Smith, 2011). Thus, internalizations of identity meanings are critical in order to ensure a successful integration of identity processes.

As previously indicated, one of the most enduring insights in symbolic interactionism is that meaning—much like the self—is not static (Lively & Smith, 2011). Rather, meaning is expected to change over time as individuals develop new understandings of their situations (Blumer, 1986). These new understandings (i.e., living as a woman post-breast cancer treatment) may result from the changed nature of the event/situation, self-reflection (Callero, 2003), or social interactions with real or imagined others (i.e., getting to know others who have experienced a similar illness) (Lively & Smith, 2011). Over time, as individuals gather more information from their social world, the meanings they subscribe to themselves and the world around them may either be reaffirmed or altered (Lively & Smith, 2011).

As may already be apparent from previous studies discussed, the notion that individuals strive for cognitive consistency underlies the premise of symbolic interactionism (Lively & Smith, 2011). Cognitive consistency theory posits that individuals are motivated to have their beliefs, thoughts, and feelings consistent with their sense of self (Heise, 1979; Lively & Smith, 2011; Stryker, 1980). When an individual fails to achieve this desired consistency, either in terms of their behaviour, attitudes, or feelings, they experience cognitive dissonance or a
disintegrated identity that often manifests itself in negative emotional reactions, such as distress (Lively & Smith, 2011). According to this perspective, individuals who develop cognitive dissonance will enact behaviours and/or cognitive changes in order to bring their situation, behaviours, thoughts, or attitudes back in line with their fundamental sense of self, even if that means surrendering one’s valued identity (Charmaz, 1983; Elson, 2003; Lively & Smith, 2011; Sabo & Gordon, 1995). Thus, integrating cognitive consistent components of an individual’s identity are critical to overall well-being. Furthermore, by viewing an individual’s behaviour as a function of the relationship between what they perceive in the situation and their self-meaning (Burke & Cast, 1997; Heise, 1979), symbolic interactionism also allows researchers to view people’s behaviours as goal directed. Thus, an individual’s behaviour can change a situation in order to match meanings perceived in the situation with meanings held by the self. As such, this theory also gives agency to the individual (Burke & Gray, 1999; Tsushima & Burke, 1999) during their illness experience.

Structural symbolic interactionism also assumes that individuals are especially motivated to act in ways that maintain their most highly committed and salient social roles (Lively & Smith, 2011). When a role identity is particularly salient, Stryker (1980) suggested that individuals may find themselves engaging in behaviours associated with the situation, even if they are not appropriate (Lively & Smith, 2011). They may also purposefully seek out people to support their roles (Lively & Smith, 2011). For example, someone who felt closely connected to the patient identity role may immerse herself in traditional treatments, or seek friends who are supportive and perhaps sympathetic to her struggles, and distance herself from those who are not (Charmaz, 1980; Lively & Smith, 2011). Alternatively, individuals who dismissed social roles associated with their illness might put their energy into maintaining identities that have little to
do with being a patient (Lively & Smith, 2011). However, when individuals are no longer able to meet the demands of their highly committed and salient roles, they may have no choice but to rearrange or alter their identity hierarchies (Lively & Smith, 2011).

Recently, psychologists have become more interested in identity hierarchies as they operate like cognitive schemas (Lively & Smith, 2011). Self-schemas refer to cognitive filters that develop over time and affect how an individual attends to, stores, and retrieves information (Kihlstrom & Cantor, 1984; Linville & Carlston, 1994; Lively & Smith, 2011; Markus & Wurf, 1987). Subsequently, individuals who hold an illness identity that is maintained within their significant social network are more likely to notice, attend to, and remember information and incidents that support their view of themselves and of their situation (Lively & Smith, 2011; Morgan & Schwalbe, 1990). This suggests that someone whose illness identity is particularly salient may pay more attention to her aches and pains than those whose illness identity is less salient (Lively & Smith, 2011). However, this is not to say that individuals wilfully choose to process some information and ignore other; rather, their identity provides filters that can operate at a more subconscious level (Lively & Smith, 2011).

One of the major strengths of symbolic interactionism as both perspective and methodology is that it allows researchers to capture the rich complexity of individuals’ lived experiences (Lively & Smith, 2011). However, while narrative and in-depth interviews are likely the best method through which to capture individuals’ lived experiences, they do not necessarily lend themselves to predictions or replication (Lively & Smith, 2011). Indeed, while one benefit of this theory is its assumption that the social world and the self are both in a state of flux or negotiation (Stryker, 1980), it has been a longstanding criticism that it fails to account for the relative stability of society or the self across diverse situations (Lively & Smith, 2011). Despite
the fluidity and flexibility of this theory, as well as its ability to predict behaviour across a broad spectrum of individuals, this approach continues to remain invisible among the majority of scholars studying the relationship between health and identity (Lively & Smith, 2011).

**Biographical disruption.** Bury (1982, 1991, 2001) and Charmaz (1983, 1995, 2002) are the forerunners of biographically informed perspectives on chronic illness (Hubbard, Kidd, & Kearney, 2010). Michael Bury coined the concept *biographical disruption* in the early 1980s (Bury, 1982) as a descriptor of people’s experience of chronic illness, and as a model used to comprehend how individuals respond and adapt to their illness. As outlined in Hubbard and colleagues (2010), Bury and Charmaz’s theoretical frameworks provide valuable insight into the understanding of the cancer experience post-medical treatment. Biographical disruption is used to confer chronic illness as a major kind of disruptive experience or critical situation (Bury, 1982). These disruptions arise because “illness throws into the air people’s taken-for-granted assumptions about the body, their selves, and the social world in which they live” (Bury, 1982; Hubbard et al., 2010, p. 4). Bury (1982) suggested that the experience of chronic illness brings to the forefront pain, suffering, and death, which are normally only seen as distant or remote possibilities in one’s life. Like Bury (1982), Charmaz (1994) also suggested that chronic illness compels people to have an awareness of death (Hubbard et al., 2010). However, she emphasized how this disrupts identity, particularly if individuals perceive themselves as too young to die, or define themselves as healthy with no previous experiences of illness. This type of disruption, caused by the perception or the reality of impending mortality, has been examined with cancer patients (Exley & Letherby, 2001; Shaha & Cox, 2003; Trachtenberg & Piran, 2012).

Charmaz (1995) specifically examined how people repair their loss of self, brought about by illness through an integration of their most salient identity. She noted that some people
struggle against illness in order to regain, restore, and preserve their salient, pre-illness identities. Charmaz illuminated some of the processes employed in preserving pre-illness identities. For example, “bracketing is a means of removing illness from the general flow of life or confining it to a separate place” (Hubbard et al., 2010, p. 7). Hubbard, Kidd, and Kearney (2010) further explained that viewing illness as an enemy serves to externalize it, which is another process that patients use to preserve pre-illness identities. In contrast, other patients who view their illness as salient adapt to it, and establish a new identity in the process. Charmaz reaffirmed this notion, stating, “Adapting implies that the individual acknowledges impairment and alters life and self in socially and personally acceptable ways” (Charmaz, 1995, p. 657).

Likewise, Bury’s (1991) examination of coping is particularly relevant to the present study and paralleled Charmaz’s view of adjustment post-illness. Specifically, Bury posited that coping refers to cognitive processes where individuals learn to tolerate their illness and maintain “a sense of value and meaning in life, in spite of symptoms of their effects” (Bury, 1991, p. 461). One example of coping includes normalizing the impact of illness so that the effects of identity are minimized. According to Bury (2001), normalization involves two types of processes in patients’ experiences of chronicity. On the one hand, patients may try to normalize or maintain their pre-illness identity. This may involve maintaining as many pre-illness activities as possible, and/or disguising or minimizing their symptoms (Hubbard et al., 2010). When studying patients with diabetes, Kelleher (1988) argued that minimizing symptoms “allows feelings of being different from others to be pushed backstage” (p. 41). On the other hand, normalization may also mean the incorporation of the illness into an altered lifestyle so that normal life is re-designed as containing the illness and being open about it (Bury, 2001; Hubbard et al., 2010). Under these
circumstances, the stories people tell of themselves are likely to disclose illness rather than disguise it, signalling a change in identity rather than preserving earlier ones.

**Identity Integration**

Integration is an emerging concept in healthcare literature and has received increased attention over the last two decades (Whittemore & Dixon, 2008). Early development of the concept has targeted chronic illness care, the aging population, and QOL issues (Whittemore & Dixon, 2008). Initially, Westra and Rodgers (1991) examined a broad base of literature to explore ways that this concept could be used to identify its utility and to evaluate successful outcomes. Using concept analysis, these researchers abstractly characterized integration as “the merging of two or more elements whereby a newly formed unity is achieved” (Whittemore & Dixon, 2008, p. 178). On a more concrete level, these researchers defined integration as the “human-environment interaction whereby new life experiences such as illness are reconciled with past and present identities and roles” (Whittemore & Dixon, 2008, p. 178). Westra and Rodgers (1991) further explained that the concept of integration represents marked improvement over currently available conceptualizations such as assimilation, adaptation, and adjustment. These latter concepts are commonly used to indicate that the individual alone changes to fit the existing environment. Typically, research and clinical practice has paid little attention to changes in the environment when interacting with the individual. Westra and Rodgers (1991) also believed that these concepts did not place sufficient emphasis on the changes to an individual’s identity. In contrast, integration represents “a dynamic process with shared responsibility for change, rather than the sacrifice of the individual to meet a resistant environment” (p. 281).

The concept of integration has also been identified and discussed in several nursing theories. Fleury (1991), in a grounded theory study of adults participating in cardiac
rehabilitation programs, reported that integrating change was a key aspect to the development of new and positive health patterns (Whittemore & Dixon, 2008). In another grounded theory investigation, Hernandez (1995) studied individuals with diabetes who identified integration as a central component to successfully living with diabetes (Whittemore & Dixon, 2008). In this study, integration was defined as a “science of one,” whereby “a person takes ownership of their diabetes self-care, focusing on living, but not on the detriments of diabetes control” (Whittemore & Dixon, 2008, p. 179). Additionally, in a phenomenological study examining cardiac rehabilitation experiences, Medich, Stuart, and Chase (1997) identified integration as a central theme to explain healing and engaging in health promotion behaviours. Dungan (1997) later proposed a model of dynamic integration where integration was defined as “optimum functioning and the integrity of one’s body, mind, and spirit within a constantly changing environment” (Whittemore & Dixon, 2008, p. 179). More recently, Whittemore, Chase, Mandle, and Roy (2002) examined identity processes among women with type 2 diabetes who were participating in a lifestyle change program. In this study, integration was conceptualized as “a process of reconciling emotions, composing a structure, striving for satisfaction, exploring self and conflict, discovering balance, and defining a new cadence of life” (Whittemore & Dixon, 2008, p. 179). These researchers consolidated their findings with existing qualitative research to identify facilitators of integration including: the need for introspection, active engagement, and participation on the part of the individual; energy commitment over time; experimentation; and the establishing of new life patterns (Whittemore & Dixon, 2008).

Yet, development of the concept of integration, while critical, continues to carry some challenges. Previous research on the concept of integration has remained confined to single studies or theories, which have limited generalizability and applicability (Whittemore & Dixon,
2008). As well, current research and measurements of this concept have been vague and conceptually inconsistent; some reports indicate that integration was a process, others an outcome, and others still as both a process and an outcome (Whittemore & Dixon, 2008). Specific subtypes of integration identified in the literature include: role integration (P.S. Jones, Jaceldo, Lee, Zhang, & Meleis, 2001), social and community integration (Minnes et al., 2003; Trigg & Wood, 2000), and temporal integration (Reed, 1991). While studies examining role integration have alluded to the value of exploring the integration of an individual’s sense of identity, no studies have exclusively targeted the specific subtype of Identity Integration.

To date, theoretical and empirical findings related to integration suggest that Identity Integration is an important process of adjustment to living with illness (Whittemore & Dixon, 2008). Although this phenomenon has never been appropriately defined, using a wide range of terms to describe the process (e.g., reformulation, reintegration, changes, etc.), Identity Integration has been discussed and elucidated within the cancer literature.

Specifically, Zebrack (2000) discussed Identity Integration within the cancer literature as the theoretical underpinning of psychosocial adjustment and well-being within this population. Although Zebrack did not provide a term for the phenomenon, he described the cancer experience as particularly disruptive to the extent that it caused an interruption of the normal process of identity formation, and a failure to match one’s self-perceptions with pre-existing identity standards (Zebrack, 2000). He explained that distress ensued when these individuals did not believe that they were living up to the expectations or ideals of who they were or who they wanted to be (Zebrack, 2000). Cancer-related tasks such as handling psychological reactions of the self and others, preserving body image ideals, maintaining social relationships, and dealing with uncertainty may be experienced as disruptive and distressing (Zebrack, 2000).
Trachtenberg and Piran (2012) also describe this phenomenon, finding that identity reformulation is embedded in breast cancer survivorship. In a qualitative interview study with young women breast cancer survivors, they found that aspects of the cancer experience, including the deconstruction of the body, generate 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 women, a mastectomy was a life-changing, potentially traumatizing experience that shook the foundation of their sense of their gendered self. In particular, following their surgical procedures, several women in this study expressed concerns that they no longer felt like a woman. Women feared that their cancer experience would challenge the connection to their gender-related identity. In fact, one woman expressed feelings that she had reverted back to being a pre-pubescent girl following her mastectomy. Thus, in order to reduce the discrepancy or cognitive dissonance between past and current selves, these women chose to consolidate their renewed gender experience and re-located themselves in relation to their gendered role expectations. Additionally, these researchers also found that several young women felt they had unfairly progressed into an older, less agile life stage. Participants experienced symptoms they assumed would be acquired much 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 limitless futures—and their current selves forced them to reformulate their identity as young people.

Zebrack (2000) also elaborated on the phenomenon, theorizing that cancer survivors’ psychosocial adjustment and well-being can be attributed to three different processes associated with Identity Integration: “1) her ability to reconcile ideal and actual experiences; 2) her achievement of success in solving role-specific disruptions; 3) her positive interactions with and
positive feedback from others” (p. 240). Not surprisingly, cancer survivors are challenged to reconcile their ideal healthy self and their actual experiences of new or different physical, existential, emotional, or social capabilities (Zebrack, 2000). At the very worst, this process involves, “a depletion of psychological resources, a sense of worthlessness and morbid depression, impairment of mental functioning or sense of reality, self-destructive acts, preoccupation with punishment and death or boredom and lack of initiative” (Zebrack, 2000, p. 240). At the very best, a survivor accepts new role demands as well as the identity of a cancer survivor; this acceptance is associated with a trajectory toward new values and ideals that form the foundation of a renewed and more fulfilled self (Zebrack, 2000).

Further research on the concept of Identity Integration is warranted. By providing a clearly defined, conceptually consistent understanding of the Identity Integration process, researchers and clinicians will be better able to target and tailor psychological treatments necessary to strengthen QOL. The term Identity Integration used in this study is based upon Westra and Rodgers’ (1991) empirically derived definition, namely: “Two or more elements are merged with sufficient interaction so that unity of the newly formed entity is achieved . . . an emphasis is placed on individual reconciliation of past and present identities and roles” (p. 280). Although alternative definitions of integration have been employed in reference to overall health, Westra and Rodgers’ definition is research based, and they have studied the relationship between identity integration and health-related outcomes. Grounded in their conceptualization, the present investigation defined Identity Integration as the reformation of post-illness identities whereby an illness experience is reconciled with past and present identities and roles.

In the present investigation, Identity Integration, the reformation of post-illness identities, and its relationship to psychosocial well-being were examined among a younger population of
breast cancer survivors. In particular, Identity Integration was examined in relation to two aspects of identity: a) illness-related identity—women’s experience of themselves in relation to developing breast cancer, and b) gender-related identity—women’s experience of themselves in relation to stereotypic and hegemonic gender constructions. These two aspects of identity were used to predict psychosocial well-being in young breast cancer survivors.

**Integration of the illness experience into identity.** Although not always discussed at length, empirically driven studies have continuously found that the integration of an illness experience into patients’ identities is critical for healing processes and engagement in health promotion behaviours among diverse populations (Dungan, 1997; Fleury, 1991; Hernandez, 1995; Whittemore et al., 2002; Whittemore & Knafl, 2005). Thus, the first component of Identity Integration to be examined in the present study is the integration of the illness experience into one’s identity.

Past research on adjustment and integration of the illness experience into identity has showcased the fluctuating tension between living a life and living an illness (Whittemore & Dixon, 2008). Paterson (2001) described this process as *illness in the foreground* or *wellness in the foreground*. Illness in the foreground is when individuals with chronic illness are absorbed in their illness; wellness in the foreground is when individuals envision opportunity and possibility despite their illness (Whittemore & Dixon, 2008). Additionally, Kralik (2002) identified *extraordinariness* and *ordinariness* as central phases to integrating the illness experience into identity (Whittemore & Dixon, 2008). Extraordinariness is a phase of turmoil and distress, while ordinariness is a phase or reconstructing one’s life post-illness (Whittemore & Dixon, 2008). Alternatively, Jarrett (2000) described the integration of an illness experience as having four distinct stages: uncertainty, disruption, striving to regain the self, and regaining wellness.
(Whittemore & Dixon, 2008). However, while this research suggested distinct phases of integration, it should be noted that adults with illness typically shift between these stages to address immediate life or illness circumstances (McWilliam, Stewart, Brown, Desai, & Coderre, 1996; Paterson, 2001).

Most recently, Whittemore and Dixon (2008) outlined a model integrating the illness experience into one’s life experiences and identity among individuals with chronic illness. Using a mixed method descriptive design, 26 participants of diverse age (25-80), education (eight to 24 years), duration of illness (one to 39 years), gender (63% female), and ethnicity (63% white) were included. Participants reported a mean of four chronic illnesses. Thirty-one percent of the sample had increased depressive symptoms. Participants described the process of integration as complex and multifactorial; a continuous amount of time and effort was needed to integrate the illness into an individual’s life context and identity. The five phase model of integration included: shifting sands, staying afloat, weathering the storms, rescuing oneself, and navigating life. Numerous factors including treatment side effects, uncertainty of the illness trajectory, comorbidity, bad days, financial hardships, and interpersonal/environmental challenges contributed to difficulty in the integration process and the disruption of the illness experience.

The first phase, shifting sands, encompassed the initial experience of facing a changed life with many personal losses. Emotional responses from participants including fear, anger, sadness, depression, anxiety, apathy, and denial were all embedded in this stage. These emotional responses often resulted from changes in participants’ bodies, changes in their ability to experience life, and perceived losses. Loss of body function, life activities, time, and control were also expressed.
Participants then shifted into the second phase of integration, staying afloat. This phase represented the considerable work that was required for participants to begin understanding their unique needs and come to terms with what it meant to live with an illness. Participants in this phase described daily attention to learning and experimenting, managing their illness, using resources, expressing emotion, and developing coping strategies. The degree of difficulty of this phase was contingent on participants’ illness experience, internal coping resources (coping strategies and personal characteristics), and external resources (others, environment). At this phase, participants also learned about their illness from several sources including family, friends, support groups, media, and healthcare professionals. This learning process typically resulted in increased confidence toward managing their illness. Additionally, at this phase, attention to both the physical and emotional demands of the illness was equally important for participants to integrate it into their life context. Coping strategies were also identified as beneficial in beginning the integration process, which included: spirituality, humour, focusing on the positive, self-talk, pets, and creative pursuits (e.g., journaling, cooking, crafts).

The third phase, weathering the storm, represented numerous barriers to integration including treatment side effects, a progressive or uncertain illness trajectory, co-morbidity, bad days, financial hardship, and interpersonal/environmental challenges. Researchers reported that there was continual tension between participants’ ability to stay afloat and move forward in the integration process, which depended on the number and intensity of barriers as well as the availability of resources.

The fourth phase, rescuing oneself, involved the demands of conscious effort and creativity to weather the storm and re-engage in a meaningful life, which required: working at one’s health, participating in life, connecting with others, developing new coping strategies, and
finding purpose or meaning. All aspects of a person’s sense of self are affected by an illness; therefore, engaging in a meaningful life was a challenging process (Whittemore & Dixon, 2008). Some participants engaged in meaningful work through volunteering. For others, previous coping strategies no longer worked because of illness symptoms or side effects, thus the development of new coping strategies was required. For all participants, engaging in enjoyment or meaning was at this phase an important aspect of the integration process, albeit a sometimes-difficult task to accomplish.

Finally, during the fifth phase, navigating life, participants fluctuated between *living a life* and *living an illness* as a result of changing and unpredictable illness experiences. Days of adjustment, inner peace, and positive self-worth were intermixed with days of struggling, frustration, and isolation. Participants were faced with ongoing emotional, physical, and spiritual challenges that required attention. Thus, Whittemore and Dixon’s (2008) model provides some clarity regarding the fluid and ongoing process necessary to fully integrate an illness experience into one’s life experiences and identity.

**Posttraumatic growth: perceived growth and loss.** Historically, research on adjustment to chronic illness indicates that many individuals experience positive personal changes following a diagnosis or once completed medical treatment (Golub, Rendina, & Gamarel, 2013). Among various terms that have been used to identify this phenomenon, posttraumatic growth is one that has described the process through which individuals experience a positive transformation as a direct result of their struggles with adversity (Tedeschi, Park, & Calhoun, 1998). Posttraumatic growth has been associated with better psychosocial well-being and lower distress levels among cancer patients and survivors (Cordova, Cunningham, Carlson, & Andrykowski, 2001; Urcuyo, Boyers, Carver, & Antoni, 2005). Although these growth experiences have been described in
positive terms, evidence regarding the association between posttraumatic growth and psychosocial well-being or physical health is variable (Golub et al., 2013). Some studies have demonstrated a positive association between growth and well-being in both cross-sectional and longitudinal designs (Carver & Antoni, 2004; Danoff-Burg & Revenson, 2005; Linley & Joseph, 2004; Milam, 2004; Updegraff, Taylor, Kemeny, & Wyatt, 2002; Urcuyo et al., 2005) while others have found no significant association either cross-sectionally (Cordova et al., 2001; Schulz & Mohamed, 2004; Sumalla, Ochoa, & Blanco, 2009) or longitudinally (Danoff-Burg & Revenson, 2005; Evers et al., 2001; Petrie, Buick, Weinman, & Booth, 1999; Siegel & Schrimshaw, 2007). In one meta-analysis that surveyed studies of multiple chronic illnesses and other stressful life events, growth was associated with more positive affect and less depression, but was unrelated to anxiety, distress, QOL, or subjective health (Helgeson, Reynolds, & Tomich, 2006). Researchers have also noted that these inconsistencies are not the result of differences in measurement since each measure has resulted in both significant and non-significant findings (Siegel & Schrimshaw, 2007).

Given these inconsistent and contradictory findings in the literature on illness, posttraumatic growth, and psychosocial well-being, the present study’s concept of Identity Integration, shaped by Westra and Rodgers’ definition, does not exclusively assume a positive association between self-growth and positive psychosocial well-being. Rather, Identity Integration assumes that perceived growth and loss are both necessary for the Identity Integration process. This explanation aligns with Westra and Rodgers’ (1991) initial conceptualization of integration as “two or more elements are merged with sufficient interaction so that unity of the newly formed entity is achieved” (p. 280). In this case, the process of Identity Integration involved the interaction of both self-growth and loss among young breast cancer survivors to
achieve a newly formed identity post-illness. Furthermore, past research has supported this notion demonstrating the significant interaction between self-growth and loss in achieving good psychosocial well-being. Specifically, studies have shown that perceived benefit associated with adversity are more strongly associated with psychosocial well-being for those who reported mixed accounts that included both negative and positive effects of a traumatic event (Cheng, Wong, & Tsang, 2006; Golub et al., 2013; Lehman et al., 1993).

Much of the posttraumatic growth literature assumed that growth and other benefits stem directly from losses, suggesting that loss lies at the opposite end of the growth spectrum (Golub et al., 2013). However, other researchers view these two concepts as independent from each other (Keyes, Shmotkin, & Ryff, 2002; Larson, Moneta, Richards, & Wilson, 2002; Russell & Carroll, 1999; Watson & Tellegen, 1985). Researchers have suggested that the perceptions of growth and loss following adversity operate independently and in interaction in their influence on overall well-being (Golub et al., 2013). Previous examinations of self-related cognitions among individuals with chronic illness, for example, suggested that these factors are differently associated with mental health and QOL outcomes. For example, in a cross-sectional study conducted by Golub, Gamarel, and Rendina (2013), 127 ethnically diverse HIV-positive gay and bisexual men completed a brief quantitative survey including a new measure, the Impact on Self-Concept Scale (ISCS), as well as gay-related stigma, QOL, and regulatory factors. Factor analysis supported the existence of two ISCS subscales: self-growth and self-loss. Results from the investigation revealed distinct patterns of association, with the self-loss subscale being more strongly associated with QOL than self-growth. Additionally, in the multivariate models, the self-growth scale moderated associations between self-loss and QOL. These findings suggested that self-growth and self-loss were meaningfully distinct constructs within the illness and identity
integration literature. Taken together, these findings suggested that growth and loss may be independent and meaningful constructs, both of which are valuable to examine as part of the Identity Integration process among young women with breast cancer.

**Integration of values that counteract traditional gender-related constructs.** In addition to the integration of the illness experience into one’s identity, it is equally important to integrate socio-cultural factors outside of the illness experience that play a significant role in survivors’ post-illness identity and psychosocial well-being. Thus, the second examined component of Identity Integration in this inquiry is gender-related identity – the internalization of values that counteract stereotypic gender-related identity and role expectations regarding standards of appearance or comportment (e.g., clothing worn, and other-oriented focus of care, respectively) into one’s identity.

**The making of the female self.** Incorporating a strong understanding of female development and gender role expectations into this investigation is necessary to provide greater insight into the Identity Integration process for young breast cancer survivors. The making of the female self, or a woman’s journey toward a gender-related identity, encompassed the development of “a private sense of, and subjective experience of her own gender” (Wood, 2012, p. 283).

Traditional scholars and theorists such as Lawrence Kohlberg and Sandra Bem emphasized the acquisition of gender occurring at a strikingly young age—in early childhood—with the view that once established, gender-related identity was very likely to go unchanged. In contrast, Sheila Greene (2003), a feminist psychologist, argued that such theories belong to the essentialist view of gender, as they see gender as fixed on the individual, resulting primarily from their biological sex. Wetherell and Potter (1986) also dispute this notion, stating that
“gender is not a matter of consistent unitary single identities . . . but develops from contradictory and frequently fragmentary pieces of discourse, repertoires and accounting systems available to individuals to make sense of their position and which historically and contingently have come to be marked as feminine or masculine responses” (p. 77). Likewise, social constructionist scholars see gender as “the property of social engagement, not as a trait” (Greene, 2003, p. 107).

Moreover, as clarified by West and Zimmerman (1987), “gender is something people do, not something people have” (p. 108). People do gender differently, according to social context. Thus, internal representations of gender are likely to wax and wane according to the salience of gender in any particular context and at any particular time (Greene, 2003). For example, after completing medical treatment including a mastectomy for a breast cancer diagnosis, many women reported viewing their gender-related identity differently; while some women chose to increase the salience of their gender-related identity, others, as cancer patients, chose to lessen its salience (Trachtenberg & Piran, 2012).

According to Judith Butler, individuals act out gender according to pre-written scripts that make our actions culturally intelligible (Moss & Dyck, 2003). It is through the continual re-enactment of these scripts that gender identities come into existence (Moss & Dyck, 2003). Although individuals cannot perform any gender at any given time, they do perform a range of gender performances that can be understood within the context of their culture (Greene, 2003). By accepting Butler’s view that gender is performed, there is a possibility that with “relative freedom of the postmodern world [and] a postmodern consciousness,” women can have the option to “accept, subvert or resist the normative performance of femininity” (Greene, 2003, p. 94). Moreover, June Ussher believed that “at an individual level, women and girls negotiate the scripts of femininity in order to take up or resist the position of women” (Greene, 2003, p. 94). In
Ussher’s book *Fantasies of Femininity* (1997), she described potential ways in which women can relate to the notion of *girl*, where *girl* is the archetype of perfect femininity (Greene, 2003). Ussher argued that women are not passive recipients of messages about femininity; rather, women can renegotiate and even subvert the demands to conform that are made on them. For example, some young breast cancer survivors, post-mastectomy, opt to completely immerse themselves in and accept normative performances of femininity via reconstructive surgery, increased use of makeup, and sexuality; alternatively, other breast cancer survivors at this time choose to resist and renegotiate normative performances of femininity by refusing reconstructive surgery and not wearing makeup or wigs (Trachtenberg & Piran, 2012). An example of a woman choosing to resist and renegotiate normative performances of femininity and beauty is included in the narrative of a 43-year-old woman with Stage II cancer, 13 months post-medical treatment:

> 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? (Trachtenberg & Piran, 2012, p. 83).

An illness experience is one of many examples that challenge the notion of a fixed and unitary feminine self. Using the cancer experience as an example, it seems evident that the feminine self experienced by each woman as she moves through her life’s course is always changing in time (Greene, 2003). Additionally, cultural and historical circumstances are integral to the meanings associated with women’s identity (Greene, 2003). Thus, the activation of gender-related schemas is also influenced by the current social and political context in which girls and women live their lives (Greene, 2003). As a result, each woman’s experience of gender
is a product of intricate social and psychological processes, which cannot be viewed as a fixed attribute of the self but instead as “an aspect of the enactment of self” (Greene, 2003, p. 112).

**Relational-cultural theory: the recognition of connection and care in identity**

*development.* While Stryker’s (Stryker, 1980) identity theory, and Bury (1982, 1991, 2001) and Charmaz’s (1983, 2002, 1994, 1995) biographical disruption models shed light on Identity Integration, the Relational-Cultural Theory (RCT) (Miller, 1976) added to this framework by emphasizing the importance of connection and care enmeshed in individuals’ identities. While traditional theoretical models of human development emphasized individuation, separation, and autonomy as markers of emotional and psychological maturity, Miller and other multicultural feminist scholars saw otherwise (Comstock et al., 2008). Miller (1976) and other theorists suggested that the lack of understanding of contextual and relational experiences of women, people of colour, and marginalized men have led health professionals to pathologize these individuals. Instead, RCT suggested that the relational-cultural context plays a significant role in how women and men experience themselves and their world; it provides a greater clarity of self through relationships. To fill the gap between traditional models of human development, which have not accurately depicted the relational experiences of women, RCT provides an alternative model of relational development throughout the lifespan (Comstock et al., 2008).

The core tenants of RCT that explain the process of psychological growth and relational development are summarized by Judith Jordan (2000) and include the following notions:

1. People grow through and toward relationships throughout the life span.
2. Movement toward mutuality rather than separation characterizes mature functioning.
3. The ability to participate in increasingly complex and diversified relational networks characterizes psychological growth.
4. Mutual empathy and mutual empowerment are at the core of growth-fostering relationships.

5. Authenticity is necessary for real engagement in growth-fostering relationships.

6. When people contribute to the development of growth-fostering relationships, they grow as a result of their participation in such relationships.

7. The goal of development is the realization of increased relational competence over the life span (Comstock et al., 2008, p. 280).

The work at the Stone Center for Developmental Services and Studies at the Wellesley Centre for Women emphasized the centrality of connection in women’s lives. RCT believes that these relational connections must be mutually validating within the nexus of the relationship; women learn to maintain relationships without sacrificing parts of themselves.

The concept of connectedness, an essential feature within RCT, is best understood in the context of relational movement—the process of moving through connection or disconnection (Comstock et al., 2008). Being aware of how all relationships move through these different phases is referred to as relational awareness (Comstock et al., 2008). Acquiring this relational awareness helps individuals develop more sophisticated relational capacities that enable one to identify, deconstruct, and resist disconnection (Comstock et al., 2008). With a strong sense of connection, one is more likely to develop a clarifying, growth-fostering, and integrated sense of self. Thus, the role of mutual connectedness is critical to maintaining an integrated sense of self. Not surprisingly, RCT posited that the experience of disconnection is likely to lead to a lack of clarity and/or disintegration of one’s self. These disconnecting experiences may result in feelings of shame, fear, humiliation, and self-blame (Comstock et al., 2008). Jordan (1997) stated that, “shame is most importantly a felt sense of unworthiness to be in connection, a deep sense of
unlovability, with the ongoing awareness of how very much one wants to connect with others” (Jordan, 1997, p. 147). Furthermore, a relational disconnection that cannot be transformed can lead to feelings of condemned isolation and disempowerment (Comstock et al., 2008; Miller & Stiver, 1997).

Consistent with feminist and multicultural/social justice theorists, Walker (2013) further explained that the context of relational development was inextricably linked to individuals’ racial, cultural, and social identities. Thus, individuals’ complex social locations and ethnocultural backgrounds were critical to the conceptualization of their identity and self-concepts. RCT suggests that “chronic exposure to disaffirming stimuli” (Walker, 2005, p. 52), such as negative race-, gender-, and class-based stereotypes, stimulates many people’s sense of self-doubt and disrupts an integrated sense of identity and selfhood (Comstock et al., 2008). For example, internalized sexism interferes with a woman’s ability to “name and interpret [her] experience in self-affirming ways” (Walker, 2005, p. 52). As a result of this social injustice, RCT suggests that individuals with marginalized social locations are less likely to seek out positive relational connections that have the potential to be a “growing medium for healthy relationships” (Walker, 2005, p. 52). Thus, through the process of marginalization, “the dominant culture distorts images of the self, images of others, and images of relational possibilities” (Walker, 1999, p. 3). For members of the dominant culture, these images confirm and “promote the experience of internalized dominance, and presumed superiority” (Comstock et al., 2008, p. 285). Consequently, these images limit the perceptions of who, how, and what these groups believe they can be in this world (Comstock et al., 2008). RCT, therefore, implies that, related to past non-mutually validating relational connections, women, and even more so women with an illness such as breast cancer, may be deprived of healthy relationships. In order to strive for such
connections, women need to counter stereotypes such as being the perpetual caregiver or the container of others’ challenges and emotions.

The Developmental Theory of Embodiment: Mental Freedom and the gendered lived experience of the body. The Developmental Theory of Embodiment (DTE) (Piran & Teall, 2012) addressed a number of key concepts regarding the gendered lived experience of the body, including a set of constructs related to the social factors that lead to states of connected versus disrupted embodiment in girls and women. Utilizing a constant comparison approach to their thematic analysis of research narratives (Glaser, 1994; Miles & Huberman, 1994), Piran and colleagues’ (Piran, 2001; Piran & Teall, 2012; Piran & Thompson, 2008) qualitative studies of girls, young women, and midlife women led to the creation of a hierarchical and categorical structure of all embodied social experiences that occur during girls’ and women’s developmental journeys. This hierarchical and categorical structure of social experiences was divided into three core constructs, coined by Piran and colleagues (Piran et al., 2009; Piran, Carter, Thompson, & Pajouhandeh, 2002): physical freedom (vs. physical corseting), mental freedom (vs. mental corseting), and social power (vs. social disempowerment). Piran and Teall (2012) explained that all these experiences are mediated through relational contexts at the peer, family, school, community, and larger cultural levels, and are shaped by social location, which includes gender, social class, ethnocultural group membership, disability, and sexual orientation, among other factors.

More specifically, the second factor described above, mental freedom (vs. mental corseting), relates to “the freedom to explore and determine one’s own sense of identity, in particular, the freedom not to belong to socially created and labelled groups (such as ‘tomboy’/‘girlie girl’, ‘butch’/‘girlie’, ‘slut’/‘prude’”) (Piran & Teall, 2012, p. 188-189). For
young women, after their breast cancer treatment for example, this may include additional labels such as survivor, victim, patient, sick person, disfigured person, and person with cancer. These potentially oppressive social discourses are believed to disrupt girls’ and women’s connections with their bodies by forcing their embodied experiences into tight and unfitting moulds, which Piran and Teall (2012) described as both “idealizing and deprecating in nature” (Piran & Teall, 2012, p. 189). Indeed, this statement holds true for young breast cancer survivors, who are told by their social world which mould they should squeeze into at this particular stage of their cancer experience (Trachtenberg & Piran, 2012).

Included in this narrative is one example of mental corseting found in previous studies of young women with breast cancer—a 39-year-old woman with Stage III cancer, 10 months post-medical treatment. This woman described her desire to maintain the societal image of femininity around others, and subsequently felt a need to conceal her altered body to adhere to the 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. (Trachtenberg & Piran, 2012, p. 80)

Another example of mental corseting relates to the compliance with the girlie girl or heightened femininity mould, which involves a particular way of living in the body. A young breast cancer survivor, aged 46 with Stage III cancer, 11 months post-treatment says:

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. (Trachtenberg & Piran, 2012, p. 88-89)

Beyond the discourse of femininity, mental corseting took place in relation to women’s sense of youth as breast cancer patients. As explained by one woman, a 36-year-old with Stage II cancer, six months post-medical treatment:

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.

(Trachtenberg & Piran, 2012, p. 103)

Additionally, Piran and Teall (2012) posited that mental freedom involved women taking a critical stance toward these social moulds. Many young breast cancer survivors have resisted oppressive discourses, as demonstrated by the following narrative of a young woman who
challenged the notion of beauty, femininity, and the victim role. The 43-year-old woman, 13 months post-treatment, provided an example in her narrative of how she rejected traditional views of femininity:

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. (Trachtenberg & Piran, 2012, p. 82)

The same woman also described resisting the idea that she must continue to remain strong and hold a positive outlook through her cancer experience:

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. (Trachtenberg & Piran, 2012, p. 103)
Finally, another woman with Stage III cancer, 24 months post-treatment, rejected the oppressive discourses of the survivor and victim roles following her cancer experience.

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 fifty to seventy 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. (Trachtenberg & Piran, 2012, p. 104)

Studies outside the realm of cancer and illness have also supported the impact of mental freedom on embodiment. For example, in a meta-analysis of 22 studies, Murnen and Smolak (1997) found both a small positive relationship between feminine identity and eating problems, and a negative relationship between masculinity and eating problems. A later meta-analysis by the same authors (Murnen & Smolak, 2009) found a positive relationship between a feminist identity and positive body attitudes. Specifically, the relationship between feminist identity and body shame was found to have a significant effect. The body shame scale (as measured by the Objectified Body Consciousness Scale) examines the extent to which women internalize cultural messages about thinness and their effect on their conception of themselves (McKinley & Hyde, 1996). Women in the study who reported increased body shame are believed to have “internalized the cultural messages that they should be thin, that they should be able to control their weight, and that they are not worthy individuals otherwise” (Murnen & Smolack, 2009, p. 193). In contrast, a feminist identity, in this study, provided some protection (mental freedom) against this internalization. A feminist identity was negatively related to internalizing the thin media ideals as measured by the Sociocultural Attitudes Towards Appearance Questionnaire
(SATAQ) (Heinberg, Thompson, & Stormer, 1995). Thus, this study demonstrated that feminist identity facilitates women’s ability to critically evaluate and perhaps avoid harmful cultural messages.

Likewise, Piran and Cormier (2005), Morrison and Sheahan (2009), and Jack and Dill (1992) found that gender-related discourses of self-objectification, anger suppression, and self-silencing related to distorted body image and disordered eating patterns. Particularly with the use of the Silencing the Self Scale developed by Jack and Dill (1992), studies have found that individuals who engaged in higher levels of self-silencing reported more disordered eating behaviours, depressive symptoms, and decreased satisfaction with their body and intimate relationships (Ali, Oatley, & Toner, 2002).

**Breast cancer, body image disruption, and gender-related identity.** As demonstrated using the Developmental Theory of Embodiment’s construct of mental freedom (vs. mental corseting), oppressive social discourses such as social labels and role identities can disrupt women’s connections with their bodies. In particular, the literature has shown that the (dis)integration of traditional gender role expectations post-mastectomy can drastically affect the extent of women’s body image dissatisfaction after breast cancer treatment (Boquiren, Esplen, Wong, Toner, & Warner, 2013; Fobair et al., 2006; Trachtenberg & Piran, 2012).

Body image, as defined by Boquiren and colleagues (2013), is a multifaceted construct as well as a “mental representation of one’s body, thoughts and feelings about one’s physical appearance, attractiveness, competence, as well as one’s perceived state of overall health, wholeness, functioning and sexuality. It is a dynamic interaction between a personal expression of being and the social world” (p. 1). For many breast cancer survivors, dissatisfaction with their altered body can have a detrimental influence over many psychosocial domains (Boquiren et al.,
Body image disturbances post-medical treatment have been shown to be consistently associated with mental distress, anxiety, reduced physical health, sexual dysfunction, and impaired QOL (Carver et al., 1998; DeFrank, Mehta, Stein, & Baker, 2007; Falk Dahl, Reinertsen, Nesvold, Fosså, & Dahl, 2010; Ganz et al., 1996; Härtl et al., 2010; Soothill et al., 2001). Although the majority of breast cancer survivors eventually return to baseline or near baseline levels of physical and psychosocial functioning, a significant subset continue to report body image-related difficulties and subsequently poorer overall psychosocial well-being (Boquiren et al., 2013). However, the literature has not clearly identified why some women have shown significantly greater body image concerns while others have not (Boquiren et al., 2013). While some studies, for example, have reported no differences in body image concerns between treatment groups (Holmberg, Omne-Pontén, Burns, Adami, & Bergström, 1989; Margolis, Goodman, & Rubin, 1990; Rowland et al., 2000), other studies have demonstrated poorer adjustment for women who have undergone a mastectomy versus a lumpectomy (Falk Dahl et al., 2010; Fobair et al., 2006; Ganz et al., 1992; Yurek, Farrar, & Andersen, 2000). These discrepancies suggest that variable factors may impact women’s body image disturbances and their subsequent level of psychosocial adjustment and well-being (Boquiren et al., 2013).

One primary explanation Boquiren and her colleagues (2013) cited as a factor believed to influence body image disturbances among breast cancer survivors is gender role socialization. Indeed, gender role socialization parallels Piran and Teall’s (2015) conceptualization of mental freedom (vs. mental corseting) from the DTE. Like mental corseting, gender role socialization involves an individual’s compliance with socially accepted (or understood) standards of physical appearance. Direct and indirect communications from various influential sources (media, family,
and friends/peers) reinforce cultural heteronormative ideals of attractiveness and role demands 
that women are encouraged to adopt in order to gain societal approval (Bepko & Krestan, 1991; 
Boquiren et al., 2013; Cash & Smolak, 2011; Tiggemann, 2011). However, research has shown 
that it is not the continuous bombardment of media messages that causes distress, but the extent 
to which an individual internalizes and integrates these media messages that they become part of 
one’s self-concept (Boquiren et al., 2013). Women who endorse more traditional gender role 
expectations and attitudes have a tendency to internalize cultural beauty standards and hold 
greater investment in their physical appearance (Cash & Smolak, 2011). Not surprisingly, 
research has demonstrated that women with breast cancer who hold a greater investment in 
physical appearance exhibit increased difficulty adjusting post-treatment relative to those with 
low levels of investment (Carver et al., 1998; Figueiredo, Cullen, Hwang, Rowland, & 

A second related explanation believed to influence body image disturbances among 
breast cancer survivors is a tendency to self-objectify. According to Self-Objectification theory 
(Choma et al., 2010; Choma, Shove, Busseri, Sadava, & Hosker, 2009; Fredrickson & Roberts, 
1997), “the sociocultural contexts that women inhabit instil a tendency to internalize an 
outsider’s gaze on the physical self, which in turn promotes habitual body monitoring, self-
surveillance, and evaluation” (Boquiren et al., 2013, p. 2). An individual’s predisposition toward 
self-objectification creates a strong belief that their bodies are being evaluated by others (Choma 
et al., 2010). Higher self-objectification has been associated with disordered eating (Calogero, 
Davis, & Thompson, 2005; Greenleaf, 2005; Greenleaf & McGreer, 2006), depression 
(Szymanski & Henning, 2007; Tiggemann & Kuring, 2004), sexual dysfunction (Grabe, Hyde, & 
Lindberg, 2007; Knauss, Paxton, & Alsaker, 2008), and greater body shame in western cultures.
(Grabe et al., 2007; Knauss et al., 2008). More recently, research has begun to establish the link between self-objectification and body image disturbances in breast cancer survivors’ level of psychosocial well-being (Boquiren et al., 2013).

A third and notable explanation believed to influence varied body image disturbances among breast cancer survivors could also be explained through Craig White’s (2000) heuristic cognitive behavioural model of body image dimensions, which, from a cognitive-behavioural perspective, attempted to understand cancer-related appearance changes. Essentially White’s (2000) model posited that cancer patients with perceived or actual appearance changes, accompanied by the presence of a threat to their ideal selves (resulting from the content of their self and body image schemas), will, “experience negative appearance-related assumptions, thoughts, images, emotions, and behaviours if this ideal self-discrepancy relates to a physical attribute in which they have significant personal investment” (p. 188).

White described four key components in this model. First, he explained that there may or may not be congruence between patients’, “objective reality regarding their appearance, and subjective perception of the extent and nature of their appearance related changes after a cancer experience” (White, 2000, p. 188). Second, White’s model postulated that perceived cancer-related appearance changes would be processed in terms of the patient’s beliefs about themselves and their appearance (White, 2000). The patient’s self-schema, an organized self-structure of internal constructs (e.g., I am adequate, I am disgusting, I am liked by others), when activated, will spread to other schemas and will influence subsequent information processing (Goldfried & Robins, 1983; Kovacs & Beck, 1978; White, 2000). Third, White (2000) proposed that the body-image schema and its contents, would determine the degree to which a patient has an investment in changed body features. Forth, White believed that patients’ body-image schema would also
determine the presence of an actual self/ideal self-discrepancy. It was assumed that the four components described by White (2000) would determine the precise nature of their cross-situational assumptions as well as situation-specific automatic thoughts and images. Once patients’ assumptions and automatic thoughts were altered, these changes would then impact patients’ predominant emotional consequences and compensatory behaviours.

White (2000) sought not to oversimplify a complicated area of body image, but to provide a framework for clinicians and researchers to examine the complexities and multiple dimensions of body image experiences among cancer patients. White (2000) also provided two testable hypotheses based on his model: a) Cancer patients with high levels of personal investment in discrete physical attributes should experience more negative psychological consequences following changes in that attribute than patients with less personal investment in the attribute, but experience similar objective changes; b) Cancer patients with more negative self-schemas in the presence of negative body image schemas will be more likely to have more ideal self-discrepancies than patients with negative self-schemas who do not have a negative body image schema.

Nonetheless, to date, no studies have critically examined the internalization of values that counteract traditional gender-related identity and role expectations as a predictor of psychosocial well-being in young breast cancer survivors. Despite the limited research, two studies have been instrumental to this area of the investigation. The first pivotal study, conducted by Boquiren, Esplen, Wong, Toner, and Warner (2013), explored the relationship between gender role socialization and objectified body consciousness on body image disturbances and quality of life among breast cancer survivors. One hundred and fifty women who had completed treatment for breast cancer participated in the study. Most participants identified themselves as Caucasian.
(83.3%) and married/common law (64%). Fifty-three percent of participants had completed university/college and 49% were working full-time. The average age of participants was 49.5 years (SD = 8.8). Participants completed a baseline battery of questionnaires including: Body Image Scale (BIS), Body Image After Breast Cancer Questionnaire (BIBCQ), Objectified Body Consciousness Scale (OBCS) measuring Body Shame and Surveillance, Gender Role Socialization Scale (GRSS) measuring internalization of traditional gender roles and attitudes, and the Functional Assessment of Cancer Therapy-Breast Quality-of-Life Instrument (FACT-B). Correlational analyses were conducted on questionnaires. Significant positive correlations were found between the body image scales and GRSS Body Shame as well as Surveillance. The BIS and BIBCQ were negatively associated with the FACT-B. The findings of the study revealed that survivors who endorse greater internalization of traditional gender roles and attitudes engage in self-surveillance and experience greater body image shame, and report greater body image disruptions and overall poorer QOL post-medical treatment. Therefore, women with these dispositions were more likely to be vulnerable to psychological distress and experience poorer long-term adjustment.

In a second critical investigation, Gurevich, Bishop, Bower, Malka, and Nyhof-Young (2004) examined how men (re)considered questions of gender and sexuality after the diagnosis and treatment of testicular cancer. Semi-structured qualitative interviews for 40 men were collected and analyzed. The findings indicated that the construction of a masculine identity was central to the experience of testicular cancer. Masculine identities were strongly linked to their sexual performance abilities and the appearance of normal genitals. Moreover, Gurevich and colleagues endorsed Butler’s (1990) notion of gender as a “performance with clear punitive consequences” (p. 139); however, the researchers added that bodies “are inscribed with gender
signification in ways that render certain bodies more or less ‘intelligible’ within the regulatory matrices of masculinity and femininity. Thus, anatomically intact bodies are designed as anatomically and socio-culturally ‘correct’ bodies. And likewise, anatomical ‘deviations,’ even if unavoidable (e.g., resulting from a life-threatening disease) risk repudiation” (Gurevich et al., 2004, p. 1,604). Thus, testicular cancer, like breast cancer, cannot be experienced without questioning gender role definitions. The participants’ narratives in the interviews stressed the “impermanence and inevitability of the body as a site for social categorization which can both adhere to or defy social/cultural imperatives” (Gurevich et al., 2004, p. 1,604). Finally, the analysis of the interviews for these men highlighted that orchiectomy represented a loss of masculinity as well as an escape from the social and culturally rigid expectations of what it means to be a man (Gurevich et al., 2004). As a result, these men are more likely to reflect upon what it means to embody their masculinity, gender identity, and sexuality (Gurevich et al., 2004).

These two instrumental studies highlighted a critical relationship between an individual’s altered body, gender role expectations, and gender-related identity after a cancer experience. While limited research currently exists in this particular area, these studies shed light on the need to create a forum for young breast cancer survivors that addresses the relationship between internalized gender role expectations and psychosocial well-being. In addition, these studies highlighted the survivorship period as a crucial time for gender and identity integration.

The Quality of Life Model in Psychosocial Oncology: How Has it Been Used?

Over the last two decades, QOL has become an increasingly popular term within medical and research communities to measure long-term health-related outcomes and psychosocial well-being (Centre for Disease Control and Prevention, 2016). QOL is conceptualized as a multidimensional concept that examines four broad life domains including: physical,
psychological, social, and spiritual. Ferrell, Dow, Curbow, and Gotay (1997) provided a definition of QOL that incorporates 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 (p. 566).

More recently, the research community has become highly attuned to various concerns impacting young breast cancer survivors by using the QOL model, which includes: pain management and late effects of treatment, psychological and emotional distress, fertility issues, relationships and sexual functioning, relationship with their partner and children, future orientation, goal achievement, re-entry into school or work, and fears of uncertainty due to potential recurrence of disease (Howard-Anderson, Ganz, Bower, & Stanton, 2012). Indeed, QOL-informed studies have provided a wealth of knowledge that has been used to enhance the understanding of a variety of unique issues for a younger group of breast cancer survivors. However, using the QOL model as the exclusive method of investigating long-term psychosocial well-being in young breast cancer survivors may be unsatisfying for the following reasons.
Firstly, the majority of QOL studies using young breast cancer survivors typically adhered to only one of the four pre-defined QOL domains to understand women’s overall well-being following breast cancer treatment (Howard-Anderson et al., 2012). This narrowly focused examination of psychosocial well-being has the potential to discount a number of variables critical to women’s long-term adjustment. Second, while QOL studies have shed light on numerous challenges faced by young women with breast cancer, they provide little information as to who might be most at risk for these challenges and disruptions, and what interventions would be most appropriate to mitigate poor adjustment. Therefore, using the pre-defined QOL domains as the sole method for measuring long-term well-being may be restrictive. While Ferrell and colleagues (1997) believed their definition of QOL to be all-encompassing, it may in fact be limiting in the areas it can examine. Third, the majority of QOL studies among young breast cancer survivors have focused on key risk factors or poor levels of adjustment after medical treatment. As a result, there is a dearth of research examining protective factors that have mitigated poorer adjustment and well-being in this specific population.

Expanding on the QOL model and the factors that contribute to it among breast cancer survivors should help to clarify which individuals might benefit from which psychosocial support interventions post-medical treatment (Zebrack, 2000). Moreover, while it has previously been important to use the QOL model to identify long-term survivors who are at-risk for psychosocial sequelae, for the purposes of developing preventive interventions and personalized psychosocial treatment options, identification may no longer be sufficient. Given that many long-term survivors of breast cancer are psychologically well-adjusted five years after treatment, and that some describe their lives as enriched by the cancer experience, there is a need to provide a more comprehensive understanding of what contributes to long-term survivors’ positive
adaptation (Zebrack, 2000). Equipped with this understanding, health care professionals, program planners, and policy makers can re-develop and create appropriate services and systems that facilitate and enhance survivors’ long-term well-being (Zebrack, 2000).

**An additional model of quality of life: The Experience of Embodiment.** Using the DTE, Piran and colleagues (2002, 2007, 2009, 2010, 2012), created a construct related to an individual’s experience of embodied engagement with the world that included both positive and negative experiences; they termed this construct the *Experience of Embodiment*. Exploring breast cancer survivors’ experiences of embodiment has been deemed imperative to the overall understanding of women’s psychosocial well-being.

The Experience of Embodiment included both an exploration of the constructs of positive/connected embodiment as well as disrupted embodiment. Utilizing thematic analysis of research narratives on studies with girls (Piran et al., 2009) and women (Piran et al., 2002) revealed that positive/connected embodiment is a complex construct that included:

Feeling “at one” with the body, embodied power and agency, body functionality/competence, a “subjective” experience of living in the body with limited external consciousness, the freedom to act/take space/move especially in private and public spheres, the freedom to challenge external standards, body-anchored joy/passion/comfort/other positive feelings, body care and protection, clarity of needs/rights/desires/internal states, connection to others regarding needs/desires/rights, the freedom to express individuality through the body, connection with the physical environment, and the openness to use the body as a source of knowledge in interacting with the world. (Piran & Teall, 2012, p. 185-186)
These dimensions, which are not used in the traditional QOL model among cancer survivors, were important characteristics of positive adjustment and psychosocial well-being, and are subsequently viewed as valuable when measuring survivors’ long-term well-being.

Piran and Teall (2012) also found disrupted embodiment to be an equally complex construct that included the following dimensions:

- body/self-disconnection, body as a site of disempowerment/vulnerability/constrained space
- body as a site of low functionality/competence, external consciousness about the body
- harsh evaluative gaze, preoccupation with fitting external standards of appearance/behavior
- predominance of body practices dictated by external standards
- self-harming behaviors/self-neglect
- the association of the body with negative feelings
- difficulty identifying needs/desires/internal states
- disconnection from others regarding needs/desires/rights
- limiting individuality in order to fit in
- disconnection from the physical environment
- not utilizing the body as a source of knowledge in interacting with the world” (Piran & Teall, 2012, p. 186).

Moreover, the experience of embodiment, both positive and negative, has demonstrated significant importance in the long-term psychosocial well-being of women across their life spans (Piran et al., 2012). Including the construct of embodiment as a dimension of psychosocial well-being places importance on what Piran and Teall (2012) term the body journey of women; this can be highly relevant to women with breast cancer. More specifically, among a population of women that have recently experienced significant changes in the physicality of their body journey, including the Experience of Embodiment Scale for Women (Piran & Teall, 2012), in addition to body image scales, can enrich the understanding of women’s well-being.

**Study Rationale**

While the field of identity and illness has progressed well beyond the Parsonian framework of the sick role (1951), studies in this area have faced challenges related to unclear and ambiguous definitions of identity and selfhood, as well as a common lack of grounding in theoretical frameworks. Further, few empirically based investigations have focused exclusively on cancer patients.

To date, no study has exclusively examined Identity Integration as a predictor of psychosocial well-being among a population of breast cancer survivors. Specifically, while the Identity Integration process has been discussed in a number of studies within cancer survivorship literature, very few studies have labelled this phenomenon or chosen to explore this process in greater detail. Indeed, the integration process has been conceptually inconsistent; some researchers have defined integration as a process, others as an outcome, and others still as both a process and an outcome (Whittemore & Dixon, 2008). While studies examining integration and
well-being have identified the importance of integrating pre- and post-illness identities, no studies have exclusively targeted Identity Integration.

Moreover, given the particular life stage for young women at the time of their cancer experience, where individuals tend to feel indestructible and see endless possibilities for themselves, breast cancer is likely to pose a pronounced disruption to their sense of self and future directions (Siegel et al., 1999; Zebrack, 2000). Yet, even with these pronounced disruptions and reportedly poor QOL for this population, no studies have explored the relationship between Identity Integration and well-being in this group.

The aim of the current study was to address these limitations in previous research by identifying a research-based definition of Identity Integration, currently defined as the reformation of post-illness identities whereby an illness experience is reconciled with past and present identities and roles. Anchored in this construct was a specific theoretical framework—symbolic interactionism—emphasizing meaning creation within socio-cultural contexts (McLeod & Lively, 2007), focused on specific and well defined dimensions of Identity Integration—the illness- and gender-related identities, as well as expanding on the construct of psychosocial well-being by including the construct of embodiment and body journey (Piran & Teall, 2012). Anchored in these ways, the study aimed to examine Identity Integration utilizing both quantitative and qualitative approaches. By making visible previously invisible female experiences, the study aimed to “correct both the invisibility and distortion of [the] female experience,” while going through the painful experience of living with breast cancer (Lather, 1991, as cited in Breitkreuz, 2005, p. 149).

**Central research question.** The mixed method study explored Identity Integration, the reformation of post-illness identities, and their impact on women’s psychosocial well-being. A
triangulation mixed method design was used, a type of design in which different but complementary data was collected on the same topic. In the quantitative arm of the study, the Impact on Self-Concept Scale was used to determine whether illness-related identity could predict psychosocial well-being in young breast cancer survivors. Likewise, the Gender Role Socialization Scale, Objectify Body Consciousness Scale, Mental Freedom Scale, and Silencing the Self Scale were used to determine if greater internalization of traditional gender-related identity could predict psychosocial well-being in young breast cancer survivors. Concurrent with this data collection, a qualitative arm of the study, using a feminist-informed, life history approach to the interviews explored the reformation of post-illness related identities after the diagnoses and treatment of breast cancer. The central question retrospectively examined the ways in which being a young breast cancer survivor led to shifts in their sense of identity, related in particular to having an illness, and to being a woman and a survivor of breast cancer. The study also explored the relationship between these identity-related shifts and women’s perceived experience of well-being. The reason for collecting both qualitative and quantitative data was to bring together the strengths of both forms of research, to compare and corroborate the results found through each methodology. The quantitative arm of the study provided the opportunity to test specific hypotheses on a larger sample, while the qualitative arm provided further explanation and context to the phenomena of identity, and identity-related shifts that resulted in better psychosocial well-being among young breast cancer survivors.

Quantitative Study Hypotheses

**Relationship between illness-related identity changes and measures of well-being.**

Hypothesis 1: Illness-related self-growth and self-loss was expected to be significantly correlated with measures of well-being. Perceived illness-related positive and negative changes to women’s
sense of self after a breast cancer experience was measured using the Impact on Self-Concept Scale (ISCS) (Golub et al., 2013). Given the ISCS’ use of subscales to assess self-loss and self-growth, and their interaction, this hypothesis was divided into three sub-hypotheses as follows:

Hypothesis 1A: High levels of self-loss among young breast cancer survivors was expected to be negatively associated with high QOL and embodiment scores (Golub et al., 2013).

Hypothesis 1B: Self-growth was expected to be positively associated with high QOL and embodiment scores.

Hypothesis 1C: Self-loss, self-growth, and their interaction was expected to predict QOL and embodiment scores among young breast cancer survivors (Golub et al., 2013).

**Relationship between gender-related identity and measures of well-being.**

Hypothesis 2: Greater internalization of values that counteract traditional gender-related identity and role expectations was expected to result in better QOL and embodiment scores. The internalization of gender-related identities was measured using four scales: the Gender Role Socialization Scale (GRSS) (Toner et al., 2012) measuring internalization of traditional gender roles and attitudes; the Objectified Body Consciousness Scale (OBCS) (McKinley & Hyde, 1996) measuring body shame and surveillance; the Mental Freedom Scale (MF) (Piran & Teall, 2012) measuring women’s critical stance toward oppressive social discourses, expectations, and gendered labels; and the Silencing the Self scale (SS) (Jack & Dill, 1992) measuring specific schemas about how women make and maintain intimacy in interpersonal relationships. This hypothesis was divided into five sub-hypotheses as follows:
Hypothesis 2A: Increased internalization of traditional gender roles and attitudes as measured by the GRSS post-medical treatment was expected to be negatively associated with QOL and embodiment scores (Boquiren et al., 2013).

Hypothesis 2B: Increased body surveillance and body shame as measured by the OBCS was expected to be negatively associated with QOL and embodiment scores (Boquiren et al., 2013).

Hypothesis 2C: Increased critical stance toward oppressive social discourses, expectations, and gendered labels as measured by the MF was expected to be positively associated with QOL and embodiment scores (Teall & Piran, 2015).

Hypothesis 2D: High levels of self-silencing as a reflection of internalized gendered scripts (Piran & Cormier, 2005) was expected to be negatively associated with QOL and embodiment scores (Ali et al., 2002; Shouse, 2009).

Hypothesis 2E: The GRSS, OBCS subscales, MF, and SS subscales were predictive of QOL and embodiment scores among a group of young women who have been diagnosed and treated for breast cancer.
Chapter Two: Mixed Methods Research

Mixed methods research (MMR) has been described as the third methodological movement and an emerging paradigm in healthcare research (Doyle, Brady, & Byrne, 2009). Its emergence has developed in response to the limitations of the singular use of quantitative or qualitative methods. Currently, MMR is considered to be a legitimate alternative to these two traditions (Doyle et al., 2009). Doyle and colleagues (2009) argued that MMR affords researchers “an opportunity to overcome this false dichotomy...the philosophical underpinning of pragmatism guides mixed method researchers to use a variety of approaches to answer questions that cannot be addressed with a singular method” (p. 175). Particularly within the realm of healthcare, researchers may benefit from the opportunity to use a dynamic and pragmatic approach to addressing multifaceted, complex issues in the field (Doyle et al., 2009).

Defining Mixed Methods

Mixed methods research can be defined as “research in which the investigator collects and analyses data, integrates the findings and draws inferences using both qualitative and quantitative approaches or methods of a single study” (Creswell & Clark, 2007, p. 4). Doyle (2009) further explained that MMR is not restricted to traditional approaches of data collection; rather MMR is “guided by a foundation of enquiry that underlies research activity” (Doyle et al., 2009, p. 176). Yet, there are many inconsistencies among researchers about what constitutes true MMR (Bryman, 2007; Sandelowski, 2001; Tashakkori & Creswell, 2007). Some researchers believe MMR is the collection and analysis of qualitative and quantitative data (Doyle et al., 2009); more contemporary interpretations promote a complete integration of the two approaches (Bryman, 2007; Hanson, Creswell, Clark, Petska, & Creswell, 2005; Tashakkori & Creswell,
As MMR is still evolving as a methodology, Tashakkori and Creswell (2007) argue that the discussion of its definition and what it can offer should be kept open.

The Paradigm Debate in Mixed Methods Research

Traditionally, researchers are urged to locate their work in a selected paradigm (Doyle et al., 2009). A paradigm is a world view that is defined by distinct elements including epistemology (how we know what we know), ontology (nature of reality), axiology (values), and methodology (the process for research) (Doyle et al., 2009). Paradigms influence “the questions that researchers pose and the methods they employ to answer them” (Doyle et al., 2009, p. 176). Typically, researchers select either the positivistic (quantitative) paradigm or the naturalistic or constructivist (qualitative) ones (Doyle et al., 2009). Purists argue that it is impossible to combine the epistemological and ontological perspectives of both traditions and thus these two paradigms are incompatible (Doyle et al., 2009).

Historically, within healthcare research, researchers focused on utilizing positivistic or quantitative traditions (Doyle et al., 2009). Healthcare research was grounded in objective and unbiased research that many considered to be the “gold standard” (Doyle et al., 2009). Positivists hypothesized that there was a single reality, and focused on finding causal relationships through objective measurement and quantitative analyses (Doyle et al., 2009; Firestone, 1987). In contrast, qualitative research emerged as an alternative to the positivist form of inquiry as research sought to examine the context in human experience (Doyle et al., 2009; Schwandt, 2000). Constructivists proposed that there are multiple realities and different interpretations may result from any one research study (Appleton & King, 2002). The research is subjective with an emphasis on a deeper understanding of the lived experience of a smaller sample of participants. Morgan (2007) explained one significant way in which qualitative and quantitative research are
differentiated: quantitative research is an objective process used through deduction, while qualitative research is subjective and used through an inductive process that can only be viewed in context (Doyle et al., 2009).

Considerable debate continues to exist in the literature between the compatibility of qualitative and quantitative methods (Bryman, 2007; Doyle et al., 2009; Howe, 1988; Morgan, 2007; Smith & Heshusius, 1986; D.D. Williams, 2006). Sandelowski (2001) argued that the qualitative versus quantitative debate has resulted in an illusion that the two approaches are mutually exclusive. Other researchers have posited that competition between the paradigms is not helpful; instead, focusing on the ways to combine these two approaches is the appropriate next step (Sale, Lohfeld, & Brazil, 2002; Stevenson, 2005). Onwuegbuzie (2002) and Doyle et al., (2009) suggested that on the epistemological continuum, positivist and non-positivist lie at either end of the continuum while mixed methods research occupies a middle ground.

**Pragmatism as a Paradigm**

Pragmatism is believed to guide MMR, using philosophical assumptions that allow the mixing of qualitative and quantitative approaches throughout the research process (Doyle et al., 2009; Hanson et al., 2005). Pragmatism has advanced the view that consequences are more important than process; in other words, the end justifies the means (Doyle et al., 2009). Pragmatism advocates for eclecticism, or a “. . . contingency-based approach to research method and concept selection” (Johnson & Onwuegbuzie, 2004, p. 17). Doyle and colleagues (2009) explained that a pragmatic approach is informed by the belief that the “particularities of research are such that it cannot be driven by theory or data exclusively and a process of abduction is recommended which enables one to move back and forth between induction and deduction through the process of inquiry” (p. 178). Johnson and Onwuegbuzie (2004) agreed, believing that
taking a non-purist position allows researchers to design studies that combine the best methods needed to answer specific research questions.

**The Rationale for Mixed Method Research**

A number of researchers have offered key reasons to pursue MMR (Bryman, 2006; Doyle et al., 2009; J.C. Greene, Caracelli, & Graham, 1989) in their research endeavours. Most recently, Doyle and colleagues (2009) shed light on seven overarching benefits to taking on mixed method research. These include:

1) **Triangulation**: This method allows for greater validity in a study by seeking confirmation between quantitative and qualitative data.

2) **Completeness**: By using a combination of research approaches, a more complete and comprehensive picture of the studied phenomenon is produced. Many authors argue that by utilizing MMR, researchers can allow for limitations of both methods to be neutralized, while their strengths are built; hence, stronger and more accurate inferences can be made (Bryman, 2006; Creswell, Plano Clark, Gutmann, & Hanson, 2003).

3) **Answering different research questions**: Creswell and Clark (2007) argued that MMR can help answer research questions that cannot be answered solely by qualitative or quantitative methods. MMR provides a wider repertoire of tools to meet the aims and objectives of a study.

4) **Explanation of findings**: Mixed method studies can use one research method (i.e., quantitative or qualitative) to explain the data generated from a study using the other research method. This is particularly useful when unanticipated findings emerge.
5) Illustration of data: Using qualitative research approaches can be used to better illustrate quantitative findings; this may be beneficial in painting a clearer picture of the phenomenon being studied.

6) Hypotheses development and testing: A qualitative phase of a study can be used to create hypotheses tested in a follow-up quantitative phase of an investigation.

7) Instrument development and testing: A qualitative study can be used to create items for inclusion in a novel questionnaire in a future quantitative study.

The Limitations of Mixed Method Research

Although MMR has much to offer, there have been many criticisms (Doyle et al., 2009). Much of these have focused on the incompatibility of the two paradigms, believing that the different ontological and epistemological origins of quantitative and qualitative research cannot be mixed in a single study (Doyle et al., 2009). In addition, Mertens (2003), who self-identifies as a mixed method researcher, posed some concerns about the pragmatic philosophy underlying MMR. She argued that basing methodological choices solely on pragmatics of what works is inadequate as it does not answer questions like “practical for whom?” and “to what end?” (Doyle et al., 2009). However, Doyle and colleagues (2009) explained that the practicality inherent in pragmatism is concerned with finding the most appropriate method to answer a research question.

Other criticisms or weaknesses of MMR have been more practical in nature (Doyle et al., 2009). Johnson and Onwuegbuzie (2004) contended that it may be more challenging for one researcher to carry out a mixed method study if the qualitative and quantitative phases are to be undertaken concurrently. Ivankova and colleagues (2006) identified sequential studies to have drawbacks as well, in that it takes considerable time and resources to undertake distinct phases of
a study. Furthermore, MMR typically requires that researchers have at least sufficient knowledge of both qualitative and quantitative methods independently (Doyle et al., 2009). Thus, methodologists have alluded to novice researchers finding some challenge when carrying out an MMR investigation.

**Mixed Method Research Design in the Present Investigation**

The present study utilized a concurrent triangulation design, the most common and well-known approach in MMR (Creswell et al., 2003). The benefits of employing a triangulated approach in the social sciences was delineated over fifty years ago by researchers who promoted quantitative and qualitative methods of research as complementary instead of as being from rival camps (Campbell & Fiske, 1959). In the present study, the triangulation design was completed as a one-phase approach in which the researchers implemented qualitative and quantitative methods during the same timeframe and with equal weight. As such, it involved the concurrent but separate collection and analysis of quantitative and qualitative data so that the researcher could best explore and understand the current research goals (Creswell & Plano Clark, 2010). The researcher then merged two data sets by bringing the separate results together in the interpretation and discussion section (Creswell & Plano Clark, 2010). Given the broad theoretical frameworks outlined in relation to identity and illness, and the limited number of empirically driven studies within the domain of psychosocial oncology that utilize these theoretical frameworks, the researchers were interested in corroborating the quantitative statistical results with the emergent findings of the qualitative exploration. This design provided a more comprehensive examination of young breast cancer survivors’ psychosocial well-being by: a) studying quantitatively the predictive power of Identity Integration (through illness- and gender-related identity shifts) on psychosocial well-being, and b) exploring young women’s narratives in
a qualitative inquiry that examined the integration of gender- and illness-related identities at the survivorship stage using an emergent methodology. It was thought that this methodological approach would enable the researcher to examine a larger sample of women, while maintaining an appreciation of both context and the lived knowledge of the individual participant’s experience.
Chapter Three: Quantitative Methodology

Participants

Women diagnosed with primary breast cancer were recruited for this study. Participants were eligible if they had been diagnosed with breast cancer between the ages of 18 and 49, had undergone either a lumpectomy or mastectomy (including reconstruction or non-reconstruction), and had completed adjuvant treatment(s) including: radiation therapy and chemotherapy. These inclusion criteria were used to ensure that women endured a form of disruption to their pre-cancer bodies. The researcher also chose to recruit participants once the majority of their adjuvant treatment(s) had been completed in order to capture participants entering the survivorship phase of their cancer journeys. Additionally, women with all stages of cancer were used in the study provided that they completed adjuvant treatment(s). Participants demonstrated sufficient proficiency in speaking and writing English.

The sample included 113 women diagnosed between ages of 18 and 49 ($M = 36.25$, $SD = 5.89$). Demographic characteristics of the 113 participants are presented in Table 1. Most participants (90.3%) were between the ages of 30 and 49 at the time of the study, and of European heritage (62.8%). Most participants had either an associate’s degree (24.8%) or a bachelor’s (31.9%) degree; had full-time work (55.8%), and had a household income of either under $35,000 (28.3%) or $50,000-$80,000 (23.0%). Most women lived with a partner or spouse (69.9%) and had a dependent child (59.3%).

Table 1

Descriptive Statistics for Demographic Variables
<table>
<thead>
<tr>
<th>Demographic Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Current age</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>8</td>
<td>7.1</td>
</tr>
<tr>
<td>30-39</td>
<td>39</td>
<td>34.5</td>
</tr>
<tr>
<td>40-49</td>
<td>63</td>
<td>55.8</td>
</tr>
<tr>
<td>50+</td>
<td>3</td>
<td>2.7</td>
</tr>
<tr>
<td>African Origin (African, Afro-Canadian, West Indian, Other African Origin)</td>
<td>4</td>
<td>3.5</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Indian, Other African Origin</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Asian (Chinese, Filipino, Indian, Japanese, Korean, Pakistani, Vietnamese, Other Asian)</td>
<td>15</td>
<td>13.3</td>
</tr>
<tr>
<td>Latin American or Hispanic (Latin American or Other Hispanic)</td>
<td>7</td>
<td>6.2</td>
</tr>
<tr>
<td>European (Anglophone Canadian, Francophone Canadian, British Isles, English, Irish, Scottish, Welsh, French, German, Greek, Italian, Polish, Portuguese, Ukrainian, Other European)</td>
<td>71</td>
<td>62.8</td>
</tr>
<tr>
<td>Middle Eastern</td>
<td>2</td>
<td>1.7</td>
</tr>
<tr>
<td>Jewish</td>
<td>5</td>
<td>4.4</td>
</tr>
<tr>
<td>Other</td>
<td>6</td>
<td>5.3</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>No high school diploma</td>
<td>1</td>
<td>0.9</td>
</tr>
<tr>
<td>Completed high school diploma</td>
<td>13</td>
<td>11.5</td>
</tr>
<tr>
<td>Completed college degree</td>
<td>28</td>
<td>24.8</td>
</tr>
<tr>
<td>Completed associate’s degree</td>
<td>36</td>
<td>31.9</td>
</tr>
<tr>
<td>Demographic Variable</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>----------------------</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed master’s degree</td>
<td>27</td>
<td>23.9</td>
</tr>
<tr>
<td>Completed MD/PhD/JD/post-doctorate</td>
<td>8</td>
<td>7.1</td>
</tr>
<tr>
<td>Employment Status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Full time</td>
<td>63</td>
<td>55.8</td>
</tr>
<tr>
<td>Part time</td>
<td>14</td>
<td>12.4</td>
</tr>
<tr>
<td>Unemployed/on disability</td>
<td>12</td>
<td>10.6</td>
</tr>
<tr>
<td>Self-employed</td>
<td>13</td>
<td>11.5</td>
</tr>
<tr>
<td>Student</td>
<td>2</td>
<td>1.8</td>
</tr>
<tr>
<td>Home-maker</td>
<td>9</td>
<td>8.0</td>
</tr>
<tr>
<td>Annual Household Income</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Under 35,000</td>
<td>32</td>
<td>28.3</td>
</tr>
<tr>
<td>35,000-50,000</td>
<td>19</td>
<td>16.8</td>
</tr>
<tr>
<td>50,000-80,000</td>
<td>26</td>
<td>23.0</td>
</tr>
<tr>
<td>80,000-100,000</td>
<td>12</td>
<td>10.6</td>
</tr>
<tr>
<td>100,000+</td>
<td>21</td>
<td>18.6</td>
</tr>
<tr>
<td>Living Arrangements</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living with partner/spouse</td>
<td>79</td>
<td>69.9</td>
</tr>
<tr>
<td>Living alone</td>
<td>19</td>
<td>16.8</td>
</tr>
<tr>
<td>Separated/divorced</td>
<td>5</td>
<td>4.42</td>
</tr>
<tr>
<td>Widowed</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Living with other family members</td>
<td>7</td>
<td>6.2</td>
</tr>
<tr>
<td>Other</td>
<td>1</td>
<td>0.8</td>
</tr>
<tr>
<td>Children</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Yes</td>
<td>67</td>
<td>59.3</td>
</tr>
<tr>
<td>No</td>
<td>46</td>
<td>40.7</td>
</tr>
</tbody>
</table>
Medical demographic characteristics are presented in Table 2. Among the 113 participants, the majority identified being diagnosed with Stage III (31.9%) or Stage II (31.0%) cancers. Most women completed adjuvant treatment(s) within the last one to six months (44%); adjuvant treatments included a combination of chemotherapy (85.0%), radiation therapy (80.5%), and hormone therapy (66.4%) for the majority of participants.

Table 2

*Descriptive Statistics for Medical Demographic Variables*

<table>
<thead>
<tr>
<th>Medical Variable</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age at Diagnosis</td>
<td></td>
<td></td>
</tr>
<tr>
<td>20-29</td>
<td>17</td>
<td>15.0</td>
</tr>
<tr>
<td>30-39</td>
<td>56</td>
<td>49.6</td>
</tr>
<tr>
<td>40-49</td>
<td>40</td>
<td>35.4</td>
</tr>
<tr>
<td>Months since trx complete</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1-6</td>
<td>50</td>
<td>44.2</td>
</tr>
<tr>
<td>7-12</td>
<td>15</td>
<td>13.0</td>
</tr>
<tr>
<td>13-18</td>
<td>13</td>
<td>12.0</td>
</tr>
<tr>
<td>19-24</td>
<td>12</td>
<td>11.0</td>
</tr>
<tr>
<td>25-30</td>
<td>3</td>
<td>3.0</td>
</tr>
<tr>
<td>31+</td>
<td>20</td>
<td>18.0</td>
</tr>
<tr>
<td>Stage of cancer</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 0 (In situ carcinoma)</td>
<td>6</td>
<td>5.3</td>
</tr>
<tr>
<td>Stage I</td>
<td>29</td>
<td>25.7</td>
</tr>
<tr>
<td>Medical Variable</td>
<td>N</td>
<td>%</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>----</td>
<td>----</td>
</tr>
<tr>
<td>Stage II</td>
<td>35</td>
<td>31.0</td>
</tr>
<tr>
<td>Stage III</td>
<td>36</td>
<td>31.9</td>
</tr>
<tr>
<td>Stage IV</td>
<td>7</td>
<td>6.2</td>
</tr>
<tr>
<td>Medical treatment received</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Lumpectomy</td>
<td>41</td>
<td>36.3</td>
</tr>
<tr>
<td>Mastectomy</td>
<td>64</td>
<td>56.6</td>
</tr>
<tr>
<td>Radiation</td>
<td>91</td>
<td>80.5</td>
</tr>
<tr>
<td>Chemotherapy</td>
<td>96</td>
<td>85</td>
</tr>
<tr>
<td>Hormone therapy</td>
<td>79</td>
<td>69.9</td>
</tr>
<tr>
<td>Herceptin</td>
<td>19</td>
<td>17.3</td>
</tr>
<tr>
<td>Reconstruction</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Completed</td>
<td>30</td>
<td>26.5</td>
</tr>
<tr>
<td>Considering</td>
<td>38</td>
<td>33.6</td>
</tr>
<tr>
<td>Not interested</td>
<td>37</td>
<td>32.7</td>
</tr>
</tbody>
</table>

*Note: Participants selected “all that apply” to medical treatment received.*

**Measures**

**Demographic information.** Participants completed a demographic questionnaire that inquired about age, marital status, level of education, occupational status, self-identified ethnicity, household income, living arrangements, number of children, and sexual orientation. Medical characteristics included age at diagnosis, stage of cancer, surgery type, months since chemotherapy and/or radiation treatment completed, and reconstruction completed (see Appendix F).

**Measures of psychosocial well-being.**
**Functional Assessment of Cancer Therapy-Breast (FACT-B).** The Functional Assessment of Cancer Therapy-Breast (FACT-B) is a well-validated multi-dimensional self-report scale designed to assess QOL in women who have been diagnosed with breast cancer (Brady et al., 1997; Hong-li, Xiao-chun, Jiang-bin, Jing-bo, & Yao, 2014; Nissen et al., 2001). The total score on the FACT-B (Version 4) is composed of the FACT-General (FACT-G), which includes 27 items, plus 10 additional breast cancer-related items. The FACT-G has four subscales including: (a) physical well-being, (b) social/family well-being, (c) emotional well-being, and (d) functional well-being. Higher scores are indicative of high reported QOL levels. The measure was developed from patient interviews with items, and then tested by patients and reviewed by an expert panel; the instrument underwent extensive psychometric analysis and was validated against the Functional Living Index-Cancer (FLIC), Profile of Mood States Short Form (POMS-SF), and the Marlowe-Crowne Social Desirability Scale (Brady et al., 1997). Internal consistency reliability was high (Cronbach’s alpha = .90) (Brady et al., 1997). Evidence also supported test-retest reliability, as well as convergent, divergent, and known group validity (Brady et al., 1997; Hong-li et al., 2014). The alpha coefficient in the current study was .91 for the total scale score.

**The Embodiment Scales for Women: Experience of Embodiment Scale for Women (EES).** The Embodiment Scales for Women, developed by Piran and Teall (2006, 2012), includes four scales corresponding with four key constructs of the DTE. The first scale, Experience of Embodiment (EES) reflects the “experience of engagement of the body with the world” (Allan, 2005, p. 177), ranging from embodied agency, positive connection and self-care to restraint, disconnection, and harmful behaviours (Piran, 2015; Teall & Piran, 2015). Examples of the items included in this scale are: “I have cared more about how my body feels than about
how it looks,” “I feel at one with my body,” and “my body has made me feel depressed/anxious.”

The EES has 34 items with a Cronbach’s alpha of .94, and was found to be significantly correlated with the Body Responsiveness Scale \((r = .73)\) (Daubenmier, 2005), Toronto Alexithymia Scale \((r = -.55)\) (Bagby, Parker, & Taylor, 1994), the Body Esteem Scale \((r=.78)\) (Mendelson, Mendelson, & White, 2001) and the EAT-26 \((r = -.45)\) (Garner, Olmsted, Bohr, & Garfinkel, 1982). The Cronbach’s alpha coefficient in the current study was .90 for the total scale score.

Predictors of psychosocial well-being.

The Impact on Self-Concept Scale (ISCS). The Impact on Self-Concept Scale (ISCS) developed by Golub, Rendina, and Gamarel (2013) was constructed based upon previous mixed-methods approaches to examining positive and negative illness-related identity changes. The scale includes 10 items related to positive and negative aspects of self-concept. Positive and negative items are rated on a 6-point Likert scale ranging from 1 (never) to 6 (always) based on how often participants felt similar to each statement. An example of a positive item included “It’s hard to think of myself without thinking of breast cancer.” An example of a negative item included “Having breast cancer has taught me that I can handle anything.” Golub and colleagues (2013) have shown in their preliminary validation of the scale good psychometric properties in a sample of HIV-positive gay and bi-sexual men. Factor analysis supported the existence of two meaningfully distinct subscales within the ISCS: self-growth and self-loss. Preliminary assessment of construct validity indicated distinct patterns of association, with self-loss being more strongly associated with QOL than self-growth \((self-loss: r = -.23, p < .05)\). In multivariate models, the association between self-loss and QOL were moderated by self-growth. The ISCS also demonstrated good reliability on both the self-loss (Cronbach’s alpha = .88) and self-growth
(Cronbach’s alpha = .82) subscales. In the current study, the alpha coefficient for the self-loss subscale was .88, and for the self-growth subscale was .83.

**Gender Role Socialization Scale (GRSS).** The Gender Role Socialization Scale (GRSS) is a 30-item self-report measure that assesses the degree to which a woman internalizes gender role norms prescribed by modern day society (Boquiren et al., 2013; Toner et al., 1999). This measure widens the scope of clinical focus from looking at individual pathology to possible restrictive and oppressive social structures that women inhabit as contributors to poor mental health (Boquiren et al., 2013). High scores reflect a greater degree of internalization of gender role norms. Examples of items include: “If I don’t accomplish everything I should, then I must be a failure,” “Whenever I see media images of women, I feel dissatisfied with my body,” and “I can’t feel good about myself unless I feel physically attractive.” Toner et al. (1999) have shown in their preliminary validation of the scale that the GRSS has good reliability (Cronbach’s alpha = 0.93). Likewise, Boquiren et al. (2013) used the GRSS scale with breast cancer survivors and also found strong reliability (Cronbach’s alpha = 0.88). The alpha coefficient in the current study was .86 for the total scale score.

**The Embodiment Scales for Women: Mental Freedom scale (MF).** The Embodiment Scales for Women, developed by Piran and Teall (2006, 2012), includes four scales corresponding with four key constructs of the DTE, including the Mental Freedom scale (Piran, 2015; Teall & Piran, 2015). The Mental Freedom scale includes items that assess the impact of gender-related social expectations on one’s embodied experience, as well as women’s critical stance toward oppressive social discourses, expectations, and labels. Items include: “I have felt that being physically strong conflicts with being a girl/woman,” and “I have been encouraged to think critically about different social pressures that I have experienced.” The items therefore
reflect collusion with, or resistance and critical stance, toward oppressive social discourses and expectations related to being a woman. This scale has 37 items, with a Cronbach’s alpha of .93 (Piran, 2015; Teall & Piran, 2015), and correlated significantly with the Self-Acceptance subscale of the How I See Myself Scale (r = .50) (Ryff, 1989), the Stereotypic Images and Activities subscales of the Femininity Ideology Scale (r = -.373) (Levant, Richmond, Cook, House, & Aupont, 2007), the Silencing the Self subscales (r = -.416) (Jack & Dill, 1992), and the Internalized General subscale for the Sociocultural Attitudes Towards of Appearance Questionnaire-3 (r = -.412) (Thompson, van den Berg, Roehrig, Guarda, & Heinberg, 2004). The alpha coefficient in the current study was .90 for the total scale score.

Objectified Body Consciousness Scale (OBCS). The Objectified Body Consciousness Scale (OBCS) is a 24-item self-report scale designed to measure objectified body consciousness in women (Boquiren et al., 2013; McKinley & Hyde, 1996). Women who reported higher scores demonstrate greater objectified body consciousness. The OBCS contains three subscales: (a) Body Shame (OBCS-BS), which explores feelings of shame when the body fails to meet social norms—a typical item is, “I feel like I must be a bad person when I don’t look as good as I could”; (b) Surveillance (OBCS-Surv), which explores individuals who survey the body from an observer’s perspective—a typical item in this subscale is, “I rarely compare how I look with how other people look”; and (c) Appearance Control Beliefs, which measures beliefs about personal responsibility and control over one’s appearance—a typical item in this scale is, “I think a person can look pretty much how they want to if they are willing to work at it.” Boquiren and colleagues (2013) used the OBCS with breast cancer survivors and found strong reliability for all three scales (Cronbach’s alphas OBCS-BS = 0.77, OBCS-Surv = 0.81, OBCS-Appearance Control Beliefs = 0.75). Only the first two subscales, OBCS-BS and OBCS-Surv, were used in the
present study, as questions from the third subscale appeared to overlap with other scales including the Mental Freedom scale. Moreover, McKinley and Hyde (1996) showed that body surveillance and body shame were the two key components that contributed to overall body dissatisfaction. The alpha coefficient in the current study was .84 for the OBCS-Body Shame total score, and .81 for the OBCS-Surveillance total score.

**Silencing the Self Scale (SS).** The Silencing the Self Scale (SS) (Jack & Dill, 1992) is composed of 31 items examining individuals’ beliefs and behaviours about interpersonal relationships. Participants are asked to rate the degree to which they are in agreement with each statement on a 5-point Likert scale. The scale was originally designed to investigate gender-specific schemas associated with depression in women (Affleck, 1999). The scale is based on a model (Jack, 1991) suggesting that cognitive schemas target the creation and maintenance of safe and intimate relationships leading women to silence certain thoughts, feelings, and actions (Affleck, 1999). Specifically, silencing the self related to stereotyped social expectations that women silence their own needs and feelings of anger in relationships, while also caring for others, in order to maintain relational connections (Affleck, 1999; Piran & Cormier, 2005). Jack and Dill (1992) suggested that silencing the self contributes to a fall in self-esteem and “loss of self,” which can lead to depression. A total score is calculated from responses to all items, with higher scores indicating a higher level of self-silencing. The scale has been found to have good internal consistency, with alpha coefficients for the total SS scores ranging from .86 to .94, and test-retest reliability ranging from .88 to .93 (Affleck, 1999; Jack & Dill, 1992). The present study used two of four subscales from this measure including the Care as Self-Sacrifice subscale (SS-2) and Silencing the Self subscale (SS-3), as they were believed to be most relevant to this
study. The alpha coefficient in the current study was .73 for the Self-Sacrifice subscale and .89 for Silencing of the Self subscale.

Procedure

Recruitment. The first stage involved obtaining approval from the Research Ethics Boards at the University of Toronto and the University Health Network. Once approved, a collaboration agreement between the two organizations was completed. With regard to community recruitment, participants were recruited via a non-randomized snowball or reputational sampling method in order to gain greater access to participants (Hessler, 1992). Recruitment occurred online and in-person. Online recruitment occurred via social networking sites including Facebook and Instagram. The researcher created pages on these sites to advertise information about the study. Instagram, in particular, was highly successful as it reached a larger number of young women within a strong connection to breast cancer. It also became a forum for people to support each other through their cancer journeys. Online community groups, message boards, and email listservs of various cancer organizations were also used for advertisement. Offline and in-person recruitment opportunities occurred through flyers and word of mouth from young women breast cancer community organizations across the Greater Toronto Area such as Rethink Breast Cancer, Caring Voices, Breast Cancer Now What, and Wellspring Cancer Centre. Specifically, in-person recruitment occurred via brief presentations by the researcher at a number of Rethink Breast Cancer informational events in Toronto, Ontario.

With regard to hospital recruitment, breast cancer patients returning for follow-up appointments to the breast cancer clinic at a major cancer-care hospital in an urban centre were recruited as well. Potential participants were pre-screened using the hospital’s electronic patient records to determine if they met eligibility criteria. On the day of their appointment, potential
participants were introduced to the researcher and provided with an electronic version of the information letter and consent form (see Appendix D). The researcher read and reviewed the webpage and answered any questions. Once participants clicked “I agree” on the online consent page, a unique study ID and URL was provided and the survey was sent to participants’ personal email addresses. Participants were sent one reminder email about the survey each week for four weeks (see Appendix C).

Seventy-one (62.83%) participants were recruited in-person and online through the community while 41 (36.28%) participants were recruited through the cancer-care hospital. Using t-tests and chi-squared tests, these samples were compared to determine if any demographic variables were significantly different from each other. Nine of the 12 demographic variables were found to have no significant difference between the two samples. Income and living area were shown to have significant differences between samples whereby the participants recruited from the downtown Toronto hospital reported a higher income bracket, and living in a large urban area. Likewise, age at diagnosis also had a significant difference between the two samples whereby participants recruited from the downtown Toronto hospital were slightly older at diagnosis than the community-based sample.

The online survey was hosted by a cost-based website called FluidSurveys, which allows for the creation and dissemination of online surveys. All participants were directed to a secure FluidSurveys link where they read the information letter, consent form, and agreed that they met eligibility criteria. The first page of the survey (i.e., the demographics page) also included a number of screening items that confirmed study eligibility. Participants confirmed that they were diagnosed with primary breast cancer between 18 to 49 years of age, completed a lumpectomy or mastectomy, and completed adjuvant treatment(s). Individuals who did not meet any of the
above requirements were automatically directed to a termination page. Eligible participants filled out a series of scales assessing quality of life, embodiment, body image, and identity issues in relation to their breast cancer diagnosis and treatment. Participants had the option of saving their responses and continuing the online survey at a later date. Most individuals completed the survey within 40 to 60 minutes.

Online data revealed that a total of 227 participants accessed the online survey link. A total of 83 participants (36.6%) did not attempt any survey questions. Of the 144 women who started the survey, 28 participants (12.3%) were excluded due to concerns regarding a high percentage of missing data throughout the survey, questionable response patterns (i.e., selecting the same response for all items, or only choosing one or two response options throughout), and quick completion time. In total, 104 participants completed all scales and were included in the study. An additional 11 participants’ percentages of missing data (per scale) ranged from 9.1% to 83.8%, clustering in the last three scales. These 11 participants completed the outcome measures (FACT-B and EES) in their entirety and appeared to be valid respondents (i.e., reasonable completion times, no questionable response pattern). They were therefore included in all analyses related to the FACT-B and EES to maximize sample size. Two additional participants were excluded from the study, as they were older than 49 years of age at diagnosis. Thus, a total final and usable sample of 113 women was analyzed for this study.

Upon completion of the entire survey, participants interested in the results of the study were re-directed to a Request for Information page. Those who completed the study package were also offered compensation through a draw for an iPad Mini. Participants who chose to enter into the draw were re-directed to a Compensation Page. The winner of the iPad Mini was selected through random number generation. Of the 104 participants who completed the study in
its entirety, 66 participants (63.46%) requested compensation and 38 participants (36.5%) declined compensation. Seventy-one participants (68.27%) requested to receive a summary of the results.

**Statistical Analyses**

**Missing data.** Of the 113 participants who were included in the study, a total of 58 participants had no items missing across each scale. Among the remaining 55 participants, 70.7% missed only one or two items on one scale; 8.1% missed three or four items on one scale; 2.4% missed five to seven items on one scale, and 8.9% missed eight or more on one scale. While a non-monotone pattern was found, the data revealed an increase in missing data across the last three scales (OBCS, MF, SS); this pattern may have been the result from respondent fatigue.

The missing value analysis also revealed the completion rate (i.e., the percentage of values completed across all participants) for each scale ranging between 99.56%-90.76% (see Table 3).

**Table 3**

*Completion Rate of all Scales: (N = 113)*

<table>
<thead>
<tr>
<th>Scale</th>
<th>Percentage of items completed</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACT-B</td>
<td>99.56%</td>
</tr>
<tr>
<td>EES</td>
<td>99.45%</td>
</tr>
<tr>
<td>ISCS</td>
<td>99.64%</td>
</tr>
<tr>
<td>Scale</td>
<td>Percentage of items completed</td>
</tr>
<tr>
<td>------------</td>
<td>-------------------------------</td>
</tr>
<tr>
<td>GRSS</td>
<td>99.73%</td>
</tr>
<tr>
<td>OBCS</td>
<td>94.86%</td>
</tr>
<tr>
<td>MF</td>
<td>93.41%</td>
</tr>
<tr>
<td>SS</td>
<td>90.76%</td>
</tr>
</tbody>
</table>

Note. FACT-B = Functional Assessment of Cancer Therapy-Breast; EES = Experience of Embodiment Scale; ISCS = Impact on Self-Concept Scale; GRSS = Gender Role Socialization Scale; OBCS = Objectify Body Consciousness; MF = Mental Freedom; SS = Silencing the Self.

Multiple imputations were used to compute the missing data. The automatic method, using SPSS software, scanned the data and used the fully conditional specification (FCS) imputation method. More specifically, the iterative Markov Chain Monte Carlo (MCMC) method was used due to an arbitrary missing data pattern. For each imputation and for each variable in the variable list, the FCS method fit a univariate (single dependent variable) model using all other available variables in the model as predictors, and then imputed missing values for the variable being fit (IBM, 2014). The method continued until the maximum number of five imputations was reached and the imputed pooled dataset was created (IBM, 2014). Linear regressions were used as the univariate model for scale variables. Constraints on imputed values, such as the minimum and maximum values, were specified for all variables.

**Descriptive statistics.** To begin, descriptive statistics for categorical data (i.e., frequencies) and for continuous variables (i.e., means, standard deviations, reliability, kurtosis,
skewness) were obtained and analyzed in order to assure that assumptions necessary for conducting correlational and multiple regressions analyses were met. An exploration of the original data set, five imputed datasets, and the pooled dataset were explored to ensure there were no major discrepancies. The distribution of each variable was examined both visually and with the use of skewness and kurtosis statistics. Based on Curran and colleagues’ (1996) and Kim’s (2013) proposed reference of substantial department of absolute skew and kurtosis values (>2.1 and >7.1, respectively), all variables were normally distributed. Relationships between the independent variables (ISCS, GRSS, OBCS, MF, SS) and the dependent variables (FACT-B, EES) were also examined for homoscedasticity and linearity through the use of residual plots. No predictors showed evidence for heteroscedasticity and non-linearity. Collinearity among the predictors was assessed for each of the analyses. All of the variance inflation factors were below two and thus there was no excessive collinearity among the predictors that would impact the results. To assess for outliers, the three residual statistics were examined: standardized predicted values, Cook’s distance, and Leverage. No case had a standardized residual larger than +/- 3.0, indicating no outliers on the dependent variables.

**Correlational and multiple regression analysis.** First, a series of bivariate correlations were conducted to assess the relationships between the dependent variables (FACT-B and EES) and the independent variables (ISCS-SL, ISCS-SG, GRSS, OBCS, MF, and SS) to ensure that all variables could be included in the regression analyses. The relationship between the five independent variables was also conducted to explain why certain predictors were significant in the subsequent regression analyses. Results demonstrated significant inter-correlations between gender identity-related predictors. The GRSS had a positively correlation with the OBCS-BS, $r = .67, p < .01$, and the OBCS-Surv, $r = .37, p < .01$. The OBCS-BS was positively correlated with
OBCS-Surv, $r = .48, p < .01$. The GRSS was positively correlated with the MF, $r = .56, p < .01$.

The GRSS was also positively correlated with SS-2, $r = .51, p < .01$. To address concerns regarding multicollinearity in the subsequent analyses, tolerance and variance inflation factors were examined and determined acceptable.

Second, an analysis was conducted to determine the covariates to be used in the subsequent series of regression analyses. A set of independent sample t-tests and one-way ANOVAs were conducted to compare the dependent variables (FACT-B, EES) to the following demographic variables including: current age, age at diagnosis, months since treatment completed, ethnicity, highest level of education, employment status, occupation, annual income, living arrangements, having children, sexual orientation, stage of breast cancer, surgery type, menstruation status, and reconstruction. These 15 demographic variables were chosen as potentially important for the regression analyses based on pilot study data (Trachtenberg & Piran, 2012) and other relevant studies (Boquiren et al., 2013; Fobair et al., 2006). The one-way ANOVAs were found using the micombine.F function which combined the F statistics from multiple imputed datasets. Of the 15 demographic variables, only three demonstrated a correlation with the outcome measures, as described in the next paragraph.

An analysis of variance showed that the effect of occupation status (i.e., full time, part time, and unemployed) on FACT-B was significant, $F(2, 112) = 3.485, p = .031$; likewise, an analysis of variance showed that the effect of occupation status (i.e., full time, part time, and unemployed) on EES was also significant, $F(2, 112) = 3.273, p = .038$. Specifically, a post-hoc multiple comparisons test using Scheffé’s method found that the effects of the EES were significantly different for participants who reported being unemployed in relation to participants who reported being part-time/self-employed, $p < .05$. A second analysis of variance showed that
the stage of breast cancer (i.e., Stage 0-I, Stage II, Stage III-IV) on the FACT-B was significant, $F(2,112) = 4.351, p < .013$. Specifically, the post-hoc multiple comparisons test using Scheffé’s method found that the effects of the FACT-B were significantly different between participants with Stage 0-I cancer diagnoses and participants with Stage II cancer diagnoses, $p < .05$. Finally, a correlational analysis was conducted to determine the relationship between the dependent variables and current age. A significant positive correlation was found between the FACT-B and current age, $r = .20, p < .05$. Likewise, a significant positive correlation was found between the EES and current age, $r = .19, p < .05$. In light of these correlations, the multiple regression analyses included the following demographic variables: current age, employment status, and stage of cancer.

Finally, a set of hierarchical linear regressions was conducted in order to test the predictability of ISCS’ self-loss and self-growth subscales, and their interaction on QOL and the experiences of embodiment among young breast cancer survivors. The second set of hierarchical linear regressions was conducted to test the contribution of gender-related identity measures in relation to QOL and the experience of embodiment. A hierarchical approach was selected in order to examine the effects of the predictor variables after the variance from the covariates had been observed. Hierarchical linear regression is supported by past literature in this area (Golub, Gamarel, & Rendina, 2014; Golub et al., 2013).

It should be noted that the terms predict and predictors have been used throughout the dissertation to discuss the regression analyses. These terms do not imply a prospective methodology and/or a temporal perspective, but merely are used in a statistical sense in regression analyses to refer to the ability of the independent variables (ISCS, GRSS, OBSC, MF, SS) to predict the variance observed in the dependent variables (FACT-B, EES).
Power analysis, alpha-related decisions. A formal a-priori power analysis for a linear regression was conducted using G-power software to determine the sufficient sample size using an alpha of 0.05, a power of 0.80, and a medium effect size ($f^2 = 0.15$) (Faul, Erdfelder, Buchner, & Lang, 2009). Based on the aforementioned assumptions, the minimum desired sample size was 94. According to Stevens (2012), 15 subjects per predictor in a standard ordinary least squares multiple regression analysis is sufficient in social science research. Thus, the present sample consisting of 113 women had sufficient power to begin data analysis and exceeded Stevens’ criterion.

Regarding internal consistency reliability, Cronbach’s alpha levels of .70 and above are considered acceptable (Nunnally, 1978). All alphas for each variable in the study were reported in the measures section and were above this level.
Chapter Four: Quantitative Results

Descriptive Statistics

Means, standard deviations, and ranges for each variable are presented in Table 3.

Table 3

Descriptive Statistics for Scales

<table>
<thead>
<tr>
<th>Measure</th>
<th>Subscale</th>
<th>N</th>
<th>M</th>
<th>SD</th>
<th>Range</th>
</tr>
</thead>
<tbody>
<tr>
<td>FACT-B</td>
<td></td>
<td>111</td>
<td>137.45</td>
<td>21.25</td>
<td>86.78-179.78</td>
</tr>
<tr>
<td>EES</td>
<td></td>
<td>102</td>
<td>121.24</td>
<td>18.48</td>
<td>81.00-162.00</td>
</tr>
<tr>
<td>ISCS</td>
<td>SG</td>
<td>112</td>
<td>4.92</td>
<td>1.09</td>
<td>1.00-6.00</td>
</tr>
<tr>
<td></td>
<td>SL</td>
<td>113</td>
<td>2.85</td>
<td>1.16</td>
<td>1.00-6.00</td>
</tr>
<tr>
<td>GRSS</td>
<td></td>
<td>107</td>
<td>99.88</td>
<td>28.96</td>
<td>30.00-163.00</td>
</tr>
<tr>
<td>OBCS</td>
<td>BS</td>
<td>104</td>
<td>30.18</td>
<td>15.01</td>
<td>8.00-56.00</td>
</tr>
<tr>
<td></td>
<td>Surv</td>
<td>111</td>
<td>32.14</td>
<td>14.07</td>
<td>8.00-56.00</td>
</tr>
<tr>
<td>MF</td>
<td></td>
<td>97</td>
<td>116.10</td>
<td>17.16</td>
<td>61.00-149.00</td>
</tr>
<tr>
<td>SS</td>
<td>3</td>
<td>99</td>
<td>23.67</td>
<td>5.73</td>
<td>10.00-40.00</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>102</td>
<td>21.87</td>
<td>7.83</td>
<td>9.00-39.00</td>
</tr>
</tbody>
</table>

Note. FACT-B = Functional Assessment of Cancer Therapy-Breast; EES = Experience of Embodiment Scale; ISCS-SG = Impact on Self Concept Scale - Self-Growth; ISCS - SL = Impact on Self-Concept Scale - Self-Loss; GRSS = Gender Role Socialization Scale; OBCS - BS = Objectified Body Consciousness Scale - Body Shame; OBCS - Surv = Objectified Body Consciousness Scale - Body Surveillance; MF = Mental Freedom; SS3 = Silencing the Self - care as self-sacrifice, SS2 = Silencing the Self - silencing the self.
Correlational Analyses

An initial set of correlational analyses were conducted to explore how each of the measures of well-being related to the two ISCS subscales, as well as the four measures of the internalization of gender stereotypes, namely: GRSS, OBCS, MF, and SS. (see Table 4). As can be seen in Table 4, the EES demonstrated stronger correlations relative to the FACT-B among seven of eight independent variables. For example, the OBCS-BS had a stronger negative correlation with EES, $r = -0.63$, $p < .01$, relative to the FACT-B, $r = -0.32$, $p < .05$. Likewise, the ISCS-SG had a stronger positive correlation with the EES, $r = 0.32$, $p < .01$, relative to the FACT-B, $r = 0.25$, $p < .01$. In contrast, the ISCS-SL was the only subscale to demonstrate a weaker correlation with the EES, $r = -0.64$, $p < .01$, relative to the FACT-B, $r = -0.48$, $p < .01$. Golub and colleagues’ (2013) original study supported this finding, indicating that ISCS self-loss would be more strongly associated with QOL scores relative to ISCS self-growth.

Correlations were also conducted to assess the relationship between the two dependent variables as measures of psychosocial well-being. Results demonstrated a strongly positive correlation, $r = 0.66$, $p < .01$.

Table 4

*Correlations between Measures of Well-being and Identity-Related Measures*

<table>
<thead>
<tr>
<th></th>
<th>FACT-B</th>
<th>EES</th>
</tr>
</thead>
<tbody>
<tr>
<td>ISCS-SL</td>
<td>-0.64**</td>
<td>-0.48**</td>
</tr>
<tr>
<td>ISCS-SG</td>
<td>0.25**</td>
<td>0.32**</td>
</tr>
<tr>
<td>GRSS</td>
<td>-0.45**</td>
<td>-0.59**</td>
</tr>
</tbody>
</table>
The two hypotheses related to the ISCS subscales and their correlations with the two measures of well-being were supported. Specifically, Hypothesis 1A, which states that higher level of self-loss among young breast cancer survivors will be negatively associated with high QOL and embodiment scores, was supported with correlations of $r = -0.64$ (p < 0.01) and $r = -0.48$ (p < 0.01), respectively. Hypothesis 1B, which states that self-growth will be positively associated with high QOL and embodiment scores, was also supported with somewhat smaller correlations of $r = 0.25$ (p < 0.01) and $r = 0.34$ (p < 0.01), respectively.

The four hypotheses related to the measures of internalization of gender stereotypes and their correlations to the two measures of well-being were also supported. Specifically, Hypothesis 2A, stating that high scores on the GRSS will be negatively associated with QOL and embodiment scores, was supported with correlations of $r = -0.45$ (p < 0.01) and $r = -0.59$ (p < 0.01), respectively. Hypothesis 2B, which states that increased body surveillance and shame scores as measured by the OBCS will be negatively associated with QOL and embodiment scores, was also supported. Correlations for OBCS-BS with QOL and embodiment scores were $r = -0.32$ (p <

<table>
<thead>
<tr>
<th>Subscale</th>
<th>Correlation with QOL</th>
<th>Correlation with Embodiment</th>
</tr>
</thead>
<tbody>
<tr>
<td>OBCS-BS</td>
<td>-0.32**</td>
<td>-0.63**</td>
</tr>
<tr>
<td>OBCS-Surv</td>
<td>-0.23*</td>
<td>-0.54**</td>
</tr>
<tr>
<td>MF</td>
<td>0.42**</td>
<td>0.57**</td>
</tr>
<tr>
<td>SS-2</td>
<td>-0.20*</td>
<td>-0.31**</td>
</tr>
<tr>
<td>SS-3</td>
<td>-0.22*</td>
<td>-0.29**</td>
</tr>
</tbody>
</table>

Note. FACT-B = Functional Assessment of Cancer Therapy-Breast; EES = Experience of Embodiment Scale; ISCS-SL = Impact on Self Concept Scale - Self-Loss; ISCS-SG = Impact on Self-Concept Scale - Self-Growth; GRSS = Gender Role Socialization Scale; OBCS-BS = Objectified Body Consciousness Scale - Body Shame; OBCS-Surv = Objectified Body Consciousness Scale - Body Surveillance; MF = Mental Freedom; SS-2= Silencing the Self - care as self-sacrifice; SS-3= Silencing the Self - silencing the self.

** $p < .01$ level (2-tailed). * $p < .05$ level (2-tailed).
and \( r = -0.63 \) (\( p < .01 \)), respectively. Correlations for OBCS-Surv with QOL and embodiment scores had somewhat weaker correlations of \( r = -0.23 \) (\( p < .05 \)) and \( r = -0.54 \) (\( p < .01 \)), respectively. Hypothesis 2C, stating that an increased critical stance toward oppressive social discourses, expectations, and gendered labels as measured by the MF will be positively associated with QOL and embodiment scores, was supported with correlations of \( r = 0.42 \) (\( p < .01 \)) and \( r = 0.57 \) (\( p < .01 \)), respectively. Finally, Hypothesis 2D, which states that high levels of self-silencing as measured by the SS subscales will be negatively associated with QOL and embodiment scores, was also supported. Care as Self-Sacrifice subscale was correlated with QOL and embodiment scores, \( r = -0.20 \) (\( p < .01 \)) and \( r = -0.31 \) (\( p < .01 \)), respectively. Likewise the Silencing the Self subscale was correlated with QOL and embodiment scores, \( r = -0.22 \), (\( p < .01 \)) and \( r = -0.29 \) (\( p < .01 \)), respectively.

**Predictive Relationship Between ISCS and Measures of Well-being**

Two hierarchical linear regressions were conducted to test Hypothesis 1C: that self-loss, self-growth, and their interaction will be predictive of QOL and embodiment scores. This hypothesis was tested separately for both well-being measures (FACT-B and EES). In order to test this hypothesis, a three-step regression was set up where current age, occupation, and stage of cancer were entered in Step 1 to statistically control for these variables. In Step 2, the two ISCS subscales (self-loss and self-growth) were entered to assess the amount of variance in each of the identity-related change variables that could be attributed to well-being. In Step 3, the interaction between self-loss and self-growth was entered to determine if the association between self-loss and well-being was moderated by self-growth. Hypothesis 1C was supported for both measures of well-being to the extent that self-loss and self-growth were significant predictors of well-being; however, the interaction between these two variables was not significant.
Predictive relationship between ISCS subscales and FACT-B scores. With regard to the FACT-B, the addition of the two-way interaction (self-loss x self-growth) in Step 3 did not account for a significant amount of variance in FACT-B scores above and beyond the first two steps, $F_{change} (1, 104) = 0.500, p = .78$. However, the main effect block predicted a significant amount of variance in FACT-B scores above and beyond the covariates, $F_{change} (2, 105) = 16.009, p < .001, R^2_{change} = .306$. Thus, the main effect block predicted another 31% of variance in FACT-B scores over and above current age, occupation, and stage of cancer.

Examination of the predictors within the main effect block showed that both self-loss (ISCS-SL) and self-growth (ISCS-SG) were significant predictors.

Table 5

Hierarchical Regression Analysis for Predicting ISCS Subscale Scores with FACT-B

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>$SE_B$</th>
<th>$\beta$</th>
<th>$T$</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
<th>$\Delta F$</th>
<th>$df$</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Covariates</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>5, 107</td>
</tr>
<tr>
<td>Age</td>
<td>.46</td>
<td>.30</td>
<td>.15</td>
<td>1.54</td>
<td>.403</td>
<td>.403</td>
<td>3.960**</td>
<td></td>
</tr>
<tr>
<td>FT</td>
<td>13.67</td>
<td>5.16</td>
<td>.32</td>
<td>2.65**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PT/SE</td>
<td>15.38</td>
<td>6.20</td>
<td>.31</td>
<td>2.48**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage 0-I</td>
<td>10.79</td>
<td>4.53</td>
<td>.24</td>
<td>2.38*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stage II</td>
<td>.80</td>
<td>4.54</td>
<td>.00</td>
<td>.02</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Main Effects</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.709</td>
<td>2, 105</td>
</tr>
<tr>
<td>ISCS-SL</td>
<td>-10.84</td>
<td>1.39</td>
<td>-.60</td>
<td>-7.80***</td>
<td></td>
<td></td>
<td>35.712***</td>
<td></td>
</tr>
<tr>
<td>ISCS-SG</td>
<td>3.40</td>
<td>1.40</td>
<td>.18</td>
<td>2.43*</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Two-way Interaction</td>
<td></td>
<td></td>
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<td></td>
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</tr>
</tbody>
</table>
Predictive relationship between ISCS subscales and EES scores. The addition of the two-way interaction (self-loss x self-growth) in Step 3 did not account for a significant amount of variance in the EES scores above and beyond the first two steps, $F_{change}(1, 104) = 0.064$, $p = .99$. The main effect block, however, predicted a significant amount of variance in EES scores above and beyond the covariates, $F_{change}(2, 105) = 16.009$, $p < .001$, $R^2_{change} = .245$. Thus, the main effect block predicted another 25% of variance in FACT-B scores over and above current age, occupation, and stage of cancer. Examination of the predictors within the main effect block showed that both self-loss (ISCS-SL) and self-growth (ISCS-SG) were significant predictors.

Table 6

Hierarchical Regression Analysis for ISCS Subscales Predicting EES Scores.

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>$SE_B$</th>
<th>$\beta$</th>
<th>$t$</th>
<th>$R^2$</th>
<th>$\Delta R^2$</th>
<th>$\Delta F$</th>
<th>$df$</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Covariates</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age</td>
<td>.33</td>
<td>.26</td>
<td>.12</td>
<td>1.25</td>
<td>.333</td>
<td>.333</td>
<td>2.667*</td>
<td>5, 107</td>
</tr>
<tr>
<td>FT</td>
<td>7.37</td>
<td>4.58</td>
<td>.20</td>
<td>1.61</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>PT/SE</td>
<td>13.08</td>
<td>5.52</td>
<td>.30</td>
<td>2.37*</td>
<td></td>
<td></td>
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Predictive Relationships Between Measures of Gender-Related Identity and Well-Being

Two hierarchical linear regressions were conducted to test Hypothesis 2E: that the internalization of values that counteract traditional gender-related identity and role expectations will be predictive of QOL and embodiment scores. In order to test this hypothesis, a two-step regression was set up where current age, occupation, and stage of cancer were entered in Step 1 to statistically control for these variables. In Step 2, all four gender-identity scales were entered including, GRSS, OBCS, MF, SS. Hypothesis 2E was fully supported for both measures of well-being (FACT-B and EES).

**Predictive relationship between gender-related identity subscales and FACT-B scores.** With regard to the FACT-B, the main effect block predicted a significant amount of variance in FACT-B scores above and beyond the covariates, \( F_{change} (6, 101) = 6.826, p < .001, R^2_{change} = .233. \) Thus, the main effect block predicted another 23% of variance in FACT-B scores over and above current age, occupation, and stage of cancer. Examination of the predictors within the main effect block showed that the gender role socialization (GRSS) and
women’s ability to take a critical stance toward oppressive social discourses (MF) were significant predictors of the FACT-B.

Table 7

*Hierarchical Regression Analysis for Gender-Related Variables Predicting the FACT-B Scores*

<table>
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<tr>
<th>Variable</th>
<th>B</th>
<th>SE_B</th>
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<th>T</th>
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<th>ΔR²</th>
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<td>6.826***</td>
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<td>.24</td>
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</table>

*Note. Age = Current age; FT = Full-time employed; PT/SE = Part-time/self-employed; Stage 0-I = Stage 0 and I cancer; Stage II = Stage II-IV cancer GRSS = Gender Role Socialization Scale; OBCS-Surv = Objectified Body Consciousness Scale – Body Surveillance; OBCS-BS = Objectified Body Consciousness Scale – Body Shame; MF = Mental Freedom; SS-2= Silencing the Self Scale - care as self-sacrifice; SS-3= Silencing the Self Scale - silencing the self.

*p < .05. **p < .01. ***p < .001.*
Predictive relationship between gender-related identity subscales and EES scores.

With regard to the EES, the main effect block predicted a significant amount of variance in the EES scores above and beyond the covariates, $F_{\text{change}} (6, 101) = 22.853, p < .001, R^2_{\text{change}} = .467$. Thus, the main effect block predicted another 47% of variance in EES scores over and above current age, occupation, and stage of cancer. Examination of the predictors within the main effect block showed that the body surveillance (OBCS-Surv), body shame (OBCS-BS) and women’s ability to take a critical stance toward oppressive social discourses (MF) were significant predictors of the EES.

Table 8

Hierarchical Regression Analysis for Gender-Related Variables Predicting the EES Scores

<table>
<thead>
<tr>
<th>Variable</th>
<th>$B$</th>
<th>$SE_B$</th>
<th>$\beta$</th>
<th>$t$</th>
<th>$R^2$</th>
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<td>.12</td>
<td>1.25</td>
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<td>.30</td>
<td>2.37*</td>
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<td>-.30</td>
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<tr>
<td>OBCS – BS</td>
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<td>-2.71**</td>
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<td>MF</td>
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<td>0.09</td>
<td>0.21</td>
<td>2.65**</td>
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</table>

*Note.* Age = Current age; FT = Full-time employed; PT/SE = Part-time/self-employed; Stage 0-I = Stage 0 and I cancer; Stage II = Stage II-IV cancer; GRSS = Gender Role Socialization Scale; OBCS-Surv = Objectified Body Consciousness Scale – Body Surveillance; OBCS-BS = Objectified Body Consciousness Scale – Body Shame; MF = Mental Freedom; SS-2= Silencing the Self Scale - care as self-sacrifice; SS-3= Silencing the Self Scale - silencing the self.

*p < .05. **p < .01. ***p < .001.
Chapter Five: Discussion of Quantitative Findings

The purpose of the quantitative arm of the study was two-fold. First, it aimed to examine the relationship between perceived illness-related identity changes and psychosocial well-being among young breast cancer survivors. Second, it aimed to examine the internalization of values that counteract traditional gender-related identity and role expectations with psychosocial well-being among young breast cancer survivors.

Relationship Between Illness-Related Identity Changes and Measures of Well-Being

The first set of hypotheses explored young breast cancer survivors’ perceived illness-related identity changes using the Impact on Self Concept Scale (ISCS) to predict psychosocial well-being scores, as measured by the Functional Assessment of Cancer Therapy-Breast (FACT-B) and the Experience of Embodiment Scale (EES). Specifically, Hypothesis 1A stated that high levels of illness-related self-loss would be negatively associated with high QOL and embodiment scores. Results supported Hypothesis 1A as the data revealed a strong negative association between self-loss and the FACT-B as well as a moderate negative association between self-loss and the EES. These findings align with two previous studies (Golub et al., 2014, 2013) indicating an inverse relationship between illness-related self-loss and psychosocial well-being in other chronically ill populations, including HIV-positive men and women. This finding also parallels the seminal work conducted by Charmaz (1983, 1991, 2002) on biographically informed perspectives of chronic illness. Specifically, Charmaz explained that

…physical pain, psychological distress, and the deleterious effects of medical procedures all cause the chronically ill to suffer as they experience their illnesses . . . a fundamental form of that suffering is the loss of self in chronically ill persons who observe their
former self-images crumbling away without the simultaneous development of equally valued new ones (p. 168).

Hypothesis 1B stated that high levels of illness-related self-growth would be positively associated with QOL and embodiment scores. Results supported this hypothesis as the data confirmed an important relationship between self-growth and psychosocial well-being among a young sample of breast cancer survivors. The overarching premise of posttraumatic growth literature is that the experience of adversity can alter one’s view of the self and the world, generating psychological distress; however, by evaluating these experiences, a new sense of meaning and self-worth can be formed (Taylor, 1983). Across a range of illnesses, including cancer, a large percentage of patients—between 59-93%—have reported growth experiences taking place after an illness (Milam, 2004; Sears, Stanton, & Danoff-Burg, 2003). However, this finding was not previously supported in the literature using the ISCS, which found no significant bivariate association between self-growth and well-being among groups of chronically ill individuals (Golub et al., 2013, 2014). In fact, past research using the ISCS reported that “a focus on growth alone may not be sufficient to understand the impact of chronic illness on identity and psychological well-being” (Golub et al., 2013, p. 2). Though, it should be noted that previous research using the ISCS examined groups of HIV-positive gay and bisexual men as well as a smaller subsample of women between the ages of 27 and 62 (Mdn = 49); as such differences in age, gender, and disease type likely played a role when examining the relationship between self-growth and well-being scores in these groups. The disease type, in particular, may play a key role, with cancer typically recognized for having clear remission and survivorship stages whereas HIV does not and is understood as a persistent, lifelong illness.
Beyond the ISCS, empirical research in oncology examining the association between posttraumatic growth and well-being has been inconsistent. On the one hand, a number of researchers have found no significant association between psychosocial well-being and posttraumatic growth (e.g., Cordova et al., 2007, 2001; Sears et al., 2003). Some studies have also shown no association between posttraumatic growth and QOL (e.g., Manne et al., 2004; Urcuyo et al., 2005). On the other hand, evidence has accumulated that growth can be related to better psychological well-being in the context of illness (Algoe & Stanton, 2009; Helgeson et al., 2006). More specifically, researchers have found posttraumatic growth to have a significant positive association between growth and perceived mental health outcomes, including QOL among breast cancer patients (Sears et al., 2003; Tomich & Helgeson, 2004).

While the results from Hypothesis 1A and 1B demonstrate that self-growth and self-loss have significant associations with the measures of psychosocial well-being, self-growth scores showed weaker correlations with well-being when compared to self-loss scores. One possible explanation for this difference may be explained by Bury’s theory of biographical disruption. Bury explained that coping after illness results in the normalization of the illness experience so that the effects on one’s identity are minimized. According to Bury (2001), normalization involves two types of processes. On the one hand, normalization may mean the incorporation of the illness into an altered lifestyle so that normal life is re-designed, containing the illness and being open about it (Bury, 2001; Hubbard et al., 2010). Under these circumstances, the stories people tell of themselves are likely to disclose illness rather than disguise it, signalling a change in identity rather than preserving earlier ones. On the other hand, patients may try to normalize or maintain their pre-illness identities. This may involve maintaining as many pre-illness activities and behaviours as possible, and/or disguising or minimizing their symptoms (Hubbard, Kidd,
Kearney, 2010). In these patients, who prefer to normalize by maintaining their pre-illness identities, perceptions of self-growth may be ego-dystonic and thus perceived as a less adaptive form of coping.

Finally, Hypotheses 1C stated that self-loss, self-growth, and their interaction would be predictive of psychosocial well-being scores among young breast cancer survivors. Two separate hierarchical regression analyses were conducted using the ISCS subscales as predictors, with the FACT-B and EES as outcome measures. Both regressions, through the main effect block, confirmed that self-loss and self-growth were significant predictors of psychosocial well-being above and beyond the demographic variables used as covariates. While to date no research has specifically examined illness-related identity change as predictors of psychosocial well-being among cancer patients, previous research has been examined through samples of HIV-positive men and women (Golub et al., 2013, 2014). These studies consistently found self-loss, but not self-growth, to predict psychosocial well-being scores. As previously mentioned, differences in age, gender, and disease type may play a critical role in understanding differences between the present study and past findings. Specifically, a chronically ill HIV-positive man, receiving constant medical treatment, may have a different psychological trajectory than a young woman who has completed medical treatment for her primary breast cancer.

Furthermore, previous psycho-oncology research on self-related cognition may also provide support for this finding. In one study conducted by Lynch, Steginga, Hawkes, Pakenham, and Dunn (2008), investigators examined cancer threat appraisal, the cognitive assessment of the impact that cancer had on personal identity and on the future, as a predictor of psychosocial distress six and 12 months post-diagnosis with 1,822 colorectal cancer patients. Cancer threat appraisal emerged as a significant and potentially modifiable predictor of well-
being, providing support for the inclusion of identity-related psychosocial interventions for cancer patients. Additional studies (Carver et al., 1993; Gallagher, Parle, & Cairns, 2002; Steginga & Occhipinti, 2006) have also found that a less negative cancer threat appraisal (i.e., low illness-related self-loss) was found to predict better psychological adjustment and well-being scores in prostate and breast cancer patients.

From a theoretical perspective, this finding also aligns with Charmaz’s (1983, 1993, 2002) conception of how individuals adjust to certain changes in the self after an illness experience. Charmaz found that those with illness often encounter a number of painful and negative reactions and life situations after their diagnosis (Lively & Smith, 2011). In dealing with this level of distress, people’s various identities and meanings of themselves may contradict and collide with one another in such a way that self-loss occurs (Lively & Smith, 2011). Someone diagnosed with breast cancer, for example, may no longer be able to fulfill her role as a worker, forcing her to take a temporary if not permanent leave of absence. This role change may also result in a changed sense of overall independence. However, Charmaz also explained that this experience of illness-related self-loss could, over time, lead to an individual’s ability to experience agency in constructing their renewed identities during and after illness. A woman diagnosed with breast cancer, for example, may redefine what it means to be a parent, a spouse, a sibling, or an employee while dealing with these changes, and subsequently experience some perceptions of illness-related self-growth as well.

Hypothesis 1C also examined the interaction between self-growth and self-loss on psychosocial well-being, as previous literature suggested that self-growth may serve as a stress-buffer in the face of affective distress for individuals living with illness (Golub et al., 2013; McMillen, Smith, & Fisher, 1997; Tran, Wiebe, Fortenberry, Butler, & Berg, 2011). Some
researchers have argued that perceived growth following trauma will only have beneficial effects for those who also acknowledge its costs (Taylor, Kemeny, Reed, & Aspinwall, 1991). In contrast to these findings, the current study found no interaction effect between self-growth and self-loss; thus, self-growth did not create a stress-buffer effect and moderate the relationship between self-loss and psychosocial well-being. It should also be noted that Golub and colleagues (2013, 2014) found inconsistent results with respect to the interaction effect between self-loss and self-growth on measures of well-being. In their first study (Golub et al., 2013), the data revealed a significant interaction between self-loss and self-growth on QOL scores; for individuals who reported high levels of self-loss, those who reported low levels of self-growth reported significantly lower QOL scores compared to those who reported high levels of self-growth. In contrast, data from a more recent study (Golub et al., 2014) revealed no interaction effect between self-loss and self-growth on some measures of well-being (depression scale), and a significant interaction on others (symptom severity scale). As previously mentioned, differences in gender, age, and disease type may play a key role in the predictability of illness-related change on psychosocial well-being. Furthermore, from a methodological perspective, Golub and colleagues used psychosocial well-being measures designed to target individuals with HIV, while the present study used a cancer-specific measure. Given inconsistent past findings, as well as differences in disease type, population, and methodology, Golub and colleagues’ findings may not be generalizable to the present population. While the present study did not align with Golub and colleagues’ conception that illness-related self-growth and self-loss operate simultaneously and interdependently on well-being scores, the present findings did support Golub and colleagues’ beliefs that self-growth and self-loss may be orthogonal constructs,
operating independently and perhaps in a “mutually influential coexistence” (Golub et al., 2013, p. 757).

Whittemore and Dixon’s (2008) model of illness-related adjustment may be one possible explanation for the independent yet related relationship between self-growth and self-loss. Whittemore and Dixon (2008) highlighted a five-phase model of illness-related adjustment including shifting sands, staying afloat, weathering the storms, rescuing oneself, and navigating life. Most importantly, Whittemore and Dixon’s (2008) model emphasized a fluid and ongoing process, which may be necessary to fully integrate illness-related self-loss and self-growth into one’s life journey and experience of well-being. Findings from the present study indicate that illness-related self-loss and self-growth may occur independently in the process of reaching optimal psychosocial well-being.

Taken together, these findings suggest that both self-loss and self-growth are meaningful yet distinct constructs for examining psychosocial well-being among a younger sample of women who have been diagnosed with and treated for breast cancer. Therefore, it is feasible that studies examining psychosocial well-being without exploring both self-loss and self-growth constructs may be missing a critical piece of the relationship among young breast cancer survivors.

**Relationship Between Gender-Related Identity and Measures of Well-Being**

The second set of hypotheses explored the internalization of values that counteract traditional gender-related identity and role expectations, using the Gender Role Socialization Scale (GRSS), Objectified Body Consciousness Scale (OBCS), Mental Freedom Scale (MF) and Silencing the Self Scale (SS) as predictors of psychosocial well-being, using the FACT-B and
EES. Specifically, Hypotheses 2A stated that an increased internalization of traditional gender roles and attitudes as measured by the GRSS would be negatively associated with high QOL and embodiment scores. Results supported Hypotheses 2A as the data revealed a moderate negative association between the GRSS and the FACT-B, and a strong negative association between the GRSS and EES. To date, there is a dearth of previous research conducted in psychosocial oncology highlighting the internalization of societal ideals and gender roles as an important psychosocial factor influencing women’s body image disturbance and overall QOL (Bessenoff & Snow, 2006). In one novel study, Boquiren and colleagues (2013) examined the relationship between gender role socialization (using the GRSS), body image disturbance (using the Body Image Scale [BIS]), and QOL (using the FACT-B) in the post-medical treatment of breast cancer survivors. Using the theoretical framework proposed by Knauss, Paxton, and Alsaker (2008), addressing the predictive links between perceived media pressure to conform to the body ideal, internalization of this ideal, body mass index, two elements of objectified body consciousness (body shame and surveillance), and body dissatisfaction in young adolescents, Boquiren and colleagues’ study constructed a model of direct, indirect, or spurious effects of gender socialization on body image and QOL among breast cancer survivors. Based on this model, Boquiren and colleagues found a strong positive association between GRSS and the BIS, and subsequently a strong negative association between the BIS and the FACT-B.

Hypothesis 2B stated that increased body surveillance (i.e., viewing the body as an outside observer) and body shame (i.e., feeling shame when the body does not conform) would be negatively associated with QOL and embodiment scores. Results also supported Hypothesis 2B as the data revealed that women’s perceived body surveillance had a significant but weak negative association with QOL and a moderate negative association with embodiment scores.
Results revealed that body shame also had a significant but weak negative association with QOL scores and a strong negative association with embodiment scores. This finding is supported by past research that explicates how the internalization of the outsiders gaze on the physical self can promote habitual self-monitoring and self-surveillance, and subsequently impact one’s overall psychosocial well-being (Choma, Visser, Pozzebon, Bogaert, Busseri, & Sadava, 2010). Individuals with greater predisposition to self-objectify tend to show a chronic pre-occupation with their physical appearance, with the belief that their bodies are and will be evaluated by others (Choma et al., 2010). Higher self-objectification scores have been shown to be associated with poor mental health and QOL outcomes including disordered eating (Calogero et al., 2005; Greenleaf & McGreer, 2006; Piran & Cormier, 2005), depression (Tiggemann & Kuring, 2004), sexual dysfunction (Calogero & Thompson, 2009), and greater body shame in western cultures (Grabe et al., 2007; Knauss et al., 2008; McKinley, 1998). For breast cancer survivors, the comparison of one’s physical appearance with internalized cultural expectations has been shown to contribute to body image disturbances and negative self-views, and subsequently “interfere with adjustment (especially with resumption of previous roles and routine), and impede the important task of rebuilding the self” (Boquiren et al., 2013, p. 3,272). Boquiren and colleagues’ (2013) study also examined the relationship between objectified body consciousness (OBCS), body image disturbance, and QOL in breast cancer survivors post-medical treatment. Consistent with the current study, findings revealed a strong positive association between the experience of body shame/body surveillance and poor body image disturbance using the BIS, as well a strong negative association between QOL and body image disturbance.

Hypothesis 2C stated that an increased critical stance toward oppressive social discourses, expectations, and gender labels, as measured by the Mental Freedom scale (MF),
would be positively associated with QOL and embodiment scores. This finding was supported as the data revealed moderate and strong positive association with the FACT-B and EES, respectively. Although the MF has never previously been examined within a breast cancer population, previous studies have examined the predictive relationship between MF and well-being scores in non-oncology-based populations. For example, in a sample of 412 women aged 18 to 45, Teall and Piran (2015) examined the associations between MF and EES among a community-based population of adult women. Results from the present study are in line with Teall and colleague’s study; both studies found a strong positive association. The comparability of results between the present study and Teall and Piran’s (2015) findings suggest that freedom from constraining gender-related discourses could be seen as a general resiliency factor, relevant to women’s well-being and adjustment in coping with varied life challenges, including, but not exclusive to illnesses, such as breast cancer.

Moreover, within the eating disorder literature, Murnen and Smolak (1997, 2009) conducted two meta-analyses investigating the internalization of the feminist identity, which assessed women’s critical stance toward oppressive social discourses and gender expectations with the presence of disordered eating behaviours. In their first meta-analysis, they found a small but significant effect size in which women with eating disorders reported higher levels of femininity than women who did not have eating disorders. In their second meta-analysis, they found that a feminist identity was associated with more positive body attitudes/lower body shame, and that a feminist identity was associated with a lower drive for thinness, lower eating disorder symptomatology, and less internalization of medial ideals (Murnen & Smolak, 2009). The comparability of results between the present study and Murmen and Smolak (1997, 2009) findings also suggest that, beyond breast cancer, a critical stance towards oppressive social
discourses could be seen as a general resiliency factor for women. Having freedom from traditional stereotypic gender discourses and practices allows women to function in the world with greater agency, self-care, and remain positively connected and attuned to their bodies.

Hypothesis 2D stated that high levels of self-silencing (SS), as a reflection of internalized scripts, would be negatively associated with the FACT-B and EES. While the results supported Hypothesis 2D, contrary to expectations, the silencing the self subscale (SS-3) and the care as a form of self-sacrifice subscale (SS-2) had significant but weak negative associations with QOL and embodiment scores. While no previous research has examined silencing the self with cancer patients, the findings from the current study align with the original work of Jack & Dill (1992); these researchers examined the Self-Silencing scale (SS) with three specific samples of women including: college students (n = 63), residents in battered women’s shelters (n= 140), and mothers of four-month-old infants who abused cocaine during pregnancy (n=270). The results of this study found that all samples of women had moderate positive associations with a specific measure of poor psychological well-being (Beck Depression Inventory). Within the field of chronic illness, Ali et al. (2000) showcased the importance of self-silencing among a sample of women with irritable bowel syndrome. The researchers found that certain characteristics typically associated with femininity, such as servility and self-subordination, were significantly associated with certain modes of illness behaviour. Finally, Ussher and Perz (2010) examined the relationship between self-silencing and psychological well-being using the Hospital Anxiety and Depression Scale (HADS) in carers (i.e., partners and/or caregivers) of individuals with cancer. The researchers recruited 484 participants (329 women, 155 men) to the study and found a significant but weak association between silencing the self and psychosocial well-being, similar to the present study. The researchers reported that female carers in their study positioned self-
silencing “as a requisite for coping and demonstrated awareness of external judgement, reflecting self-policing linked to constructions of idealized femininity, in particular the positioning of women as natural carers” (Ussher & Perz, 2010, p. 228).

Finally, Hypothesis 2E stated that GRSS, OBCS, MF and the SS would predict psychosocial well-being using the FACT-B and EES. Two separate hierarchical regression analyses were conducted using the four gender-related variables to predict psychosocial well-being. The first regression, which examined gender role expectations and identity variables as predictors of the FACT-B, demonstrated that gender role socialization and mental freedom were significant predictors above and beyond the demographic variables used as covariates. The FACT-B demonstrated that the internalization of gender roles and expectations, as well as a the formation of a critical stance toward gender labels, could strongly predict women’s ability to return to previous levels of social, psychological, spiritual, or physical functioning post-medical treatment.

Boquiren and colleagues (2013) suggested that for women whose self-worth is directly linked to an adherence to traditional gender roles and expectations, adjustment in the survivorship period may be challenging as they (family, friends, and peers) expect them to return to normal and resume routine home and work duties. For breast cancer survivors with strong, traditional feminine identities such as “the selfless, emotional caretaker, nurturing child-bearer and/or sexual lover, perceived failure to fully meet such socialized roles will negatively impact one’s self-esteem and confidence, contributing to continued poor QOL” (Boquiren et al., 2013, p. 2,183). Boquiren and colleagues’ (2013) study hypothesized that the endorsement of traditional gender role expectations and identity, using the GRSS, contributed to increased body shame and surveillance (OBCS), which in turn led to BI disturbances and poorer QOL. Path analyses
provides empirical support to their hypothesis that gender role socialization has direct and indirect pathways to women’s body image disturbances and poor QOL. As highlighted by these researchers, one possible explanation in regards to the predictive relationship between gender role socialization and the FACT-B is that greater gender role socialization exerts “a pressure on breast cancer survivors to continue to meet personal standards held prior to their illness” (Boquiren et al., 2013, p. 2,183), which is difficult to attain.

From a theoretical perspective, Bepko and Krestan’s (1991) model may also provide some insight for the results of the present study. Bepko and Krestan (1991) proposed a *Women’s Codes of Goodness*, which is believed to delineate the characteristics of an idealized woman as valued by Western society. They explain:

Goodness consists of all those small things you do each day from the time you plant your feet on the floor. The gestures are simple, and because they are, we barely notice them and neither does anyone else. You give, create, work, plan, design, clean, organize, straighten, put yourself out, try hard and expect yourself to be there emotionally for men, children, bosses, coworkers, employees, friends, parents, your church, stray cats, and the rest of the world at large (Bepko & Krestan, 1991, p. 5).

Bepko and Krestan (1991) identified five major rules at the core of the Women’s Code of Goodness including

1) Be Attractive: a woman is as good as she looks,

2) Be a Lady: A good woman stays in control,

3) Be Unselfish and of Service: A good woman lives to give,
4) Make Relationships Work: A good woman loves first, and

5) Be Competent without Complaint: A good woman does it all and never looks overwhelmed.

These codes, particularly the first three, “form the bedrock of [women’s] sense of femininity. They define what it means to be female” (Bepko & Krestan, 1991, p. 14). Bepko and Krestan (1991) explained that these “old messages that seemingly had more impact on our mothers than on ourselves have a lingering hold in our subconscious” (p. 14).

While for some women these Codes of Goodness may have been perceived as achievable prior to their illness, the experience of cancer may greatly impact the ways in which women are able to carry out these codes they have previously been accustomed to reaching. An illness experience may be one example that showcases what Bepko and Krestan (1991) describe as “goodness gone bad” (p. 59). The cancer experience may be a poignant one highlighting how women are unable to live up to these Codes of Goodness. Furthermore, Bepko and Krestan believe that the harder one tries to live up to these codes, the worse one feels about their sense of self. This experience is likely to be heightened as women try harder to return to these codes of behaviour following their cancer experience. Women with breast cancer may be forced to choose between complying with these codes of femininity, by continuing to be good women, or challenging them. The present study found that, in line with Bepko and Krestan, women who complied with traditional gender role expectations and identities were more likely to describe worse overall well-being post-medical treatment.

Mental freedom, reflecting a critical stance toward oppressive gender-related social discourses, was another important predictor of women’s overall well-being post-treatment. While
no studies to date have examined mental freedom in the cancer community, Teall and Piran (2015) stated that post-structural feminists including Bronwyn Davies (1989) and Valerie Walkerdine (1989) examined this concept, and discussed how “gendered subjectivities are not shaped passively, but rather are actively developed as individuals personally take up discourses, discourses that shape their identity” (Teall & Piran, 2015, p. 79). Further, Jones (1993) discussed how “girls can no longer be seen as simply socialized into their appropriate gender roles. They ‘position themselves’” (Jones, 1993, p. 159). A young breast cancer survivor, for example, may choose to resist and renegotiate their normative performances of femininity (i.e., refusing reconstructive surgery). In a qualitative study by Trachtenberg and Piran (2012), a 43-year-old woman with Stage II cancer, 13 months post-medical treatment, chose to resist and renegotiate her normative performances of femininity and beauty. In her interview, she stated, “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?” (Trachtenberg & Piran, 2012, p. 83).

Moreover, as proposed by Bepko and Krestan’s (1991) Code of Goodness, women who are able to challenge codes of femininity can generate new principles that allow them to “change their assumptions about how [they] need to be good” (p. 78). Consistent with this theory, the findings of the present study showcase the value of taking a critical stance toward discourses that reflect traditional gendered expectations after a breast cancer experience, as a way to further strengthen one’s perceived QOL (i.e., social, psychological, spiritual, and physical functioning). Taken together, a cancer experience is one example that can challenge the notion of a fixed and
unitary feminine self. Mental freedom allows women to explore and determine their own sense of identity in relation to these social discourses, which ultimately can help strengthen QOL.

In contrast, the second regression, which examined gender role expectations and identity variables as predictors of the EES, demonstrated that the experience of body surveillance (OBCS-Surv) and body shame (OBCS-BS), as well as mental freedom (MF), were significant predictors of the EES above and beyond the demographic variables used as covariates. The predictive relationship between body shame (i.e., feeling shame when the body does not conform to idealized representations of beauty) and body surveillance (i.e., viewing the body as an outside observer), and between a woman’s experience of embodied agency and attuned self-care, as reflected by the EES, is in line with Objectification Theory (Fredrickson & Roberts, 1997). This theory suggested that the objectification of women’s bodies leads to enhanced body shame and surveillance. The experience of breast cancer, including the experience of a mastectomy, could promote body shame and surveillance due to failure to comply with idealized representations of beauty.

In the oncology literature, greater self-evaluative salience has been associated with lower appearance satisfaction (Moreira & Canavarro, 2010) and poorer QOL (Boquiren et al., 2013; Moreira & Canavarro, 2010; Moreira, Silva, & Canavarro, 2010). In a more recent study, Sherman, Woon, French, and Elder (2016) assessed the levels of body image disturbance and psychological distress in women undergoing nipple-sparing mastectomy with immediate breast reconstruction (NSM + IBR). Seventy-five women with breast cancer completed the BIS, general and cancer-specific psychological distress measures, as well as an appearance investment scale. MANCOVA analyses indicated a significant moderating effect of appearance investment on the body image disturbance-distress relationship, such that participants with low appearance
investment experienced lower distress when compared with individuals with higher appearance investment. The results of the present investigation are therefore in line with Sherman et al.’s findings in that higher scores of body shame and surveillance, reflecting high appearance investment, predicted poor outcomes on the embodiment scale. Further, participants in Sherman and colleagues’ (2016) study who completed an NSM + IBR procedure reported less body image disturbance and subclinical levels of distress when compared with women undergoing non-nipple sparing mastectomy (Hopwood, Fletcher, Lee, & Al Ghazal, 2001; Neff, 2003; Przezdziecki et al., 2013; Sheehan, Sherman, Lam, & Boyages, 2007). It should be noted, however, that women’s choices regarding surgical options might reflect their appearance investment, such that the observed relationships in the series of studies by Sherman and colleagues between surgical procedures and body image could be accounted for by self-selection.

Piran and Teall (2012) suggested that maintaining idealized body shapes might increase individuals’ experience of social power. For example, choosing the NSM + IBR’s surgical procedure may reinforce one’s sense of social power by adhering to stereotyped images of female beauty. Nonetheless, Piran and Teall also cautioned that appearance-based social power could ultimately leads to one’s disempowerment since it inherently limits options women pursue in achieving agency in acting in and on the world. Future studies should examine women’s level of social (dis)empowerment in relation to psychosocial well-being and body image dissatisfaction. Using Piran and Teall’s (2012) Social Power scale may add additional insight into women’s experience of embodiment and experience of well-being among breast cancer survivors.

Although body image as an outcome measure has been an important construct used in the literature to examine breast cancer survivors’ health and well-being, the EES was chosen instead
for the present study. In contrast to the body image construct, which involves an external gaze at one’s body, the experience of embodiment construct includes an emphasis on internal experiences. It also addresses a broader range of experiences, all the way from body disconnection to joy and agency. Specifically, the Experience of Embodiment construct includes five central dimensions: body connection and comfort, agency through physical activity and voice, the experience and expression of desires, attuned self care, and freedom from self objectification (Piran, 2016). The results of the present study suggest that body shame and body surveillance are related not only to body image, but also to the broader experience of embodiment.

In addition to body shame and surveillance, mental freedom was also significantly related to breast cancer survivors’ experience of embodiment. This finding is in line with a study of 412 adult women, ages 18 to 45, conducted by Teall and Piran (2015). Using a multiple regression analysis, these authors found that mental freedom predicted participants’ scores on the Experience of Embodiment Scale. A critical stance toward discourses of femininity therefore relates to positive experiences of embodiment.

Furthermore, mental freedom was the only gender-related variable to significantly predict both measures of well-being. Mental freedom, reflecting a critical stance toward oppressive social discourses related to femininity, predicted both women’s overall QOL as well as the way women felt about inhabiting their bodies as they continued to engage with the social world around them following a mastectomy or lumpectomy. Bepko and Kresten (1991) highlighted case studies showing how women’s ways of interacting with the world, through the five Codes of Goodness, typically result in poor levels of well-being. In order to break free from these codes, Bepko and Kresten advocated for new guidelines of goodness that could help change women’s
assumptions about how and what it means to be good. The authors labelled these new guidelines the *Codes of Balance*, which were ways to contradict and/or challenge the original codes. The Codes of Balance included:

1) Be Comfortable: A woman in balance values feeling good more than looking good,

2) Be Direct: A woman in balance is honest about how she feels,

3) Be Responsive: A woman in balance empathizes with others,

4) Be Nurturing: A woman in balance empowers herself and others,

5) Be Firm: A woman in balance sets limits.

Interestingly, these five Codes of Balance described by Bepko and Kresten paralleled some of the items on the Mental Freedom scale. Taken together, ways of challenging stereotyped assumptions about one’s embodied practices in the world related to one’s quality of life as well as embodied agency and attuned self-care.

Finally, while the quantitative inquiry did not have a specific hypothesis about the relationship between the FACT-B and EES, the present investigation found a strong correlation between the two outcome measures. Past literature has found both the FACT-B and EES to have strong correlations with varied measures of well-being. In particular, the FACT-B has been strongly correlated with measures examining patients’ function-oriented QOL and well-being, depression, and anxiety (Brady et al., 1997; Cella et al., 2008). Likewise, the EES has been found to be strongly correlated with such measures as well (Teall & Piran, 2015); in addition, the EES has also been strongly correlated with disordered eating, body-esteem, sexual assertiveness,
body responsiveness, objectification of the body, physical self-worth and specific body related practices (Teall & Piran, 2015).

The strong correlation between the FACT-B and EES suggested that QOL in this group of young breast cancer survivors related to women’s experience of embodiment, which involved five core dimensions including: a) connection and comfort with the body, b) sense of agency in the body, c) experience and expression of bodily desires, d) attuned self-care, and e) inhabiting the body with freedom from objectification (Piran, 2016). Taken together, the correlation of the two outcome measures of well-being suggest that the embodied experience of participants was relevant to their QOL and experience of well-being as young breast cancer survivors.

**Strengths and Limitations of the Quantitative Section of the Study**

Prior to considering the qualitative findings of this study, it may be useful to outline several strengths and limitations of the quantitative arm of this mixed-method study. It is important to note, however, that additional strengths and limitations will be addressed in the qualitative arm of this study as well.

The study involved a number of strengths. First, the study used an innovative measure of embodiment to assess well-being in addition to QOL, a commonly utilized measure in the field of medicine. The Experience of Embodiment construct assesses the quality of women’s experiences in their bodies as they engaged with the social and physical environment around them. The study therefore helped clarify the relevance of embodiment to women’s experience of psychosocial well-being. Second, historically, the breast cancer literature has explored women’s QOL and experience of well-being across a broad range of ages. In contrast, the present investigation focused on a younger group of women. Third, majority of such studies within the
field of psychosocial oncology and post-traumatic growth typically only examine either illness-related self-growth or illness-related self-loss. In contrast, based on Golub and colleague’s (2013, 2014) previous studies, the present investigation chose to study both constructs as interrelated components of illness-related identity. Finally, four different scales were used to quantitatively examine diverse aspects of gender-related identity as predictors of psychosocial well-being. Consistent findings across these four scales demonstrated the relevance of gender to young women’s experience of psychosocial well-being at cancer survivorship.

Importantly, there were also a number of limitations to this quantitative study. Given the 60-minute length of the study, respondent fatigue was a major challenge. Subsequently, the sample size was smaller than expected (n = 113) and had substantial amount of missing data in the last two questionnaires. Imputations were thus conducted on the data in order to run correlation and regression analyses.

Other limitations of the study relate to particular demographic characteristics of the sample. In particular, the study included women up to the age of 49 during the time of diagnosis. While this age range may be comparable to other studies that aimed at recruiting young samples of women breast cancer survivors, this is a broad age range. There indeed may be important differences within this age range in women’s well-being and the factors which shape them. While participants’ current age was used as a covariate in the regression analyses, and was thus controlled for, the group-based analysis of the results may have masked differences related to varied age groups. Future studies could focus on a younger age group of women breast cancer survivors or even compare different age groups within the broader age range (e.g., women aged 20-29, versus women aged 30-39, versus women age 40-49). A larger group of participants may have also given the opportunity to study, with greater statistical power, the effects of
demographic variables such as motherhood on women’s experiences with survivorship from breast cancer.

Additionally, in order to maximize sample size, participants from all four stages of breast cancer were included. While the majority of participants were between Stage I-III (88.6%), a small subset of participants had a Stage IV (11.4%) diagnosis. Therefore, these results cannot be generalized to individuals diagnosed with carcinoma in-situ, or individuals with metastatic disease. It is possible that a larger group of participants would have allowed the researcher to empirically study the effects of cancer stage on the breast cancer experience. Furthermore, the majority of participants were Caucasian (62.3%), earned a bachelor’s degree (31.9%), and reported working full time (55.8%). As a result, generalizations to women of diverse social locations in terms of ethnic background, level of education, and employment status should be considered cautiously. As well, the current demographic questionnaire did not address previous/current psychological treatment received in relation to women’s experiences of psychosocial well-being. Thus, future studies examining illness- and/or gender-related identity shifts post-breast cancer treatment should include this variable.

Contrary to previous research, time since diagnosis was not associated with well-being scores in the study; however, the majority of study participants were in their first six months post-treatment (44.2%). Future studies should be conducted longitudinally, measuring changes in illness- and/or gender-related identity change; this would allow researchers to examine the extent to which women’s identity in relation to their cancer fluctuates over time post-treatment. Nonetheless, the present findings are important and apply to a younger subset of women who have recently been diagnosed and treated for breast cancer.
The study also used a correlational design to identify potential relationship among variables. While the use of correlational designs is important, especially when the variable of interest cannot be manipulated, these types of analyses are not able to establish a causal relationship among variables (Kirk, 1984). As stated previously, longitudinal studies are needed to provide more answers about causality.

The present study also did not use a control group of healthy adults to compare and contrast illness- and/or gender-related identity changes. Examining the psychosocial well-being of non-cancer patients using the same predictors could have helped to better determine the clinical significance of the findings.

Lastly, within the medical psychology literature, few scales to date have developed a scale examining illness-related identity changes; indeed, within the identity literature, scales related to Ego Identity such as the Extended Objective Measure of Ego Identity Status (Bennion & Adams, 1986), the Ego Identity Process Questionnaire (Balistreri, Busch-Rosnagel, & Geisinger, 1995), The Modified Erikson Psychosocial Stage Inventory (Leidy & Darling-Fisher, 1995) and the Ego Identity Scale (Tan, Kendis, Porac, & Fine, 1977) have been generated. However, within the illness/health domain, identity scales are few and far between. While clinically health professionals continue to emphasize the importance of examining identity in order to reduce distress and promote positive adjustment and well-being in cancer patients (e.g., Managing Cancer and Living Meaningfully [CALM] [Nissim et al., 2012]), few researchers have attempted to quantify the patients’ perception of the impact of their illness on their identity. In addition to the Impact on the Self-Concept Scale (ISCS) used in the present study, the Head Injury Semantic Differential Scale (Tyerman & Humphrey, 1984), which examines changes in self-concept through a semantic differential paradigm for individuals with severe head injury, the
BRCA Self-Concept Scale (Esplen et al., 2009) measuring the self-concept among individuals who test positive for the BRCA1/2 mutation, and the Illness Perception Questionnaire (Broadbent, Petrie, Main, & Weinman, 2006), examining individuals’ cognitive and emotional representation of illness are examples of scales developed to assess identity among individuals facing health challenges. Nevertheless, the majority of these scales have not specifically targeted issues of self-concept, role-identity/expectations, or identity changes post-treatment. Moreover, unlike the majority of these scales, the ISCS examines both positive and negative changes in the self after an illness experience, which is typically missing in this field. Thus, with a dearth of scales examining the intersection of illness and identity-related issues, the ISCS was selected.

Methodologically speaking, however, the ISCS is a relatively new measure with only two major published studies using the scale. Nonetheless, the scale was necessary and critical to the present study in order to further elucidate research within this area of illness-related identity. Future studies should consider developing a new measure that specifically targets cancer patients’ self-concept, as well as positive and negative identity-related changes post-medical treatment.
Chapter Six: Qualitative Methodology

Feminist-Informed Research

Gray (2015) and colleagues contend that feminist-informed research comes from a particular standpoint that targets specific “motives, concerns and knowledge brought to the research process” (Gray, Agllias, Schubert, & Boddy, 2015, p. 759). The present inquiry, as a feminist-informed investigation, took women’s perspective on the world as the basis from which to explore, understand, and analyze the qualitative arm of the study (Beckman, 2014; Gray et al., 2015). The present inquiry prioritized women’s voices and experiences, and aimed to change and improve the ways in which breast cancer survivors understand and go about their lives (Gray et al., 2015; Gringeri, Wahab, & Anderson-Nathe, 2010). Overall, the present study was informed by three overarching feminist research principles: a) understanding women’s reflections on their lived experiences, b) equalizing or reducing power imbalances in the research-participant relationship, and c) improving the lives of young survivors through thoughtful explication of key socio-cultural and clinical implications (Gray et al., 2015).

In line with the first feminist research principle, the present inquiry attempted to understand and “capture women’s lived experiences in a respectful manner by accepting the stories of their lives as legitimate sources of knowledge” (Mizevich & Piran, 2012, p. 44). By viewing participants as experts in their own lived experiences, it uncovered women’s subjugated knowledge, and challenged the structures and ideologies viewed through gender, culture, racial, political, and economic lenses (Mizevich & Piran, 2012; Preissle & Han, 2007). Further, Orne (2003) emphasized that utilizing women’s own terminology was another hallmark of feminist-informed research. Indeed, the present study was grounded in women’s daily experiences as well
as their language. Stoppard and McMullen (2003), for example, showcased the narrative of a young woman named Evelyn struggling with her clinical depression, frustrated with 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 a specific population like young breast cancer survivors was critical in providing a more meaningful and adequate understanding of their lives. In fostering understanding of women’s lived experiences, feminist-informed research “carr[ies] messages of empowerment that challenge the encircling of knowledge claims by those who occupy privileged positions” (Hesse-Biber, 2012, p. 3). Hence, the present study aimed to empower and emancipate women in their marginalized group(s) (Hesse-Biber, 2007; Mizevich & Piran, 2012). Likewise, self-reflexivity, being aware of the ways in which the researcher’s position—class, race, status, culture, whiteness, and privilege—affected the research process, was critical to the present investigation (Daley, 2010). Self-reflexivity required that the researchers be aware of and critically reflective, throughout the research process, about the ways in which their own positionality hindered or assisted the achievement of knowledge (Hesse-Biber, 2007; Mizevich & Piran, 2012).

The second feminist-informed research principle examines the equalization or reduction of power imbalances in the researcher-participant relationship. Gray and colleagues (2015) highlighted that like Marxism, feminism is a theory rooted in power and its unequal distribution in society. Feminists view the chief cause of women’s oppression as the outcome of power inequality (Gray et al., 2015). As such, the present investigation sought to reduce power imbalances in the researcher-participant relationship, and take responsibility to ensure that these
power differences were attended to and/or taken into account (Gray, et al., 2015). While the
dynamics of power were inevitable, Shore (2006) suggested the researchers aim for an “equitable
research process wherein inclusive partnerships are created by leveling the playfield, to ensure
participants’ voices are heard, valued and respected throughout the research process” (Gray et
al., 2015, p.761).

The third and final overarching principle of feminist-informed research used in the
present investigation was improving women’s lives. Feminist-informed research is conducted
against a critical analysis of the impact of women’s oppression and with a radical critique of the
politics of patriarchy (Ackerly & True, 2010; Gray et al., 2015). Thus, working toward social
justice for those marginalized and disadvantaged by unfair processes is central. Reinharz and
Davidman (1992) explained that feminist research creates a “dual responsibility of contributing
to the welfare of women as well as contributing to knowledge” (as cited by Mizevich & Piran,
2012, p. 46). Thus, the present study focused on working toward making explicit clinical
recommendations with suggestions about how health professionals can use the findings
(Mizevich & Piran, 2012; Reinharz & Davidman, 1992).

**Situating the Breast Cancer Experience in a Feminist Perspective**

Most research within the biomedical, physical, and even behavioural sciences has been
anchored in the scientific empirical method, and believes in the power of its objective truths
(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 healthcare research and diagnosis, the social
context of people’s life circumstances and everyday 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 additional information is extraordinarily
valuable, casting new light on the experience of living with a deadly disease like cancer. Re-
contextualizing the experience of a woman who has gone through 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; rather, these
symptoms or feelings of distress are conceptualized differently, embedded in relationships and in
a variety of social settings (Stoppard & McMullen, 2003).

As previously discussed, this study was grounded in a feminist perspective; by making
visible previously invisible female experiences, the feminist perspective was effectively able to
“correct both the invisibility and distortion of [the] female experience,” while going through the
argued that political, social, cultural, sexist, and racist factors intersect in the field of breast
cancer, and that this should be recognized and incorporated into research surrounding the
disease. Subsequently, the feminist perspective in the investigation served as a potentially
validating lens for young breast cancer survivors who reported experiences of oppression.

By opening up questions about power, ideologies, practices of gender, and social and
structural inequalities in women’s lives, the present inquiry provided a deeper understanding of
women’s overall survivorship experience. Being more aware of the taken-for-granted forms of
discourse that exist in our culture (included our healthcare system) strengthened the interpretive
and critical analysis that followed from these narratives (Stoppard & McMullen, 2003).
**Subjectivity of the Researcher**

Research subjectivity is inevitably part of a qualitative inquiry. The researcher must bring both their bias and assumptions to the research process (Cole & Knowles, 2001). Therefore, it was important to be transparent and forthcoming about these biases.

As discussed in my master’s thesis, my initial interest in psychosocial oncology stemmed from past work experience as a research associate at a cancer-specific hospital. I spent time interacting with patients and learning from a holistic perspective (i.e., from physical, psychological, spiritual, social, and functional levels) what it meant to be a cancer patient at a hospital. My curiosity in exploring the intersection of identity and psychosocial well-being in cancer patients stemmed from a specific encounter I had with a patient who explained that he used separate and isolated identities in and out of the hospital to cope with his illness.

Furthermore, the process of creating my master’s thesis and analyzing the narratives of 10 young breast cancer survivors in a small-scale pilot study was another critical influence in the development of this present inquiry. In particular, the master’s thesis highlighted the value of acquiring a comprehensive life history approach with respect to the ways in which women live in their bodies before, during, and after their breast cancer diagnosis and treatment. In addition, during the latter years of my doctoral training, I have had a number of opportunities to gain clinical experience working with cancer patients (breast as well as other cancer sites) across the disease trajectory and lifespan. Working as a student-therapist within a hospital setting at one of the largest cancer centres in Canada helped shape my knowledge from the perspectives of both professionals and patients.
A feminist theoretical lens influenced my qualitative inquiry, which in conjunction with the literature review helped form the interview guide and probes. Grounded in Dr. Niva Piran’s Developmental Theory of Embodiment and how it is used to analyze and understand women’s narratives across the lifespan made me more attuned to how women live in their bodies; in particular, I was attuned to issues such as: experiences of physical freedom, social (dis)empowerment, and objectification of the male gaze.

Finally, one critical factor that influenced both the qualitative research arm and my own subjectivity was the mixed method design of the present investigation. Given that the data collection for both the qualitative and quantitative arms was conducted concurrently, I initially found some challenges in moving between the two arms. In particular, I can reflexively recall, in my first interview, attempting to gain answers from participants to specific research questions addressed in the quantitative arm of the investigation. After some discussion with my supervisor, it was evident that I had attempted to force the interview into pre-conceived categories based on the quantitative research hypotheses. Charmaz (2006) specifically stated that we must “guard against forcing interview data into preconceived categories . . . [and challenge ourselves] to create a balance between asking significant questions and forcing responses” (p. 32). Thus, after the first interview and an extensive reflexive exercise with my supervisor, I recognized the importance of distancing myself as much as possible from the quantitative arm of the study while conducting interviews. I re-read Charmaz’s (2006) grounded theory text *Constructing Grounded Theory* and focused on eliciting women’s lived experiences through my original interview guide, while also allowing the data to stay emergent and unrestricted.

Despite certain pre-existing thoughts and expectations, I believe that being conscious of these interests allowed me to be open to other aspects of participants’ experiences.
Qualitative Interviewing

The present inquiry used particular elements from the life history approach to interviewing. Specifically, in line with a life history approach, the interviews invited participants to reflect about the meaning they made of their present experiences as survivors of breast cancer, viewing the cancer diagnosis, treatment, and survivorship as significant points of transition in their life journeys. Furthermore, in line with a life history approach, participants were invited to examine their present experiences within the context of their past experiences. A similar focus on the social context that shaped participants’ experiences comprised another element of the life history approach. While the study did not proceed with chronological life histories, it examined present experiences within the context of life long journeys and emphasized points of transition, similar to other life history studies (e.g., Measor, 1985; Piran & Teall, 2012).

The emphasis on allowing “participants to actively reconstruct their lives by shaping their stories with the researcher, who guides them by prompting their memories and encouraging their reflections, interpretations and insights” (Mizevich & Piran, 2012, p. 47) is also a shared element between the present investigation and a life history approach. The key role of the researcher is to create a conversational space where phenomena can be discussed and understood together, as well as the process in which the phenomena relate to the participant (Mizevich & Piran, 2012; Cole & Knowles, 2001). The researcher attempts to gain an insider’s perspective on the participant’s lived experience. The researcher also provides opportunities for the participant to clarify any inaccuracies or misrepresentations made while the researcher collects data (Antoniou, 2009). The participant is considered the expert and the authority on her life (Atkinson, 2002). Participants are not viewed 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). This approach also places importance on intimacy and the genuineness of the research relationship (Antoniou, 2009), which promotes qualities of mutual care and friendship, disclosure of respect for personal vulnerabilities, and attention to relational ethics and power relations. As such, a collaborative and connected relationship is extremely critical to the research.

Context is another critical factor in the implementation of a life history approach, which was also central in the present investigation. Coles and Knowles (2001) stressed the importance of an in-depth understanding of context in life history research, emphasizing that people’s lives are never completely isolated from context. Antoniou (2009) explained that the 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). Similar to other qualitative approaches, the life history approach values depth over breadth (Antoniou, 2009). The approach requires only a small number of participants for a more intensive exploration of their lived experiences (Antoniou, 2009). As a result, the focus 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).

**Constructivist Grounded Theory**

Grounded theory (GT) emerged from the collaborative efforts of sociologists Barney Glaser and Anselm Strauss (1965, 1967). They introduced the term to label the research method designed and used to return to data-driven theorizing in qualitative research (Johnson, McGowan, & Turner, 2010). They conceptualized GT as a way to generate theory by systematically gathering and analyzing data, and working back and forth between data and
theory (Johnson, McGowan, et al., 2010; Mizevich & Piran, 2012). Over time, GT became known as the most realist and positivist of the modernist qualitative methods (Mills, Bonner, & Francis, 2006; Van Maanen, 1998). It drew upon objectivist assumptions that data represents objective facts about a knowable world (Charmaz, 2006; Mizevich & Piran, 2012). The researcher was viewed as an unbiased observer, separate and distant from the data, recording facts about it (Mizevich & Piran, 2012; Charmaz, 2002).

In contrast to the classic, objectivist, epistemological GT, Kathy Charmaz (2000) emerged with a transformed constructivist GT (Mills, Bonner, & Francis, 2006). She (2011) explained that in the constructivist version, researchers view reality as multiple and “attempt to see it from the inside” (Charmaz, 2011, p. 366). Emphasis is also placed on meaning. In contrast to classic GT, the researcher and the participant co-construct meaning and the developing theory is grounded in both the participants’ and the researchers’ experiences (Mills et al., 2006; Mizevich & Piran, 2012). Greckhamer and Koro-Ljungberg (2005) contended that with one set of data, multiple meanings may be present (because different research analysts will find different meanings), resulting in different grounded theories. Further, constructivist GT does not view researchers as impartial observers; instead it believes in the importance of taking a reflexive stance toward the research process, valuing the notion of locating the researcher within the realities they are studying (Mizevich & Piran, 2012). Constructivist GT also analyzes the power imbalance between the researcher and the participant, and attempts to modify it. Notably, strong constructivists and postmodernists often disavow the word discovery, contending that the term is an objectivistic term (Johnson, McGowan, & Turner, 2010). Charmaz (2006) asserted that “neither data nor theories are discovered. Rather, we are part of the world we study and the data we collect. We construct our grounded theories through our past and present involvements and
interactions with people, perspectives, and research practices” (p.10). Additionally, constructivist GT emphasizes the importance of locating the data in context (Mizevich & Piran, 2012). Charmaz (2011) stated that “data reflects their historical, social, situational locations, including those of the researcher” (p.366). Charmaz’s (2006) GT also aligns with its Chicago school antecedents, building on the pragmatist underpinning in GT. The pragmatic approach views human beings as active agents in their lives and worlds rather than as passive recipients of larger social forces (Charmaz, 2006). This approach brings to grounded theory notions of human agency, emergent processes, social and subjective meanings, problem-solving practices, and the open-ended study of action (Charmaz, 2006). Currently, agreement exists among GT scholars regarding key analytic strategies such as: continual or iterative data collection (e.g., interviews), interim analysis, memo writing, theoretical sampling, theoretical sensitivity, and theoretical saturation.

The emphasis constructivist GT places on co-creating meaning, locating the research in the reality of the study, focusing on social justice, and modifying power imbalances aligns with the feminist-informed research principles in the present inquiry. Likewise, focus on participants’ social locations as well as their reflexive stance throughout the research process is critical to the present inquiry’s life history approach. Finally, pragmatism, the underlying epistemology Charmaz (2006) links to constructivist GT, is also a leading philosophical paradigm used in mixed method research (Johnson, Mcgowan, et al., 2010). This too suggests that constructivist GT may be well-suited for a mixed methods study. However, it should be noted that Charmaz, (2012) indicated that the use of GT in mixed methods studies can be “fraught with knotty problems,” and may “divide, collide or cohere” data (Charmaz, 2012, p. 12). Nonetheless, she
also acknowledged that mixed method researchers most commonly look to GT as a useful qualitative method for their studies.

**Participants**

Similar to the quantitative inquiry, participants were eligible if they had been diagnosed with breast cancer between the ages of 18 and 49, had undergone either a lumpectomy or mastectomy, and completed adjuvant treatment(s). These inclusion criteria were used to ensure that women endured a form of disruption to their pre-cancer bodies. All women who consecutively contacted the researcher were considered for participation. However, out of the 16 who contacted the researcher, three women did not participate since the goal was to include a diverse sample in terms of sexual orientation, ethno-cultural diversity, socio-economic status, age, and time since treatment completed. For these reasons, three women who were Caucasian and middle class were not included in the group of interviewed participants.

Twelve women diagnosed with breast cancer between ages 24 to 44 were interviewed for the study. With regards to medical information, four participants were between one and 12 months since completing medical treatment, four participants were between 13 and 24 months, and four participants were 30 or more months post-completion of their medical treatment. Two participants identified as having Stage I breast cancer, six participants identified as having Stage II, four participants identified as having Stage III. Five women were treated with surgery, chemotherapy, radiation therapy, and tamoxifen; four women were treated with surgery, chemotherapy, and tamoxifen; one woman was treated with surgery and chemotherapy, and one woman with surgery and radiation. Seven women reported having mastectomies, four women reported having lumpectomies, and one woman reported having a lymphadenectomy.
With regard to non-medical information, five women reported being immigrants to Canada while seven were Canadian born. Seven participants identified their heritage as European-Canadian/American, two women identified their heritage as Eastern European, one identified their heritage as Canadian and Israeli, one identified her heritage as Chinese and Greek, and one identified her heritage as Afghani and Muslim. Ten women identified as a mother, co-parent or stepmother; two women did not have any children. Nine of the 10 women had children under the age of 13. One woman had adult children who were in their early 20s. In terms of highest level of education, three women had completed high school diplomas, four women had completed bachelor’s degrees, four women had completed master’s degree, and one woman had completed a doctoral degree. Nine women identified as heterosexual, two identified as Queer, and one did not identify their sexual orientation. Four women worked full time, three women worked part time, one woman was on maternity leave, one woman identified as a “stay at home mom,” one woman was on sick leave, and one woman was unemployed. Seven women reported being married and living with their partner and child(ren), one reported living with her common-law partner, one reported being separated from her husband and living with children, one reported being homeless, one reported living alone, and one reported living with friends.

**Participant summaries.** Following is a brief description of each participant.

**Alison.** Alison is a woman in her mid-30s, married, and of European-Canadian descent. She described her sexual orientation as heterosexual. She lives with her husband and sons in a rural area in Eastern Canada and works part-time in the educational field. Approximately one-year prior to the study, Alison was diagnosed with Stage II breast cancer and completed a mastectomy, followed by chemotherapy and radiation treatments. Once medical treatment was completed, Alison requested a meeting with her medical team to discuss the possibility of
reconstructive surgery, a prophylactic mastectomy on her second breast, and an oophorectomy. She had a strong desire to take all preventative measures to deter a cancer recurrence.

As a breast cancer survivor, Alison identified herself as a strong woman for a number of reasons. First, she explained that she took care of most household responsibilities for her husband and children. Second, Alison chose not to disclose her cancer experience to her children and consequently, believed that keeping this secret throughout treatment made her a stronger person.

Prior to her breast cancer experience, Alison felt content in her body. She reported never struggling with weight or body-image concerns. She exercised six days per week and enjoyed seeing how her body strengthened and toned over time. During chemotherapy treatment, however, Alison experienced significant weight gain, which she acknowledged bothered her to a great extent. Nonetheless, she recalled trying to look at the bigger picture, and be thankful that she was not given a life sentence with Stage IV metastatic breast cancer, for example. She reported maintaining a sense of hopefulness by repeatedly telling herself, “this is temporary”, and an inconvenience in her life; she was confident that her life would return to a “normal status quo” after treatment was completed.

**Erin.** Erin is in her mid-30s and of European-American descent, residing in an urban center in North America. She described her sexual orientation as Queer. She is separated from her partner, with whom she shares parenting responsibilities of their 12-year old child. Erin reported being homeless during the time of the study and living on her friend’s couch. During her early 30s, Erin was diagnosed with Stage II breast cancer. She completed a bilateral
mamectomy with lymph node removal followed by chemotherapy treatment. Erin did not wish to have any reconstructive surgery on her breasts.

Prior to her breast cancer diagnosis, Erin felt most comfortable identifying herself as gender queer with a butch identity. However, since her cancer treatment, she viewed herself as post-gender, explaining that she wanted her gender to be irrelevant to her identity.

Although Erin candidly spoke about feeling discomfort in, and disconnection from, her body immediately after her mastectomy, she also reported developing a strong sense of confidence in who she was and how she wanted to present herself and her body to the world after treatment. She explained, “It doesn't matter how beautiful you are like you could be the most traditionally beautiful person but if you don't have good self-esteem or if you don't carry yourself with confidence then you're not going to be appealing . . .”

With the help of several Queer breast cancer patients, Erin passionately developed a social movement to support other survivors undergoing breast cancer treatments. Erin is an advocate and supporter for individuals who choose non-reconstruction options after mastectomy.

**Jamie.** Jamie is in her mid-40s and of European-American descent. She described her sexual orientation as Queer. She is married and living with her wife and son. During her early 40s, Jamie was diagnosed with Stage II breast cancer and completed a bilateral mastectomy followed by chemotherapy treatment. Jamie chose not to have reconstructive surgery. Currently, Jamie identifies herself as a geek, Queer person, mother, scholar, bike rider, and a “pain in the ass”.

As a child, Jamie reported a number of instances where she felt disconnected from her body. For example, she recalled at a very young age being objectified by older men.
Additionally, while Jamie loved being physically active, her parents restricted her from playing sports with other children, and instead reinforced the notion of “acting like a lady”. Jamie used her schooling as a place to feel safe in her body, and achieve a sense of mastery. This positive connection ultimately led her down a path towards pursuing a career as a scholar.

Jamie reported that after undergoing a bilateral mastectomy, she felt more connected to her body, explaining that her gender identity better matched her androgynous self. She said, “I actually feel like my exterior more matches how I feel on the interior.” Jamie also emphasized that while the breast cancer experience was tragic, it did not significantly alter her overarching identity, explaining that she felt more connected to parts of herself that she chose beyond her physical appearance (e.g., career, motherhood and wife…etc.).

**Judy.** Judy is a woman in her late 20s and of European-Canadian descent. She described her sexual orientation as heterosexual. She lives with her husband and daughter in an urban city in Southwestern Ontario. During her mid-20s, Judy was diagnosed with Stage III breast cancer and completed neoadjuvant chemotherapy, followed by a lumpectomy and radiation therapy. Judy chose not to have reconstructive surgery.

As a child, Judy recalled being a sensitive yet resilient young girl. On the one hand, she explained that she would get emotional at the drop of a hat, but at the same time, she was incredibly determined and willing to challenge herself to get done what was needed. For example, as a young girl, she was home alone when one of her parents became acutely ill. Although scared and in distress, she sprang into action and called 9-1-1; in that moment she felt both strong and resilient, stating, “I kept it together. I did what needed to be done.”
Judy explained that her roles and responsibilities as a wife and mother have shifted since her breast cancer diagnosis. When Judy and her husband first married, she described having a very traditional role, focused on household responsibilities. However, once diagnosed with breast cancer, her husband took over most of her responsibilities. After completed cancer treatments, Judy explained that they have each found “a new balance” in their responsibilities and relationship as a whole.

Lauren. Lauren is a woman in her early 40s of Jewish heritage. She described her sexual orientation as heterosexual. She lives with her husband and children. At the time of her cancer diagnosis, during her early 30s, Lauren was single and living in the Middle East working long-hours for a large corporation. Although she felt a lump in her breast at the time, she neglected it for several months. Once she received her diagnosis, she returned to Canada to complete treatment with her immediate family by her side. She received a lumpectomy followed by chemotherapy and radiation treatment.

Lauren grew up with several older brothers in an urban city in Southwestern Ontario. She described herself as a “tomboy” who spent lots of time with her brothers. Lauren reported not identifying with a strong feminine identity prior to her cancer experience. However, since completing treatment, and the birth of her children, she has felt more comfortable expressing her femininity.

Maria. Maria is a woman in her early 40s of East-Asian and Greek descent. She described her sexual orientation as heterosexual. She lives with her husband and children in an urban city in Southwestern Ontario. Two years prior to the study, Maria was diagnosed with
triple negative Stage II breast cancer. Maria had a lumpectomy, followed by chemotherapy and daily radiation treatment. Maria chose not to have reconstructive surgery.

As a child, Maria lived as an expatriate, where she frequently travelled to different countries all over the world with her family. During the early 1990s, she settled in Canada and earned a Bachelor’s degree. At that time, she met her husband and subsequently made Canada her home base. Maria attributed her desire to travel the world, and her adventurous spirit to her childhood travels. She also described having an active lifestyle with her family; she enjoys scuba diving, biking, playing tennis, and zip-lining.

When asked to describe her connection to her body after her breast cancer experience, Maria said, “with my clothes on I feel okay. Without my clothes on [I feel] deformed [and] scarred”. Maria also indicated being frustrated with her cancer-related weight gain. Nonetheless, Maria reported feeling comfortable most of the time in her body.

**Megan.** Megan is a woman in her late 20s and of European-Canadian descent. She described her sexual orientation as heterosexual. She is engaged and living with her fiancé and child. A year prior to the study, Megan was diagnosed with estrogen positive Stage III breast cancer. She received a mastectomy and expanders in her chest, followed by chemotherapy. Megan is hoping to receive reconstructive surgery with breast implants in the near future.

When asked to describe her current identity, Megan stated that she is a mother first and foremost. Taking on the role of caretaker and mother has always been important to her; therefore, Megan felt “useless” during her cancer treatments. She described a lot of guilt putting her daughter and husband on the backburner while taking care of her physical self during her cancer treatments. However, after completing treatment, Megan believed her priority was to
make up for lost time with her child. Megan noted that she and her child have been very close since her cancer; they do everything together, such as crafts, singing, and dancing.

Megan said she felt very sexy prior to her illness. She took a lot of pride in her appearance and enjoyed body-based compliments from others. Megan noted that she was frequently complimented on her breasts and hair, which were tied to her femininity. She later highlighted that these changes to her body negatively affected her connection to her femininity.

**Morgan.** Morgan is a woman in her early 40s and of European-Canadian descent. She is divorced and living alone. During her early 30s, she was diagnosed with estrogen receptive Stage III breast cancer. She completed a mastectomy followed by chemotherapy treatment. Morgan also chose to have reconstructive surgery on her breasts. Currently, she identifies herself as a strong, independent, attractive and well-grounded woman.

Prior to her breast cancer diagnosis, Morgan explained that she was on a typical developmental trajectory; she owned a home with her husband and had small children. One week before her diagnosis, however, she planned to separate from her husband. Morgan was looking forward to starting a new life stage. However, once she received her cancer diagnosis, her plans changed, and her husband remained by her side during treatment.

During her first year as a breast cancer survivor, Morgan reported feeling very uncomfortable in her body; however, she refused to let this discomfort affect interactions with her children. Morgan believed that her children were a primary motivating force that gave her the strength to adjust and accept her altered body.

**Nikola.** Nikola is a woman in her mid-40s of Eastern-European descent. She described her sexual orientation as heterosexual. She is living with her fiancé in an urban city in
Southwestern Ontario. Two years prior to participating in the study, Nikola was diagnosed with Stage III breast cancer. She completed a mastectomy, followed by chemotherapy and radiation treatment. Nikola is undecided about reconstructive surgery on her breasts.

Nikola described her pre-cancer self as a young, beautiful, slim, world traveler professional. She described her life as “perfect” and enjoyed receiving praise about her body by men. Nikola and her fiancé planned to get married during the past year; however, she postponed the wedding by one year as she still felt sick and uncomfortable in her body from the illness. When describing her body at the time of the study, she said, “It’s ugly…I hate it”.

**Olivia.** Olivia is a woman in her late 30s of Eastern-European descent. She described her sexual orientation as heterosexual. She is currently living with her children and mother in an urban center in Western Canada. She separated from her husband to whom she was married for over 20 years, just prior to her participation in the study. One year earlier, Olivia was diagnosed with Stage II breast cancer. She had a skin and nipple sparing bilateral mastectomy, followed by chemotherapy treatment. Olivia chose to have reconstructive surgery on her breasts.

Olivia reported that she was born in a small town in Eastern Europe. Prior to immigrating to Canada, Olivia completed a Master’s Degree in the sciences. Around 2000, Olivia moved to Canada where she pursued a career in the health field.

Olivia explained that it has always been important for her to be perceived as a strong, tough and independent woman with a good heart. She stated that many of her medical colleagues perceived her in this way as well. Olivia indicated that she enjoyed the experience of being a beautiful woman and did not want this part of her identity to change after her cancer diagnosis. During chemotherapy, she said that she could not use her mascara because she had no eyelashes
or eyebrows; nonetheless, it was important for her to continue to wear makeup every day, as she did prior to her cancer diagnosis.

**Rachel.** Rachel is a woman in her mid-20s, single, and of European-Canadian descent living in a rural town in Southwestern Ontario. She described her sexual orientation as heterosexual. She was diagnosed with Stage II, estrogen receptor positive breast cancer approximately two years prior to the study. At that time, she was a graduate student completing a degree in the health field. At age 24, Rachel had a lymphadenectomy followed by chemotherapy and radiation treatment. She also completed fertility treatments. Rachel did not receive any reconstructive surgery on her breasts.

After the breast cancer experience, Rachel described herself as a woman, a helping professional, a sister, a friend, a survivor and a supporter. She also indicated that an important part of her identity was “giving back” to her community through volunteering.

Rachel mentioned that she felt more connected to her body after her treatment, in that she was more aware of her body cues. Prior to her illness, as a student, Rachel ignored aches and pains in her body and would worry about it later. In contrast, after her breast cancer experience, she attended to her body immediately.

**Sabrina.** Sabrina is a woman in her mid-40s and of South-Asian descent. She described her sexual orientation as heterosexual. She is married and living with her husband and children. Two years prior to her participation in the study, Sabrina was diagnosed with Stage I breast cancer; she received a lumpectomy followed by radiation treatment. She did not receive any reconstructive surgery.
Sabrina was born in a war-torn country within South Asia; she immigrated to Europe as a young girl, and eventually moved to Canada to marry her husband over 25 years ago. In addition to taking on the majority of household responsibilities for her husband and children, Sabrina has worked tirelessly to support immigrants who have recently moved to Canada and need additional support and resources.

Prior to her cancer experience, Sabrina explained that her priorities were other-oriented; she focused on looking after her children, her husband and her extended family. She indicated that she had little time to take care of herself. However, since her cancer diagnosis and treatment, Sabrina has put more effort into focusing on her needs and desires.

Sabrina also reported that around age 40, prior to her breast cancer diagnosis, she felt less desire to focus on her external appearance. As a result, she reported feeling comfortable and content in her body. She also mentioned that being a busy mom allowed her to focus less on idealized feminine beauty standards. After completing breast cancer treatment, Sabrina continued to report a positive connection to her body; however, she shared that at large public gatherings, including weddings, she feels some discomfort and self-criticism in her body.

**Procedure**

Participants were recruited through: a) print advertisements (see Appendix A) posted in diverse neighbourhoods in urban and suburban settings including community centres, stores, libraries, post-secondary institutions, and athletic facilities; b) young breast cancer specific events held by Rethink Breast Cancer Canada; and c) online advertisements through cancer-specific community organization websites such as Rethink Breast Cancer, Wellspring Cancer
Centre, Gilda’s Club, and Young Adult Cancer Canada. Inclusion and exclusion criteria were clearly outlined in the advertisements.

The study invited participants to explore the ways in which being a survivor of breast cancer may have changed how they see themselves in the world. In line with constructivist GT methodology, a process of theoretical sampling was used; for example, in order to acquire diverse connections to the body at survivorship, we added women with varied reported levels of embodiment ranging from very comfortable, mixed experiences, and very uncomfortable in their bodies. As well, participants associated with a Queer-specific community cancer group were actively recruited.

Participants living in Toronto were interviewed in a pre-booked office at a local university, or at the participant’s home. Participants living outside of Toronto were interviewed over online video conferencing. A telephone and/or email screening process was done for individuals interested in taking part in the qualitative arm of the study (See Appendix B). This ensured that all participants met inclusion criteria and that participants with diverse backgrounds were gathered. If the potential participant informally consented to participate in this study, an interview time and meeting place was set over phone/email. Formal written consent (see Appendix G) was obtained at the beginning of each interview. Participants were also given the opportunity at this time to ask any questions about the consent form and the research study. They were also asked to come up with a pseudonym of their choice, in order to protect confidentiality. All interviews were audio recorded. Upon completion of their interview, all participants were offered a list of suggested resources (Appendix E) and received a token gift of appreciation. The participants were notified that a summary of their interview would be created for them to review.
All interviews were transcribed verbatim. Identifying information was removed from the transcripts, and each woman’s name was replaced with the pseudonym they had previously selected. Next, a written summary for each interview was created outlining the participant’s story, organized in chronological order; the summary was emailed to participants, along with a note thanking them and encouraging their feedback on the summaries. The purpose of the written summary was twofold: to elicit feedback concerning content accuracy and to provide an opportunity for participants to alter their stories and allow the researcher to ask clarifying questions about the data collected (Antoniou, 2009). Providing participants with an active role in the current study was essential to the feminist-informed and qualitative life history approaches used. Summaries were revised based on participants’ feedback and clarification. Two women requested changes to summaries and transcripts, which involved changes to the wording of their quotations, as well as changes to certain dates of events.

The interview. The interviews ranged in length from 70 minutes to 100 minutes. The interviews began with a brief introduction by the researcher regarding her past work and interests in the field of psychosocial oncology. The researcher then inquired about participants’ own motivations to take part in the study, followed by demographic questions. Next, participants were asked to describe their current sense of identity in the world, which was grounded in their current lived experiences, roles, and identities. The researcher then presented participants with the central question of the interview, namely: participants’ reflections about the ways in which being a young breast cancer survivor led to shifts in their sense of identity, related in particular to having an illness, and to being a woman and a survivor of breast cancer. The researcher introduced the following central question to participants thusly: “How has being a young woman diagnosed and treated for breast cancer led to changes in the way you see yourself in the world
(as a woman but also as worker, partner, mother, friend . . . etc.)” Participants were asked to reflect on these shifts throughout their lives, leading up to and including their cancer experience and the aftermath, consistent with the life history approach (Cole & Knowles, 2001).

In addition to exploring each identity segment introduced by the participant, the interview was guided with probes found in the interview guide (see Appendix H). Probes included questions related to the integration of illness- and gender-related identities and role expectations. Probes also examined different described meanings and shifts related to well-being, self-care, and experiences of embodiment. Congruent with a life history approach, the researcher also followed participants in their discussions of their experiences, which promoted “a wide latitude of responses and richer insight” (Antoniou, 2009).

Data Analysis

The present investigation utilized the constructivist GT approach (Charmaz, 2006) for data analysis as this approach led to the construction of a conceptual understanding of the phenomenon under study. First, throughout the process of data collection, the researcher kept notes about her observations, thoughts, and ideas regarding each interview conducted. These notes were critical in gathering a broad understanding of the individual and their sense of identity over time, as well as non-verbal body language; these notes also provided ideas regarding gender, cultural, social, and medical structures and values influencing participants’ pre- and post-cancer experiences. Charmaz (2006) argued that utilizing interview notes allows researchers to explore and analyze “disparities between observed realities and written responses” (p. 36).

Next, memo writing was a pivotal intermediate step between data collection and written analysis of the work (Charmaz, 2006). It constituted a crucial process in GT because it prompted
the researcher to analyze the data and codes early in the research process (Charmaz, 1994b, 2002, 2006). Memos were most impactful in capturing comparisons and connections between and within participants. The memos were also used to highlight major chronological shifts in women’s (dis)connection to their body and identities leading up to and after the cancer experience. These memos were also useful in outlining the researcher’s preconceived assumptions, including an assumption that masking the cancer illness was, to some extent, used to maintain pre-cancer beauty standards. While participants frequently acknowledged this, making this assumption explicit was beneficial in noticing several exceptions, which included participants who reported masking their illness solely to feel *normal* or *healthy* in front of friends and family.

Data analysis was ongoing throughout recruitment of participants. Once theoretical saturation was reached, namely, no new themes or categories emerged after analyzing 12 protocols, women were no longer interviewed and recruitment stopped for the study.

Transcribed interviews were analyzed using NVIVO 10 software. Specifically, line-by-line coding was the first major step used in the data analysis. This process allowed the researcher to generate as many themes as possible from lower level text units. Given that the quantitative data collection and analysis had just been completed, staying close to the qualitative data through line-by-line coding was critical. The researcher and thesis supervisor wanted to ensure that the analysis was not shaped by results from the quantitative arm of the study at this stage of the analysis. The list of these initial descriptive codes was revised and discussed with the thesis supervisor. As initial coding progressed, the constant comparison method was used, in which data segments were compared to each other in search of similarities and differences both within and between interviews, in order to identify patterns and processes related to the emerging
categories (Charmaz, 2006). Initial lower level themes were reviewed and validated by the thesis supervisor.

Once initial coding occurred, an attempt was made to develop and maintain theoretical sensitivity, which Charmaz (2006) classified as, “stopping, pondering, and rethinking anew” (p. 135). Mills, Bonner, and Francis (2006) described it as the researcher’s ability to have insights into the data, to reconstruct meaning from the data, to have the capacity to understand the data, and to be attuned to the complexities of participants’ narratives (Mizevitch & Piran, 2012). Holton (2010) argued that theoretical sensitivity required two things from a researcher: analytic temperament and analytic competence. Analytic temperament allowed the researcher in the present investigation to maintain analytic distance from the data, tolerate regression and confusion, and facilitate trust in the power of preconscious processing for conceptual emergence (Holton, 2010). Analytic competence developed through theoretical insights and abstract conceptual ideas from various theoretical sources (Holton, 2010). Additionally, as part of the theoretical sampling process, concise yet in-depth conceptualizations of each individual participant and their life history were written leading up to and after the cancer experience. This process allowed the researcher to remain grounded not only in the data but in the social location and specific context of each individual participant throughout their cancer journey. In each of the participant conceptualizations created, questions raised included: “How do people construct beliefs,” and “Why do they think, feel, and act the way that they do” (Charmaz, 1990, p. 1,165). Charmaz (1990) suggested these are critical for this stage of theoretical sensitivity. In reflecting on these conceptualizations, it became apparent that women’s pre-cancer selves and ways of engaging with the world played an instrumental role in how their identities shifted during the
cancer journey. All written conceptualizations were reviewed and discussed with the thesis supervisor.

The following step involved focused coding, which has been described as more “directed, selective and conceptual” than the initial coding stage (Charmaz, 2006, p. 58). Focused coding involved using the most significant and/or frequently initial codes representing recurrent themes to sort through and synthesize larger segments of data. This stage also involved identifying codes to be included as major categories. Hierarchical coding schemes involving tentative sets of categories were created for each of the twelve research participants. This was conducted to ensure that the context within each interview, through participants’ life histories, was not lost at this stage of the analysis. In the process of focused coding, data segments and the relationships between them continued to be compared with one another within the context of each individual interview. A revised and consolidated hierarchical coding scheme for each research participant was created. The thesis supervisor then examined all schemes and consensus was reached regarding a consolidated overarching scheme for participants. The relationship between data continued to be compared both within individual interviews and between different interviews, in line with the constant comparison method. In the final stage of analysis, axis coding was used to bring the data back together again as a coherent whole (Charmaz, 2006); the researcher further specified the properties and dimensions of each core category, as well as their relationship to subcategories and themes within the overarching coding scheme. Memos and participant-specific conceptualization reports were also used to assist in defining properties of each core category, its association with other categories, and the chronological order of the categories.

The final hierarchy structure that resulted from the analysis contained six higher-level dimensions, or core categories: 1) Loss and Adversity, 2) Connection to the Physical Body, 3)
Social Power Related to Bodily Experiences, 4) Internalization Versus Rejection of Gender- and Illness-Related Discourse, 5) Relational Connections, and 6) Meaning and Life Goals. All six core categories appeared in all 12 participants’ interviews. Some participants articulated their experiences in greater detail in relation to specific categories than others. Some women were generally more detailed in their interviews. Therefore, while quotations from all participants are included in the manuscript, some participants’ narratives have been used more commonly to describe the meaning of particular categories. These six core categories were presented across three key life stages: A) Pre-Cancer Phase, B) Experience at Diagnosis and Treatment, and C) Post-Cancer Phase. The seventh chapter explores the six core categories across these three life stages.
Chapter Seven: Qualitative Results

The analysis of women’s narratives related to the central research question regarding changes to their experience of identity in the world during survivorship as related to breast cancer diagnosis and treatment led to the emergence of six core categories. These six core categories included: 1) Loss and Adversity, 2) Connection to the Physical Body, 3) Social Power Related to Bodily Experiences, 4) Internalization Versus Rejection of Gender- and Illness-Related Discourses, 5) Relational Connections, and 6) Meaning and Life Goals. The narratives included in each of these core categories were divided into three subcategories reflecting three distinct phases: Pre-Cancer Phase, Diagnosis and Treatment Phase, and Post-Cancer Phase.

Table 9 illustrates the six core categories and the three subcategories that fell under them. As indicated in this table, most of the narratives in these six core categories were tied to body-based experiences. Themes included under the subcategories were included in the text.

Table 9

<table>
<thead>
<tr>
<th>Core Categories</th>
<th>Pre-Cancer Phase</th>
<th>Diagnosis and Treatment Phase</th>
<th>Post-Cancer Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Loss and Adversity</td>
<td>● Body-based adversity ● Socially-based adversity</td>
<td>● Shock at diagnosis ● Experience of body-specific losses ● Unsolicited disclosure of illness</td>
<td>● Refocused on psychological well-being ● Experience of depression and guilt ● “There is a crack in...”</td>
</tr>
</tbody>
</table>
| 2) Connection to the Physical Body | - Acting in the world with a sense of freedom versus restriction  
- (Dis)comfort in, and attunement to, the body | - Body ownership and agency  
- Concerns over fertility treatment | - Discomfort, self-criticism, and fears in the altered body  
- Reconnection to the body |
| 3) Social Power Related to Bodily Experiences | - Increased joy and confidence in body through self-objectification  
- Rejecting power produced through self-objectification  
- Alternative non-body-based experiences of power | - Asserting rights and needs | - Recaptured social power through appearance and roles demands  
- Alternative non-body-based experiences of power  
- Lost Social Power through compromised appearance or objectification |
### Loss and Adversity

Participants’ narratives contained numerous examples of Loss and Adversity that took place before, during, and after their breast cancer experiences. The Pre-Cancer Phase described participants’ Body- and Socially-Based Experiences of Adversity. The Diagnosis and Treatment Phase involved three overarching experiences of loss between the initial diagnoses to the end.
stages of adjuvant treatment(s) including Shock at Diagnosis, Experience of Body-Specific Losses, and adversity through Unsolicited Disclosure of Illness. The Post-Cancer Phase described the period of survivorship as the first opportunity for participants to Refocus on Their Psychological Well-Being. As such, this phase also described the experience of processing depression and guilt, as well as strength and self-growth. Table 10 illustrates the subcategories explored in the first core category, Loss and Adversity.

Table 10

*Subcategories Found in the First Core Category, Loss and Adversity*

<table>
<thead>
<tr>
<th>Core Categories</th>
<th>Pre-Cancer Phase</th>
<th>Diagnosis and Treatment Phase</th>
<th>Post-Cancer Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>1) Loss and Adversity</td>
<td>• Body-based adversity</td>
<td>• Shock at diagnosis</td>
<td>• Refocused on psychological well-being</td>
</tr>
<tr>
<td></td>
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<td>• Experience of depression and guilt</td>
</tr>
<tr>
<td></td>
<td></td>
<td>• Unsolicited disclosure of illness</td>
<td>• “There is a crack in everything, that’s how the light gets in”</td>
</tr>
</tbody>
</table>

**Loss and Adversity: Pre-Cancer Phase**

When addressing Loss and Adversity in relation to surviving breast cancer, participants often described experiences of adversity they experienced prior to the breast cancer diagnosis. These experiences included both Body-Based Adversity that involved negative experiences related to their own bodies, and Socially-Based Adversity that related to negative events—often
bodily-based—with significant individuals in their lives. Often these narratives also included references to ways of coping with such adversity.

**Body-Based Adversity.** The majority of participants’ experiences of Body-Based Adversity, defined as negative experiences related to their own bodies, occurred in the childhood and adolescent years, though some experiences of adversity extended into their twenties and thirties. The following narratives exemplified such descriptions from childhood, through adolescence, and into adulthood.

Well I mean like I said I came from unfortunate circumstances and as soon as I had breasts I had my dad staring at me, I had boys staring at me. I was sexually abused when I was a kid.

(Jamie, early 40s at dx)

I’ve gone through a lot in my lifetime you know like I didn’t have a very easy upbringing like I was homeless when I was a teenager . . . I was brought up so religious so it was like my value was based on how I was in a family you know . . . and at some point it occurred to me just sort of like well they’re all fucking wrong and so like once I started having that feeling like wow they were all wrong and they were really in the wrong to treat me that way, to treat me as though I was so small and insignificant I guess I became very outraged . . . I am really fucking amazing [laugh] okay, I’m really awesome and I do have all these like assets to offer the world and myself and so it was like almost again like a reaction to being treated otherwise and to feeling otherwise for so many years.

(Erin, early 30s at dx)
I mean I went through hell in my entire twenties. I had cervical cancer when I was twenty, I had a stillborn when I was twenty-four, and then now with breast cancer it’s, I mean I’ve had a really rough go . . .

(Megan, late 20s at dx)

**Socially-Based Adversity.** Participants also identified Socially-Based Adversity, defined as negative events—often bodily-based—with significant individuals in their lives. While the majority of participants identified this type of adversity prior to their breast cancer diagnosis, they often highlighted finding strength and resiliency in these challenges. The following quotations reflect this emphasis on challenges and resilience.

. . . We all were hoping we going to have a fairy-tale life you know and that prince charming will come on a white horse and, and rescue us and we’ll live happily ever after. When I was nineteen years old my father passed away in [European country] and basically his life was, we could save his life but the [European country] government neglected. That’s where my, first reality came to life when I had to hire a lawyer and basically fight with the [European country] government while being a [European] citizen you know so this is the person and that’s where I became stronger. I became the fighter at that time so I believe this innocent girl kind of was somewhere in the background and I started to create this strong shield that would help me to survive . . .

(Olivia, late 30s at dx)

I was eight when [my parents] divorced. My mom was in Afghanistan but she wasn’t with us. . . . [And] my dad had to leave because of the war. He had to go to [European country] so we were left basically by ourselves with my grandma. . . . So yeah I think
I’ve always been that type of person that’s, you know you have to be strong. . . . [And] when you first get to Canada it’s like okay, they get you a health card, they get you to school, English classes, and then that’s it. You’re left, you’re supposed to you know learn everything. . . . If you’re new to Canada, it’s not easy.

(Sabrina, early 40s at dx)

. . . I was twelve my father died of a heart attack. My mother had gone to the corner store literally for ten minutes and left me and my two younger brothers at home with my dad. My dad went upstairs to take a nap or something and within those ten minutes he had his heart attack. So my brothers and I were alone with him. We heard him struggling and I, I don’t know if he was asleep or what but he wasn’t conscious and we heard him coughing and you know really struggling so we called 9-1-1 and in that time I felt I was really strong and resilient. I kept it together. I did what needed to be done . . .

(Judy, late 20s at dx)

**Loss and Adversity: Diagnosis and Treatment Phase**

Loss and Adversity during the Diagnosis and Treatment Phase involved three overarching and chronological experiences of loss that often accompanied participants as they moved through their experiences of diagnosis and treatment. These themes included: Shock at Diagnosis, Experience of Body-Specific Losses from Cancer (including hair and breast loss), and Experience of Adversity (and Marginalization) Through the Disclosure of Illness.

**Shock at Diagnosis.** Perhaps the most common phenomenon and experience of loss described by participants at the discovery of their cancer was that of shock and disbelief.
So everything is in shock like I just went under shock, I don’t understand what’s going on. . . The first person I told was my boss . . . I didn’t say I have breast cancer because I didn’t even realize I had breast cancer . . .

(Lauren, early 30s at dx)

Well since the diagnosis, everything just seemed so surreal like even until my chemotherapy was done I still didn’t even really believe it . . .

(Megan, late 20s at dx)

Not only were participants describing their experience of shock from the diagnosis, but many also spoke about the specific reasons why it was surprising for them. Women cited as factors their ages, lack of family history of cancer, and healthy lifestyles.

So it was a huge shock when I was diagnosed because like none of my aunts had it, my mom never had it . . . there’s really no history of cancer at all so it was a huge shock I think for them . . .

(Rachel, mid 20s at dx)

. . . I was thirty-five when I was diagnosed. I have no family history, I don’t smoke, I’m not a heavy drinker, I work out every day, I eat very healthy. I kind of went like okay, what the heck like you’re, I’m doing everything I’m supposed to do . . . I honestly really wasn’t expecting it would be cancer . . .

(Alison, mid 30s at dx)
**Experiences of Body-Specific Losses.** After their diagnosis, participants went on to complete medical treatments, which typically involved surgery on the breast plus adjuvant treatment(s) such as chemotherapy and/or radiation treatment. All women described some form of body-specific loss as a result of these treatments. The majority of these women viewed themselves as having been in the prime of their lives, feeling indestructible; subsequently, these losses had a major impact on their lives and those closest to them. Nikola, for example explained her desire to postpone her wedding due to her cancer diagnosis and treatment.

> Our wedding was supposed to be last year, it was supposed to be [date of wedding] but at that time I didn’t have my hair and I was still sick and burnt from radiation so I just asked my fiancé, I just said you know would it be okay if we postponed the wedding . . . prior to cancer I was you know a young, beautiful, slim [professional in travel industry] traveling the world . . . I always had you know men compliment me on my looks and suddenly now I felt like I just, overnight like I aged, I am no longer sexy, I have one breast, I put on weight through all the treatments . . .

(Nikola, early 40s at dx)

**Hair Loss.** The majority of the participants cited alopecia as one of the most challenging experiences endured during their cancer treatment. Participants typically described one of two reasons for why alopecia was such a disturbing form of body-based loss. First, women identified hair loss as a symbolic experience that moved them away from their pre-cancer identity as a beautiful, feminine woman.

> Probably the biggest thing for me that everybody laughs about is I had had long blonde hair [and] when I had to shave that off, [that] was a big thing . . . I especially had this
long blonde hair that I had always you know highlighted. I liked my hair so for me to have to shave that off was big . . . I felt like losing my hair was losing a big part of me . . . I just have always had long hair since I was a little girl. That’s just been how it always was and so yeah it, it sort of was a weird feeling. . . . I would say that was a big, probably one of the biggest things I’ve had to do in my life . . .

(Alison, mid 30s at dx)

. . . My entire life I had long hair so this was like, I felt so almost like a lesbian and everybody was making fun of me they’re like you’re not a lesbian. I’m like I know but my hair is like a boy buzz cut and I feel so unfeminine and I went to work and I stopped wearing skirts because I thought skirt and this short hair looks dumb so I started to wear pants . . .

(Nikola, early 40s at dx)

Second, hair loss also symbolized that participants were officially *cancer patients*; it reminded them that they were sick and not their normal healthy selves.

When I was losing my hair . . . like I was really emotional and it wasn’t because I was ugly or you know bald. I mean I wasn’t pleased with my bald scalp but you know aesthetically but it was real. It meant that I was actually dealing with cancer, you know [crying] I had cut my hair really short before I lost my hair and that was okay. I could deal with cancer but I appeared normal. When I started losing my hair it was, it was that reality that shit I have to face this, I have to deal with this, and I did not want to be
reminded of that. . . . When you look at yourself and you have no eyebrows and no eyelashes and no hair [crying] it’s, it’s scary to think that cancer is deadly . . .

(Judy, late 20s at dx)

The biggest thing [laugh] I think for me is my hair because I mean everything else I can cover and I can hide but my hair I mean as soon as I walk out the door everybody, I feel like I have cancer written my forehead and everybody just knows.

(Megan, late 20s at dx)

Interestingly, some women were less negatively impacted by the experience of hair loss during treatment. Morgan, for example, explained that she refused to let her hair loss bother her around her children.

I didn’t want the hair and the makeup, all the wigs are itchy and they make you flat and [laugh] it was a great pain in the butt right . . . I’m stubborn and I remember thinking right after my diagnosis looking at my four-year-old daughter and thinking like because [hair is] so female in nature you know . . . I had already struggled with so many body issues I, the one thing I wanted my kids to see out of this whether I lived or died I, I needed them to see that you can go through life and hit these speed bumps and progress through them with at least dignity and strength.

(Morgan, early 30s at dx)

Rachel also spoke about hair loss not being as devastating on her sense of womanhood.
. . . I’ve lost my lashes, I’ve lost my eyebrows, I’ve lost my hair, and like you’re still a woman without those things. Losing my hair didn’t really bother me . . . I found that losing my hair wasn’t really a big thing for me like it was kind of something that I expected.

(Rachel, mid 20s at dx)

**Breast Loss.** In addition to hair loss, participants also described the experience of breast loss as a result of either a lumpectomy or mastectomy. Similar to hair loss, the experience of breast loss differed between participants. Nikola, for example, described the challenges faced with losing one breast as someone who identified having the perfect body and breasts prior to her cancer. This loss was also stressed when she reflected on becoming a bride.

It’s losing the breast that was really what was difficult for me. . . . You know listening to myself this sounds awful . . . I think because everything else I can sort of control but this doesn’t, this I have no control over . . . what kind of a bride am I going to be where I you know have to wear a certain dress because I have to have a breast prosthesis and you know like it was really hard . . .

(Nikola, early 40s at dx)

Although Morgan chose to have reconstructive surgery, she too described feeling significant breast loss, and identified the experience of a “missing piece”; Morgan felt disconnected from her reconstructed breast.

. . . they really tried to focus on the fact that you’re going to not wake up with that missing piece, that missing part that you’re going to have to struggle with and I don’t think that’s accurate because it doesn’t look anything like your other breast and it doesn’t
look like a breast you had before right so now you’re not supposed to feel guilty because you’re supposed to be so thankful that you’ve woken up with two breasts instead of one.

. . . I didn’t relate to it as a breast.

(Morgan, early 30s at dx)

Erin, among others, articulated that she did not aesthetically identify strongly with her breasts prior to her cancer diagnosis; nonetheless, she described breast loss as a functional loss—a loss of means to breastfeed future children.

. . . my breasts were not something that defined me so that was a certain freedom that I had and I was really sad to lose them and I was really sad like I think the hardest part for me was thinking of not being able to breastfeed a child because I hadn’t let go of the idea of having a child of my own . . .

(Erin, early 30s at dx)

**Unsolicited Disclosure of Illness.** Toward the end of treatment, participants described the unsolicited disclosure of their illness to others resulting in added anxiety and a loss of control.

One time I ran into somebody from a support group . . . I ran into her in a biking venue and we were chatting and we were chatting about non-support group stuff you know and somebody comes up to us and says, “Oh hey so-and-so how do you guys know each other?” “Oh she’s in my breast cancer support group.” And I’m like did you really just break confidentially like that and announce to this guy that I’m a cancer patient so then what happened the next twenty minutes of the conversation was him grilling me about
cancer. . . . I was flying under the radar, I was just a person until she did that and I hate that right.

(Jamie, early 40s at dx)

Alison described her discomfort and anxiety around disclosing her illness to non-cancer patients during treatment.

. . . the hardest part is going out there and having a great attitude and feeling very strong and being okay with things and going out there and peoples’ comments like, “well you know I’ve heard that you know once you have cancer even if it goes away you know odds are it’s just going to come back later in your life . . .” I find the comments from people all of a sudden make you question yourself, question okay, am I just being a fool here, is this, like am I, you know am, am I being foolish here like this is this actually what’s going to happen and so I found then you start getting yourself scared and I don’t like being in that situation. I don’t like feeling nervous, I don’t like feeling scared . . .

(Alison, mid 30s at dx)

Some women also described feeling marginalized by others during their cancer treatment.

. . . my experience with the cancer was I felt very marginalized for the things that you mentioned like for being young and being you know a sexual minority.

(Erin, early 30s at dx)

. . . it’s funny [be]cause, I have young cousins and you know there was that kind of misconception that kids have a problem with bald head but really it’s adults. Kids don’t
care and they’ll be the ones that ask you straight out so, but it’s the adults that have this, are more the ones that are like oh that girl is bald like I wonder, they don’t think especially as a young person that oh she might have cancer . . . I feel like sometimes like you know the crazy girl with the fashion statement . . .

(Rachel, mid 20s at dx)

Loss and Adversity: Post-Cancer Phase

Loss and Adversity during the Post-Cancer Phase included three subcategories:
Refocusing on Psychological Well-Being—reflecting a shift from an exclusive focus on physical health to addressing psychological health; Experiences of Depression and Guilt—describing the challenges of processing the breast cancer experience and living with negative emotions; and the subcategory of “There Is A Crack In Everything, That’s How The Light Gets In”—examining the experience of resiliency and self-growth after diagnosis and treatment. In particular, women who described overcoming adversity at the Pre-Cancer Phase (i.e., Erin, Jamie, Sabrina, and Megan) were more likely to identify their breast cancer experience in these terms. Overall, the Post-Cancer Phase included a focus on psychological health, the integration and processing of negative emotional experiences, and the presence of hope and growth as a result of the illness experience.

Refocused on Psychological Well-Being. Following completion of medical treatment(s), many participants identified a new stage in their cancer journey during which they refocused on their psychological well-being. Participants also described it as a time when the “real work” began.
Well that’s what it’s been like [during treatment], I was just worried about my physical well-being because I had such a hard time and I didn’t think about my soul, I didn’t think about my heart you know and then as soon as treatment was over and I didn’t have to worry about my physical [well-being] then all of that came rushing in and my soul just felt broken . . .

(Megan, late 20s at dx)

. . . I’m just figuring out you know being able to process things as they come up and, because I think a lot of the emotional side of cancer happens after you’re done treatment. There’s really no time for it when you’re doing treatment like you’re just working on like surviving and getting onto the next day and you know that kind of thing but the real work really happens after you’re done.

(Rachel, mid 20s at dx)

**Experiences of Depression and Guilt.** Given that the Post-Cancer Phase commonly resulted in participants’ re-focusing on their psychological well-being, many women described the challenges of processing their illness experience, and subsequently living with negative emotions such as depression and guilt. Megan and Nikola, among others, described the experience of depression in the Post-Cancer Phase.

I would wake up and instantly start crying and I would cry all day about the stupidest little things . . .

(Megan, late 20s at dx)
I found a really good [psychologist] and he really helped me out a lot with my depression. . . . You know I [was] not happy like I used to be before. I [was] just always miserable and sort of negative and I [didn’t] want to do anything and go anywhere you know . . . I keep telling my brain just be happy you survived like everybody tells me, the psychologist tells me just be happy you survived but yes, I can keep telling myself but it’s just not working . . . 

(Nikola, early 40s at dx)

For many women, their experience of depression and distress resulted from a dissonance between their current and past selves.

I went to a psychologist and you know I said to him I’m just trying my best to get back to normal and he says what’s normal and I said well Nikola before cancer and he goes but that will never happen and I had to sort of deal with that because I still think sometimes I’m trying [to go back to somewhere I can’t be] . . . 

(Nikola, early 40s at dx)

. . . it was a difficult time you know I was depressed. I certainly was depressed. [I] cried all the time. You know you just don’t know your place. . . . I had come to [city in Canada], I stayed with my brother and his family and I was doing the treatment there and so I wasn’t in my own space, I was in somebody else’s, I was a guest. Then I went back to [country of origin] . . . I got back and it’s like, but this time you’re without your family, you need a lot of comfort, and I had to go to work and if you come back then you’re supposed to be working because you’re better . . . I had to go find an apartment
and I stayed at a friend’s house like it was so hard. It was so hard, it was so hard. It was one; it was definitely harder than the cancer. It was so hard. I was so depressed . . .

(Lauren, early 30s at dx)

Many women also described some experience of guilt in relation to their close family members following treatment.

Going through the treatment and everything I felt a lot of guilt for kind of putting my daughter on the backburner like she was the one taking care of me and as a five-year-old I mean that’s just not right, right? So now that I’m done my treatment I’m trying my best to make it up to her I guess so I feel guilty putting my attention anywhere else but her . . . for me to even go read a book in the bath for a half an hour a day I, I won’t do it . . .

(Megan, late 20s at dx)

. . . if I come back and I have like these genetic you know mutations that are linked with breast cancer then that affects all of my family and so that was really hard for me and I’m like well you know if I could choose to be the one who went through this so my other, my siblings or anyone else didn’t have to then I would definitely choose that but still it was like well I didn’t want to be the harbinger of bad news for them.

(Erin, early 30s at dx)

“There is a Crack in Everything, That’s How the Light Gets In.” Although the Post-Cancer Phase encompassed a painful form of processing of negative emotions in relation to participants’ illness, many participants also experienced the emergence of hope, resilience, and self-growth. In particular, women who described overcoming adversity at the Pre-Cancer
Phase—both body- and socially-based forms of adversity—were more likely to identify the breast cancer experience in these terms. Similar to Leonard Cohen’s lyrics, “there is a crack in everything, that’s how the light gets in.” Erin explained this notion in her own survivorship experience.

Once you become like cracked, if you have this crack in your sense of self or in your body or whatever in your psyche then that’s also making an opening for possibility. And so, so much about it is how you conceptualize what you’re going through . . . for me like losing my breasts, having gone, going through this experience ended up being very liberatory and I think that you know in a, in a very, in a very simple way the things that we think will break us also give us the chance to re-make ourselves and so if we can re-frame the way that we’re thinking about this experience then we can utilize it as potential for change . . .

(Erin, early 30s at dx)

Jamie also articulated strength and self-growth through her illness experience.

I do think we strengthened as a family you know I think adversity does strengthen you and you know so I think we, we had that experience as a family but I just wouldn’t say anything like these weird profound things that some people have. . . . There’s that sense of like wow this could really break me and this could like make me become a small weak person or I can use it and like fight with it and make it help, like utilize it to make me even bigger . . . I think I have plenty of reasons to be broken down and upset and bitter about life you know so just like to be out in the world and to be happy and not feel like it’s broken me I think is a huge accomplishment.
For Sabrina, her kids were a major source of strength and helped pull her through her depression following her cancer treatment.

. . . I could have just gone into a deeper depression you know and said okay, I’m going to die, I have cancer, and my kids I think motivated me. . . . Yeah because when, you get diagnosed with breast cancer you have two choices. You could either sleep all day, feel depressed, and go in a corner and cry and say I’m going to die or you could take the other option and say okay, I’m going to be a fighter, I’m going to you know beat this and do stuff that’s good for you . . .

(Sabrina, early 40s at dx)

Other women highlighted their own strengths in dealing with the breast cancer diagnosis and treatment. For example, Olivia highlighted how she’d always survived, having to fight in different capacities throughout her life.

I think in every single step in our life we are trying to survive and that’s how we live every day you know like we go to work, we eat, this is a part of this survival. It’s just a different strength so that when you hit a major problem in your life . . . [it] increases the whole speed, not the speed, the intensity to survive it, the ability or effort [to survive] . . .

(Olivia, late 30s at dx)
Morgan also recalled the Post-Cancer Phase, rejecting the notion that she had experienced major loss; instead, she viewed her illness experience as an opportunity for self-growth.

... I had come across a blog about a lady and basically she said “learning to live with my loss, I miss my boob,” or something like that ... I didn’t feel that it was a loss. I felt that it was you know an opportunity to learn more about me and who I want to be and how to get there in life and that this really accelerated the process for me and that really upset the ladies.

(Morgan, early 30s at dx)

**Loss and Adversity: Summary**

Participants’ narratives contained numerous examples of Loss and Adversity that took place before, during, and after the illness experience. The Pre-Cancer Phase described Body-Based Experiences of Adversity—reflecting negative experiences related to participants’ own bodies—as well as Socially-Based Experiences of Adversity—reflecting negative events, often bodily-based, with significant individuals in participants’ lives. Often, pre-cancer experiences of adversity included references to finding strength and resiliency, suggesting that participants who connected earlier found resilience with their post-cancer journey. The Diagnosis and Treatment Phase involved three overarching and chronological experiences of loss between initial diagnoses to the end stages of their adjuvant treatment(s). Three subcategories emerged including: Shock at Diagnosis, reflecting women’s shock and disbelief at their cancer diagnosis; the Experience of Body-Specific Losses, reflecting the physical and psychological challenges faced as a result of hair and breast loss; and the experience of adversity through the Unsolicited Disclosure of Illness, reflecting the adversity faced and marginalizing experiences of interacting
with non-cancer patients. Unlike the Pre-Cancer or Diagnosis and Treatment Phases, the Post-Cancer Phase underscored a critical time period in which participants had the opportunity to move away from an exclusive focus on their physical health, toward their psychological well-being. As a result, at survivorship participants were more vulnerable to processing negative emotions including depression and guilt; however, a number of participants who described past adversity and loss also described utilizing these experiences to learn how to live with and integrate these negative emotions into survivorship. The Leonard Cohen lyric “There is a Crack in Everything, That’s How the Light Gets In” was used as the final subcategory in the Post-Cancer Phase to examine the experience of hope and resiliency at survivorship. Most participants at this phase attempted to process and integrate strength, hope, and self-growth into their cancer-related losses. Connecting with pre-cancer experiences of resilience and strength when confronting illness-related losses seemed to enhance such self-growth processes.

**Connection to the Physical Body**

Participants’ narratives contained numerous examples of connection and disconnection to the physical body before, during, and after their illness experience. The Pre-Cancer Phase explored women’s narratives as they reflected on key opportunities to Act in the World with a Sense of Physical Freedom; however, some women were not provided with these opportunities and inhabited their bodies with restriction. Participants also explored experiences of Discomfort in, and Attunement to, the Body primarily as a result of bodily changes (i.e., puberty and pregnancy) before their cancer diagnosis and treatment. In the Diagnosis and Treatment Phase, two subcategories emerged: Body Ownership and Agency, examining women’s decreased body ownership as a cancer patient as well as ways to combat it; and Concerns over Fertility Treatment, examining the challenges of fertility treatments at the time of diagnosis. In the Post-
Cancer Phase, two contrasting subcategories were discussed: Discomfort, Self-Criticism, and Fears in the Altered Body; and the process of Reconnection to the Body after treatment. Reconnecting to the body at the Post-Cancer Phase facilitated participants critically and creatively questioning aspects of the self in order to reconnect with and care for their physical bodies in a way that aligned best with their post-cancer needs and desires. Table 11 illustrates the subcategories explored in the second core category, Connection to the Physical Body.

**Table 11**

*Subcategories found in the second core category, Connection to the Physical Body*

<table>
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<th>Core Categories</th>
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<td>• Acting in the world with a sense of freedom versus restriction&lt;br&gt;• (Dis)comfort in, and attunement to, the body</td>
<td>• Body ownership and agency&lt;br&gt;• Concerns over fertility treatment</td>
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**Connection to the Physical Body: Pre-Cancer Phase**

When addressing Connection to the Physical Body in relation to the survivorship phase of the breast cancer journey, participants often described powerful encounters of connection to, or disconnection from, their bodies prior to the breast cancer diagnosis. Two subcategories emerged including: Acting in the World with a Sense of Freedom versus Restriction, which focused on women’s opportunities for physical freedom, joy, and pleasure in the body; and (Dis)comfort in and Attunement to the Body, which focused on women’s experiences of safety...
and security needed to achieve comfort in the body. Participants described actively choosing a path, aligned with their pre-cancer selves, toward greater comfort and connection in their bodies.

**Acting in the World with a Sense of Freedom Versus Restriction.** Beginning in childhood and going through to adolescence and into adulthood, participants described opportunities to act in the world joyfully and with a sense of physical freedom. These opportunities usually occurred through a freedom of movement, travel, and exploration; however, many women, particularly due to their social location or interpersonal family dynamics, did not receive these opportunities. From a young age, some women did not have the freedom to act in the world, already feeling restricted in their bodies prior to their cancer diagnosis.

**Acting in the World with a Sense of Freedom.** Prior to their cancer diagnosis, some women reported opportunities for physical freedom, where they freely acted on and in the world with a sense of movement, travel, and exploration. With this physical freedom, participants described a sense of joy and pleasure in their bodies. Maria, for example, described her love of travel, which developed during her time as a child expat and was treasured still as an adult.

I grew up as an expat . . . we’d get swimming pool privileges at a hotel so like in [country] you’d belong to the [hotel chain] and you know you’d go to the pool every day . . . now it’s like I have friends all over the world . . . you know people are calling up and saying you know why don’t we go here together so you’ll meet up with you know people from all over the world and go to various places. For me I like it now maybe, well I guess I liked it also as a kid and I, for me I think it, that’s why I’ve always had like this traveling bug, like I need to move.

(Maria, early 40s at dx)
Nikola, as a travel-related professional, also enjoyed frequently travelling the world and being physically active with her partner prior to her cancer diagnosis.

... prior to cancer I was a [travel profession] travelling the world, had an amazing you know fiancé, my life was just so perfect... I wanted to be able for us to do lots like we travel a lot, we play tennis, we do other sports where, so that’s the person I was before.

(Nikola, early 40s at dx)

Other participants, like Nikola, also emphasized the joy they experienced being physically active, keeping healthy, and acting in the world with a sense of functionality prior to the cancer diagnosis.

I did feel comfortable with my body but I did work out more so not to have you know a perfect body or a nice body but more so to look after the heart as I did have you know grandparents and stuff like that with heart problems so I was kind of more, never was cancer a concern for me.

(Alison, mid 30s at dx)

**Acting in the World with a Sense of Restriction.** In contrast, many women were not provided with the same opportunities to act in the world with a sense of freedom. Some participants relayed traumatic early childhood experiences of physical restriction; they described acting on and in the world with a lack of functionality or competence. As a child, for example, Jamie loved playing sports and being physically active; however, upon puberty, her mother told her that she was no longer allowed to play.

I was informed by my mom that I could no longer play sports because now I was a young lady, oh yeah thanks for that so she forbade me from playing the sports that I really
wanted to play. I was told you know time and time again that now I had to act like a lady and I had to restrict myself and all this kind of bullshit and it just was so against my personality that I was like, I was like what the fuck can’t I choose what I want to do and you know that’s kind of just how that happened . . .

(Jamie, early 40s at dx)

For other women, like Sabrina, war and other challenges in their countries of origin led to them being uprooted to new countries. For Sabrina, such challenges resulted in some experience of restriction, and that of a lack of safety and competence as a young girl.

Yeah when I came to [Western country] in ’80, was it ’82, yeah ’84 I was in [European country] for two years there wasn’t anything in ’84 in [Western country] basically. I don’t know about Canada but there they didn’t have any agencies, nothing, nobody to help you, you’re just left on your own, and try to find stuff . . . I was fourteen.

(Sabrina, early 40s at dx)

Later in the interview, Sabrina explained that as an adult with children, at times she was also confined to the home, and to tasks with little to no pleasure.

. . . I’ve always liked helping people . . . but the part of caring and being like you know physical work like you know cooking, cleaning, those things I really don’t like it.

[Laugh] It’s, it shouldn’t define me but it sort of does I guess. [Laugh] . . .

(Dis)comfort In, and Attunement to, the Body. During times of bodily change, such as puberty or pregnancy, many participants, beginning at an early age, described feeling discomfort in and disconnection from their bodies. During these periods, women often reported a lack of
control in how they lived in their bodies. However, after having these negative bodily experiences, women described actively choosing paths to increase their connection and attunement to their bodies.

**Discomfort and Lack of Attunement in the Body.** Prior to the cancer diagnosis, many women described discomfort in their breasts and other body parts, particularly around times of bodily change (i.e., puberty, pregnancy). The discomfort typically stemmed from a lack of safety or choice in how they were able to portray their bodies. Jamie, for example, described a sense of discomfort with her breasts from a very early age, feeling betrayed by her body after puberty.

. . . I actually felt quite betrayed by my body when I was in fifth grade and I suddenly had boobs actually [laugh] . . . I was not allowed to wear sports bras. When I started wearing bras, my mom forced me to wear underwire, lift, and separate bras because I had to be ladylike. Yeah so I had like calluses on the side of my boobs from this underwire. I don’t know who the hell does this to their kids.

(Jamie, early 40s at dx)

Alison, for example, mentioned a period of mild discomfort during and after her three pregnancies.

. . . you know with my three pregnancies I had gained about eighty pounds the first couple and then about sixty the third one so you know I was quite large and that sort of thing . . . even if you kind of look in the mirror and you’re doubting yourself the people around you make you feel like you still look good . . .

(Alison, mid 30s at dx)
Other women described discomfort related to experiences of lack of safety or harassment. Erin, a woman who in her twenties had a strong sense of physical freedom, managed to identify an experience that resulted in her body lacking safety and becoming a site of discomfort.

You know I worked as a bartender and so as, you know as a bartender you’re always highly sexualized which was really frustrating to me so like in the world I didn’t wear a bra like for the most part like that was not something I ever wanted to do. I’m from [region]; we’re hippies but when I was bartending, I would always wear a bra or I would wear like, what do you call it a binder . . . I would wear those to work a lot just because I didn’t want the attention like on my breasts.

(Erin, early 30s at dx)

Comfort and Attunement to the Body. While several participants noted times of discomfort in, and disconnection from, their bodies, many women from an early age (adolescence) described actively choosing paths that enhanced their comfort and attunement. In particular, participants described feeling greater confidence and safety in their bodies in academic forums and during physical practices like yoga. Since puberty, Jamie, for example, felt betrayed and disconnected from her body; however, in grade eight and beyond, she found ways to create safety and comfort in her body by “flying under the radar,” which she viewed as an important component of her pre-cancer, childhood self.

I decided to run an experiment and actually turn in my homework and then suddenly I was getting As and Bs and I was like huh oh that’s interesting because suddenly people at school were not messing with me anymore. The teachers and the counsellors. They weren’t like on my case all the time . . . flying under the radar is a lot better than flying on the radar. So then eighth grade I decided to just kind of like I don’t know do school I
guess and I got all As . . . school became a place where I was actually safe and where you know things didn’t totally suck and so I then started seeing kind of academics as my way out . . . When I got to college I don’t know like suddenly I was safe every day and I could make my own decisions . . .  
(Jamie, early 40s at dx)

Other women found additional paths to feeling comfortable in their bodies. While Erin reported some discomfort being objectified in her body as a bartender, she described a broader feeling of confidence in her body outside her job. Part of her self-confidence as an adult was shown in her enjoyment of being topless in public.

I really loved my breasts but I mean I’m kind of, a, a nudist so I’d been, I mean I was topless wherever I could anyways like if I at work I was hiking and I was just like you know fuck everyone this is what I’m doing . . .  
(Erin, early 30s at dx)

While Alison also discussed feeling some mild discomfort in her body during pregnancy, she reported that as she got older, she felt a strong sense of comfort and connection to her body as an aspect of self-acceptance.

. . . I think as you get older I find that you’re more comfortable with who you are and I think you get to a certain stage as an adult where you’re kind of okay . . . I think there comes a time as an adult where you’re, you know that you’re exactly where you want to be, you know you don’t question things as much like I find that as I get older I, I sort of do more things for you know what I know is right for me . . .
(Alison, mid 30s at dx)

Others felt body attunement through physical practices, such as yoga.
I did a yoga teacher training course you know when I was in university in my first undergrad . . . I was like nineteen or something and so I started to learn more about it then . . .

(Judy, late 20s at dx)

**Connection to the Physical Body: Diagnosis and Treatment Phase**

Two overarching subcategories emerged at the Diagnosis and Treatment Phase. The first subcategory examined women’s Body Ownership and Agency. While most participants described decreased body ownership and agency—losing control of one’s body and putting faith in their medical team—some women also reported ways during medical treatment to combat decreased body ownership and agency. In addition to these hardships, many women who identified a desire for biological children after completing their medical treatment discussed the concerns of considering fertility treatment.

**Body Ownership and Agency.** At the Diagnosis and Treatment Phase, women commonly reported a decrease in body ownership and agency—losing control of one’s body and putting faith in their medical team and/or supportive system to help treat their body; however, women’s experiences of body ownership and agency were not entirely lost during this phase. Many participants described ways to combat decreased ownership. Specifically, women described the importance of maintaining past physical activity and cognitively challenging the
notion that their bodies have betrayed them. Instead, some women described the importance of working collaboratively with their bodies to not only heal but to regain control of their bodies.

**Decreased Body Ownership and Agency.** While many women identified the Diagnosis and Treatment Phase as a period of greater focus on the physical body, the majority of participants detailed a decrease in body ownership. Participants described having to hand their bodies over to the medical community and put faith and control into their medical team and treatments. Erin articulated:

. . . I think my sense of it is that like you get broken, like you get absolutely broken going through this treatment like without a doubt like I was completely lost. I had lost like every sense of like agency I felt like I, my body belonged to all these medical professionals and it belonged to like you know this list, laundry list of people but it didn’t belong to me for a really long time because you just have to hand over your body and say like okay make this body like whole again and make the body work so that I can get back into it . . .

(Erin, early 30s at dx)

Lauren described the experience of decreased body ownership as parallel to a rollercoaster ride, to having no control.

I think it was during radiation . . . I went with a friend every week to [Amusement Park] and we went on every ride . . . there’s such a parallel between going on these rides and facing your fear and the parallel of your fear of the cancer and letting go because you don’t control anything both in cancer and when you’re on a ride. You know it’s some seventeen-year-old kid who you hope is not drugged out of his mind and is running the
controls and when you’re on this crazy ride you have to let go because you have no control and when you’re on this crazy ride of cancer you have to let go cause you have no control . . .

(Lauren, early 30s at dx)

Maria described, in a particularly poignant manner, how the diagnosis and treatment compromised her ability to move and explore, making her feel trapped and isolated.

[Treatment] made me really, really tired . . . it was hard to get up sometimes. When they give you the white blood cell booster shot . . . it feels like your bones are melting inside, you can’t walk, you can’t move, you can’t sleep. There’s a lot of things you can’t do. . . . [During treatment, the doctors said], “oh well you know your white blood cell count is zero . . . anybody can give you something right now and you wouldn’t be able to fight it off.” I’m like trapped in isolation and people are coming to visit me with masks on and gowns on . . .

(Maria, early 40s at dx)

**Combating Decreased Body Ownership.** While participants described decreased ownership and agency during the Diagnosis and Treatment Phase, many women also described ways to combat decreased body ownership. Specifically, participants described re-engaging in past physical activities, as well as challenging the notion of being betrayed by their bodies. For example, during her treatment, Jamie, with the support of her wife, was able to maintain some level of physical activity and joy in her body.

. . . [My wife] took care of like just about everything so that I would have as much energy for like being with people, being a parent . . . I was able to like take [my child] to a bike
race, I was able to you know go to sporting activities and you know, and you know I was able to work at about the 85% level which is pretty damn good considering that really the only time I wasn’t at work was when I was actively receiving the chemotherapy . . .

(Jamie, early 40s)

Nikola and Olivia shared that physical activity was a major component to maintaining body ownership and well-being during medical treatment.

I played tennis . . . I actually even played a little bit through cancer whenever I felt up to it. . . . So tennis has always been sort of a, a thing I loved . . . I play tennis I don’t really concentrate on [cancer]. I don’t have much time to think about oh poor me I have cancer .

(Nikola, early 40s at dx)

Physical activity first of all it helps your body you know become stronger . . . every time you exercise it releases the hormones that positively affect everything . . . it helps you to heal you know and if there’s any bad cells it works on that so it helps you so this is just this part. Also when you exercise I find it makes you emotionally stronger because the more you do that, the stronger you say yes, my body can do that . . . there is lots of potential in my body.

(Olivia, late 30s at dx)

Similarly, Maria continued her travelling.

Well after surgery we went to Myrtle Beach for a week to recover. After chemo I went to Chicago and New York to recover. . . . Then after radiation I flew to Italy for two weeks
to recover. [Travelling] takes you away from Canada, it takes you away from [the hospital]. . . . Travelling for me was just like a way to escape it all. And it is a way to recover because you're not constantly, you know you’re not doing everything that you’re doing here so you’re not doing the run of the mill, I don’t know painting the house, dropping off the kids at school, picking them up after . . .

(Maria, early 40s at dx)

Another interesting perspective toward continued positive body ownership involved challenging the viewpoint of body betrayal, as described by Olivia and Judy. They, instead, worked collaboratively with their bodies.

I did not see cancer as my enemy because it was, the cancer is our own cells so you cannot be angry at your own cells you know which means you won’t be angry at yourself you know so there was something that triggered my body to become sick and you cannot be angry at the sick person. I decided to help my body you know through this tough cancer journey and you know and being always connected to my body . . .

(Olivia, late 30s at dx)

I spoke with one other young woman once and she got a double mastectomy and she described it as my breasts had you know betrayed me [laugh] and I was getting rid of it and that is exactly the opposite of how I felt and feel. I feel like my breast was sick and I need to tend to it and we’re going to work together like the whole body will come together to help this breast and you know that, that we all work together . . .

(Judy, late 20s at dx)
**Concerns Over Fertility Treatment.** Many women who were single and/or had no biological children discussed the possibility of receiving fertility treatments during the Diagnosis and Treatment Phase. Lauren, for example, revealed feeling overwhelmed when learning about her medical treatments, as well as the possibility of fertility treatments.

I was single; the first thing my oncologist said to me, “You have to go to a fertility specialist and freeze your eggs.” And it was like just as shocking as hearing about a double mastectomy like what do you mean? You’re still going to have cancer, I can’t deal with fertility issues now. I’m going to deal with the cancer like so that was you know . . . you had to freeze fertilized eggs and I didn’t have a sperm to do that so I was just, it was just so huge to deal with that and to deal with cancer at the same time.

(Lauren, early 30s at dx)

Some of the younger women described desiring biological children in the future; however, participants were aware that fertility treatments increased their risk of recurrence, or caused delays in adjuvant treatment. Judy decided not to go through with fertility treatments in order to start her chemotherapy as soon as possible.

. . . Ideally I would love to have at least one biological child but when I found out the doctor told me I had an aggressive form of cancer . . . they gave me the options to have eggs frozen and embryos frozen. I looked into it, I did research it, I spoke to the doctors, and they said well okay, so this is the process, you’ll have to wait until your next period and then we’ll have to harvest the eggs and it would have taken about an extra month before I could have started chemo and I said no, thank you. I just wanted to start chemo
as soon as possible so I kind of made the decision that I do want to but I didn’t want to delay treatment and risk not being around for my embryos [laugh] . . .

(Judy, late 20s at dx)

Megan spoke about the challenges faced in deciding not to have fertility treatment.

. . . Once I got the cancer diagnosis we went to a fertility clinic and that was a complete waste of time. . . . They wanted $10,000.00 the following day. . . . They wanted to pump me full of oestrogen whereas my cancer is estrogen positive. So my husband was like uh-uh, no way, you know this is ridiculous for me to put my life in danger to bring, possibly bring a child into the world and then after my chemo and now I’m going to be starting hormone therapy . . . we were both totally on two different pages and then we just got frustrated with each other because we were just miscommunicating and misunderstanding why each other was upset because I thought that he would be like okay, you know I’m leaving her to find someone who can have my babies . . .

(Megan, late 20s at dx)

**Connection to the Physical Body: Post-Cancer Phase**

Connection to the Physical Body at the Post-Cancer Phase involved two contrasting subcategories: Discomfort, Self-Criticism, and Fears in the Altered Body, which typically occurred immediately after completion of treatment and involved experiencing a lack of safety, trust, or care for the body; and Reconnection to the Body, which typically occurred several months to years after completing treatment and involved increased body ownership and agency, body attunement, self-care, and physical freedom.
**Discomfort, Self-Criticism, and Fears in the Altered Body.** Upon completing medical treatment(s), many women described feeling discomfort in their body. Similar to the experience of disconnection described at the Pre-Cancer Phase, participants discussed a lack of safety and choice in how their post-treatment bodies were presented to the world. In addition to their discomfort, participants reported experiences of self-deprecation and self-critical comments made on their bodies. Participants also discussed their fears of recurrence at this time. Morgan, for example, discussed the discomfort she felt in her body following reconstructive surgery.

I was very uncomfortable with my body because I had, it wasn’t just losing a breast. I had a complete mastectomy with reconstruction on the table and then that sort of failed. It didn’t, my body didn’t like it so it started encapsulating the implant so I had to gain some weight and then I had a TRAM. . . . [Then] I had, my hysterectomy . . .

(Morgan, early 30s at dx)

Nikola described feeling a strong level of discomfort and disconnection to her post-cancer body while shopping for new clothes.

. . . I remember I went to The Bay and I was looking for some new clothes because none of my pants fit so I took my clothes off and I was still just, I had very little hair and I’m you know putting these jeans on, trying them on, and I just looked at myself and I started crying because my legs were huge, I had like no breast, and I’m, and I just thought oh how can I even buy any clothes. I might as well wear sweatpants because what’s the point?

(Nikola, early 40s at dx)
Nikola, among other women, also described feeling a lack of safety in her body after medical treatment.

. . . I don’t feel like Nikola, I think like a piece of me has been stolen and will never come back you know the Nikola before and the Nikola after are like two different people and I don’t know if it’s almost like if your virginity has been taken away or just the, I think it’s the sense of safety like I will never, ever have that feeling of safety like I’ll always now worry like I am, I feel like it’s been stolen from me.

(Nikola, early 40s at dx)

Feeling discomfort in their bodies also prompted many women to discuss the challenges they faced in their sex lives following treatment—connecting with their partners physically with their altered body. Erin, for example, described experiencing a loss in libido after her medical treatment, resulting in an inability to connect with anyone at a physical level.

. . . Like I said I didn’t feel like I was in my body and so those things definitely affected my, my sex drive and my ability to connect with anyone on a physical level. . .

(Erin, early 30s at dx)

Similarly, Nikola described the difficulties she faced in being intimate with her partner following treatment.

. . . At home in the bedroom where like I would not have like sex unless I have, I’m wearing something right so I always have lingerie on, I always have the breast prosthesis in and like if you know my partner tries to like touch me there or something I am just absolutely like it terrifies me because I don’t want him to see me that way.
After treatment, participants were also self-critical of their bodies. Erin described her self-deprecating humour following her surgery:

I think coming out of surgery I did lose a lot of that confidence. . . . In my own mind like I thought people will think I’m a monster and those are words that I had in my brain like I would jokingly call myself Franken-Tits and like when I think about that now it makes me cringe because like that was self-deprecating humour and at the time I was just like well that’s how I’m dealing with it but now it seems just kind of hurtful . . .

(Erin, early 30s at dx)

Megan, among others, described being self-critical of her weight gain after medical treatment.

. . . I’ve always been like a hundred pounds soaking wet—and with chemo I mean it sounds stupid but I gained fifteen pounds and on a five-foot stature that’s huge. I mean that was a massive difference so my weight I’m struggling with, taking off my shirt, and looking at my breast with no nipple is really hard.

(Megan, late 20s at dx)

Likewise, a number of women described a period after treatment where they were unable to look at themselves in a mirror.

I don’t know I still struggle looking in the mirror every day.

(Megan, late 20s at dx)
...I’m not there yet. I can’t even look at myself in the mirror. I was like so fragile emotionally...

(Lauren, early 30s at dx)

Finally, a number of participants reported fears of recurrence, which subsequently kept them disconnected as well as hyper-vigilant in their bodies.

Actually anytime I have like an ache or a pain or a headache that’s exactly where my thoughts go and it’s been kind of you know it’s been hard to keep it out of my head. ... I do think about it and I am very aware that, that I don’t know why I got it and then it could come back.

(Judy, late 20s at dx)

I think there, sometimes your mind goes to that dark place. It’s not every day, maybe once a month or you lose somebody to breast cancer that’s, or if you get your mammogram I had mine in January you’re you know thinking what if they find something else you know of course yeah you remember it all, like not all the time but you have days where you, you go there.

(Sabrina, early 40s at dx)

**Reconnection to the Body.** At some point following medical treatment, many participants described being able to reconnect with their bodies. Four themes emerged from this including: a) returned body ownership, b) increased body attunement, c) increased self-care activities, and d) increased physical freedom. As previously discussed in the Pre-Cancer Phase,
women were able to reconnect to and re-engage with their body after experiencing instances of disconnection by actively choosing a path of greater comfort and attunement. However, one fundamental difference between the Pre- and Post-Cancer phases was that the experience of reconnection to the physical body after a breast cancer experience resulted in greater opportunities to re-assess components of the self, and subsequently experience a self-transformation. Often participants were able to critically and creatively question aspects of the self in order to reconnect with and care for their physical bodies in a way that aligned best with their post-cancer needs and desires.

**Returned Body Ownership.** Many women described a general experience of feeling broken, and then regaining ownership and agency in their body. Erin, for example, discussed the importance in making the active choice, following treatment, to rebuild parts of herself that she deemed worth having while simultaneously letting go of other parts that no longer felt important.

But once you’re broken, like your life is shattered but then you, there’s this very empowering sense of, I mean you can get into this mindset of thinking I get to choose how I rebuild myself like I get to choose which parts of myself are worth like recreating and saving and which can I let go because there’s also that sense of like well every part of my life like from like my intellect, my body, like my heart, like everything is shattered like I get to choose what I want to like carry with me and maybe there are things about you that you, you need to let go and here’s this opportunity because everything about you is broken. . . . It’s a huge process. Some people can do it very quickly and for some people it takes a really long time. I feel like it was a year and a half before I felt like I owned my body again . . .

(Erin, early 30s at dx)
Olivia also discussed the importance of rebuilding or changing oneself following treatment.

After the treatment when all this became a quiet time when I can think about what just has happened for the last year I realized I have to change myself. I need to give up on the, some of this leadership activities and ask for help and let people, and let my friends to help me you know and support people to help me you know.

(Olivia, late 30s at dx)

Changing oneself involved, at times, pursuing a whole different career. Prior to her cancer experience, Alison was interested in becoming a personal trainer but doubted her abilities. After her medical treatment, part of her process of regaining body ownership was by finally becoming a personal trainer.

. . . I feel that now I definitely have the confidence to be able to enrol in the classes, get my certification, and be able to work as a personal trainer. I do feel that to be a personal trainer not only do you have to be in physically good shape which I feel I am but also mentally as well . . . had I not had the breast cancer I don”t know if I would have had the guts to do it.

(Alison, mid 30s at dx)

**Increased Body Attunement.** Many women discussed in survivorship experiencing increased attunement to their bodies. Erin, for example, explained that she spent time touching the scars on her chest, re-engaging with physical and sexual sensations.
...this is the body that I have now... I’ve been very mindful in engaging with the body that I do have so that the sensations of the body that feel good to me... I think one thing is you know so... I don’t have breasts. I have like two five-inch scars; that’s what I have and the last thing that ever grew in that area is nerve tissue so if you touch the area like my experience... you don’t have just that very clean sensation. It’s like sending lightning bolts up and down the area. I think if I hadn’t done like intellectual work around it that would remain just a very bizarre sensation but I sort of decided like wait that’s fun like that’s a really interesting, fun sensation I can think about it in that way and so then that became like, like a source of like physical, sexual pleasure for me.

(Erin, early 30s at dx)

Other women, including Rachel and Judy, also described experiencing a greater attunement to their bodies after treatment.

... I’m more aware of my body so like I’m more in tune in the sense that like if something hurts I take care of it... it’s just really more conscientious of how my body is feeling and what I can do if there’s pain or anything like that to reduce that or, and making, you know even in eating making healthier choices and not just picking the fast thing... I take a second kind of thought about it before whereas before cancer I didn’t really think about it at all...

(Rachel, mid 20s at dx)
I have to wear this ugly looking sleeve that people notice but I’m definitely, my relationship with my body is that, that I’m kind to it and that I work with it and that I listen to it and I try to work with it.

(Judy, late 20s at dx)

**Increased Self-Care.** A number of women also discussed placing greater value on self-care activities in survivorship. Sabrina, for example, came from a background where it was customary to spend time focusing on housework and children; however, in the Post-Cancer Phase, Sabrina placed greater importance on carrying out self-care activities.

. . . I take care of more of myself. I am very involved in the, in the dragon boating so if there is a party that night sorry can’t make it . . . I think, more aware of my needs. If I need to take a nap, I’ll go take a nap, the laundry can wait. If I don’t feel like I’m super tired and I can’t cook okay, guys we’re getting pizza. . . . Always think of yourself first, take care of yourself because at the end of the day no one else will. If you’re really sick, yeah somebody might come and give you a cup of tea but at the end of it, it’s all on you. Always self-care is the most important thing.

(Sabrina, early 40s at dx)

Other women also reported that they felt good in their bodies when taking more time to look after themselves.

. . . I guess before I just kind of thought I guess for me too I was always busy, I was always you know like okay, I don’t have time so I’m just not going to wear makeup today, I got to take the kids to their places, and this and that and I was out . . . whereas now I kind of think I take more of the time to look after myself and take care of myself.
Increased Physical Freedom. Following treatment, a number of participants also discussed experiencing an increase in physical freedom through travel and exploration. Maria explained that she re-emerged after finishing her treatments feeling an even stronger “travel bug” than she had before.

[ Cancer ] allowed me to travel more. It’s probably pushed us to do more spur of the thing, spur of the moment travelling than it did before like the Australia trip we kept putting it off, we kept putting it off because we kept thinking you know we were going to need like more time to do it . . . there was always an excuse . . .

(Jamie, early 40s at dx)

Jamie and Lauren, among others, described experiencing an increase in physical freedom through movement after their treatment.

. . . physically it’s a hell of a lot more comfortable. I could just like run downstairs now. I can just like run across the yard. I can go over a pothole on my bike. It doesn’t hurt.

(Jamie, early 40s at dx)

Lauren trained for a triathlon after her treatment. She explained that the level of physicality was good for her body and soul; it gave her a sense of empowerment and mastery.

. . . I meet the trainer and I said . . . I just had you know breast cancer, here’s my story . . . my body is so weak . . . I have no muscles, my left arm is like so weak because of the lumpectomy . . . etc. He goes so do you want to do a marathon or a triathlon? . . . and I like laugh in his face. . . . I couldn’t ride my bike . . . I haven’t swam since I was a child. . 
Six months later I did my first triathlon. . . [On date], I did my first triathlon which of course I probably never would have done or never gotten to it if I hadn’t had had breast cancer you know that’s like again one of the gifts I got from breast cancer . . this is healthy and this is good for my body and for my soul and sense of achievement and something different . . .

(Lauren, early 30s at dx)

Connection to the Physical Body: Summary

Participants’ narratives contained numerous examples of connection and disconnection to the physical body before, during, and after their illness experience. The Pre-Cancer Phase explored key opportunities, encountered by women, to act in the world with a sense of freedom; however, not all women were granted these opportunities, and many inhabited their bodies with restriction. Bodily changes related to puberty or pregnancies sometimes led to feelings of discomfort and disconnection in the body. From an early age, many women who experienced instances of discomfort also described actively choosing paths that enhanced comfort and attunement.

In the Diagnosis and Treatment Phase, two subcategories emerged. The first subcategory, Body Ownership and Agency, examined women’s decreased body ownership as a cancer patient as well as ways to combat it. For example, while many participants described feeling betrayed by their bodies as a result of the cancer, others chose to combat this belief by challenging the notion of a betrayed body; instead, these participants described the importance of working collaboratively with their bodies, to heal and regain control over them. The second subcategory,
Concerns over Fertility Treatment, examined the challenges faced when dealing simultaneously with fertility issues and cancer.

The Post-Cancer Phase outlined two contrasting subcategories: Discomfort, Self-Criticism, and Fears in the Altered Body; and Reconnection to the Body. Similar to the Pre-Cancer Phase, these subcategories in the Post-Cancer Phase described a disconnection that occurred when the physical body faced drastic changes. As such, many participants described actively choosing a path that led to greater comfort and connection in their bodies. However, unlike with the Pre-Cancer Phase, the path used to reconnect to the body at the Post-Cancer Phase generated an opportunity to re-assess pre-cancer components of the self and, subsequently, experiences of self-transformation. The Post-Cancer Phase invited participants to critically and creatively question aspects of the self in order to reconnect with and care for their physical bodies in a way that aligned with their post-cancer needs and desires.

**Social Power Related to Bodily Experiences**

Many women in this study described experiences of social power—the relative degree of privilege/power associated with one’s appearance and social location (i.e., gender, socio-economic status, sexual orientation, ethno-cultural group membership, and health status)—before, during, and after their breast cancer experience. The Pre-Cancer Phase contained three key subcategories including: Increased Joy and Confidence in the Body Through Self-Objectification, examining participants’ experiences of joy and confidence in the body obtained through compliance with objectified and idealized images of women; Rejecting Power Produced Through Self-Objectification, examining the social power obtained by rejecting such experiences of objectification; and Alternative Non-Body-Based Experiences of Power, examining
participants’ alternative experiences of power, confidence, and mastery. The Diagnosis and Treatment Phase described women Asserting Rights and Needs when interacting with their health care team and families. Unlike the Pre-Cancer and Diagnosis and Treatment Phases, the Post-Cancer Phase described a period of survivorship when participants not only had to adjust to their post-cancer bodies, but also had to adjust to and compensate for the subsequent changes in social power originally identified in the Pre-Cancer Phase.

At the Post-Cancer Phase, three subcategories emerged: Recaptured Social Power Through Appearance and Role Demands, whereby participants who placed greater importance on their feminine appearance successfully internalized body-based objectification and thereby regained social power; Alternative Non-Body-Based Experiences of Power, examining participants who used alternative, non-body-based means to regain power, confidence, and mastery; and Lost Social Power Through Compromised Appearance or Objectification, examining participants who were both unable to internalize forms of objectification in order to regain social power, or use alternative non-body-based measures to develop new forms of power, confidence, and mastery. Table 12 illustrates the subcategories explored in the third core category, Social Power Related to Bodily Experiences.

Table 12

Subcategories found in the third core category, Social Power Related to Bodily Experiences

<table>
<thead>
<tr>
<th>Core Categories</th>
<th>Pre-Cancer Phase</th>
<th>Diagnosis and Treatment Phase</th>
<th>Post-Cancer Phase</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Power Related to Bodily Experiences</td>
<td>• Increased joy and confidence in body</td>
<td>• Asserting rights and needs</td>
<td>• Recaptured social power through</td>
</tr>
</tbody>
</table>
When addressing Social Power Related to Bodily Experiences in relation to surviving breast cancer, participants often described the internalization or rejection of social power obtained through self-objectification prior to their cancer diagnosis and treatment. Many women described their twenties as a period of heightened focus on their bodies as objects of the male gaze; however, a small subset of women described rejecting social power through self-objectification. Three overarching subcategories emerged at the Pre-Cancer Phase including: a) Increased Joy and Confidence in the Body Through Self-Objectification—relying on the acquisition of social power through the objectified body; b) Rejecting Power Produced Through Self-Objectification; and c) Alternative Non-Body-Based Experiences of Power, examining social, occupational, and relational roles that created alternative forms of power for women.

**Increased Joy and Confidence in the Body Through Self-Objectification.** Prior to the cancer diagnosis, many participants, particularly those in their twenties, discussed the acquisition
of social power through self-objectification. Women described the importance of embodying idealized feminine appearance standards and using their bodies as capital to secure romantic partners. For example, Megan discussed the joy and confidence earned in being complimented on her hair and breasts before having breast cancer.

I felt sexy, I always did my makeup. I was very proud of how I looked. I did my hair every day, people would always compliment me on how I did my hair you know. People would look at me . . . I mean my whole life, honestly, my boobs and my hair were the thing that people would complement me on, and both of those just got, were gone in an instant. I’ve always loved my hair, I’ve always loved doing it, and my boobs were one of the things that I was [laugh] most proud of . . .

(Megan, late 20s at dx)

Similarly, Judy described that, prior to her marriage, she placed a greater focus on her appearance, attempting to fit in with ideal feminine appearance standards.

. . . when I was younger it was more so the outward appearance. When I was younger I would wear the uncomfortable shoes. It gave me blisters; it gave me you know like my calves would ache. I mean it was terrible and not a chance would I not wear those shoes. You know so it was all about doing it for the outside world; the gym membership, everything . . .

(Judy, late 20s at dx)

Many participants also described using their bodies as capital, which was believed to attract and secure romantic partners.
I don’t know when you’re young and you attract whoever you want that’s great . . . get this guy and you know at university it’s wonderful. You can use it all and you know when you get married you’re like yes; well this is the way to keep them right.

(Maria, early 40s at dx)

Well before like I said I wanted to be beautiful and sexy for him and I wanted him to adore me. I think most women do that and you know I wanted to be able for us to do lots like we travel a lot, we play tennis, we do other sports where, so that’s the person I was before.

(Nikola, early 40s at dx)

Although Alison did not place great attention on her appearance prior to her cancer diagnosis, citing her busy lifestyle with her children as the reason, she reported feeling embarrassed that her appearance was not a greater priority in life.

I think it was just more before I kind of just never really knew, I mean not that I want to say I don’t, everyone knows how to put on makeup but I guess before I just kind of thought well I don’t really know what to do. I just was more natural and I guess for me too I was always busy, I was always you know like okay, I don’t have time so I’m just not going to wear makeup today, I got to take the kids to their places, and this and that and I was out, I would always feel not embarrassed to be out with makeup but I would always think oh geez I’m not looking my best today and that sort of thing

(Alison, mid 30s at dx)
Rejecting Power Produced Through Self-Objectification. While a number of women described readily using their bodies as objects, others reported the rejection of obtaining power through self-objectification. Although the majority of participants acknowledged being an object of male gaze, these participants chose not to internalize body-based comments or expectations by disregarding and condemning feedback, hiding their bodies, or relying on alternative values regarding the body and their self-worth. Jamie, for example, was objectified both as a bike racer, wearing tight-fitting clothes, and at work in a male-dominated field. While cognizant of it, she disregarded and/or explicitly condemned the comments made toward her.

Yeah so I mean being a bike racer you wear kind of like tight-fitting clothes you know and the number of dumb shit that men say and then being in a field that’s male dominated. The number of dumb shit things that men say are unbelievable yeah . . . I tell them to “fuck off.”

(Jamie, early 40s at dx)

As a bartender, Erin was also cognizant of the objectification she encountered at work. Although she described herself as having exceptional confidence and physical freedom prior to breast cancer, at work she avoided objectification by hiding her body with a bra or binder.

. . . when I was bartending I would either, I would always wear a bra . . . I would wear those to work a lot just because I didn’t want the attention like on my breasts.

(Erin, early 30s at dx)

At times, women referred to other values or priorities that helped them resist objectification. Sabrina, for example, referred both to her religious values and to being older as
protecting her from relying on self-objectification in order to obtain social power prior to her cancer diagnosis.

I think I became more, I wouldn’t say more religious but more important things in life then you know just worrying about how your body is. I think as you get older you’re expecting you know okay, you’re not going to have the body of a model. It’s, that’s it. You, maybe you know change, lose ten, twenty pounds or whatever but other stuff it’s not actually going to change anything like you’re getting wrinkles, your hair is you know getting grey and stuff like that so you, you kind of come to the conclusion that okay, this is it, you can’t really, okay, you can go get plastic surgery but how long is that going to last for?

(Sabrina, early 40s at dx)

**Alternative Non-Body-Based Experiences of Power.** Several women described alternative non-body-based experiences used prior to their cancer diagnosis to gain power, confidence, and security. Participants described gaining power through a sense of competence, functionality, and accomplishment in social, relational, and occupational roles. Jamie, for example, described the confidence and power she gained both in herself and others as a bike racer, an academic, a partner, and a parent.

I’ve worked my ass off to be a professor and I trained hard to be a bike racer and you know we made a decision together to grow our family to include a child you know it gives me my confidence, my power . . .

(Jamie, early 40s at dx)

Similarly, Maria identified the power that came with climbing the “corporate ladder.”
. . . I mean that was all about let’s see how much work we can put in, let’s move around, let’s, you know there’s like, you know you’re always trying to climb, climb up the corporate ladder.

(Maria, early 40s at dx)

Social Power Related to Bodily Experiences: Diagnosis and Treatment Phase

Social Power Related to Bodily Experiences during the Diagnosis and Treatment Phase included one subcategory: Asserting Rights and Needs. Participants’ ability to assert themselves during this stage of the breast cancer experience was challenged on a number of occasions.

Asserting Rights and Needs. Participants’ ability to assert their rights and needs waxed and waned during the Diagnosis and Treatment Phase of their breast cancer experience. At the onset of the cancer diagnosis, many participants made claims of general discomfort with asserting their needs in their daily lives. At this time, the majority of women described feeling dismissed by their health care team involved in the diagnosis of their cancer. Only once physical symptoms worsened did many women increasingly choose to assert their rights with medical staff. After a clear diagnosis was provided, participants typically described taking on an other-oriented focus—concentrating their worries and concerns on loved ones over themselves. As participants moved into the treatment stage of their cancer experience, many women re-affirmed their ability to assert themselves with medical staff and family members.

A number of women’s narratives described a general discomfort with asserting their rights and needs, not wanting to confront or upset others in the process.
Do I assert myself? Well, I hate confrontations . . . when I think of confrontation I think of the person will be upset with me or the person will be upset period and I don’t like that . . .

(Judy, late 20s at dx)

Nonetheless, women commonly started to assert their needs after feeling neglected at the time of diagnosis. As young women, many participants reported feeling dismissed by healthcare professionals—most were initially told that their symptoms were not indicative of cancer. Thus, many participants described a worsening of symptoms before they chose to, more forcefully, assert their needs.

I would say it was May 2013 and I had an ultrasound done. The doctor said it was fine, it was, I forget what she called it but she said it was fine, that it was benign, and that it’s very normal for people of, women of my age to get these and I had no history, family history of breast cancer so, and I’m so young so it's fine. Then I actually, a couple of months later I noticed a discharge coming you know from that breast and I, I said listen, this is not right, something is wrong . . .

(Judy, late 20s at dx)

Another common experience at diagnosis involved participants shifting their worries and concerns toward their loved ones.

My initial experience with cancer was that like I didn’t think about myself, I didn’t worry about myself like it was just, it was so far back in my priority list because everyone else was either thinking about how it affected everyone else . . . I didn’t talk to anyone for, for
a while but she didn’t come back into town for a week and as soon as she found out she came back into town but you know my sense was like well I don’t want to put you guys through . . . my original sense was like I’m not going to put you guys through this like I can just go away and not deal with it and I’m like I’m just going to go to South America or something.

(Erin, early 30s at dx)

However, as participants moved from the diagnosis stage to the treatment stage, women described a greater urge to assert their needs as patients.

But you know I didn’t care [how I spoke to the doctor]. I really didn’t care. I thought okay, well this is really important so maybe there’s a little bit of, yeah maybe I am okay with confrontation in certain circumstances. . . . I’m really aware of my own needs and boundaries now . . . it kind of happened because I started with chemotherapy so it, it almost happened through that process. I mean I became aware of it quite early on in the process but I would say it was, it was a long time before I could implement it the way I thought it. . . . I suppose it still is a work in progress.

(Judy, late 20s at dx)

Yeah I mean clearly I chose to not have reconstruction . . . it did take me a little bit of time. People always think it was like so easy for me but it did take me, and when I say a long time like a couple of weeks maybe but I think, I chose to not have reconstructive surgery, I chose to have a bi-lateral mastectomy . . . I mean for anything that I want to do it’s like you do the least harm possible and make the least cuts possible and you know,
and so I wanted to have the best healthiest outcome with the least medical and especially surgical intervention so even just from that perspective it was just very like pragmatic for me.

(Erin, early 30s at dx)

As a university student, Rachel’s parents assumed she would move into their home during her treatment. However, Rachel chose to stay close to her university town and receive treatment at a local hospital where she felt comfortable.

I’m originally from [town 1 in Canada] which is just north of [city in Canada] but I chose to do my treatment in [town 2 in Canada] because I was actually working at the hospital doing music therapy at the time . . . I knew the hospital and so I decided to do my treatment here which I think made it hard in terms of my relationship with my parents because they wanted me home and couldn’t care for me full time . . .

(Rachel, mid 20s at dx)

Social Power Related to Bodily Experiences: Post-Cancer Phase

Social Power Related to Bodily Experience during the Post-Cancer Phase included three separate but related categories: Recaptured Social Power through Appearance and Role Demands, reflecting women’s desire to maintain power through the body by heightening their appearance investment or previous role demands; Alternative Non-Body-Based Experiences of Power, examining women’s ability to use alternative forms of power by taking on tasks and activities that reject societal, cultural, and familial norms; and Lost Social Power through Compromised Appearance or Objectification, reflecting participants’ resistance to accepting body-based praise and compliments, or their immersion in alternative forms of power as
survivors. Overall, the Post-Cancer Phase included a focus on women’s attempts to regain social power with or without the use of their bodies.

**Recaptured Social Power Through Appearance and Roles Demands.** After completing medical treatment, some participants reported returning to the capture of body-based power through a heightened focus on embodying idealized feminine standards as well as fulfilling gender-based role demands. These were typically the same participants who reported some increased power in their bodies through self-objectification at the Pre-Cancer Phase.

Like many women in the study, Alison was not satisfied with her appearance after her cancer treatment. She was less capable of acquiring appearance-based social power, unlike during her Pre-Cancer Phase. After completing treatment, Alison booked a photo-shoot for herself, to regain confidence and find new joy in her body and appearance. The photo shoot and pictures provided her with a new experience of body-based social power. To hold onto this renewed power, Alison, like others, described a greater investment in idealized feminine appearance demands relative to the investment made prior to their cancer diagnosis.

I always tried to do things to kind of keep me happy . . . so I booked myself a [photo shoot] . . . it’s one of those things where you walk in and I had no makeup on, had no hair, and I took a picture of myself and then I, she took an hour for her to do my makeup. She did my makeup, put on the false lashes, I put my wig on, you know put on an outfit, and started doing the photo shoot and when you look at the picture of when you walk in to the photo-shoot pictures I mean it’s unbelievable that it’s the same person like you, you can’t even get over it . . . I would say since [the photo shoot], I actually, probably wear more makeup now that I kind of sort of know how to do it than I did before.

(Alison, mid 30s at dx)
Judy also reported desiring a greater focus on her appearance after completing cancer treatments.

... I kind of you know didn’t work on improving my appearance [pre- and during cancer] and now since then I feel like I would like to, I would like to invest more in and I’m not sure what that means but that’s where I’m at right now.

(Judy, late 20s at dx)

Some participants received appearance-based praise and internalized it as a form of power. For example, following her treatment, Alison received and internalized body-based praise from her girlfriends.

A lot of my close girlfriends you know always very good support, always telling me you know you still look so good, you know you, I would never guess you gained ten pounds like very good support system where you feel like you still, even if you kind of look in the mirror and you’re doubting yourself the people around you make you feel like you still look good ... 

(Alison, mid 30s at dx)

**Alternative Non-Body-Based Experiences of Power.** While some women, in order to maintain social power, heightened their appearance investment after completing medical treatment, others used alternative non-body-based experiences to regain power, confidence, and mastery. Many participants who discussed at the Pre-Cancer Phase using non-body-based experiences to attain power were more likely to re-create these experiences after their breast cancer experience. In survivorship, these alternative non-body-based experiences typically
involved the rejection of societal, cultural, or familial norms. Participants also described finding a community of like-minded others to facilitate this process and gain power.

Jamie discussed the importance of making an impact on others through her job by “kick[ing] down barriers . . . and ask[ing] for forgiveness later.”

At work . . . if I see somewhere where I think I can have an impact then I’ll go for it even, even if I don’t necessarily have the approval of my colleagues. For example, recently there was an article about a young girl in [city in USA] who is transgender and she had an article written about her . . . and she had written in there I want to be an [scientist] when I grow up and so I wrote her and I said come to the university for a half day and do some science and have a great time. . . . I didn’t give a shit that some people were like why are you making such a big deal about this girl. . . . In my job I can just do stuff like that . . . anytime I can just kick down a barrier I just do it and I ask forgiveness later . . .

(Jamie, early 40s at dx)

Sabrina used her dragon boat racing team as an alternative means of regaining power. Although many of her relatives were against the activity, she chose to pursue it anyway.

I got to go practice and in my culture that’s like a big no-no. Well you missed this because of your dragon boating so it’s, it has and it hasn’t because I really don’t share these things that I do with other close family members . . . so if there is a party that night sorry can’t make it.

(Sabrina, early 40s at dx)
Morgan discussed the value in moving away from the cancer community to find like-minded women who rejected idealized feminine appearance demands.

I think that was the key. It was finding people that felt this way outside of this breast cancer community and being able to engage with people that maybe other women that felt this they didn’t meet the [societal] standard either and it wasn’t because they lost a breast so that really helped me. That really helped me realize that you know I have a lot more to offer than a few scars.

(Morgan, early 30s at dx)

Lost Social Power through Compromised Appearance or Objectification. While the first group of participants used their appearance and past role demands, and the second group used alternative non-body-based tasks to regain social power, the third group of participants found it challenging to recapture social power. Like the first group of participants, these women commonly described experiencing increased joy and confidence in their bodies through self-objectification at the Pre-Cancer Phase. However, after their treatment, these women focused on their compromised appearance. Participants were both unable to internalize forms of objectification to regain social power or use alternative non-body-based measures to develop new forms of power, confidence, and mastery.

Many women were struck by the changes in social power they experienced as a result of their body-based cancer-related changes at the Post-Cancer Phase, and experienced significant distress as a result.

. . . I was twenty-five, I was a young [job in travel profession] you know we would go and we would go to a club and you know I, I got asked out a lot so like before I started dating [my partner]. I would always have you know [people] ask me out, [travel
professionals] ask me out, I was kind of popular and now I feel like I am like this oh she had cancer. . . . It just took a huge dive for me like you know how some woman are let’s say you know they’re already overweight to begin with right so they put on more weight and they don’t really [care], but for me I’ve never been fat before and I didn’t know what that’s like. I have never been bald before. I didn’t know what that’s like. I thought I could handle it but then when it was happening [but I can’t].

(Nikola, early 40s at dx)

Nikola showcased her understanding of her pre-cancer body as a critical form of capital in her romantic relationship. She viewed her body as a primary means of keeping her partner interested and connected to her; however, with her “damaged” post-cancer body and subsequent reduction in power, she reported feeling insecure in the relationship.

Suddenly now I felt like I just, overnight like I aged, I am no longer sexy, I have one breast, I put on weight through all the treatments. . . . I am thinking thank God I have [my partner] and we’re engaged because if I didn’t meet him and I was single how the hell would I date and what would I tell these people like I am damaged now so they don’t look at me like they did before like I notice that yeah I don’t get the same, people don’t treat me the same as they did before . . .

(Nikola, early 40s at dx)

Megan and other women in the study explained that their partners frequently complimented them on their appearance in the same ways they did prior to their illness; however,
in the Post-Cancer Phase, participants could not accept these compliments in the same way they had in the past. They no longer gained power from these appearance-based forms of praise.

My husband has been the biggest supporter and it doesn’t matter what I’m wearing or what I’m doing. I mean he tells me I’m beautiful ten times a day and I know that he believes that. He believes that but I just, I don’t know I still struggle looking in the mirror every day. . . . I can’t get in that mood when I don’t feel sexy and I think that that’s a lot harder for, for guys to understand. I know my partner is having a really tough time trying to understand it and then you know he’ll poor more attention on me and it’s like no, I don’t, I don’t want that but oh it’s so awful to say but I just, I guess I just want space and that’s tough to explain to someone you know, particularly, I mean he just wants me to feel beautiful.

(Megan, late 20s at dx)

Social Power Related to Bodily Experiences: Summary

Participants’ narratives described the importance of social power, and common avenues for women in obtaining social power through embodying idealized and objectified images of women; nonetheless, this avenue for obtaining social power was resisted by some women. The Pre-Cancer and the Diagnosis and Treatment Phases set the stage to best understand women’s experiences of social power at survivorship.

In the Pre-Cancer Phase, three subcategories were discussed: Increased Joy and Confidence in the Body Through Self-Objectification—women acquired confidence and security in relationships through self-objectification; Rejecting Power Produced Through Self-Objectification—women sought to obtain power through other means, or resist self-
objectification through holding other values; and Alternative Non-Body-Based Experiences of Power—women used non-body-based experiences to gain power, confidence, and security.

During the Diagnosis and Treatment Phase, social power was most commonly expressed through women Asserting their Rights and Needs.

Finally, the Post-Cancer Phase contained three subcategories that divided participants into three groups. The first group, Recapturing Social Power Through Appearance and Role Demands, recaptured social power by embodying idealized images of women or returning to perform feminine role expectations such as taking care of others. The second group, Alternative Non-Body-Based Experiences of Power, rejected societal, cultural, or familial norms to achieve alternative forms of power, confidence, and mastery. The third group, Lost Social Power Through Compromised Appearance or Objectification, found it hard to recapture social power, which became a source of distress for them.

More poignantly though, women in the first (Recapturing Social Power Through Appearance and Role Demands) and third (Lost Social Power Through Compromised Appearance or Objectification) groups at the Post-Cancer Phase were typically the same women who endorsed Increased Joy and Confidence in the Body Through Self-Objectification at the Pre-Cancer Phase. Thus, women who gained most of their power, confidence, and self-worth through self-objectification prior to their cancer diagnosis were more likely to attempt to recapture social power through appearance and self-objectification. While some reported feeling successful in their ability to do so, primarily through greater appearance investment (group 1), others (group 3) who were already highly invested in their appearance felt unable to recapture this form of social power and hence experienced increased distress. Likewise, the second group described in the Post-Cancer Phase (Alternative Non-Body-Based Experiences of Power) was
typically the same group of women who’d endorsed Alternative Non-Body-Based Experiences of Power at the Pre-Cancer Phase. Prior to their illness, these women were successfully able to acquire power, confidence, and self-worth through alternative non-appearance or self-objectifying means. In sum, participants who tended to self-objectify at the Pre-Cancer Phase continued to do so after their breast cancer treatment; others who connected with alternative aspects within themselves—outside of self-objectification—that resulted in social power, were less likely to return to self-objectification at the Post-Cancer Phase.

**Internalization Versus Rejection of Gender- and Illness-Related Discourses**

Participants’ narratives encompassed a number of gender- and illness-related discourses before, during, and after their breast cancer experience. The Pre-Cancer Phase contained two subcategories: Description of Self in Relation to Expected Gender Roles and Identity, reflecting participants’ compliance with or resistance toward traditional heteronormative gender role expectations and identities; and the Illness-Free Identity, reflecting most participants’ disconnection from illness as a young person. The Diagnosis and Treatment Phase explored women’s Heightened Versus Rejection of Appearance Focus, exploring participants’ attempt to preserve their feminine and healthy pre-cancer selves through their appearance; and the Desire to Escape the Sick Role, reflecting most women’s need to disconnect from the illness at treatment.

Within the Post-Cancer Phase, two overarching subcategories emerged: Shifts in Description of Self in Relation to Expected Gender Roles and Identity, reflecting positive and negative shifts in the ways women described themselves in relation to gender roles, identity, and standards of appearance; and Connection to Survivor Identity, examining participants’ connection to the *cancer survivor* identity. Table 13 illustrates the subcategories explored in the fourth core category, Internalization Versus Rejection of Gender- and Illness-Related Discourses.
Table 13

Subcategories examined in the fourth core category, Internalization vs. Rejection of Gender- and Illness-Related Discourses

<table>
<thead>
<tr>
<th>Core Categories</th>
<th>Pre-Cancer Phase</th>
<th>Diagnosis and Treatment Phase</th>
<th>Post-Cancer Phase</th>
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<tr>
<td><strong>Internalization Versus Rejection of Gender- and Illness-Related Discourses</strong></td>
<td>• Description of self in relation to expected gender roles and identity</td>
<td>• Heightened versus rejection of appearance focus</td>
<td>• Shifts in description of self in relation to gender roles and identity</td>
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<tr>
<td></td>
<td>• Illness-free identity</td>
<td>• Desire to escape the sick role</td>
<td>• Connection to survivor identity</td>
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Internalization Versus Rejection of Gender- and Illness-Related Discourses: Pre-Cancer Phase

When addressing the Internalization Versus Rejection of Gender- and Illness-Related Discourses in relation to surviving breast cancer, participants often described engaging with these discourses prior to their breast cancer. Two predominant subcategories emerged:

Description of Self in Relation to Expected Gender Roles and Identity, which reflected participants’ compliance with or resistance toward gender role expectations and identity; and the Illness-Free Identity, reflecting most participants’ disconnection from illness as a young person.

**Description of Self in Relation to Expected Gender Roles and Identity.** Prior to the breast cancer diagnosis, participants spoke about themselves in relation to their gender roles and
identities. Participants described a spectrum of connectedness to expected gender roles and identities. On the one hand, many women discussed a compliance with and connectedness to traditional feminine roles and responsibilities; many of these participants held strong beliefs about their duties as women to take on household and child-related responsibilities. These participants also typically reported heightened associations to heteronormative standards of appearance. On the other hand, some women described their rejection of expected gender roles and identities; these participants typically had more flexible views on gender and standards of appearance. They also typically had more fluid descriptions of themselves in relation to their gender-related identity.

Many women described a compliance with and strong connection to traditional feminine roles and responsibilities. Prior to their breast cancer diagnosis, they also reported more definitive views regarding how to be a woman in the world.

Before cancer like I grew up in [European country] where you know my mom did everything and my dad didn’t do much right. My mom cooked and clean and took care of the family and my dad did oil change on the car that’s about it . . . so I was like that in the beginning with [my partner] right. I just felt that’s sort of my job so I always did everything for him. I clean and cook and did everything.

(Nikola, early 40s at dx)

I’ve been a stay-at-home mom pretty much since my daughter was born so yes doing the womanly duties is my main job.

(Megan, late 20s at dx)
[Being a woman] means you’re nurturing, you’re patient, you’re always putting yourself second putting other people first. . . . I think that has always been like I don’t know drilled into me that you know you’re second and men are always first . . .

(Sabrina, early 40s at dx)

Other women prior to their cancer diagnosis demonstrated a compliance with and connection to traditional feminine roles and responsibilities, though on a lesser scale. These women indicated more flexibility in relation to traditional gender roles and identities. For example, while Olivia described taking on traditional feminine roles and responsibilities in her family, she also felt overwhelmed in these roles, feeling little to no support from others, including her partner. As such, she began to question the extent of these roles in her life.

. . . I was always [doing] everything in the family. . . . [It was] a lot to take plus kids’ activities and school and everything. [I had] this heavy load of the entire family [on] just my shoulders in addition to the full-time job. . . . It was too much . . . something needed to change.

(Olivia, late 30s at dx)

When asked what it meant to be a woman, Morgan, among others, emphasized a number of roles outside the traditional gender roles that she felt connected to prior to her cancer diagnosis.

[Who am I as a woman?] I’m a mother, I’m a, I’m a businesswoman, I am a productive member of my community I would say . . . I love being a business owner and I love being an entrepreneur and I, I’m, I’m good at getting things started and going.
Another group of participants described greater psychological flexibility around gender roles and identities prior to their cancer diagnosis. In fact, many of these women described feeling less connected to heteronormative standards of gender and beauty. Jamie, for example, described feeling little to no connection to a feminine identity; she chose not to place herself within the context of the traditional gender binary of feminine or masculine. Instead, she described herself as gender fluid.

. . . Being in the field of science and engineering a lot of people talk a lot about women and science and everything else and you know internally I know that I’m much more kind of in the middle, gender fluid, whatever but I have been assigned women by other people or female by other people like all my life and I don’t know it’s not important enough to me that I would like fuck it and say no . . . I just kind of deal with it I guess. Does that make any sense? I just kind of accept it.

(Jamie, early 40s at dx)

Jamie’s psychological flexibility and fluidity with respect to her gender-related identity was further portrayed through her conception of beauty. She explained finding beauty outside normative means of viewing it.

. . . when you see an athlete like going at it it’s like an amazing thing. And so it’s like I don’t know their motion . . . when you see somebody in that Zen place it’s a beautiful thing.

(Jamie, early 40s at dx)
Likewise, Erin described a flexible viewpoint in relation to traditional gender roles and identities. Prior to her cancer diagnosis, she had little to no connection to a feminine identity but instead described feeling connected to her butch identity.

I used to be more, very much more like macho in the way that I carried myself . . . I was more butch before this process like in the way that I dressed and my mannerisms like in my attitude in every way you know it was a part, it was a part of my identity to like be butch . . .

(Erin, early 30s at dx)

Erin also showcased her psychological flexibility around gender- and appearance-related constructs through her understanding of beauty and the body.

. . . I mean I think the sentiment is, is out there that like beauty is being comfortable in your own skin and I absolutely believe that and you know that’s it. I mean being beautiful is being comfortable and confident in who you are and what you are and it’s something that, that surpasses your physical body . . .

(Erin, early 30s at dx)

Prior to her cancer diagnosis, Rachel also demonstrated psychological flexibility in relation to constructs of gender and appearance.

. . . For me you know being a woman was just kind of being true to yourself and for each, you know each person may experience being a woman differently . . . I mean I never really associated beauty necessarily with the outside appearance but I know society does a lot. . . . Beauty for me is the way you treat people and how much you care about other people and taking the time to do, to just take that, the next steps . . .
Unlike the last three participants, Lauren did demonstrate a strong connection to traditional feminine roles and identities; however, she also chose not to abide by traditional feminine roles, identities, or appearances. Lauren attributed this to an incident as a child where she was mistaken for a boy.

I remember my dad cutting my hair once [as a child] and it was like so short and I got mistaken for a boy and how you know like traumatic all these things are of course. . . . I didn’t take it so bad. I mean it was annoying but it made me think of myself too and, you know deal with my own femininity. . . . It’s not that I didn’t put on makeup [prior to my diagnosis] and it’s not as if I didn’t have dresses. . . . I did. But I think it was much more internal than external in terms of [my] feeling of femininity . . .

(Illess-Free Identity. Not surprisingly, as young people, most participants reported no connection to an illness identity prior to their cancer diagnosis. Most women felt young, strong, healthy, and ill prepared to deviate from their current life path due to illness.

I remember years earlier being at some job and somebody came to talk about breast cancer but I guess it’s so far removed because I was twenty, you know in my early twenties like, like it’s like you know when you hear and you don’t hear at the same time so it was that kind of thing.

(Rachel, mid 20s at dx)

(Lauren, early 30s at dx)
. . . before I was more conscious of you know thinking I’m going to live forever . . . I just always thought this happens to other people, it happens to old people, it doesn’t happen to me. I was supposed to get married, everything, my life was so perfect . . .

(Nikola, early 40s at dx)

Only one woman described significant health challenges (previously identified as a Body-Based Adversity) that resulted in a pre-breast cancer illness identity.

. . . I mean I went through hell in my entire twenties. I had cervical cancer when I was twenty, I had a stillborn when I was twenty-four, and then now with breast cancer it’s, I mean I’ve had a really rough go . . .

(Megan, late 20s at dx)

Internalization Versus Rejection of Gender- and Illness-Related Discourses: Diagnosis and Treatment Phase

The Diagnosis and Treatment Phase encompassed two subcategories related to Internalization Versus Rejection of Gender- and Illness-Related Discourses. The first subcategory, Heightened Versus Rejection of Appearance Focus, reflected women’s efforts to preserve their healthy and feminine pre-cancer selves. This method of preservation, however, also increased women’s body-consciousness as cancer patients. Conversely, other women rejected such a focus during treatment; instead, they critiqued societal and medical pressures focusing on appearance demands in order to feel better adjusted during treatment. The second subcategory, Desire to Escape the Sick Role, described another tool used to distance themselves further from their present experience as a cancer patient.
**Heightened Versus Rejection of Appearance Focus.** The completion of medical treatment(s) including surgery, chemotherapy, and radiation therapy resulted in obvious changes to the physical body (i.e., alopecia, breast loss, weight gain, scars, and fatigue) among participants. These physical changes commonly led participants to a heightened focus toward their appearance, masking any drastic changes to their physical body as well as their gender- and illness-related identities. Focusing on appearance was a key tool used by participants in an attempt to preserve their pre-cancer selves. However, many women utilizing this tool also described a heightened body consciousness, feeling shame and disappointment in their cancer bodies. Conversely, a small subset of women rejected the focus on appearance, critiquing societal and medical systems for this focus, disinterested in making it a priority at the time.

For most women, like Olivia and Alison, using makeup and wigs to mask their appearance was an important tool used to preserve their feminine and healthy pre-cancer selves.

When I was going through chemotherapy, I could not use mascara because there were no eyelashes you know, no eyebrows but I still was wearing the makeup all the time you know just to preserve myself, like to present myself as who I am, who I was before. Even if [my] face was sunk in because I was dehydrated and I was grey colour because low hemoglobin but I still was try to do the best I could do to myself to feel and show I’m okay.

(Olivia, late 30s at dx)

. . . yes, I do have cancer but that’s not what I’m focusing my whole entire life on is the fact that I have cancer. I still want to be able to live my life and do my stuff without
having to just always think oh I have cancer. I think the wig just helped me with that; with people who didn’t know, to not have to always feel like people are looking and knowing you have cancer.

(Alison, mid 30s at dx)

Although hair and makeup were used to preserve women’s pre-cancer selves, many participants also reported heightened body consciousness at treatment. As women felt they no longer conformed to prescribed gender roles and heteronormative standards, they reported experiencing shame and disappointment. Women like Nikola described feeling shame and disappointment resulting from their hair loss during chemotherapy.

Before when my hair was really short, tiny short . . . I felt so almost like a lesbian and everybody was making fun of me . . . I’m like I know but my hair is like a boy buzz cut and I feel so unfeminine and I went to work and I stopped wearing skirts because I thought skirt and this short hair looks dumb so I started to wear pants . . .

(Nikola, early 40s at dx)

I would always be afraid that [my wig] would shift or something and then you know I’d look even more ridiculous so I’ve been, I’ve been wearing mostly toques . . .

(Megan, late 20s at dx)

In contrast, a small subset of women rejected the focus of appearance. These participants did not report heightened body consciousness, nor did they report feelings of shame about being
unable to conform to feminine beauty standards. Instead, during treatment, women like Morgan took a critical stance on the medical and societal focus on beauty and appearance standards.

When we tell somebody that it’s more important for them to wear makeup and put on a wig while they’re struggling with a life-threatening illness. I think as a society we have our priorities wrong and I just wasn’t willing to buy into that and I just wasn’t willing, you know if my bald head makes you uncomfortable then I’m sorry but chemo makes me feel pretty uncomfortable . . . I had much bigger issues to worry about than throwing on some makeup and putting on a wig . . . I was frustrated at [the women] that surrounded me whether it be oncology nurses or [cancer therapists] . . . I really felt dis-aligned with them . . . when really for me all that was important for me was surviving.

(Morgan, early 30s at dx)

Rachel also reported that she rejected a focus on appearance, as she had other, more important priorities at the time.

. . . I found during treatment I didn’t really have time to think about femininity. . . . And I was okay with that.

(Rachel, mid 20s at dx)

Desire to Escape the Sick Role. Some women discussed the importance of avoiding or attempting to escape the traditional sick role as a cancer patient. Judy, in particular, felt no need to talk about her cancer at treatment.

It’s very important [to mask my illness] and, maybe not for the reasons that people might think. I didn’t care if people thought I was ugly or sick or anything. I just didn’t want
them to mention it because I didn’t want to talk about it. I just didn’t want to have to deal
with explaining anything or talking about it. I just almost wanted to get through it without
thinking about it . . .

(Judy, late 20s at dx)

Nikola reported being disappointed that she could not escape the stereotypical sick role
around her partner.

. . . we moved in together and like he’s always seen me at my best and now suddenly you
know after my first chemo I got really, really sick so he had to call 9-1-1 and we had to
go to the emerg and he was lost. He had no idea and he had never seen me like I was
throwing up, I was sick as a dog . . . I was so sick so I didn’t want him to see me like that.
He’d only seen me before you know.

(Nikola, early 40s at dx)

**Internalization Versus Rejection of Gender- and Illness-Related Discourses: Post-Cancer
Phase**

At the Post-Cancer Phase, discussions regarding the Internalization Versus Rejection of
Gender- and Illness-Related Discourses were widespread in participants’ narratives. Two critical
subcategories emerged at this phase including: Shifts in Description of Self in Relation to Gender
Roles and Identity, reflecting both positive and negative shifts in participants’ gendered selves
based on their level of psychological flexibility in feminine roles and identities prior to
diagnosis; and the Connection to Survivor Identity, reflecting participants’ association with the
cancer survivor label.

**Shifts in Description of Self in Relation to Gender Roles and Identity.** The majority
of participants after completing treatment for breast cancer described shifts in descriptions of themselves in relation to their gender roles and identities. One subset of participants who were notably more psychologically flexible and fluid in their views regarding gender roles, identity, and heteronormative standards commonly described experiencing meaningful and adaptive shifts within their gendered selves. A second subset of participants who were strongly connected to traditional feminine roles, identities, and heteronormative standards typically described experiencing challenging shifts within their gendered selves. A third subset of participants who described some connection to traditional feminine roles and identities were successfully able to acquire adaptive changes in their gendered selves.

Participants at the Pre-Cancer Phase who described having greater psychological flexibility in their views regarding gender roles, identity, and appearance demands continued to maintain levels of psychological flexibility at survivorship that created meaningful and adaptive shifts in their gender-related identity. For example, the removal of Jamie’s breasts caused her to identify as more androgynous, which made her feel more in line with her pre-cancer gender-related identity. Without her breasts, she reported feeling less contrast between the internal and external experiences of herself.

I feel pretty androgynous. . . . When I think about myself and I’m like talking to myself I don’t, I don’t think you know female woman whatever. I just think Jamie. It’s kind of an androgynous person and now I feel like I look more like that too so my exterior kind of more matches sort of how I am.

(Jamie, early 40s at dx)
Likewise, prior to her cancer diagnosis, Erin was flexible in her views of gender and appearance standards. After her cancer experience, she too described a meaningful and adaptive shift in her gender-related identity whereby she moved away from her pre-cancer identity as butch, toward one in which gender was less relevant. Erin felt freed by this shift, having a body that complied less with gender binary or heteronormative standards of appearance.

... Being butch is just you know supporting a gender binary and I always had that sense but now I feel even more so like why would I put energy into that. ... I believe that gender is always a performance and it’s, it’s always a show but it’s not something that I’m willing to put my energy into because there’s so many more important things to think about ... at times I do, at times I feel masculine, at times I feel feminine but I don’t feel like a, a man or a woman. I don’t feel like either of those things and so why would I put energy into trying to, like to present that way. ... I think of myself as post-gender ... I want it to be irrelevant. I want my gender to not matter at all like I have a body, I have a physical body and I have felt experiences within that body but what that has to do with gender I feel like is much more like tenuous and complicated than people give credit for.

(Erin, early 30s at dx)

Erin’s psychological flexibility in gender and appearance discourses also made her more open to appreciating and valuing the physical changes in her body post-treatment. In fact, Erin described seeing a “special beauty” in not meeting or complying with appearance standards.

... I do think there’s a special beauty in different, you know it’s like in quirkiness or just variation like for me I think that that’s beautiful. ... If I see somebody ... if I see a friend of mine who’s [had a double mastectomy without reconstruction, like me] and
they’re going out with like confidence and they’re out in the world and like that’s especially beautiful to me because I know that they’ve had to overcome feeling like, or being told that they weren’t attractive or weren't beautiful or weren’t physically valuable right and, and so that sort of makes a person especially beautiful to me . . .

(Erin, early 30s at dx)

Rachel also described having psychological flexibility in gender roles and identity at the Pre-Cancer Phase, and experienced a positive shift in how she viewed herself as a woman, becoming more aligned with her attitudes and values.

I think [my identity as a woman] has changed a lot like I don’t really associate necessarily kind of the more superficial things like beauty you know doing my hair and makeup. Hair and makeup has never been a really huge thing for me but I feel like it’s even less since having cancer because I’ve lost my lashes, I’ve lost my eyebrows, I’ve lost my hair, and like you’re still a woman . . . to me it just means you know being a supporter and you know being aware that it isn’t your outside that makes you who you are and it’s really more your attitudes and your values and what you see being woman as and how you respond to that . . .

(Rachel, mid 20s at dx)

As previously discussed, Lauren demonstrated some psychological flexibility in how she related to and expressed her gender-related identity prior to her cancer diagnosis—for example, she did not abide by traditional gender roles or appearance demands. However, she also noted some discomfort around expressing femininity. After her cancer treatment though, Lauren
described an adaptive shift in her gender-related identity, moving toward a softer, more feminine side. She explained that her two daughters helped her reconnect with her feminine identity.

. . . I didn’t used to wear pink, I’m wearing pink like just somehow it softened like if I think of myself how I look now and how like there’s like a [softening] . . . but in general there’s a much more, I think, softer and more feminine look to who, like when I see myself now and I look at pictures of me when I’m younger I definitely see a much softer, more feminine woman. . . . It’s fun now because you know what I mean I have [daughters], they’re my dollies and, and I find it really allows me to enjoy that sort of like to really touch on that femininity like through my kids that is like they’re me and it’s me and it’s, it’s fun . . . seeing these girls was to me bringing out even more of my femininity . . .

(Lauren, early 30s at dx)

In contrast to the participants described above, among women who prior to their illness abided by traditional heteronormative ideals of gender and appearance, their changed physical appearances disrupted their gender identities, causing painful and more challenging shifts within themselves. Megan spoke about moving away from her pre-cancer feminine identity, which she greatly valued at the Pre-Cancer Phase.

Honestly, all of [my] femininity has been stripped away from me. All of it. It’s so hard to be a wife and a woman. Honestly, I, when I put on makeup I don’t feel pretty anymore. I’ve never had problems with self-esteem or confidence at all in twenty-eight years and then now it’s, everything has just been stripped. . . . Knowing I guess that I have these pills that I have to take every day for ten years that’s going to take my estrogen I mean
I’ve already lost my hair, I’ve lost my boob, I’ve lost my femininity [laugh] now I’m getting stripped of my estrogen, yeah . . .

(Megan, late 20s at dx)

Likewise, Nikola described moving away from her pre-cancer feminine identity, which caused a disruptive shift within herself. As a result, she labelled herself a failure.

If I don’t [take on the homemaker role], then I feel like I failed because my house isn’t clean and my bathroom isn’t spotless and you know there’s dishes in the sink and it drives me crazy but I can’t do it anymore because I’m so tired . . . it’s been a failure for me that I can’t have the same beautiful home like I used to. . . . His question was “What’s to eat?” I’m like “Well why can’t you cook something?” Well “You do it better,” you know what I mean? We’re struggling where I really need a lot more, more help than I did before . . . I used to take care of everything . . . but now I feel like a little bit of a failure because I can’t do it all . . .

(Nikola, early 40s at dx)

Interestingly, a small subsample of women who at the Pre-Cancer Phase reported some connection to traditional feminine gender roles and identities also described attaining adaptive shifts within their gendered selves. At the Post-Cancer Phase, these women began thinking about aspects of the self that, prior to their cancer, were not represented by their gender roles and/or identity, and hence were never allowed to be expressed. These women freed themselves from traditional gender discourses, and as a result provided themselves with new possibilities and ways to act that were not confined to preconceived views regarding traditional gender roles.
Sabrina, for example, emphasized that one of the most important duties for women in her culture was to focus all their attention of their husbands and children. Women were treated as secondary; however, after her breast cancer experience, Sabrina explained experiencing a significant shift in her view of women’s roles and responsibilities. She recognized that as a woman, she could have a voice and choose to make herself a priority within her family.

I think the part that has changed for me is I’m doing more stuff for myself because of cancer and before I wasn’t. I didn’t stand up and you know say okay, I want to do this for myself. I think that’s one of the biggest thing that changed in me since having diagnosis...

. . . when you’re diagnosed with a disease like that, it makes you think like okay, what’s going to happen right if I don’t take care of myself . . .

(Sabrina, early 40s at dx)

At the Pre-Cancer Phase, Olivia described having a strong connection to traditional feminine roles and responsibilities. She also described feeling overwhelmed by the imbalance in responsibilities and duties in her immediate family prior to her illness. However, at the Post-Cancer Phase, she described making positive shifts within herself; she chose to let go of some traditional feminine roles and duties by letting her friends help and support her when needed, and ultimately separating from her husband.

After the treatment when all this became a quiet time when I can think about what just has happened for the last year I realized I have to change myself. I need to give up on the, some of this leadership activities and ask for help and let people, and let my friends to help me you know and support people to help me you know so just that’s why I started to change my life . . . the newest changes in my family is that I, a week ago I . . . split with
my husband.

(Olivia, late 30s at dx)

While Morgan reported having a connection to some traditional feminine roles and identities prior to her cancer diagnosis, she also indicated some flexibility in her views of gender roles and identity. After completing treatment, she described experiencing a meaningful and adaptive shift in relation to heteronormative standards of gender and appearance by finding like-minded women outside the cancer community who were also interested in rejecting said discourses.

I think that was the key. It was finding people that felt this way outside of this breast cancer community and being able to engage with people that maybe other women that felt this they didn’t meet the standard either and it wasn’t because they lost a breast so that really helped me. That really helped me realize that you know I have a lot more to offer than a few scars.

(Morgan, early 30s at dx)

**Connection to Survivor Identity.**

Many participants felt comfortable identifying as cancer survivors because of their cancer support groups. Others were less comfortable with this label, citing fear, not being a victim, or being defined by their cancer as reasons behind this disconnection.

Sabrina and Alison reported having a positive connection to a cancer-survivor identity.

I do identify as a breast cancer survivor. I think especially when I’m with the dragon boat there’s always a reminder [laugh] that we are survivors . . .

(Sabrina, early 40s at dx)
I feel like a survivor [at the community cancer group]. I feel, you know it, it helps remind myself that these people are going through this and you were fortunate enough to be out of it, don’t worry about it anymore, you’re done.

(Alison, mid 30s at dx)

Others felt disconnected from the survivor identity. In fact, one woman chose not to associate any word with her cancer experience.

. . . I almost feel better about not having a word for it because this is just part of life and a really important thing that I had to go through for some good reason and having a word for it would mean that it is unique in some way and maybe as a result more scary and you know so not having a word is, makes me feel more comfortable and more comforted knowing that yes, this is normal, a part of life, no, not a lot of young women get it but you know for lack of a better term shit happens and you just have to deal with it.

(Judy, late 20s at dx)

People are like oh you’re a survivor, you’re, well I don’t like the term survivor and it’s not a Lance Armstrong thing. I don’t believe I’m a champion. I guess I never feel like I was a victim . . . I was a young woman with a medical diagnosis.

(Morgan, early 30s at dx)

If somebody is like oh here’s Jamie, she’s a cancer survivor or whatever, I say and I’m a professor and I’m a bike racer and I’m a parent and all this other stuff too and so I just try
to emphasize the fact that you can’t boil down a person to that one phrase . . . I feel like people say oh you know they’re a breast cancer survivor and they’re trying to just boil me down to that one thing. It’s so not consistent with the choices that I’ve actually made in life right . . .

(Jamie, early 40s at dx)

Internalization Versus Rejection of Gender- and Illness-Related Discourses: Summary

Participants were faced with a number of opportunities to internalize or reject gender- and illness-related discourses before, during, and after their breast cancer experience. At each Phase, one gender- and illness-related subcategory was discussed. At the Pre-Cancer Phase, the subcategory Description of Self in Relation to Expected Gender Roles and Identity examined participants’ compliance with or resistance toward gender role expectations, identity, and heteronormative standards of appearance. This subcategory provided important information regarding women’s capacity for psychological flexibility in relation to prescribed gender roles and identities prior to their cancer diagnosis. Some women were more psychologically flexible towards feminine role expectations, identity and appearance demands. The second subcategory, Illness-Free Identity, reflected most participants’ disconnection from illness as a young person.

The Diagnosis and Treatment Phase explored women’s Heightening Versus Rejection of Appearance Focus, examining women’s attempt to preserve their feminine and healthy pre-cancer selves through their appearance. However, many women who pursued a heightened focus on their appearance also discussed increased body consciousness and shame. The second subcategory in this phase, Desire to Escape the Sick Role, reflected participants’ desire to cope with illness by disconnecting from their present experience.
Finally, two subcategories emerged at the Post-Cancer Phase. The first subcategory, Shifts in Description of Self in Relation to Expected Gender Roles and Identity was tightly linked to the Pre-Cancer Phase. This subcategory reflected three different experiences for women 1) meaningful and adaptive shifts among participants who described psychological flexibility, holding broader views in relation to gender roles and identities at the Pre-Cancer Phase, 2) disruptive shifts among participants who described less psychological flexibility towards traditional feminine roles and identities at the Pre-Cancer Phase, and 3) adaptive shifts among a subset of women who also described connection to traditional views of feminine roles and identities at the Pre-Cancer Phase. This third group of participants explored aspects of the self that, prior to their cancer, were not represented in their gender roles and/or identities, and hence were never expressed. These participants freed themselves from traditional gender discourses, and subsequently provided new possibilities to act in ways that did not confine them to preconceived views on gender. The second subcategory, Connection to Survivor Identity, reflected women’s comfort with the label cancer survivor. Overall, a critical perspective toward gender- and illness-related discourses at the Pre- and Post-Cancer Phases seemed to facilitate women’s increased well-being, while holding on to prescribed gender- and illness-related roles seemed to relate to self-criticism and reduced well-being.

Relational Connections

The fifth core category, Relational Connections, was perhaps the most common category described and interwoven into the Pre-Cancer, Diagnosis and Treatment, and Post-Cancer phases. The Pre-Cancer Phase described women’s Connection to Partners, Family, and Close Others, examining the importance of close and meaningful relationships within and outside of
their family; and an Other-Oriented Focus of Care, which stressed women’s prioritization of others over and above themselves.

In the Diagnosis and Treatment Phase, three overarching subcategories emerged including: Connection to the Medical Team, reflecting women’s experience of feeling supported, grounded, and connected versus dismissed, betrayed, or objectified by the team; Disclosure of Illness, examining women’s struggle to share their diagnosis with their children, extended family, co-workers, and friends; Hiding Versus Uncovering The Illness, reflecting diverse coping mechanisms women used to feel safe and protected with others while in their cancer-inhabited bodies; and the experience of Feeling Alone Versus Supported and Validated, reflecting women’s use of close others for emotional and practical forms of support.

The Post-Cancer Phase examined women’s relational dynamics with close others, including partners, family members, and close friends at survivorship. Three subcategories were discussed including: Recognizing True Friendships, reflecting women’s abilities to narrow down their most meaningful relationships with friends; Altered Connection to Partner, reflecting the trials and tribulations faced in returning to levels of connection and intimacy with their partner; and Staying Connected Versus Letting Go of the Illness, exploring participants’ decisions to remain connected to their illness through cancer support groups, or to move away from such connection. Overall, Relational Connections showcased women’s capacity for renewed meaning making within relationships at the survivorship stage. Table 14 illustrates the subcategories explored in the fifth core category, Relational Connections.

Table 14

Subcategories found in the fifth core category, Relational Connections.
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<th>Core Categories</th>
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**Relational Connections: Pre-Cancer Phase**

When addressing Relational Connections with respect to surviving breast cancer, participants often described pivotal relationships that they had prior to their cancer diagnosis. During this phase, participants demonstrated their level of investment and attachment to close others. These identified relationships typically included their partners, immediate family members, and close friends. In many of these Connections to Partners, Family, and Close Others, participants often described taking specific roles (i.e., as protectors, saviours, or housewives) to ensure a well-functioning family system. As well, many patients described the importance of close and meaningful relationships within and outside their family. Furthermore, within many relationships, an Other-Oriented Focus of Care was frequently discussed where women prioritized the needs of others over and above their own.

**Connection to Partners, Family, and Close Others.** Prior to their cancer diagnosis, participants illustrated a wide array of positively and negatively connected relationships with close others including partners, children, family members, and friends. Participants identified
taking on unbalanced or balanced roles within their family systems (i.e., as protector, saviour, or housewife). Many participants also described the value placed on relationships both within and outside their families.

With respect to partnered relationships, some participants described taking on prescribed roles that felt balanced in relation to their partners’ roles and responsibilities. Judy, for example, described having a more traditional role as a housewife prior to her diagnosis, but said that it felt balanced, “equal but not the same.” Others, like Olivia, described a non-balanced partnership within her family dynamic whereby she was forced to become the “saviour” of her romantic relationship and family.

When we were first married we had the very traditional roles . . . I would take care of the house things; laundry and dishes and cooking and things and he was the breadwinner you know and I was doing my degree on the side. . . . There were certain roles that I took on and there were certain roles that he took on and we kind of figured out how, how that balance worked for us kind of yeah it’s so hard to describe but kind of like this harmony of you know equal but not the same.

(Judy, late 20s at dx)

We were married for almost twenty-one years and I was the strongest in the family. He was always more dependent on me . . . I am the brain in the family you know so, and maybe what I would prefer to have a stronger man in my life who will take some responsibilities of taking care of me and my children rather than put this heavy load of the entire family into just my shoulders in addition to the full-time job you know . . . we
were together for like I said twenty-one years and I, for many, many years was trying to rescue our marriage you know working hard.

(Olivia, late 30s at dx)

Connections to close family members and friends were also explored at the Pre-Cancer Phase. Some women, like Judy, spoke about the importance of maintaining close friendships in their lives, and committing to events or activities for other people. Other participants, like Megan, identified having fewer close friendships outside their family, but nonetheless found important connections within their family members.

Also friends were very important to me . . . even friends and acquaintances and just committing to things, doing things for other people, over-committing, doing, just doing things to be nice and to be helpful.

(Judy, late 20s at dx)

I didn’t have many close friends to me [prior to my cancer diagnosis]. I mean my best friend was my mom [laugh] but I mean my parents were amazing. My husband was amazing and my daughter and I mean that’s, that’s pretty much all I got.

(Megan, late 20s at dx)

**Other-Oriented Focus of Care.** Prior to their breast cancer diagnosis, many women described an Other-Oriented Focus of Care, focusing on the well-being and needs of close others before their own. In particular, women with children typically emphasized this form of care.

Yeah like in my culture it’s like once you get married that’s it. It’s your kids and your husband and that’s it. They don’t really focus on yourself . . . I grew up in a culture
[where] women were always you know second and are, and still is and I think that has always been like I don’t know drilled into me that you know you’re second and men are always first. . . . I think before the cancer I was always doing things for other people, meaning my kids, my family. I always didn’t take care of myself. I wasn’t on the top of my list of taking care of myself . . .

(Sabrina, early 40s at dx)

… Before [cancer], I would focus probably the majority of my life on the kids, everything was about the kids, and making sure the kids are happy and you know the kids are this, the kids are that.

(Alison, mid 30s at dx)

**Relational Connections: Diagnosis and Treatment Phase**

The Diagnosis and Treatment Phase often tested the stability of many close relationships for participants. Many women, not surprisingly, sought out safety and security through close others during this turbulent time. Four major subcategories emerged including: Connection to the Medical Team, reflecting women’s experience of feeling supported, grounded, and connected versus dismissed, betrayed, or objectified by their medical team; Disclosure of Illness, examining how women grappled with the decision to share their diagnosis with their children, extended family, co-workers, and friends; Hiding Versus Uncovering The Illness, reflecting the diverse coping mechanisms women used to feel safe and protected from others while undergoing treatment; and the experience of Feeling Alone Versus Supported and Validated, reflecting women’s need to rely on close others for emotional and practical forms of support. Overall, each
of these subcategories shed light on women’s need to seek out safety and support in close others during their medical treatment.

**Connection to the Medical Team.** Among the twelve participants, there was an assortment of women who reported feeling well-supported, grounded, and connected to their medical team, believing that their unique needs as patients were acknowledged and met by the team. Others, however, described feeling dismissed, betrayed, or objectified by the team; some of these participants’ narratives described cultural-, gender-, and body-related insensitivities.

**Feeling Supported, Grounded, and Connected to the Medical Team.** A group of participants described feeling supported, grounded, and connected to their team. These participants typically felt that their unique needs (e.g., being a young person, Queer, and interested in future children) were acknowledged and supported.

I was really fortunate in a lot of ways. I had a really fantastic surgeon. She was a queer woman of colour and an activist and so she was already really very much in my corner. . . . She was phenomenal. She went above and beyond what she needed to do as a surgeon.

(Erin, early 30s at dx)

. . . I was happy in the fact that I had a good healthcare team that really made sure that I was taken care of and I mean recommended fertility treatments and were aware of the fact that I was a young woman and the oncologist that I had, I’m pretty sure I was probably her youngest patient but she had experience with younger women with breast cancer so that was really good too. I just had a really positive experience with my own health team for the most part.
Feeling Dismissed and Betrayed by the Medical Team. However, most participants described experiences of feeling dismissed and betrayed by the medical team at some point in the Diagnosis and Treatment Phase. Around the time of diagnosis, many women reported feeling dismissed. Many health professionals reportedly assumed participants were too young to have a cancer diagnosis; subsequently, their concerns were usually invalidated. Likewise, some participants felt that treatment options, particularly around the topic of surgery and reconstruction, were not well explained or discussed with them. Additionally, women cited instances during treatment when medical staff made insensitive comments regarding gender, body, and cultural heritage.

A number of women described feeling dismissed by their medical team around the time of diagnosis.

I found that everybody within the healthcare system until my true diagnosis came through kind of just brushed me off because of my age. There was a lot of assumptions made that it wouldn’t be cancer and it certainly wouldn’t be breast cancer. . . . I had to jump through hoops to even get into the diagnostic phase . . .

(Morgan, early 30s at dx)

I went to a surgeon . . . I go for results and the surgeon says yep it’s not cancer, it’s non-malignant you know it’s just probably some kind of a cyst or fat deposit. I said well shouldn’t we cut it out, like I don’t really think I want it there. He says “oh my God if we were, every woman that walks around with a cyst or a lump, if we were cutting her out
open that would be every second woman on this planet . . .” So I go home. Within like three weeks my right breast was getting huge . . .

(Nikola, early 40s at dx)

Toward the end of treatment, when considering surgical reconstruction, some women also described a lack of open discussion with their doctors regarding options.

You’re really put on the spot like you sit down in front of the surgeon and you’re scooted off and instantly they want to know do you want one breast gone or two. . . . It would have been nice to have the perspective of the plastic surgeon that was then going to reconstruct the breast tell me okay, now is it easier for you to do two as it is to do one or if reconstruction is important to me then what’s the easiest way to get the best result . . . there didn’t seem to be a lot of, like there was options but they were really limited in their scope or their perspective right. The option was based on what that doctor did . . .

(Morgan, early 30s at dx)

In addition to feeling dismissed or unheard, some women reported feeling betrayed or objectified by their doctors, citing gender- and body-related insensitivities.

I went to this gynecologist, I didn’t know which doctor to go to you know so I’ll go to a gynecologist. I went to the gynecologist and it was like some old man and he told me that I was fat.

(Lauren, early 30s at dx)
I remember this one time seeing a nurse practitioner who was a female and . . . she literally like her jaw dropped. She was like you don’t have a nipple and I’m like no, of course I don’t. I had a complete mastectomy.

(Morgan, early 30s at dx)

In addition to gender- and body-related insensitivities, Sabrina described cultural and religious insensitivities within the medical system. She highlighted the importance of awareness and respect for diverse cultural and religious practices by health professionals.

Personally I’ve been to a lot of doctors, the nurses, they have no clue about this person’s religion or culture and I’m not saying go write a Ph.D. or whatever on them but at least look out. . . . If they could have little booklets on you know how to deal with different cultures. . . . Different people are coming into Canada and you have to try to understand especially with breast cancer it’s such a sensitive issue with women you know having a male doctor or a female doctor it’s hard.

(Sabrina, early 40s at dx)

**Disclosure of Illness.** At the Diagnosis and Treatment Phase, the majority of participants grappled with the right ways in which to disclose their illness. Disclosing the illness to participants’ children was understandably a much difference experience than to their co-workers and friends. The majority of participants with young children spent time providing age-appropriate information to their children regarding their diagnosis and treatment. These conversations were typically very open and honest, and emphasized cancer not being a death sentence. Outside the immediate family, participants were less inclined to share their illness with others, including co-workers; instead, participants enjoyed maintaining some form of their pre-
cancer self. While some participants recognized the value in disclosing the illness to others with whom they felt close, they were also unsure as to how to approach such disclosure. Some chose to employ social media to disclose their illness, as a way of making everyone in their lives aware of the situation.

**Children.** The majority of mothers believed it was important to engage in age-appropriate discussions with their children regarding their cancer diagnosis and treatment. Many of these participants were concerned that their children would link their cancer diagnosis with death and dying. As such, many participants educated their children, instilling hope and understanding that cancer was not a death sentence. While participants like Olivia stressed the importance of being honest and open with her children during this time, one participant chose to keep her cancer hidden from her children.

Some women, like Maria, spoke about using age-appropriate tools, like children’s books, to help educate their families about breast cancer. These mothers stressed that death was not necessarily a part of their cancer experience.

My kids went through a lot I think in the nine months that I was going through everything. . . . We went through a very good book while I was undergoing everything. It was called *Mommy has Breast Cancer* . . . the first question I asked my kids when I was diagnosed is like you know what do you guys know about cancer and my oldest one who at the time was eight she said well Terry Fox had it and he died so yeah it was like well [laugh] not everybody dies but [laugh] I see your point. So we read through the book . . .

(Maria, early 40s at dx)
Many women also explained the importance of being open and honest with their children regarding their cancer diagnosis and treatment.

My son actually asked me the question “Mom, why did you decide to say us the truth and not hide it from us you know just say oh you are sick or you are just, and you’re weak?” And here I taught him a lesson you know we are the family, we have to share the truth no matter how bad is that because . . . if I were to keep it quiet and somebody will tell you later on “Oh how is your mom doing with cancer?” and you say “What cancer?” Will you trust me again because I hid something from you? He said “No, I wouldn’t.” We just need to be together and to be honest with each other.

(Olivia, late 30s at dx)

One participant, however, chose to keep her breast cancer hidden from her three young boys. Alison described her rationale, explaining that she wanted to keep some normalcy for them and herself in their home.

Boys are boys and so because I had boys I was able to do it. I don’t think I would have been able to with girls. . . . My husband and I enjoyed it to be able to you know you go to the school and you have all the parents talking to you and how are you doing and what’s going on and oh my goodness I can’t imagine having to do that. . . . And then you come home and it’s nice that the kids don’t know and it just kind of felt normal you know we’re helping them with homework and that sort of thing and we didn’t have to always be talking about it or reassuring them or things like that so it was I’m, I’m happy with the decision too that I didn’t tell them. I will tell them when they’re older because they will need to know for family history and that sort of thing so I will tell them when they’re
teenagers and they fully understand but I, I a 100% am, am glad with the decision that we went with.

(Alison, mid 30s at dx)

**Co-workers and Friends.** While the majority of participants felt it was important to disclose their illness to their immediate family members, many felt uncomfortable disclosing such details to co-workers and friends. Participants also described the challenge of finding the right time to disclose their illness to others; some participants used social media as a way to let everyone in their lives be made aware of the situation.

Like the majority of participants, Olivia shared her illness with few co-workers (including her manager). She felt it was important to maintain her identity as a “strong” woman at work, smiling even with the cancer inside her.

When I was diagnosed I still was maintaining the role of strong person because I was, I kept working until two days before my surgery and basically only my team manager and one of the [health-related co-worker] who helped me through this journey of cancer knew about my diagnosis. The rest of the team had no idea you know so I remained this strong, positive personality smiling even carrying this cancer inside of my body.

(Olivia, late 30s at dx)

Many women described the challenges in finding the right time to share their illness with others. Some chose to disclose their illness using social media.

... for me I was diagnosed and then I did my defence for my master’s thesis and then a friend of mine got married that weekend and then I had surgery and it’s a hard time to figure out when you’re going to tell somebody ... I wasn’t going to tell everybody in my
master’s class when we were doing our defences and I didn’t want to tell them at my friend’s wedding and then the next time we saw each other was convocation so I didn’t want to tell them then so you know there’s a little bit of taboo around when you should tell people about cancer . . . I didn’t make it public on Facebook that I had cancer until my very last chemo . . .

(Rachel, mid 20s at dx)

When I got my biopsy I messaged everybody on Facebook, all my family all over the world. I said I had a lump, waiting for the biopsy. I think that was a big mistake on my part and then when I did get the diagnosis I told everybody. I made a group and told everybody that I had cancer . . . I think I should have waited. All my aunts all in Germany were like in tears . . . in our religion you always believe that if you tell people they can maybe keep you in their prayers or good energy or whatever so I think my thing was that that I wanted everybody to keep me in their prayers . . .

(Sabrina, early 40s at dx)

**Hiding Versus Uncovering The Illness.** Tied to participants’ experience of disclosing illness was the ways in which they chose to hide or uncover their cancer-inhabited bodies to others. Women who chose to hide or mask their illness felt it was a necessary coping mechanism, to increase their experience of safety within themselves to the outside world. It also reduced the level of cognitive dissonance between their pre- and post-cancer selves. Alternatively, some participants rejected the common trend to hide physical signs of cancer or cancer treatment; instead, their coping mechanism involved public exposure to cancer and cancer treatment-related changes such that their internal experiences matched their external ones. This increased
resonance between their external and internal experiences made them feel empowered.

Particularly with chemotherapy treatments, many women reported the belief that cancer was “written on their foreheads,” and that caused them great distress. Many women felt major cognitive dissonance between their healthy and beautiful pre-cancer selves and their cancer selves. As a result, the majority of women described hiding the illness as a necessary coping mechanism. Olivia, for example, reported that she went “undercover” during her chemotherapy treatment, choosing to wear a turban on her head to feel more attractive and safe from the judgement of others.

I bought myself a wig out of natural hair but I always felt not quite comfortable wearing that because I felt it’s kind of not me . . . I saw a couple women at the waiting room and they were black women wearing turbans so I went on the YouTube and I Googled “making a fancy turbans” and that’s [what] I did. I found how to tie a turban in a very beautiful way . . . those scarves on my head were so nicely tied you know and I have big black eyes so people actually were thinking that I’m a Muslim woman so I was thinking okay, I’m undercover . . . lots of people did not even realize [I had cancer] . . . I think I was undercover . . . it helped me to preserve my identity . . . being attractive woman you know but stay woman, do not neglect myself in a way of “oh I am sick so I’m just giving up on everything . . . on the beauty part . . .

(Olivia, late 30s at dx)

Like many women, Alison used her wigs to preserve the idea of normalcy and her pre-cancer identity as a young, healthy, beautiful person. Wearing wigs was one example that helped participants feel “normal,” safe, and less anxious with and around others.
So I bought myself a couple of wigs . . . a lot of people said they felt stronger, said they felt like it was a proud thing to have their bald head [shown] . . . for me . . . I’m more the type where I didn’t need everybody to know. I thought I just want to put the hair on and go out and feel normal while I’m going through this just not have people know what I’m going through, to not be treated different, that sort of thing so . . . [I] realized this is just a stage and I’m not just going to focus on “I have cancer, I have cancer, this is horrible . . .” I said to my husband it sounds silly but I said I kind of like not having my hair and just brushing my wig and putting it on and it looks like I just spent an hour doing my hair and it looks nice . . .

(Alison, mid 30s at dx)

Alternatively, some women rejected the conventional view that cancer patients should hide their cancer-inhabited bodies from others. Instead, they uncovered the way their bodies were changed by cancer or cancer treatment. These women also reported feeling more attuned to their internal experiences.

Erin poignantly discussed her view on the damaging effects of hiding a breast cancer diagnosis; she believed that not masking the impact of cancer or its treatment was an adaptive and empowering coping mechanism that helped her maintain a level of consistency between her internal and external experiences.

. . . that’s something that’s really damaging for women because they feel like they need to hide it and mask it and like again if a woman feels better like during treatment if she wants to wear a wig and makeup and all those things and they help her feel better then that’s fantastic but it’s also masking what you’re going through and I think that it can be
really empowering to instead like acknowledge what you’re going through, acknowledge that you’re in pain, acknowledge that you’re like suffering instead of trying to hide [be]cause I think that that creates a barrier between like what you’re going through internally and the world. . . . I will flaunt it right because it’s nothing to be ashamed of . . . I’m like proud like a fucking peacock like are you insulting a peacock for flaunting? No, flaunting is a good thing . . .

(Erin, early 30s at dx)

Morgan, among others, spoke about the importance of rejecting the concept of hiding the impact of cancer treatment on the body; it was important for her to reject the “mould” of hiding the impact of cancer.

If it was uncomfortable for you to look at my bald head then that’s on you . . . I just feel like I need to break the mould somehow so for me I, I, not wearing the wigs and not wearing the makeup was it, it, part of it was because . . . I didn’t have the energy or want to right and . . . the second part is if this is what’s important to you watch me do the opposite. It’s crazy, right? . . . Yeah we don’t all fit the mould and here I am to show you that . . .

(Morgan, early 30s at dx)

**Feeling Alone Versus Supported and Validated.** At the Diagnosis and Treatment Phase, when participants were in a state of fear, anxiety, and loss of control, support from family members and friends was crucial. Some women described feeling alone both within the hospital and in their homes with their families. These women felt invalidated by others; however, the
majority of women described feeling well-supported and validated by family and friends, citing those closest to them as being their “rocks” or “angels.”

**Feeling Alone: Lack of Safety, Validation, Support.** Some women described feeling alone within the context of the hospital, unable to find other women who shared their unique needs. Additionally, within their family systems, some participants also described experiencing a lack of support or validation from their partners.

Judy and Morgan, among others, described feeling alone, unable to connect with other young breast cancer patients during treatment.

I think the biggest reason was because I felt quite alone when I was going through the process. I knew that there were other young women going through this treatment but I never seemed to encounter them; not in waiting rooms, not during any part of my treatment, and I felt very alone . . .

(Judy, late 20s at dx)

. . . that’s what made me feel very alone because there are a lot of people out there but there wasn’t a lot of like-minded people out there for me to find. I’m sure there’s plenty of them. I didn’t know how to find them because there’s nowhere for us to meet.

(Morgan, early 30s at dx)

Many women, including Morgan and Nikola, described feeling unsupported by their families and partners.
I just really felt like the people around me especially at that time weren’t necessarily really strong, independent people . . . I had a spouse that maybe just wasn’t really super supportive to the body changes that I was going through and the surgeries and such . . .

(Morgan, early 30s at dx)

I asked [my fiancé], I said could you go get groceries and he says “No, you’re going.” It wasn’t because he didn’t want to but because the doctor said she has to have some type of exercise or something every day. She can’t just lay in bed. So you know it was really hard for us to determine like he was trying but his trying wasn’t good enough like we did lots of fighting and there was a couple of times we almost broke up during cancer treatments because I didn’t feel he did enough for me . . . I wanted him to be more empathetic but [he’s] an [male-driven job], he’s a hockey player. I thought well he doesn’t really feel sorry for me or he has no empathy . . .

(Nikola, early 40s at dx)

**Feeling Supported and Validated.** Most participants reported feeling supported and validated by their family members and friends during treatment. For some women, like Judy, these relationships reportedly provided important forms of emotional support; for others, like Sabrina and Olivia, these relationships provided practical means of support.

I feel like they were my rocks . . . but there were some days where I didn’t [feel strong] at all. I felt like I just wanted to fall apart and they were great. My husband especially; he was wonderful in that he let me cry and then at a certain point he said okay, you know that’s it now you can’t, you can’t just feel sorry for yourself. You need to step up and be strong so it was a good balance of hearing me out and then putting me back together.
(Judy, late 20s at dx)

I didn’t feel alone or like I was scared . . . I was busy with all my you know sister-in-laws and my aunt and everybody. I really didn’t, they didn’t leave me alone for like five minutes [laugh]. . . . Even my friends that live in Toronto they would always tell me to come to [name of friend] place on the weekend to just get my mind off things . . .

(Sabrina, early 40s at dx)

I have a couple great friends. One of that was my ex-colleague who is the retired palliative care nurse. She was the one who assumed responsibility of being my angel you know so she went for every single appointment with me including chemotherapy.

(Olivia, late 30s at dx)

Relational Connections: Post-Cancer Phase

Relational Connections at the Post-Cancer Phase examined women’s meaning-making capabilities with close others, including partners, family, and close friends. After completing treatment, participants at times questioned their investment in and the meaning of past relationships. Three subcategories emerged, including: Recognizing True Friendship, reflecting women’s narrowing down and identifying their most meaningful relationships with close friends; Altered Connection to Partner, reflecting the trials and tribulations faced in returning to levels of connection and intimacy with their partners; and Staying Connected Versus Letting Go of the Illness, exploring participants decisions to remain connected to their illness through cancer support groups or to move forward in their lives without integrating the illness experience.
Recognizing True Friendship. Most participants, after going through a devastating experience like breast cancer, reflected on who they felt were their true friends. Those identified as true friends were recognized as being more meaningful and important relationships for participants. While some women reported feeling more connected with and closer to their friends post-cancer, others explained that they lost a number of friends who were unable to support them during the Diagnosis and Treatment Phase.

Two of my three friends, like one came from England and two came from Canada to watch and cheer me [on at the triathlon]. I didn’t understand until afterwards when I crossed the finish line and they’re both crying . . . and I kind of got it afterwards like it was really beautiful. . . . I’m so grateful for the friends that I have and people that I’ve met . . .

(Lauren, early 30s at dx)

. . . you find out who, who your like real friends are . . . I had some friends that I just stopped talking, got rid of them on Facebook . . . it’s true like it makes you think you know are they really your friends or are they just faking it?

(Sabrina, early 40s at dx)

[I] actually lost quite a few friends and I’m not sure if it’s because they were just uncomfortable and didn’t know what to say and didn’t know how to connect with me . . . I was kind of a hermit at the beginning where it was like I don’t want to see anyone. I don’t want to explain what’s going on . . . I know that if it would have been the other way around I would have done anything for my friends you know as simple as making them
dinner . . . but I didn’t even get phone calls or, do you know what I mean? Everybody just kind of disappeared.

(Megan, late 20s at dx)

**Altered Connection to Partner.** At the Post-Cancer Phase, many participants reported that their partners were hopeful their relationship would return to normal; however, issues often arose within these relationships, particularly among couples that struggled prior to the breast cancer experience. After completing treatment, some participants chose to leave their partners, recognizing that they were no longer interested in investing in that relationship. Among those women who chose to stay in their relationships both during and after the cancer experience, they reported changes in intimacy with their partners during the first year of survivorship. Among those with secured and invested partnerships, participants reported experiencing an increase in desire, intimacy, and connection after the first year of survivorship. After completing treatment, some women described shifts from an other-oriented focus of care at the Pre-Cancer Phase, toward a more balanced and sometimes deeper connection, informed by the illness experience.

**Intimacy and Sex with Partner.** Some women reported after treatment experiencing shifts in intimacy and sexuality with their partners. Particularly in the first year of survivorship, participants described feeling discomfort being intimate with their partners; they also reported feelings of guilt and shame, unable to return to the pre-cancer connection that their partner desired.

It was a really rough year, year and a half maybe because we did struggle with [intimacy] . . . it wasn’t easy to get back to where we are now though . . . what six, eight, ten months I’m thinking we didn’t even have sex right so suddenly now how do you start again?
(Nikola, early 40s at dx)

Since [cancer], sex has been a complete chore. I hate it. I don’t look forward to it and that’s really, really sad . . . sex became non-existent. I still feel a ton of guilt for that. I mean I’m not, I’m not doing what I’m supposed to be doing to make my husband happy . . . how are you supposed to love somebody if you don’t love yourself?

(Megan, late 20s at dx)

**Greater Desire and Connection to Partner.** Other participants reported feeling a stronger connection to their partners, typically after one year of survivorship; these shifts in connection were exemplified through increases in physical intimacy and empathy. Further, some participants described shifts in the types of roles and responsibilities they carried out within their partnerships. This theme uncovered that, after some time had passed following the breast cancer experience, women could shift from an other-oriented, over-committed focus of care in relationships at the Pre-Cancer Phase toward a more balanced and sometimes deeper connection, informed by the illness experience.

I’ll tell you one thing that I really like is I pretty much always sleep without a shirt on now like no, no top whatsoever and that’s kind of like awesome . . . when we cuddle we’re like actually closer than before so that kind of I think facilitated sort of that really connection in that regard.

(Jamie, early 40s at dx)
I’m still on the waiting list to see a psychologist but even having [my husband] know what’s going on with me and understanding it has been huge for me otherwise he could have just been like okay, well whatever she’s sad about what happened, big deal.

(Olivia, late 30s at dx)

Some women, including Judy and Alison, described finding renewed balance in the roles and responsibilities within their partnership.

[Our roles] have kind of morphed a little bit and adapted as necessary so when we were first married you know we had the very traditional . . . but then when I got sick I couldn’t do a lot of stuff and he completely jumped in. He did all that stuff, all of it, all of it. He just took over everything and he took care of me and so after now we’ve kind of found a new balance so it’s not so, and it wasn’t explicitly discussed it just kind of happened . . .

(Judy, late 20s at dx)

[Going through cancer treatment] was an eye opener for [my husband] because he had no idea what it was like to do everything in the house . . . now that I’m back to normal you know I said to him well it’s okay like I can do the dishes and he had said no, he said I can’t, I can’t just as a person go back to letting you do everything. I didn’t realize how much it consisted of so I actually find after this he does a lot more around the house and helping with the kids . . .

(Alison, mid 30s at dx)

**Staying Connected Versus Letting Go of the Illness.** Many women maintained their connection to other breast cancer patients and their local cancer communities; they described the
importance of keeping friendships with others who understood the cancer journey. These participants also described discovering an interest in helping other women with similar social locations currently facing breast cancer. Subsequently, connections with others incorporated the cancer experience. Alternatively, some women chose to let go and move forward in their lives without these connections, such that these connections did not incorporate elements of the cancer experience.

Rachel and Sabrina, among others, described maintaining some connection to the cancer community post-treatment.

We actually have a young women’s support group but I mean it’s still an under forty-five support group so there’s still quite a range of ages but you know those people have become friends outside of the support group so we meet fairly frequently. . . . I’m finding the support group is really helpful too to kind of talk about those things and not even to talk about them all the time but to listen to other people because then you get that oh I’m not the only person going through it you know so this must be a normal feeling. . . .

(Rachel, mid 20s at dx)

Through this group I actually joined a dragon boat team. [Laugh] Yeah so I’ve been with them for two years now and that has also because it’s all breast cancer survivors so that has, it’s like a full day . . . I’ve made a lot of friends that have bond with us and they had worse you know diagnosis than me . . .

(Sabrina, early 40s at dx)
These women also described the value in helping others with similar social locations during their breast cancer experience. Some women volunteered within cancer organizations, while others created or played active roles in online support groups for breast cancer patients and survivors.

I volunteer at the [name of organization] in [city in Canada] as a volunteer as a cancer survivor . . . I help out with a class . . . we talk to all breast cancer patients who are going through radiation and they let me tell my story and I do think it’s really important especially because I am young and a lot of people there they’re not as young but the odd time there is young people I find it’s very important to be able to let people know this will come to an end . . . it helps remind myself that these people are going through this and you were fortunate enough to be out of it . . . I feel good going there . . .

(Alison, mid 30s at dx)

I wanted to like be able to conceptualize my felt experience like in, in theoretical terms . . . I just really like thrust everything on the Internet and, and I realized like I, I was in a position where I could help, I could reach out to people, I could reach out to women, and I could help them and I could give them a voice and I could give them community support and I could only do that online for the most part . . .

(Erin, early 30s at dx)

In contrast, other women, like Morgan and Nikola, emphasized the need to let go of ties made to the cancer community.
I have found the people that do it because they had cancer [it] becomes their identity . . . the people that were survivors, that were very involved in these groups these are the same people where this has become them. They celebrate their cancer-versary. [Laugh] What? Like I don’t even understand that terminology like I don’t know that loses me, definitely loses me. I was in a car accident when I was you know twenty-one and broke my back. I certainly don’t celebrate that day every year . . .

(Morgan, early 30s at dx)

It took me a while maybe a year to be able to relate to other women [who did not have cancer]. Even now I sort of a little bit prefer some of my friends I met through [the cancer community], just because I feel a little bit like they get me more but I do realize that I have to just, in order to be back to my normal life or, or stuff I have to be you know suddenly it can’t be all about surviving cancer. . . . Now I find that the more time passes by the better I get. I think it’s just something I think is going to come with time.

(Nikola, early 40s at dx)

**Relational Connections: Summary**

Participants’ narratives described a number of connected and disconnected relationships before, during, and after their breast cancer experiences. The Pre-Cancer Phase described women’s Connection to Partners, Family, and Close Others, exploring the importance of close and meaningful relationships both within and outside of their families; and an Other-Oriented Focus of Care, stressing women’s prioritization of the needs of others over and above their own. During this phase, participants demonstrated their level of investment and attachment to close others.
The Diagnosis and Treatment Phase was a critical period that often tested the safety and stability of many relationships. Three overarching subcategories emerged including: Connection to the Medical Team, reflecting women’s experiences of feeling supported, grounded, and connected versus dismissed, betrayed, or objectified by their medical team; Disclosure of Illness, examining how women grappled with sharing their diagnosis with their children, extended family, co-workers, and friends; Hiding Versus Uncovering The Illness, reflecting the diverse coping mechanisms women used to feel safe and protected in their cancer-inhabited bodies; and the experience of Feeling Alone Versus Supported and Validated, reflecting women’s need to rely on close others for emotional and practical forms of support at treatment.

Unlike the other phases, the Post-Cancer Phase was a time of reflection whereby participants were able to re-examine past Relational Connections, their importance, and their meaning. Three subcategories emerged including: Recognizing True Friendship, reflecting women’s abilities to narrow down their most meaningful relationships with friends; Altered Connection to Partner, reflecting the trials and tribulations faced in returning to levels of connection and intimacy with their partner; and Staying Connected Versus Letting Go of the Illness, exploring participants’ decisions to remain connected to their illness through cancer support groups, or to move forward in their lives without integrating the illness experience into their relational connections.

Overall, the core category of Relational Connections shed light on women’s capacity for illness-related meaning making within relationships at survivorship. Relational Connections demonstrated participants’ desires to seek safety and support from close others during the turbulent time of their breast cancer experience. Once treatment was completed, however, the investment and meaning of past relationships was, at times, questioned. The Relational
Connections category also uncovered women’s ability to shift from an other-oriented, over-committed focus of care in relationships at the Pre-Cancer Phase toward more balanced and sometimes deeper connections, informed by the illness experience. This was associated with enhanced pleasure and well-being.

**Meaning and Life Goals**

Participants’ narratives explored their meanings, priorities, and life goals before, during, and after their breast cancer experience. The Pre-Cancer Phase examined women’s Pre-Cancer Priorities, reflecting women’s personal priorities and goals, and the ways they were understood by others. The Diagnosis and Treatment Phase examined women’s ability to Embrace Experiences of Change and New Opportunities in Self, reflecting the willingness of some participants to transform the cancer experience into opportunities to enhance their self-experiences. Most importantly, at the Post-Cancer Phase, participants discussed a Greater Awareness of Values and Life Goals, reflecting their meaning-making capabilities within the self from both practical and existential perspectives. Overall, the core category, Meaning and Life Goals, shed light on participants’ meaning-making capabilities and re-prioritization of values within the self. Table 15 illustrates the subcategories explored in the sixth and final core category, Meaning and Life Goals.

Table 15

*Subcategories found in the sixth core category, Meaning and Life Goals*

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<th>Core Categories</th>
<th>Pre-Cancer Phase</th>
<th>Diagnosis and Treatment Phase</th>
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Meaning and Life Goals: Pre-Cancer Phase

When addressing participants’ Meaning and Life Goals in relation to surviving breast cancer, participants often identified their priorities and values prior to their cancer experience. This exploration was critical as it demonstrated important shifts in Meaning and Life Goals at survivorship.

Pre-Cancer Priorities. At the Pre-Cancer Phase, most participants reflected upon pre-cancer priorities and life goals. This subcategory not only identified participants’ personal beliefs in relation to their priorities and values, but also the ways in which close others understood their priorities prior to their cancer diagnosis. Many participants retrospectively described their priorities as including work, volunteering, or their children.

For example, Rachel described her connection to volunteering as a major source of meaning and identity in her life.

That’s kind of how I was raised was to give back so yeah it’s, and it’s part of my identity, it’s part of who I am and I think it just makes the world a better place if you’re able to spend that little bit of extra time and we all have you know gifts and talents and they can be shared with people that maybe don’t get to experience those things all the time. (Rachel, mid 20s at dx)

Maria described the priority she placed on her work life prior to her cancer diagnosis.
. . . until I hit twenty-seven when I got married I mean that was all about let’s see how much work we can put in . . . you know you’re always trying to climb, climb up the corporate ladder. . . . Once you have kids it’s much harder but still you know after your year of mat leave you go back into work and you try and immerse yourself back in and there are lots of times where you’re calling up your husband or calling up the nanny or calling up whoever and you know look after the kids I’m not coming home tonight . . . (Maria, early 40s at dx)

Prior to having breast cancer, Olivia self-identified as a “strong” woman; at work, she enjoyed being given the nickname “[The Police Squad]” as she appreciated being perceived as both tough and aloof around her co-workers.

Even at work [my co-workers] gave me a name because I speak [non-English] language so there was a name of “[The Police Squad]” so [laugh]. . . . They said [be]cause you know you are tough. That’s why they call me “[The Police Squad]” because they say all information goes inside of you but not much you opening to us [laugh].

(Olivia, late 30s at dx)

Before [cancer], I would focus probably the majority of my life on the kids, everything was about the kids, and making sure the kids are happy. . .

(Alison, mid 30s at dx)

**Meaning and Life Goals: Diagnosis and Treatment Phase**

Most commonly, women did not describe reflecting on their life goals during the Diagnosis and Treatment Phase. As previously outlined, for many patients, this phase was
focused on their physical health and well-being rather than on psychological or existential issues. Nonetheless, toward the end of their medical treatment, some participants reflected upon and embraced experiences of change, and new opportunities within themselves. These reflections typically demonstrated an initial shift in relation to the ways women understood their personal values and priorities prior to having breast cancer.

**Embrace Experiences of Change and New Opportunities in Self.** Toward the end of treatment, some participants explored the ways in which the cancer experience was associated with meaningful and existential shifts in their values and life goals. Some women embraced change and new opportunities within themselves, making space for a *new normal*. For example, these women described shifts in their expression of femininity, self-confidence, and ambitions.

At times, shifts were expressed through new and concrete changes about the ways in which the women dressed or made other daily choices. Lauren, for example, described experiencing an existential shift between “old” and “new” Lauren through the gift of a red wallet.

I mean I never really wore a lot of pink until I had breast cancer and, and I remember I was just so in denial. . . . [Before cancer], a woman gave me a gift . . . it was a red leather wallet and I never had a red leather, like all my wallets have always been black, black leather wallets. . . . And to have a red leather wallet was such a big deal because it was so different. . . . Like it’s so stupid it’s such a small example . . . [but] all of a sudden you take it, you change, it’s so small but it’s so significant . . . it’s so not you, oh my God it’s so not you . . . wearing something that’s not you or your old you and now you’re different . . . it is part of the new you . . .

(Lauren, early 30s at dx)
For other women, the changes related to shifts in their self-experience or ambition. For example, toward the end of her treatment, Erin described her breast cancer experience as being a major catalyst for change within herself; it granted her greater self-confidence and ambition.

I mean [cancer] was absolutely a catalyst for change and again there’s that sense of like wow this could really break me and this could like make me become a small weak person or I can use it and like fight with it and make it help, like utilize it to make me even bigger . . . this is the first time I’ve ever been ambitious in my life you know I was always really afraid to put effort into anything or have ambition and like this [cancer website I created], this is the first time I put ambition into anything and it like is huge. . . . [Audre] Lord said, “in the process of losing a breast I have become a more whole person.” I too became a more whole person, I became more ambitious, I became more self-assured, I became more intently focused on raising awareness on the intersectionality of breast cancer and queerness.

(Erin, early 30s at dx)

**Meaning and Life Goals: Post-Cancer Phase**

Shifts in Meaning and Life Goals were most present during the Post-Cancer Phase. Participants described a heightened awareness of values and life goals, expressed both through practical decisions and existential reflections. Practically, women described the importance of protecting their time by putting greater emphasis on people and activities that gave them pleasure and joy in their lives. Existentially, women described a softening of the self, a greater appreciation for beauty in the world, and a search for enlightenment.
Greater Awareness of Values and Life Goals. Once medical treatment was completed, some participants described engaging in a re-evaluation of life goals and priorities, and examining the meaning behind different facets of themselves. Women described practical steps they took to reach their life goals (e.g., reprioritizing their time). Unlike in the Pre-Cancer Phase, many women in the Post-Cancer Phase recognized the importance of placing more time and energy on activities that gave them joy, peace, or greater meaning in life. For many, less focus was placed on work and volunteering ventures. Participants also described experiencing existential shifts in the way they lived in the world after completing treatment (e.g., softening of the self, greater appreciation for and mindfulness in the world, and searching for enlightenment).

More generally, women continued to articulate the Post-Cancer Phase as an opportunity to re-evaluate their meaning and values.

It definitely made me evaluate my priorities. It constantly makes me evaluate my priorities to this day and I think too that meaning, meaning, meaning don’t want to say that priorities because it’s not priorities. I guess it, it really changed what I value and how I value it and why I value it right . . .

(Morgan, early 30s at dx)

I think in a lot of ways like once you’ve gone through something that’s you know where you feel like you, you, where you fear for the loss of your life you have to, I mean certainly you re-prioritize . . .

(Erin, early 30s at dx)
More specifically, many participants described practical ways in which the cancer experience helped shape their values. Specifically, they explained the importance of protecting their time for people and activities that gave them, joy, happiness, or peace in their lives.

It taught me to really slow down . . . and to really put a value on my time too which I never really did before . . . just kind of figuring out like you know do I want to say yes to this opportunity or should I pass it along to somebody else and making more time for myself too like for example taking weekends off. I never used to really do that. . . . [Now], I need to have the weekend to kind of just relax and center myself and just finding opportunities to take time for myself . . .

(Rachel, mid 20s at dx)

Before [cancer], I was working for an onshore firm and I’d be at work until 3:00 in the morning, go home, go back into work for 8:00 o’clock. Now I’m gone by 4:00 in the afternoon.

(Maria, early 40s at dx)

Now, you know [when] I still [have an extra] couple of [work] shifts I get rid of them and I go home for more time because you know it’s not as important. . . . That’s the one positive thing that came out of cancer. I just sometimes think I wish I could come up with that without having cancer. Why did it have to take cancer for me to realize how this is?

(Nikola, early 40s at dx)
In addition to practical changes, participants also described meaning-making opportunities within the self through existential shifts in the ways they interacted with the world. Many participants described experiencing existential shifts in terms of an internal softening of themselves after their breast cancer.

... [before my cancer experience], it was a part of my identity to like be butch and then I didn’t, you know it took me a while to realize that I had kind of lost that in a sense, I won’t say lost but just that I didn’t rebuild that; maybe that’s a better way of thinking of it but it took me a while to realize that it was different and I get that comment a lot like people just say like I feel a lot softer and I feel a lot softer. I feel softer in the sense that like I’m more, I’m more in tune with my emotions and more just softer in a very literal sense like and having a conversation like I’m not always debating and, and, and in the way that I present...

(Erin, early 30s at dx)

[The cancer experience], it softened like if I think of myself how I look now and how like there’s like a softening ... in general there’s a much more, I think, softer and more feminine look to like when I see myself now...

(Lauren, early 30s at dx)

As well, Lauren and Judy, like many other participants, went on to describe a greater appreciation for, and mindfulness of, the world and beauty around them.

There’s two main things that cancer I think changed in terms of my perspective. One it made me appreciate things more you know being aware of this flower that’s so beautiful
or when you open a pomegranate you see the colour and just how amazing that is. I’m definitely appreciate the small things, definitely you know exacerbated that aspect and the other thing is not to judge people because you have absolutely no idea what they’re going through or what’s going on the other side . . .

(Lauren, early 30s at dx)

I feel like I have, I appreciate things more. I get that is a little cliché to say but I truly do. I, you know I pay attention to things more, I, you know I had a mindfulness practice before I got sick but I understand it better now [laugh] you know what it means to be mindful and what it is to use mindfulness.

(Judy, late 20s at dx)

Even when no specific shifts could be articulated, women described searching or yearning for meaningful shifts.

I certainly hit the overachiever enlightenment stage [after breast cancer]. I had maybe just become like I don’t know Ghandi or something. . . . Well I just needed to find enlightenment in everything like I was just really searching for it. You know if I could have spent two years on the top of a mountain in Nepal just meditating, I probably would have right. . . . But that didn’t really work well for me either so I had to find [laugh] some balance on the other side . . .

(Morgan, early 30s at dx)
Judy also described a shift in her values. In particular, she discussed the notion of learning to “let go” of things that once bothered her; she saw value in removing parts of herself that no longer fit with her post-cancer perspective or values.

I’m a little bit better at letting go of things . . . I [used to] really hang onto things. For example my step-daughter loves Coca-Cola and I’m like oh my gosh it’s so much sugar, it’s so unhealthy, you know and I would never make a fuss about it out loud but it would eat me alive inside. . . . I mean, yes, it is unhealthy for her and I don’t have to get insanely worked up about it . . . it is a good thing for sure that I’ve been able to let go and maybe remove that part of you know intense holding onto things.

(Judy, late 20s at dx)

**Meaning and Life Goals: Summary**

In sum, participants’ narratives described women’s Meaning and Life Goals before, during, and after their breast cancer experience. The Pre-Cancer Phase described women’s Pre-Cancer Priorities, reflecting women’s central priorities and goals, and how others perceived them. The Diagnosis and Treatment Phase examined women’s ability to Embrace Experiences of Change and New Opportunities in Self, reflecting the willingness of some participants to transform their cancer experience into one of opportunity in order to enhance the self. Most importantly, participants in the Post-Cancer Phase reflected a Greater Awareness of Values and Life Goals, which involved shifts in the meaning of life and life goals from both practical and existential perspectives. Practically, women described the importance of protecting their time for themselves and those closest to them. Unlike in the Pre-Cancer Phase, many women in the Post-Cancer Phase spent less time focused on work and volunteer activities, and put greater emphasis on people and activities that gave them pleasure, joy, and peace in their lives. Following their
breast cancer experience, women described experiencing an existential softening of the self, a
greater appreciation for and mindfulness of the world, as well as a search for enlightenment.
While participants’ narratives at the Pre-Cancer Phase described general domains of meaning
and values within their lives, narratives at the Post-Cancer Phase showcased a critical shift
within many women’s priorities whereby they felt more attuned to their true values.

Overall, the sixth and final core category, Meaning and Life Goals, examined meaning-
making opportunities and the re-prioritization of values within the participants.
Chapter Eight: Discussion of Qualitative Inquiry in Relation to Previous Literature and Quantitative Findings

Breast cancer, as a form of biographical disruption (Bury, 1982), has the potential to cause interruptions to normal processes in identity formation among young women. Breast cancer also has the capacity to shake earlier taken-for-granted meanings regarding one’s identity (Sedgwick, 1993) and destabilize certain assumptions about possessing a smoothly functioning body by drastically disrupting any sense of body-self unity. The qualitative inquiry was one of the first studies to explore identity as a complex and multidimensional construct among a younger sample of women with breast cancer. The qualitative inquiry focused on interviews of twelve young women between the ages of 24 and 44 at the time of diagnosis who identified diverse experiences in relation to social location, and positive and negative experiences of inhabiting the body. The aim of the qualitative arm of this investigation was to retrospectively examine the ways in which being a young woman breast cancer survivor led to shifts in identity between pre- and post-cancer phases. The study explored the relationship between these identity-related shifts and women’s perceived experience of well-being. When women in the study reflected upon the ways in which being a young breast cancer survivor led to shifts in identity, they described six core dimensions: 1) Loss and Adversity, 2) Connection to the Physical Body, 3) Social Power Related to Bodily Experiences, 4) Internalization Versus Rejection of Gender-and Illness-Related Discourses, 5) Relational Connections, and 6) Meaning and Life Goals. These six core categories took a central role in women’s experience of identity and subsequent perceived experience of well-being at survivorship.
Theoretical Findings on the Construct of Identity

Results from the qualitative inquiry shed light on two key theoretical findings that expand upon the current construct of identity and the ways in which it has been scientifically examined in the field of psychosocial oncology.

1) While past conceptions of identity within psychosocial oncology tended to be defined more narrowly, the current qualitative inquiry found that the construct of identity, as narrated by the women, was multifaceted—containing six core dimensions that, in turn, were strongly related to women’s inhabited bodies. Subsequently, the construct of identity was revised and relabelled to encompass such changes, using the term Embodied Identity.

2) The construct of Identity Integration referred to in the literature was expanded upon in the present investigation based on identity-related shifts found in the qualitative study. Through the Pre-Cancer, Diagnosis and Treatment, and Post-Cancer phases used to analyze the data, the qualitative inquiry examined women’s Embodied Identity and its respective shifts across the cancer journey. These two theoretical findings are discussed further below.

First, despite long-standing recognition of identity as a theoretical construct that may shape health-related behaviours and outcomes, it has historically been difficult to translate this intuitive understanding of identity into an empirically supported theoretical framework. Previous research in the field of psychosocial oncology has attempted to theorize and define the construct of identity, but in limited ways. Identity has typically been defined in ways that often lacked intimate connection to people’s lived experiences. Based on past literature, the construct of
identity utilized in the present investigation was defined as “meanings that persons attach to the multiple roles they typically play in highly differentiated contemporary societies” (Stryker & Burke, 2000). This definition, among others, commonly described a person’s identity as having the capacity to explore what they had in common as well as what differentiates them from others (Stryker & Burke, 2000). Moreover, the majority of studies in psychosocial oncology have focused narrowly on single, more measurable aspects of identity. For example, researchers have used the construct of identity to examine participants’ internalization of the cancer survivor identity (Bellizzi & Blank, 2006; Deimling, Bowman, & Wagner, 2007; Kaiser, 2008; Park, Zlateva, & Blank, 2009; Zebrack, 2000). Other researchers have used the construct to examine the reformation of the sexual self (Beckmann, Johansen, Richardt, & Blichert-Toft, 1983; Berterö & Chamberlain Wilmoth, 2007; Male, Fergus, & Cullen, 2016; Yurek et al., 2000), while others have used the construct to examine shifts in the gendered self (Boquiren, Esplen, Wong, Toner, & Warner, 2013; Gurevich et al., 2004; Rubin & Tanenbaum, 2011). Although these examinations of identity have had significant merit, these approaches may have overlooked additional and critical components of identity after a cancer experience. Based on findings from the qualitative inquiry, the researchers chose to revise the previously held definition of identity. Specifically, women’s narratives shed light on the need to broaden the scope of identity by capturing a more comprehensive, six-dimensional construction of identity. The six dimensions of identity included: Loss and Adversity, Connection to the Physical Body, Social Power Related to Bodily Experiences, Internalization Versus Rejection of Gender- and Illness-Related Discourses, Relational Connections, and Meaning and Life Goals.

Another missing ingredient from previous definitions of identity involved the centrality of the body. Women’s experience of inhabiting the body was dominant in each of the six core
dimensions of identity, suggesting an inextricable link between the body and the self in the context of breast cancer. For many of the young women interviewed, the body and its respective losses were often the central foundation of how women redefined themselves, and how others redefined them. Hence, the body became an important site for their identity-related processing. This notion regarding the integration of mind and body is best supported by Merleau-Ponty (1962), the pre-eminent philosopher of the body; he proposed that mind and body are equivalent, intertwined, and inseparable (Csordas, 1994; Howe, 2003). Further, coining the term body-subject, Merleau-Ponty viewed the body as “sentinel in perceiving, interpreting, and experiencing the world meaningfully, and therefore as a center of subjectivity” (Piran, 2016, p. 44). Likewise Piran (2016), through her construct of the Experience of Embodiment and the related Developmental Theory of Embodiment, also emphasized this association between mind and body, and in similar fashion.

Of the six central dimensions identified, two were explicitly anchored in body-based experiences: Connection to the Physical Body—reflecting experiences of agency, ownership, and connectedness in the body; and, Social Power Related to Bodily Experiences—reflecting the ways women used their bodies to embody or reject idealized and objectified images of women to (re)gain social-power. However, even among the other four dimensions of identity, the body was central. For example, in Loss and Adversity, women described a number of losses, particularly during the cancer experience, anchored in the body (e.g., hair loss, breast loss). Likewise, in Internalization Versus Rejection of Gender- and Illness-Related Discourses, women’s appearance was central to the ways in which the body was used to preserve their pre-cancer healthy and feminine selves both during and after completing their cancer treatments. As well, in Relational Connections, women’s bodies helped facilitate the processes of intimacy, or
withdrawal from partners and family members at survivorship. Thus, based on the qualitative findings, the centrality of the body appeared to be a critical feature of the revised construct of identity.

Based on the qualitative findings, the term identity was revised to better characterize the construct of identity as being multifaceted—containing six core dimensions and carrying a central relationship to women’s inhabited bodies. These revisions warranted the researcher to re-label the construct as Embodied Identity. The term Embodied Identity has rarely been used or defined in the context of illness; however, Gyllensten, Skar, Miller, and Gard (2010) discussed Embodied Identity as a deeper understanding of body awareness as it pertained to patients and therapists engaged in psychiatric/psychosomatic rehabilitation. Among these researchers, Embodied Identity encompassed two related components: living in the body—becoming “more aware of the body and to experience oneself from within in order to recognize one’s needs” (p. 439); and living in relation to others and in society—using “the embodied self to interact with others and for societal participation” (p. 439). Koszalinski and Williams (2012) also used and defined Embodied Identity in relation to cancer patients who had received chemotherapy-induced alopecia. These researchers described it as, “the way in which persons changed how they viewed the self (mind, body, and spirit) in an effort to reconcile alterations in health-related function and/or appearance” (p. 119).

Although the qualitative findings have shed light on the need to describe identity through an embodied lens, the psychosocial oncology literature has yet to give a clear definition that systematically fits the findings from the qualitative study. Nevertheless, grounded in Merleau-Ponty’s definition of embodiment is the “perceptual experience of engagement of the body in the world” (Allan, 2005, p. 175). Piran (2016) noted that Merleau-Ponty’s perceptual experiences
can refer to a meaningful position of being-in-the-world. As such, embodiment as a whole can be described as the “lived experience of engagement of the body in the world (Piran & Teall, 2012, p. 171). Using this framework, and based on the emergent findings in the six core dimensions of identity, Embodied Identity can best be defined in the present study as: women’s lived experience of engagement of the body, in the world, as they experience a biographical disruption through breast cancer. Embodied Identity, within the context of the present investigation, also included all six core dimensions (i.e., Loss and Adversity, Connection to the Physical Body, Social Power Related to Bodily Experiences, Internalization Versus Rejection of Gender- and Illness-Related Discourses, Relational Connections, and Meaning and Life Goals). All six dimensions were understood as interwoven, co-existing, and fluid.

Second, the term Identity Integration, used in the present investigation to conceptualize identity-related shifts in young breast cancer survivors, was expanded upon based on the qualitative findings. Previous researchers Westra and Rodgers’ (1991) initially defined the integration as “two or more elements [that] are merged with sufficient interaction so that unity of the newly formed entity is achieved” (p. 280). Later, Whittemore and Dixon (2008) provided an illness-specific definition of Identity Integration, defining it as the reformation of post-illness identities whereby an illness experience is reconciled with past and present identities and roles. In the quantitative arm of the study, Identity Integration was further specified to examine whether two aspects of identity-related shifts, namely illness- and gender-related identity, were related to women’s experience of well-being. The quantitative findings in the present investigation confirmed that both gender and illness aspects of identity were predictive of women breast cancer survivors’ well-being and experience of embodiment. Rather than focusing narrowly on two aspects of identity-related shifts (through illness- and gender-related identities),
as conducted in the quantitative arm of the study, the qualitative findings expanded upon these two dimensions, finding six core dimensions of Embodied Identity. While the quantitative and qualitative findings both demonstrated the importance of gender- and illness-related aspects of identity, the qualitative findings expanded upon these results to capture a broader, multidimensional construct of identity and their impact on psychosocial well-being at survivorship.

Moreover, while participants’ experience of Identity Integration was explored solely at the survivorship stage in the quantitative arm of the study, and in previous literature (Fleury 1991; Whittemore & Dixon, 2008), the qualitative study retrospectively gained greater insight into the Identity Integration process through the Pre-Cancer, Diagnosis and Treatment, and Post-Cancer phases of women’s narratives. As a result, women’s perceptions of pre-cancer identities were identified and analyzed when considering any reported cancer-related identity shifts. Examining the lived experiences of women across these three time frames was critical to the analysis of women’s six core dimensions of Embodied Identity, as well as their overall experience of well-being at survivorship.

The following section will examine key findings from each of the six core dimensions of women’s Embodied Identity.

**Examining Six Core Dimensions of Women’s Embodied Identity**

The results of the qualitative inquiry described six core dimensions of women’s Embodied Identity, including: 1) Loss and Adversity, 2) Connection to the Physical Body, 3) Social Power Related to Bodily Experiences, 4) Internalization Versus Rejection of Gender- and Illness-Related Discourses, 5) Relational Connections, and 6) Meaning and Life Goals. These six
dimensions were analyzed at pre-, during, and post-cancer phases in order to comprehensively analyze and understand women’s Embodied Identity at survivorship.

**Loss and Adversity.** The first core category to emerge from the narratives of young women breast cancer survivors was Loss and Adversity. Participants’ narratives contained numerous examples of adversity throughout their lives, with the breast cancer experience commonly viewed as the most painful experience of loss. Two key findings from this core dimension were discussed.

First, when women subjectively appraised their cancer experience as progressive losses that repeatedly threatened their body and self-integrity, they reported more negative psychological sequelae and worse psychosocial well-being at survivorship. These findings are in line with earlier research in psychosocial oncology (Cordova et al., 2007; Glanz & Lerman, 1992; Moyer & Salovey, 1996; Spiegel & Nemeroff, 1997) as well as the seminal work by Charmaz (1983, 1991, 2002) on biographically informed perspectives of chronic illness. Sumalla, Ochoa, and Blanco (2009) further explained this finding by describing the importance of women’s *future memory* (Little et al., 2002). Future memory is comprised of attributes of personal identity that form an image of the self in an imaginary or advanced way; they ensure that our lives are coherently focused on the future (Little et al., 2002). However, cancer can cause a rupture in future memories, curtailing any sense of continuity in women’s existence (Sumalla, Ochoa, & Blanco, 2009). Sumalla, Ochoa, and Blanco (2009) continue to explain, “unlike typical traumas where the past can become the present in the shape of a recurrence of traumatic experiences, in a cancer-associated trauma, what is present is an ill-fated future, resulting in the inability of the patients to picture themselves over time because of the distress this causes” (p. 26). More recently, Golub and colleagues (2013, 2014) empirically examined
illness-related loss using the Impact on Self-Concept Scale and found an inverse relationship between perceptions of self-loss and well-being in chronically ill populations. Although findings from the study revealed self-loss was associated with participants’ physical well-being scores, its association to aspects of well-being appeared independent of that relationship. As such, the psychological contribution of illness-related self-loss and depression, for example, existed over and above participants’ objective physical health status. Likewise, the qualitative finding was also supported by the present investigation’s quantitative results (Hypothesis 1A); using the Impact on Self-Concept Scale as a predictor variable, high levels of perceived self-loss were negatively associated with high QOL and experience of embodiment scores.

Second, in the qualitative study, survivorship was a critical time period in which women had the opportunity to move away from an exclusive focus on their physical health, toward their psychological well-being. Women who reported processing and integrating strength, hope, or self-growth into their breast cancer experience reported less psychological sequelae and greater well-being at survivorship. Importantly, this finding was supported by the quantitative results, which found high levels of perceived self-growth to be positively associated with and predictive of QOL and experience of embodiment scores. This finding also aligned with the growing body of literature suggesting the positive impact that growth can have on cancer patients’ lives through posttraumatic growth (PTG) following a breast cancer experience (Antoni et al., 2001; Ashing-Giwa et al., 1999; Bower et al., 2005; Carver & Antoni, 2004; Cordova et al., 2001; Tedeschi & Calhoun, 1996). However, as previously noted in the quantitative study, empirical research in psychosocial oncology examining the relationship between PTG and well-being has been inconsistent (Costanzo, Ryff, & Singer, 2009). Some studies have found a direct association between self-growth and well-being in cancer and other chronically ill populations (Danoff-Burg
& Revenson, 2005; Evers et al., 2001; Golub et al., 2014; K. Siegel & Schrimshaw, 2007; Urcuyo et al., 2005), while others have not (Bradley, Rose, Lutgendorf, Costanzo, & Anderson, 2006; Dorval, Maunsell, Deschenes, Brisson, & Masse, 1998; Ganz et al., 1998; Golub et al., 2013; Helgeson et al., 2006). Golub and her colleagues also noted that, “a focus on growth alone may not be sufficient to understand the impact of chronic illness on identity and psychological well-being” (Golub et al., 2013, p. 2).

The mixed findings in the PTG literature may be a result of constraining methods used to understand the construct of PTG. Much of the research examining PTG does not take into consideration participants’ pre-cancer or pre-illness experiences of loss and growth. Therefore, the most critical finding in Loss and Adversity was women’s ability to connect with pre-cancer experiences of resilience and strength when confronting adversity and loss; in doing so, self-growth processes and subsequent well-being appeared to have been strengthened in these women. Unlike the majority of studies examining PTG in cancer populations, the qualitative findings conceptualized self-growth processes by moving beyond women’s narratives within the cancer experience; findings from the qualitative inquiry add to the pre-existing literature by emphasizing the critical role that pre-cancer experiences of adversity and resiliency play in women’s capacities to adjust and recover at survivorship.

**Connection to the Physical Body.** The second core dimension of Embodied Identity related to women’s physical connection and disconnection to the body before, during, and after the cancer experience. Three key findings emerged.

First, prior to the cancer diagnosis, the majority of women described key memories in which they acted in the world with a sense of freedom or a sense of restriction. Bodily changes
related to puberty and, sometimes, pregnancy, for example, led to feelings of discomfort and even disconnection from the body. This finding contrasted with some earlier researchers and theorists in the feminist and disability communities. According to Leder (1990), the body disappears from conscious awareness when it functions in a non-problematic state; it “not only reaches outward in experience but falls back into unexperiencable depths” (p. 53). That is, the body becomes an absent presence. However, based on the twelve interviews conducted in the present qualitative inquiry, women indicated that their bodies were not an absent presence; rather they described a full spectrum of experiences, from positively inhabiting the body to experiences of disrupted embodiment.

The finding of participants’ pre-cancer connection to the body in the present investigation is in line with Piran’s (2016) qualitative research program. Piran (2016) examined the lived experiences of embodiment among girls and women by conducting 171 interviews with 69 girls and women in three separate studies: (a) a life history study of 30 interviews with 11 women, ages 20-27; (b) a five-year prospective interview study of 87 interviews with 27 girls, ages 9-14; and (c) a life history study of 54 interviews with 31 women, ages 50-68. Piran’s (2016) research program on girls and women’s experiences of embodiment described five central categories; one of these categories was entitled, Body Connection and Comfort vs. Disrupted Body Connection and Discomfort. Among the 11 women interviewed, ages 20-27 (an age that encompassed the majority of women in the present study’s pre-cancer selves), Piran (2016) identified young women who detailed a positive connection with their body, describing comfort in inhabiting the body and using self-talk to support acceptance of their natural body shape. Other women in her study, though, described ongoing challenges with inhabiting their bodies comfortably in their twenties; for example, one woman of Caribbean Canadian heritage and a working class
background described marked shifts in body connection in her teens and twenties after adverse body-based experiences, such as a body violation. Thus, Piran’s (2016) findings shed light on the intricate and complicated form women take in connecting to their bodies throughout the lifespan.

Second, at the time of medical diagnosis and treatment, all women in the present study described their cancer illness as an experience of restricted agency and restrained ownership in the body. Piran (2016), and the results from her research program, best elucidate this finding; she explained that restrictions in agency and body ownership are associated with experiences of loss, “either of never having the opportunity to develop physical agency, or more commonly, losing the valued experience of physical agency . . .” (p. 49). For a majority of young breast cancer survivors, the latter was true; they described losing their valued experience of physical agency. Piran (2016) also outlined the consequences that follow a disruption in agency for women; she asserted that the joyful immersion and agency in physical activities are commonly replaced with compulsive, often joyless activities anchored in experiences of deficiency versus agency. For example, Maria in the qualitative inquiry, like many other women, described experiencing a striking shift from physical joyful immersion and agency in physical activities toward one of joyless activities with isolation and segregation as a stereotypic bed-ridden cancer patient.

The third and most critical finding in this dimension was women’s ability to re-capture their physical agency and body ownership, both during treatment and at survivorship. During these phases of their cancer experience, women critically and creatively questioned aspects of their self in order to reconnect with and care for their physical bodies in a way that aligned with their post-cancer needs. This movement from restricted agency and restrained ownership in the body toward agency and functionality in the body (e.g., through exercise, sports, or travel) was reported by women as leading to experiences of well-being. Likewise, Piran’s (2016) research
program supported this finding, highlighting that girls and adult women who are able to maintain
agency and body ownership in the physical environment, and even those who re-captured
physical agency as adults, reported more positive experiences of embodiment and well-being.
Beyond Piran’s (2016) research program, extensive research has focused on re-capturing
physical agency in the body, particularly within the areas of sports and disability (Piran & Teall,
2012). Within the disability literature, Guthrie and Castelnuovo (2001) shed light on the value
physical activities, including exercise and sports, have on the connection to the physical body
among women with physical disabilities. These authors examined the ways women with physical
disabilities shaped their identities and managed (i.e., coped or came to terms with) their
disabilities while living in an able-bodyist culture. Particular emphasis was placed on how these
women used physical activities in the management process. Findings suggested that physical
activities, and more specifically sports can act as a site in which restrictive notions of the body,
ability, and physical performance can be effectively challenged (Piran & Teall, 2012; Guthrie &
Castelnuovo, 2001).

Additionally, many women who felt well adjusted at survivorship in the qualitative study
described increased body attunement (e.g., re-engaging with physical and sexual sensations) and
physical freedom (e.g., through travel, exploration, and sport). Guthrie’s (1999) qualitative study,
conducted with 37 women with chronic illness and physical mobility disabilities, supported and
further elucidated this finding. In her study, she examined women’s ability to manage (i.e., cope
or come to terms with) disability through the body and emphasized a critical relationship
between physical freedom and body attunement with women’s experience of embodiment.
Specifically, the results from their study found that the most effective approach to managing
disability was through optimizing mind-body functioning: women used physical activity to
optimize the functioning of their minds and bodies rather than normalize or beautify themselves. Physical activity kept women in touch with their physical selves—thereby increasing body attunement—and satisfied their desire to do whatever movement was feasible—thereby increasing physical freedom. Thus, optimizing mind-body functioning through regular physical activity became paramount to women’s later experiences of embodiment. Guthrie (1999) also posited that it played a “critical role in the development of an empowered female self,” by enhancing physical and global self-perceptions (p. 378). In accordance with findings from the present qualitative inquiry, optimizing mind-body functioning through experiences of physical freedom and body attainment can lead to greater experiences of embodiment through the development of an empowered self.

**Social Power Related to Bodily Experiences.** The third core dimension of Embodied Identity explored the importance women placed on gaining social power through embodying idealized and objectified images of women. The majority of women in the study reported that they acquired confidence and security in relationships, and within themselves, through self-objectification, namely: aiming to adhere to idealized norms of appearance. As Rubin and colleagues (2004) explained, within current gender/power relations, women’s access to power and privilege is often tied to their accommodation to mainstream ideals. *Buying into* feminine ideals can give certain women access to social power (Hurtado, 1989). Indeed, in the present investigation, women often reported that they tried to adhere to idealized appearance norms before the cancer diagnoses, and that such adherence was associated with access to social and economic resources, mainly through relationships with men. Feminist scholars, including Bartky (1998) and Piran (2016), have underscored the centrality of power in the way women inhabit their bodies. As described by Piran (2016), Foucault (1979) suggested that “in modern society,
so called ‘invisible’ power acts on visible subjects from the ‘bottom-up’ through widely disseminated and accepted societal discourses . . . as individuals comply with restrictive social expectations, they produce ‘docile bodies’” (Piran, 2016, p. 44). Bartky (1998) too emphasized that these “disciplinary powers that inscribe femininity in the female body is everywhere and it is nowhere; the discipline is everyone and yet it is no one in particular” (p. 74).

As well, women in the present study who acquired most of their power, confidence, and self-worth through self-objectification prior to their cancer diagnosis were more likely to attempt to recapture social power through appearance and self-objectification at the survivorship phase. Past studies have demonstrated the ways in which women practice gender can lead to discrimination, loss of social power, and adverse consequences to health and well-being (Dumas, Laberge, & Straka, 2005; Martin, 2003; Piran, 2001; Piran et al., 2006; Piran & Gadalla, 2007; Silverstein & Blumenthal, 1997; Striegel-Moore & Franko, 2002; Zitzelsberger, 2005). This finding is also supported by Fredrickson and Roberts (1997), and their Objectification theory that maintained that the “cultural milieu of objectification functions to socialize girls and women to, at some level, treat themselves as objects to be looked at and evaluated” (p. 177). Hence, many women are drawn toward continuing the cycle of self-objectification. The findings of the present investigation are also in line with the Developmental Theory of Embodiment (Piran & Teall, 2012). The theory suggests that experiences of social power related to individuals’ social locations shape the experience of embodiment. A change in health status can therefore disrupt one’s experience of embodiment, which individuals may seek to restore by pursuing an appearance unaffected by illness and in compliance with idealized appearance norms.

While some women in the study reported successfully recapturing social power through greater appearance investment, many women already highly invested in their appearance felt
unable to recapture their social power. Given that these women perceived themselves, after their cancer experience, to be even further away from embodying idealized and objectified images of women, they reported distress and poorer adjustment. This finding is supported by the quantitative results (Hypothesis 2B) of the present investigation, as the data revealed that women who reported greater perceived body surveillance—a greater tendency to scrutinize the way their bodies complied with idealized social norms of appearance—had worse QOL and embodiment scores. This finding also aligns with previous research showing that women with a greater disposition to self-objectify were in poorer mental health. For example, women with higher scores on self objectification measures showed greater depression (Choma et al., 2010; Szymanski & Henning, 2007; Tiggemann & Kuring, 2004), greater body shame (Grabe et al., 2007; Knauss et al., 2008; McKinley, 1998), and higher rates of disordered eating (Calogero et al., 2005; Greenleaf & McGreer, 2006; Steer & Tiggemann, 2008) and sexual dysfunction (Calogero & Thompson, 2009; Steer & Tiggemann, 2008). The results of the present investigation are also in line with a qualitative participatory action project (Piran, 2001) that aimed at addressing body weight and shape preoccupation in school environments. The study demonstrated that young women’s lack of social power greatly contributed to difficulties with accepting their bodies. Piran (2001) stated:

It seemed that, for the young women who participated in the project, body weight and shape preoccupation worsened when their sense of ownership over their body was disrupted, when their bodies were used as a medium to express pervasive societal prejudices, and when the social construction of women constrained and demeaned ways of being in the body that did not comply with perceived societal expectations. (p. 227-228)
An important finding in this dimension was the path some women took to re-negotiate and resist returning to social power through self-objectification; this, in turn, had a positive impact on well-being at survivorship. Rubin, Nemeroff, and Russo (2004) noted that feminist researchers have an important role to play in investigating women’s strategies for negotiating, resisting, subverting, or navigating gender/power concerns within the constraints of a culture that objectifies women’s bodies. Rubin and colleagues (2004) explored this topic through a qualitative investigation of young feminists’ experiences of body consciousness. These researchers sought to understand how feminists attempted to maintain positive feelings in their bodies while living in an objectified culture that linked women’s economic and social power to their appearance. Twenty-five women participated in one of six focus groups examining the ways they experienced their bodies and negotiated cultural messages about women’s appearance. Rubin and colleagues (2004) highlighted the importance the women placed on finding emancipatory strategies that resisted body image-related distress:

While participants indicated that thinking differently about beauty ideals had only a limited effect on their body image, devising new ways of inhabiting their body was described as a more liberating approach. Participants described strategies to celebrate the body and develop new ways of seeing her own body. (p. 34)

Indeed, in the present investigation, young breast cancer survivors who connected with alternative aspects within themselves—outside of self-objectification—that resulted in social power, such as engagement in physical or other meaningful activities, were less likely to return to self-objectification. This was associated with increased well-being at survivorship.
In a similar vein, Zitzelsberger (2005) also examined women’s capacity to resist powerful cultural messages and aesthetic ideals. Through qualitative interviews, Zitzelsberger (2005) studied the relationship between contemporary Western cultural representations of bodies and the experiences of women with physical disabilities and differences. In multiple in-depth interviews, 14 women described the ways their embodiment was shaped by cultural discourses of disability, difference, and gender. Participants’ narratives indicated an ability to (re)gain power, confidence, and self-worth through exposure to alternative discourses such as those offered by feminist, disability, or deaf cultures and activism. Reconstructing and manifesting alternative definitions of themselves and their bodies, a number of women went beyond the imposed and narrowly defined range of cultural representations of female embodiment among women with physical differences. Participants described their own processes of renegotiating the value and meaning of their bodies outside the limits of social stereotypes; this process occurred after periods of questioning and reflecting on their experiences of (in)visibility in many social contexts. Taken together, the results of the present investigation are in line with both Rubin and colleagues (2004) and Zitzelsberger (2005), highlighting the importance of connecting to alternative forms of social power, outside of self-objectification, for women’s experience of well-being at survivorship.

**Internalization Versus Rejection of Gender- and Illness-Related Discourses.** The fourth dimension of Embodied Identity was women’s Internalization Versus Rejection of Gender- and Illness-Related Discourses. Overall findings from the qualitative study revealed that women’s critical perspective toward gender- and illness-related discourses prior to, during, and after the illness experience seemed to facilitate women’s increased well-being, while holding on
to prescribed gender- and illness-related roles at survivorship seemed to relate to self-criticism and reduced well-being.

Three critical findings from the qualitative inquiry are discussed. First, women who maintained strong connections to their pre-cancer healthy and/or traditional feminine selves described less adaptive shifts in identity, and subsequent challenges in psychosocial well-being at survivorship. This finding was well supported by previous literature in the fields of illness and disability. According to Charmaz (1994a), in the face of what are experienced as major losses through illness, including a breast cancer experience, some individuals attempt to remain tightly tied to what they and their identities once were. Charmaz (1994a) referred to this strategy, or coping style, as an entrenched self. She further explained:

Restoring an entrenched self means being wedded to a self-conception situated in the past. These persons hold clear images of their self-concepts, which they can readily articulate. The entrenched self represents patterns of action, conviction, and habit built up over the years. These unchanged patterns had been a source of self-respect before illness. After illness, resuming these patterns becomes the person’s major objective. . . . Restoring an entrenched self also has the imagery of a “comeback.” (Charmaz, 1987, p. 302).

Charmz (1994a) further stated that those with entrenched selves who fail to recapture the past self may experience “despondency as all valued social and personal identities remain in the irretrievable past” (Sparkes & Smith, 2002, p. 272).

As well, within the field of disability studies, Sparkes and Smith’s (2002) qualitative investigation entitled *Sports, Spinal Cord Injury, Embodied Masculinities and the Dilemmas of*
*Narrative Identity* examined the narrative identity dilemmas of four men who experienced spinal cord injury through playing rugby and now define themselves as disabled. Among the four men interviewed, Sparkes and Smith (2002) explained how “being unable to measure up to the past self resulted in further preoccupation with it and with heightened identity dilemmas” (p. 272). Moreover, as distance increased between the past self (restructured in their memories as an idealized past self) and present identities, the former valued identities collapsed and the new ones were viewed as negative (Sparkes and Smith, 2002). With each important identity lost due to illness, the preservation of valued, past, and performed identities became increasingly difficult (Sparkes and Smith, 2002).

Findings in the present investigation about gender-related discourses showed a similar pattern. As identified by Medved and Brockmeier (2010), women take “specific gendered positions” (p.330) that can impact their approach to healing and returned well-being. In particular, the present qualitative study found that women who resisted gender-related discourses described more positive embodiment and enhanced well-being. These results are in line with the quantitative arm of the study where a moderate negative association was discovered between the Gender Role Socialization Scale, which measures the internalization of traditional gender roles and attitudes, and women’s QOL and experience of embodiment. The results of the qualitative study are also in line with the quantitative study conducted by Boquiren and colleagues (2013). As previously mentioned, Boquiren and colleagues (2013) were the first researchers who reported that breast cancer survivors who endorsed greater internalization of traditional gender roles and attitudes had greater body image-related disturbance and poorer QOL post-treatment, at survivorship.
However, while some women in the study described a strong connection to their healthy, pre-cancer selves, and/or traditional, hegemonic feminine identities, other women described taking a critical stance, rejecting traditional illness-related identities (i.e., Parsonian’s sick role) and/or gender-related identities (i.e., traditional hegemonic gender roles). These women were more likely to report adaptive shifts in their identity post-treatment and subsequently report more positive experiences of well-being at survivorship. Despite the large amount of research supporting the challenges faced when individuals maintain strong pre-cancer identities, little empirical evidence exists suggesting that women’s ability to counteract and reject traditional illness- and gender-related identities can facilitate well-being.

From a theoretical perspective, Gerschick and Miller (1995) suggested that there are three dominant gender-related identity patterns that individuals used to cope with a disability or illness, which he called the three Rs: Reliance, Reformation, and Rejection. Reliance entailed individuals’ internalizing of contemporary aspects of hegemonic gender identity and attempting to meet these standards. Reformation involved individuals redefining standards of hegemonic characteristics on their own terms. And Rejection entailed the renunciation of hegemonic standards whereby individuals created alternative gender identities and subcultures. These latter two identity patterns supported the ways in which some women in the present qualitative study redefined certain aspects of their illness- and gender-related selves as well as developed/reinforced alternative identities outside the traditional stereotypic norm.

The importance of developing a critical stance toward traditional definitions of femininity found in the present qualitative study was also supported by the results in the quantitative arm of present investigation. In the quantitative study, an increased critical stance toward oppressive social discourses, expectations, and gender labels, as measured by the Mental Freedom Scale,
was positively associated with more positive QOL and experience of embodiment among young breast cancer survivors (Hypothesis 2C). Importantly, the Mental Freedom Scale was the only gender-related variable studied to significantly predict both outcome measures of well-being (the FACT-B and the EES). As previously mentioned in the quantitative study, the act of taking a critical stance against oppressive social and gender discourses is rarely discussed or studied within the context of illness. However, the quantitative inquiry highlighted Bepko and Kresten’s (1991) emphasis on the importance of breaking free from women’s five Codes of Goodness, which focus on internalizing oppressive social and gender discourses. Instead, they advocate for new guidelines of women’s goodness, labelled as the Codes of Balance, which were ways to contradict and/or challenge these original codes. Taken together, the ability to be critical and counteract messages of hegemonic gender and illness discourse is central to improving QOL and well-being.

The third finding in this dimension of Embodied Identity was women’s capacity for psychological flexibility—specifically women’s level of flexibility in defining themselves in relation to gender and illness appeared to facilitate greater adjustment and well-being. While no research to date has demonstrated the protective nature that psychological flexibility may play on women’s gender- and illness-related identities in cancer populations, limited research exists on the relationship between psychological flexibility and well-being. Kashdan and Rottenberg (2010) conducted a literature review which offered substantial evidence for the prominence of psychological flexibility in psychological health. He synthesized the work in emotion regulation, mindfulness and acceptance, social and personality psychology, and neuropsychology, and concluded that psychological flexibility has been shown to play a critical role in individuals’ experience of psychological health (Kashdan & Rottenberg, 2010). Kashdan and Rottenberg
(2010) concluded that psychological flexibility spans a wide range of human abilities, including the abilities to,

- Recognize and adapt to various situational demands; shift mindsets or behavioral repertoires when these strategies compromise personal or social functioning; maintain balance among important life domains; and be aware, open, and committed to behaviors that are congruent with deeply held values (p. 865).

Within the field of psychosocial oncology, few studies have empirically examined psychological flexibility; however, one preliminary study to date, conducted by Feros, Lane, Ciarrochi, and Blackledge (2013), examined the effectiveness of psychological flexibility through an Acceptance and Commitment Therapy (ACT) intervention aimed at improving QOL among cancer patients. Researchers hypothesized that over the course of the intervention patients would report increased psychological flexibility, leading to improvements in distress, mood, and QOL. Data for 45 patients were collected during pre-, mid, and post-intervention, and three-month follow-up time points. The results of their regression analysis showed that changes in psychological flexibility predicted changes in QOL; increases in psychological flexibility as rated using the AAQ-II (Acceptance and Action Questionnaire – II) from mid intervention to post-intervention led to increases in QOL using the FACT-B. In sum, these preliminary findings demonstrated that an increase in breast cancer survivors’ psychological flexibility (perhaps in relation to women’s identities) may lead to better psychological adjustment and well-being at survivorship.

**Relational Connections.** Articulated in the twelve participants’ narratives were the contrasting poles of a relational continuum of connection and disconnection. Women’s
Relational Connections, particularly within the family system, was the fifth core dimension of Embodied Identity. One relational component participants in the qualitative inquiry described was seeking safety and stability from close others and medical staff during turbulent times in their breast cancer experience. For some, seeking safety resulted in negative outcomes leading to experiences of disconnection as well as feeling invalidated and unsupported. For others, these wishes led to finding mutual connectedness, or mutuality, with others as well as validation and support. Relational-Cultural Theory (RCT) articulated the vital role of mutuality and validation in individuals’ lives. In particular, mutuality is one of RCT’s key tenets, which Jordan (1991) also referred to as mutual empathy. Genero, Miller, Surrey, and Baldwin (1992) defined mutual empathy as the “bi-directional movement of feelings, thoughts and activities between persons and relationships” (Genero et al., 1992, p. 36). Past research has also linked mutuality to numerous positive relational and personal outcomes such as: intimacy (Reis, 1990), emotional resiliency (Beardslee & Podorefsky, 1989), self-disclosure (Chelune, Vosk, Waring, Sultan, & Ogden, 1984), and satisfaction and cohesion (Genero et al., 1992). Within the cancer literature, Sormanti, Kayser, and Strainchamps (1997) reported on negative correlations between depression and mutuality. These authors described that women diagnosed with cancer whose primary relationship was higher in mutuality experienced greater levels of well-being, were more likely to value health priorities, and demonstrated a stronger attitude of responsibility and a higher motivation to care for themselves.

Additionally, the qualitative inquiry found that many women felt the need to question the meaningfulness or connectedness of many of their close relationships, including those with partners. Past literature supported this finding, suggesting that women who perceived constraints in their future lives due to illness became more selective about their social ties, and preferred to
spend time with contacts that provided emotionally meaningful and satisfying experiences (Ashida, Palmquist, Basen-Engquist, Singletary, & Koehly, 2009; Carstensen, Isaacowitz, & Charles, 1999; Kayser & Sormanti, 2002). Using a relational perspective to research within psychosocial oncology, Kayser and Sormanti (2002) examined changes experienced by interviewing 41 women who had undergone cancer. Approximately half of participants mentioned establishing changes in their ongoing relationships as well as establishing new relationships. These changes included making family a higher priority than work, helping people with cancer or similar illnesses, being more involved in their roles as mothers, and setting limits on their responsibilities for others. Likewise, Ashida and colleagues (2008) evaluated changes in social networks of older and young breast cancer patients. Newly diagnosed breast cancer patients were interviewed after their diagnosis and again six months later. Findings indicated that younger breast cancer patients (under age 50) who were unable to elicit support from other women dropped these members as emotional support providers and placed more emphasis on other relations that provided more meaningful interactions.

The core category of Relational Connection in the present qualitative inquiry also uncovered women’s ability to shift from an other-oriented, over-committed focus of care in relationships before their diagnosis toward more balanced and sometimes deeper connections, informed by the illness experience at survivorship. This experience was also associated with enhanced pleasure and well-being. Similarly, Sulik (2007) described women’s shift from other-oriented to self-oriented care among women breast cancer survivors. In Sulik’s (2007) qualitative study, she interviewed 60 breast cancer survivors over a three-year period and used a grounded theory approach to data analysis. When faced with a chronic and life-threatening illness such as breast cancer, Sulik (2007) suggested that women learned to perform self-care work. She stated,
The disruption of the breast cancer diagnosis and treatment can initiate opportunities for women to make changes in their lives and identities. . . . Gendered cultural expectations, which construct women as nurturing, empathic and self-sacrificing, place limitations on women’s capacity to maintain a focus on themselves for very long (p. 874).

Sulik (2007) specifically discussed that following the completion of cancer treatment, women in her study learned to balance their needs with the needs of others. This included setting clearer boundaries with others, and establishing criteria for accepting and asking for help. A few participants took on less responsibility for others, saying no to people and setting limits on their caregiving role. The results of the present inquiry are in line with Sulnik’s (2007) inquiry. Connection to personal needs can empower women to express their needs more clearly to those around them, ultimately enhancing their connection with others.

**Meaning and Life Goals.** The sixth and final core dimension of Embodied Identity at survivorship was women’s experience of Meaning and Life Goals. Prior to their breast cancer, participants’ narratives described general domains of meaning and values within their lives; however, the narratives at survivorship showcased a critical shift within their priorities whereby they felt more attuned to their most meaningful values. In particular, women described experiencing an existential softening of the self, whereby they felt less self-hatred or anger, and instead greater openness and compassion toward themselves. In addition, women also described a greater appreciation for and mindfulness of the world around them, and a search for enlightenment. These experiences led to greater adjustment and well-being at survivorship.

The results of the present qualitative investigation are in line with previous psychosocial oncology research. Park, Edmondson, Fenster, and Bank (2008) highlighted the intersection
between meaning-making processes and the self among cancer patients; they explained that when people are confronted with a severe stressor, like a cancer diagnosis, this often leads to a shattering of global meaning systems including meaning systems about the self. As a result, cognitive processing or meaning-making efforts are initiated in order to re-build this meaning system (Park et al., 2008). Bertero and Chamberlain’s (2007) meta-synthesis of qualitative research on breast cancer and its treatment effects on the self-concept also focused on the importance of meaning-making processes within the self. Bertero and Chamberlain (2007) concluded that the cancer diagnosis led women to ask existential questions and to discover their psychological resilience. The results also identified that women breast cancer survivors tended to analyze what they had accomplished in life up to the point of diagnosis and, accordingly, re-order life’s priorities. Ordinary events in everyday life sometimes assumed enhanced importance, while small, irritating events lost any meaning. Other researchers, such as Brown, Stewart, and McWilliams (1999) and Westman, Bergenmar, and Anderson (2006), described similar changes in meaning and life priorities.

The findings of the present qualitative study were also, to some extent, in line with the quantitative inquiry. When examining illness-related identity shifts, the quantitative study found self-growth to be a significant predictor of psychosocial well-being—though less strongly predictive than illness-related self-loss—at survivorship. Park and colleagues (2008) explained that self-growth, or perceptions of positive life changes, may be one core type of meaning-making process after a cancer experience. However, Park and colleagues (2008) later added that in addition to self-growth, there are other types of meaning-making processes that cancer survivors experience, leading to greater adjustment and well-being (Park et al., 2008). These included: a) a deepening sense of life meaningfulness, and b) a restoration of core beliefs about
one’s experience in the world. Life meaningfulness was often a central concern of cancer survivors, and was heavily discussed and described in women’s narratives in the present qualitative study, in addition to experiences of self-growth. Numerous studies have also found high levels of perceived life meaning linked to numerous aspects of adjustment at survivorship, including better health-related QOL (Brady, Peterman, Fitchett, Mo, & Cella, 1999) and psychosocial adjustment (Laubmeier, Zakowski, & Bair, 2004; McClain, Rosenfeld, & Breitbart, 2003). As well, core beliefs about one’s experience in the world (e.g., the world is a safe and just place) may have been shattered by the cancer experience and caused great distress (Brennan, 2001; Holland & Reznik, 2005); thus, restoring women’s core belief was another central focus of women’s meaning-making processes after a cancer experience. Hence, Park and colleagues (2008) clarified that meaning-making processes beyond patients’ experiences of self-growth must be empirically examined.

Finally, Whittemore and Dixon’s (2008) model of integration provides further support to the value of meaning-making and changed life goals as a critical feature in creating an integrated Embodied Identity at survivorship as found in the present investigation. Whittemore and Dixon (2008) described five phases needed to integrate an illness experience into women’s life context: shifting sands, staying afloat, weathering the storms, rescuing oneself, and navigating life. One of the main tenets in the rescuing oneself phase was “seeking purpose and meaning” (p. 18). Thus, based on this model, the core dimension, Meaning and Life Goals, was evidently a critical component to integrating an illness experience into men and women’s identities. Whittemore and Dixon (2008) also highlighted that conscious effort and creativity were required for patients to re-engage in a meaningful life. Taken together, research is starting to accumulate suggesting that
support for meaning-making processes may enhance the integration of the illness experience into Embodied Identities among young breast cancer survivors.

**Strengths and Limitations of the Qualitative Section of the Study**

The qualitative study involved both strengths and weaknesses. One of the strengths of the study was the presence of diversity among participants. There was some diversity in relation to ethno-cultural background and sexual orientation, and greater diversity in terms of socio-economic background, and medical variables, including age at diagnosis, months since completing treatment, and stage of breast cancer. Importantly, the women in the study also described diverse views in relation to the way they identified with stereotypic social roles for women and social discourses of femininity. Correspondingly, the women also described different positions of resistance to femininity discourses. In turn, this range in the internalization of feminine stereotypes, or resistance to such internalization, gave an opportunity to examine in detail the ways in which internalization or resistance is associated with challenges related to identity. Similarly, participants also described differences in relation to existential meaning of the breast cancer experience; for some women, the cancer experience provided an opportunity for growth and new meaning, while for others, it was viewed as a terrible incident that distracted them from their lives.

Another strength was the incorporation of the life history lens into the interview and data analysis processes. This life journey perspective provided an important developmental context to women’s experiences in their bodies, existential challenges related to prior adversities, and identities as girls and younger women. For example, several women in the study spoke about their participation in physical activities as children and young adults, which helped them develop
agency and attunement in their bodies. They thus learned to value their bodies based on their functionality, sometimes lessening the importance of appearance. Similarly, this approach helped examine the social context of women’s lives, such as their home environment and interpersonal relationships from childhood to their cancer diagnosis.

In addition, through women’s reflections about their past experiences in relation to present identity processes, emergent narratives seemed to belong to three distinct phases: Pre-Cancer Phase, Diagnosis and Treatment Phase, and Post-Cancer Phase. These phases highlighted both phase-specific factors and ongoing factors that operated throughout these women’s lives. For example, while the distress associated with specific treatment related losses (such as hair) was phase specific, resistance to constraining gender roles was an active factor in some women’s lives already during girlhood and continued to shape identity-related experiences following the cancer.

Finally, the present study contributed to the current body of research in psychosocial oncology about young breast cancer survivors by examining post-cancer identities from critical feminist and social constructionist perspectives. While most research to date has pathologized survivors’ experiences of distress, focusing on their diminished QOL and well-being as a result of the cancer experience, the present study aimed to understand young breast cancer survivors’ experiences by focusing on their resiliency after experiencing an illness like breast cancer through identity-related factors. As a result, the study brought attention to the importance of taking into account women’s experience of their Embodied Identity in order to gain a fuller understanding of their lived experiences and help foster increased psychosocial well-being.
The qualitative arm also had several limitations that should be addressed. First, the size of the group of participants should be considered. While interviewing continued until saturation was reached, namely: components of each category were developed and no new components emerged, it is possible that additional interviews might have resulted in more categories and themes.

Second, the qualitative study conducted one-time interviews with young breast cancer survivors in which they were asked to retrospectively account for identity processes and related shifts before, during, and after their breast cancer treatment. Multiple interviews per participant may have added value to gaining more knowledge about their respective identity-related shifts, especially if they were conducted over a period of time. In the future, researchers could examine identity shifts in younger women utilizing a prospective longitudinal perspective. This knowledge would further the understanding of the fluidity involved in survivors’ identities and healing journeys.

Third, despite some ethno-cultural diversity in the participant group, the majority of the women identified as Caucasian, heterosexual, and able-bodied. There were no women of Caribbean, East Asian, or Aboriginal heritage in the group, for example. Recruiting more diverse samples of younger women that include greater diversity in race, ethnicity, and sexual orientation may have resulted in additional emergent themes. Importantly, there were only two women who identified as non-heterosexual in the study. These women’s breast cancer experience seemed to be somewhat different, especially due to the pre-cancer disconnection from feminine expectations. Therefore future research in this area should place greater emphasis on the exploration of non-heterosexual women’s lived experiences throughout the breast cancer journey.
Fourth, although participants were all 45 years of age or younger at diagnosis, the age range was still large enough that participants were at divergent developmental life stages. The American Cancer Society recognizes the young adult age demographic to be between ages 20 and 39 (American Cancer Society, 2016). Therefore, future studies may reduce the age range to less than 40 years of age.

Finally, the qualitative study developed an interview guide that focused primarily on women’s experience of identity in relation to gender and illness; however, a number of dimensions of identity emerged in the interviews. As a result, dimensions of identity outside the realm of gender and illness were analyzed and described. Focusing exclusively on each of these dimensions in follow-up qualitative studies may give women a greater opportunity to describe their experiences in these domains, leading to a deeper understanding of each of these dimensions, such as the dimension of Meaning and Life Goals.

**Study Implications**

Feminist-inspired studies of the body in medicine have begun to account for the taken-for-granted categories of female/male, nature/culture, and body/mind (Price & Shildrick, 1999). Price and Shildrick (1999) explained that these types of binary categories reveal the ways in which female corporeality has historically been constituted in illness and medicine; not only by values of objectivity and rationality, but also by androcentrism, racism, classism, and misogyny. Yet, few studies have examined young women’s experiences of living with and through breast cancer from an embodied lens. Likewise, few studies have conceptualized the construct of identity in a way that is anchored in patients’ experiences of cancer. Thus, the present study provided a contextually rich roadmap for young women’s embodied experiences that led to
critical shifts in their identity from pre- to post-cancer phases. The construct of Embodied Identity and its six core dimensions can provide a useful framework to be utilized in future research, as well as health promotion and clinical interventions. Future research may benefit from continued exploration of women’s Embodied Identity through cancer as well as other illnesses. Future studies may also benefit from the development of a reliable and valid measure of Embodied Identity to enable researchers to continue to evaluate factors that hamper and facilitate the process of positive Embodied Identity among young women with breast cancer.

In addition to recognizing the utility of the construct of Embodied Identity for research purposes, the present investigation also provided support for clinically relevant psychological interventions that foster women’s ability to retain control of their bodies early into young women’s breast cancer survivorship. Both the quantitative and qualitative arms of the study provided suggestions regarding psychological interventions aimed at addressing identity-related shifts and associated experiences of well-being. Shortly after completing medical treatment, women may benefit from psychosocial interventions that address the following: 1) re-gaining control over and connection to the physical body; 2) taking a critical stance toward objectified and idealized images of women; 3) enhancing psychological flexibility within women’s illness- and gender-related identities; and 4) providing meaning-making opportunities within themselves and in relation to others, contextualized in their recent cancer experience and life shifts.

First, psychologists and other healthcare practitioners can facilitate women’s re-gaining control over and connection to their bodies after completing breast cancer treatment. Validating women’s feelings of betrayal, being let down, and other related criticisms of the body would be vital; however, equally important would be the re-development of women’s physical freedom and agency in the body. Therapists may help facilitate this process by encouraging patients to
engage in activities that enhance their appreciation for and control over the body through travel, athletics, painting, drama, and/or becoming more comfortable with altered physical and sexual sensations in the body.

Second, in a group or individual therapy context, therapists can provide young breast cancer survivors a safe space to share their own strategies and struggles in resisting normalized or medicalized beauty ideals, by validating their struggles as well as celebrating their courage to name and take a critical stance against their experiences of oppression in relation to their cancer (Rubin et al., 2004). As highlighted by Rubin and colleagues (2004), psychologists and other healthcare practitioners can make visible alternative, positive images of women’s beauty ideals, and encourage young women to seek non-objectifying ways to experience their bodies (e.g., yoga, dance, or sexual exploration).

Third, psychologists and other healthcare practitioners can promote young breast cancer survivors’ psychological flexibility in managing shifts in one’s experienced identity in relation to having incurred a serious illness impacting the body, work, gender roles, and other domains. One possible method therapists may use to enhance such psychological flexibility is through a third-wave cognitive-behavioural therapy called Acceptance and Commitment Therapy (ACT). ACT is a contextual behavioural approach that uses a collection of techniques aimed at increasing psychological flexibility to reduce distress and enhance well-being (Low et al., 2016). Within the context of ACT, psychological flexibility is defined as, “the ability to persist in valued life activities alongside distressing or unwanted private events” (Low et al., 2016, p. 3). In order to reach psychological flexibility, two main processes are used: mindfulness and acceptance strategies, and commitment and behaviour change. Therefore, ACT may be a valuable tool used to encourage psychological flexibility in relation to shifts in gender- and illness-related identity.
constructs, among others. For example, using this therapy approach, therapists may try to move survivors towards broader views around gender role expectations, and allow them to recognize new ways of acting and being in the world as women. Limited data exists employing ACT as a tool to enhance psychological flexibility related to an illness experience; thus, more research is needed to investigate its utility with this population (Low et al., 2016). In addition to ACT, utilizing a well-established and researched intervention namely, mindfulness meditation may be another helpful tool that can be used by psychologists and other healthcare practitioners to enhance women’s psychological flexibility. In particular, mindfulness meditation may result in the process of de-centering, a shifting of cognitive sets that enable alternative appraisals of life events for breast cancer survivors (Garland, Gaylord & Park, 2009). Therefore, creating a reappraisal of critical life events among breast cancer survivors may ultimately lead to greater psychological flexibility.

Finally, psychologists and other healthcare practitioners may also focus interventions on meaning-making opportunities by survivors in relation to their self-experiences as well as in relation to others in their lives. Lee, Cohen, Edgar, Laizner, and Gagnon (2006) reported that breast cancer survivors who received meaning-making coping interventions had significantly higher levels of self-esteem, optimism, and self-efficacy than a control group. Therefore, the opportunity to engage in guided discussions about the existential impact of cancer on one’s experience of the self, including experiences of self-loss and self-growth, may provide a buffer against increased psychological distress and poor psychosocial well-being. Importantly, these interventions may also lead to increased connection to one’s passions, desires, and life priorities that ultimately result in experiences of re-gained body ownership, agency, and mastery at survivorship.
Integrating the Quantitative and Qualitative Findings: A Call for Future Considerations in Psycho-Oncology

The results of this mixed-method investigation point at new possibilities for progress in psycho-oncology research and practice. First, the impact of gender-related discourses on well-being and on addressing identity-related challenges among women survivors of breast cancer emerged as an important factor to consider both in the quantitative and qualitative arms of the inquiry. The mixed-method investigation therefore provided a cross-method and cross-validation of the importance of gender-related variables. This suggests that gender-related discourses may be important to assess early in the process of assessment and treatment (e.g., how central is compliance with idealized appearance norms to one’s identity). Ongoing treatment and support, therefore, should also include discussions of these issues, and ideally, forming relational norms in intervention forums that are conducive to freedom from constraining gender identification. Further, even though gender-related variables were examined only with women and in relation to breast cancer, this should be examined in relation to men and women dealing with different types of cancer.

The second finding shared by both arms of this investigation relates to the importance of embodiment in examining both the well-being of women breast cancer survivors and their identity-related processes. The components of the investigation shed somewhat different light on the importance of embodiment. In the quantitative study, the strong correlation between a well-established measure in the field of psychosocial oncology, the Functional Assessment of Cancer Therapy – Breast (FACT-B), and the Experience of Embodiment (EES) reflect the potential contribution of considering embodiment as an aspect of well-being. At the same time, the qualitative study clarified the centrality of embodiment and the experience of the body to
different aspects of identity, in relation to cancer, and its overall impact on survivors’ well-being. For example, in the third core dimension of Embodied Identity, Social Power Related to Bodily Experiences, young breast cancer survivors who were able to connect with alternative physical aspects within themselves that gave them a sense of social power beyond self-objectification, such as engagement in physical activities, were less likely to be distressed about cancer- and treatment-related changes to their appearance. For many participants, this process was associated with an increase in perceived well-being at survivorship. Similarly, in the fifth core dimension of Embodied Identity, namely: Relational Connections, young breast cancer survivors who were able to shift from an other-oriented focus of care towards more balanced and sometimes deeper relational connections after their breast cancer treatments, also tended to make their needs and desires a priority which resulted in a perceived strengthening in their daily experience of embodiment and overall well-being.

A third finding was also shared by the quantitative and qualitative investigations about identity and illness-related identity changes (e.g., illness-related self-growth and self-loss). In the quantitative arm, the results revealed that illness-related self-growth predicted QOL and the experience of embodiment independent of illness-related self-loss. The qualitative arm of the investigation enriched these findings, particularly with the data obtained in the first and last core dimensions of women’s Embodied Identity, namely: Loss and Adversity and Meaning and Life Goals. In the first dimension, Loss and Adversity, for example, findings demonstrated that women who reported processing and integrating strength, hope and self-growth into their post-illness identity indicated less psychological sequelae and greater experiences of well-being at survivorship. Likewise, in the last dimension, Meaning and Life Goals, some women showcased a critical shift in their meaning-making processes whereby they felt more attuned to their most
meaningful values and life goals. In turn, participants described this shift in meaningful priorities to be valuable during survivorship, guiding women to live life to the fullest and experience well-being.

The retrospective reflections by participants in the qualitative study allowed for different findings to emerge that could not be tested quantitatively in the present investigation. However, they may guide future quantitative studies. An example of such finding is the importance of considering individuals’ past experiences in relation to identity formation, resilience to adversity, or existential meaning making prior to the cancer diagnosis. Relying exclusively on post-cancer experiences may omit important and relevant information. In addition, the qualitative study provided an opportunity to examine the uniqueness of each individual’s identity processes that should be taken into account in both assessment and treatment.

Finally, the psycho-oncology literature has paid much attention to factors related to depression, anxiety, and coping styles among breast cancer patients and survivors. However, the present quantitative arm of the study suggests that adaptation and well-being after a cancer experience relates to factors beyond symptom control and coping styles. In particular, the present investigation highlighted the relevance of embodied identity, internalized gender roles, and meaning making to well-being. The qualitative study further sheds light on the complexity of adaptation, well-being, and identity-related shifts among young breast cancer survivors. Listening to women’s voices about their identity-related processes, and in particular Embodied Identity, brings factors to the foreground that may have otherwise not been considered. One such example is control and ownership of one’s body. Before, during and following treatment, women reported that medical staff and physicians made assumptions about what was best for their patients and their bodies. In particular, health-professionals who blankly reinforce the
importance of reconstructive surgery, and through that, of complying with hetero-normative appearance standards, may disregard women’s needs to arrive at meaningful decisions about ways in which they want to live in their own bodies. Jamie highlighted this important point in the following narrative,

I feel like a lot of people who get reconstruction are never presented with flat [chested] as a realistic and viable option. . . . [Doctors should ask], ‘What outcome are you hoping for?’ ‘What appearance do you want? ‘What function do you want? . . . When the plastic surgeon brings out the book there should be examples of flat [chested] results alongside the examples of reconstructive results. There shouldn't be this idea that reconstruction is this thing that people need in order to heal somehow or feel whole. . . .

Being mindful of young breast cancer patients’ values and interests, listening to their wishes, and ultimately returning control back to women and their bodies is a vital factor in the future of psycho-oncology assessment and treatment.
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Gender differences in self-silencing and psychological distress in informal cancer carers.


EXPLORING THE EXPERIENCES OF YOUNG BREAST CANCER SURVIVORS

You are being asked to participate in a study that explores your experiences as a young woman who has been diagnosed and treated for breast cancer. We are looking for diverse experiences (e.g., ethnicity, sexual orientation). Your experiences will help other young women beginning their survivorship journey.

Who is eligible to participate?

Women who have:

- Been diagnosed with breast cancer between ages 18 to 45
- Had either a lumpectomy or mastectomy
- Completed treatment

What Will Participants Do?

Participants can complete an online survey that will take about 45-60 min. The survey focuses on your experiences as a young woman who has had breast cancer. (If you chose to take a break from the survey and return to complete it later, a link will be provided for you to re-access your survey)

Participation is confidential.

Please visit the following website address to complete the online survey: http://fluidsurveys.com/s/youngbreastcancersurvivors_uhn/

OR

Please contact:
Lianne Trachtenberg
416 978-0834

Mary Jane Esplen, UHN Investigator
416 340-3024
HELP SUPPORT

YOUNG BREAST CANCER SURVIVORS:

Share your experiences

- Diagnosed with breast cancer between ages 18-45?
- Completed surgery, chemotherapy, and/or radiation?

We are inviting you to participate in a study that explores the ways in which being a survivor of breast cancer may have changed how you see yourself in the world. Issues related to how you connect to your body and sense of identity will be explored. Your experiences can help other young women beginning their survivorship journey.

**Participation Details:**

Complete a 90 minute interview
To take part, please contact Lianne at: youngbreastcancersurvivors@gmail.com or 4169780834
Appendix B: Telephone Script

Hello, my name is Lianne Trachtenberg. You left a message for me indicating 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?

**Introduction 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 University of Toronto. I am working towards the completion of a Doctoral degree in Clinical Psychology. As part of this process I am conducting a research project to explore the impact of identity, or sense of self on psychological wellbeing among young breast cancer survivors.

Are you open to hearing more about the study?

**Confidentiality**
If you decide to participate, your participation is completely voluntary and if you decide not to take part, your care at Princess Margaret Cancer Centre will not be affected in any way. Before beginning the online questionnaire package, you will be asked to read, review, and sign a consent form online. After clicking submit you will be assigned a unique Study ID.

**Inclusion Criteria**
I wanted to go over the inclusion criteria on the poster advertisement. To take part in the study, I am seeking women who have:

1) been diagnosed with breast cancer between the ages of 18-45,
2) had either a lumpectomy or mastectomy,
3) completed treatment, and
4) no evidence of a breast cancer recurrence.

Do all of these apply to you?

If yes, then I would like to tell you more about the study if you would still like to hear about it.

If no, I thank you for your interest in this study, but at this time we are not able to have you participate.

**Procedure**
I would like to tell you a little about the research and what would be involved in your participation. This will help you decide whether you are interested in taking part. If you decided to take part in this research it would involve filling out an online questionnaire package 45-60 minutes in length about your cancer experience.

**Benefits**
The questionnaire package will explore how your cancer experience has impacted aspects of your identity, or sense of self. Discussing your thoughts and beliefs may be a personally rewarding experience. However, it is possible that in this process may stir up feelings that are upsetting to you. Should the need arise, members of the research team, including myself 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! Here is the link to the consent form and online questionnaire package.

*Provide potential participate with link.*

I hope that you will find the study to be a positive experience. Also, the results of this study will help us understand how to move forward in terms of conducting research on the experiences of young breast cancer survivors. Therefore, your participation in this study will assist us in achieving this purpose and for that, we want to thank you in advance for your participation.

Have a nice day.

**If the individual is not interested in participating:**
I appreciate you taking the time to speak to me and expressing an interest in the research project. I wish you all the best. Thank you.
Appendix C: Reminder Email

Dear [First Name]

We haven’t heard from you, but your opinion is important to us. Please consider taking the time to fill out our survey [here](#).

Thank you.

Sincerely,
Lianne Trachtenberg
PhD Candidate, Clinical and Counselling Psychology
Department of Applied Psychology and Human Development
Ontario Institute for Studies in Education, University of Toronto
252 Bloor Street West, 9-270
Toronto, Ontario M5S 1V6
Office phone: 416-978-0834
[lianne.trachtenberg@uhn.ca](mailto:lianne.trachtenberg@uhn.ca)

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If you have received this e-mail in error, please contact the sender and delete all copies.
Opinions, conclusions or other information contained in this e-mail may not be that of the organization.
Appendix D: Consent Form for Quantitative Study

CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

Study Title: Identity Integration as a Predictor of Psychosocial Adjustment in Young Breast Cancer Survivors

Principal Investigator/Study Doctor: Dr. Mary Jane Esplen, UHN
mesplen@uhnresearch.ca

416-340-3024

Doctoral Supervisor, Psychologist: Dr. Niva Piran, University of Toronto
(416) 978-0712
niva.piran@utoronto.ca

Research Trainee: Lianne Trachtenberg, University of Toronto
416-978-0834
lianne.trachtenberg@uhn.ca

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Sponsor: Canadian Institute for Health Research

Introduction
You are being asked to take part in a research study. Please read the information about the study presented in this form. The form includes details on study’s risks and benefits that you should know before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study doctor or study staff to explain anything that you do not understand and make sure that all of your questions have been answered before signing this consent form. Before you make your decision, feel free to talk about this study with anyone you wish including your friends, family, and family doctor. Participation in this study is voluntary.

Background/Purpose
The purpose of this research study is to examine Identity Integration, defined as the changes in post-illness identities as a predictor of psychological well-being among young women with breast cancer. Specifically, Identity Integration is used as an umbrella term to measure two key components of identity that have been found to predict psychological well-being among
individuals with illness. These two components are as follows: a) the integration of an illness experience into an identity, and b) the integration of non-traditional gender role expectations into one’s identity. It is likely that women experience their identity and a way of living in their body differently after their breast cancer experience.

This study is taking place at the Princess Margaret Cancer Centre and Toronto General Hospital in addition to the Greater Toronto community. We estimate that 150 participants will be enrolled in the study.

You are being asked to take part in a research study to explore your experiences as a young woman who has been diagnosed and treated for breast cancer. It is possible that you will find it interesting and informative to think about what it means to live in your body as a cancer survivor in a more or less connected way, how it affects the way you live in your body and your overall well-being. Your participation may also help many other young women who struggle with challenges faced after breast cancer.

**Study Procedures**
If you agree to take part in the online survey, you will complete a series of questionnaires. The questionnaires assess different areas, including: women’s ability to identify body experiences and connections, gender role expectations, the impact of illness on overall self-concept, body and self-image, and overall quality of life. It is expected that completing all the questionnaires will take approximately 45-60 minutes. Given the length of the survey, if you chose to take a break from the survey and return to complete it later, a link will be provided for you to re-access your survey at the point at which you previously stopped.

**Risks**
There are no medical risks if you take part in this study. However, you will be asked to reflect on your personal experiences with cancer. There may be some emotional risks to participating when being self-reflective on your own personal experiences. In this case you may decline to participate. If you find the discomfort to be more than minor, please contact Lianne Trachtenberg, Dr. Mary Jane Esplen, or Dr. Niva Piran to discuss how to receive support (contact information can be found above and will be provided upon completion of the study). If you decide to participate you may skip any question, request a break, or withdraw from the study at any time.

**Benefits**
You may not receive any direct benefit from your participation in this study. However, your participation will allow the researchers to better understand the experiences of young women who have been diagnosed and treated for breast cancer. This is expected to benefit future patients, such as through contributing to the development of effective interventions (a type of
support) for women who have been treated for breast cancer at the hospital and in the community.

Alternatives to Being in the Study
The alternative to this study is not to participate.

Confidentiality
If you agree to join this study, the research team will collect and use only the information they need to complete the study. This information will only be used for the purposes of this study.

This information will include:
• Demographics information such as marital status, education, occupational status, ethnicity, income and age.
• Medical history and use of additional support services
• Information from questionnaires about your feelings

The information that is collected for the study will be kept in a locked and secure area at Toronto General Hospital. Data will be kept by the study investigators for 10 years. Participants completing the online questionnaire will be identified by a study number. Only the study team will be allowed to look at your study record.

Representatives of the University Health Network Research Ethics Board may look at the study records to check that the information collected for the study is correct and to make sure the study followed proper laws and guidelines.

All information collected during this study will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

If you decide to leave the study, the information about you that was collected before you left the study will still be used. No new information will be collected without your permission.

Voluntary Participation:
Your participation in this study is voluntary. You may decide not to be in this study, or to be in the study now and then change your mind later. You may leave the study at any time without affecting your medical care or follow up.

Withdrawal from the Study:
If you withdraw your consent, the study team will no longer collect any information for research purposes. All questionnaires are anonymous and assigned by participant number. If you are
willing to provide feedback as to why you are withdrawing, we would appreciate knowing the reason for the benefit of our continued research.

Rights as a Participant:
While physical risks are not expected for this study, if you are harmed as a direct result of taking part in this study, all necessary medical treatment will be made available to you at no cost.

By signing this form you do not give up any of your legal rights against the investigators, sponsor or involved institutions for compensation, nor does this form relieve the investigators, sponsor or involved institutions of their legal and professional responsibilities.

You will be told in a timely fashion of any new findings during the study that could affect your willingness to continue in the study.

Conflict of Interest:
This study is conducted by a research team at UHN which receives funding from the Canadian Institute for Health Research. The project team is interested in exploring the experiences of young breast cancer survivors. Their interests should not influence your decision to participate in this study. You should not feel pressured to join this study.

Questions about the Study:
If you have any questions, concerns or would like to speak to the study team for any reason, please call Lianne Trachtenberg at 416-978-0834 or lianne.trachtenberg@uhn.ca. Please note, any communications made via email are not absolutely secure. Please do not communicate any sensitive personal information via email.

If you have any questions about your rights as a research participant or have concerns about this study, call the Chair of the University Health Network Research Ethics Board (UHN REB) or the Research Ethics office number at 416-581-7849. The REB is a group of people who oversee the ethical conduct of research studies. The UHN REB is not part of the study team. Everything that you discuss will be kept confidential.

Consent:
This study has been explained to me and any questions I had have been answered. I know that I may leave the study at any time. I agree to the use of my information as described in this form. By checking the “I agree” option, I am indicating my consent to participate in this study.

☐ I agree
Appendix E: List of Suggested Resources

**Wellspring**: [http://www.wellspring.ca/](http://www.wellspring.ca/)
Wellspring Downtown: (416) 961-1928
Odette House & The Coach House: 416-961-1928
Westerkirk House at Sunnybrook: 416-480-4440

Wellspring programs are open to individuals and caregivers who are coping with any type of cancer, at any stage. Programs include individual and group support, coping skills, expressive therapies, educational workshops and presentations, and cancer rehab programs. Programs are delivered within warm, welcoming Wellspring centres.

**Pynk**: PYNK, (416) 480-5000

Pynk at Toronto’s Sunnybrook Health Sciences Centre, offers young women with breast cancer and their families the opportunity to be guided through their entire journey by a highly specialized nurse. She acts as a kind of systems navigator for young women with breast cancer, ensuring that her patients receive a continuum of promising new treatments and care, from diagnosis through recovery and long-term follow-up. She also coordinates appointments and tests and provides expert advice on available resources.

**Women’s College Hospital**: 416-323-6400 x4240

Wellspring programs are open to individuals and caregivers who are coping with any type of cancer, at any stage. Programs include individual and group support, coping skills, expressive therapies, educational workshops and presentations, and cancer rehab programs. Programs are delivered within warm, welcoming Wellspring centres.

**Rethink Breast Cancer**: 416-920-0980

Launched in 2001, Rethink Breast Cancer is the first-ever, Canadian breast cancer charity to bring bold, relevant awareness to the 40s and under crowd; foster a new generation of young and influential breast cancer supporters; infuse sass and style into the cause; and, most importantly, respond to the unique needs of young (or youngish) women going through it.

**Women’s Health in Women’s Hands Community Health Centre**: (416) 593-7655

The WHIWH community health centre provides Primary Healthcare to Black Women and Women of Colour from the Caribbean, African, Latin American and South Asian communities in Metropolitan Toronto and surrounding municipalities.

**Toronto Phone Line Distress Centres**: (416) 408-4357

The Distress Centers provided 24-hour telephone support, 365 days a day. Hundreds of thousands of calls later, this agency continues to offer round the clock response to those experiencing emotional distress or in need of crisis intervention and suicide prevention.
Psychiatric Emergency Services, Toronto Western Hospital:
Phone: 416 603 5800 extension 2453
Urgent Care Clinic: (416 603 5809

St. Michael’s Psychiatric Emergency Services
30 Bond Street, Toronto Ontario
Phone: 416 864 5346

Brief Psychotherapy Center for Women: (416) 591-2000
The Brief Psychotherapy Centre for Women is the only program of its kind in Canada. The therapy offered at the Brief Psychotherapy Centre for Women is most useful for women who are having emotional difficulties with any of the following: self-esteem, depression, aging, dealing with anger, discrimination/cultural adjustment, health problems/disabilities, separation or divorce, education, anxiety, body image, loneliness, parenting, loss and/or bereavement, relationship issues, employment, physical, emotional, verbal or financial abuse, sexual abuse, sexual assault and/or sexual harassment, stress related to poverty or employment. The program is not suited to women who are in crisis or require immediate help, have current, serious substance-abuse problems, or acute psychiatric difficulties.

Gerstein Center: (416) 929-5200
The Gerstein Centre provides crisis intervention to adults, living in the City of Toronto, who experience mental health problems. The Centre provides supportive counselling for immediate, crisis issues and referrals to other services for on-going, non-crisis issues. Our service is a community mental health service and is non-medical.

Barbara Schlifer Clinic: (416) 323-9149
The Barbra Schlifer Commemorative Clinic provides free and integrated legal, counselling, interpretation, information and referral services for women who have experienced violence – including partner assault, incest/childhood sexual abuse and sexual assault. As well, the Clinic is involved in public education, training, community development and advocacy and takes multifaceted approaches to achieve freedom from violence for all women.
Appendix F: Demographic Information

Current age: 

Age at diagnosis: 

Months since adjuvant therapy completed: 

Presented below are six broad racial/ethnic groupings people living in Canada might use to describe their racial or ethnic background or identity. Please indicate which of the groups you feel most accurately describes you.

- African Origin (African, Afro-Canadian, West Indian, Other African Origin)
- Asian (Chinese, Filipino, Indian, Japanese, Korean, Pakistani, Vietnamese, Other Asian)
- Latin American or Hispanic (Latin American or Other Hispanic)
- Aboriginal/Indigenous (First Nations, Metis, Inuit, Other Native Canadian)
- Other European (Anglophone Canadian, Francophone Canadian, British Isles, English, Irish, Scottish, Welsh, French, German, Greek, Italian, Polish, Portuguese, Ukrainian, Other European)
- Other (American, Arab, Jewish, Middle Eastern, Other Ethnic Group). Please specify:

Highest level of education completed:
- High school
- College degree
- Bachelor's degree
- Master's degree
- JD/Ph.D/Postdoctoral

Other, please specify: 

Employment status:
- Employed Full-Time
- Employed Part-Time
- Self-employed
Not employed, but looking for work
Not employed and not looking for work
Homemaker
Retired
Student
Other, please specify...

If working, please indicate your profession and/or vocational title:

Current income level:
Under $35,000
$35,000 - $50,000
$50,000 - $80,000
$80,000 - $100,000
More than $100,000

At present are you living with a partner/spouse, separated/divorced, widowed, living alone, or other?
Living with partner/spouse
Separated/Divorced
Widowed
Living alone
Other, please specify...

Do you have children?
Yes
No

If yes, how many children? How old are they?
How would you describe your sexual orientation (e.g., heterosexual, homosexual, bisexual...etc)?

Which of the following areas do you currently live in?
- Large urban
- Small urban
- Rural

Stage/Type of Breast Cancer:
Please provide as much detail as possible
- Stage 0 (carcinoma in situ)
- Stage I
- Stage II
- Stage III
- Stage IV

Surgery Type:
Please specify any additional details
- Lumpectomy
- Mastectomy
- Other, please specify...

Types of adjuvant treatment received:
Please provide any additional details in space provided.
- Radiation
- Hormone
Therapy/Tamoxifen

Chemotherapy

Other, please specify...

Menstruation status:
- Menstrating
- Menopausal

Additional clarifying information

Reconstruction option:
- My reconstruction is complete. Please provide approximate date:
- I am considering reconstruction or, in the process of reconstruction.
- I have no interest in reconstruction.
Appendix G: Consent form for Qualitative Study

My name is Lianne Trachtenberg and I am a doctoral student in the Department of Applied Psychology and Human Development at the Ontario Institute for Studies in Education at the University of Toronto. I am working on this research project with my supervisor, Dr. Niva Piran, who is a professor at the Department of Applied Psychology and Human Development at the Ontario Institute for Studies in Education.

We are currently working on a study that aims to examine Identity Integration, defined as changes in post-illness identities as a predictor of psychological well-being among young women with breast cancer. Specifically, Identity Integration is used as an umbrella term to measure two key components of identity that have been found to predict psychological well-being among individuals with illness. These two components are as follows: a) the integration of an illness experience into an identity, and b) the integration of non-traditional gender role expectations into an identity. It is likely that different women experience their identity and ways of living in their body after their breast cancer experience differently.

Participants should be primary breast cancer survivors, between age 18 and 45, who have had either a lumpectomy or mastectomy, have completed adjuvant treatments, have been treated for Stage I, II or III cancer, and with no history of or current evidence of metastatic disease. Women should also be comfortable in using the English language to communicate.

If you agree to participate, you will be interviewed once for about 60-90 minutes. During the interview, I will ask questions related to your current sense of identity which will encompass your understanding of your gender identity, body consciousness, and the overall illness experience; I will also ask you how these variables have impacted your overall wellbeing and quality of life as a young breast cancer survivor.

I will use an audio recorder to record all interviews. I will conduct the interview at a private room at the Ontario Institute for Studies in Education of the University of Toronto, or at another place of your choosing. When I have finished interviewing all women who are participating in the research and analyzing the interviews, I will be glad to share with you the results of the research. I would ask you for the way you prefer to receive this information, by mail, email, or by phone. If you have further questions about the results of the study, you are welcome to contact me.

Confidentiality will be respected and your identity will be protected unless required by law. The tapes will be kept in locked files for 1 year and then destroyed. The tapes will be identified by a research code name only. The tapes will be transcribed and all identifying names and
information will be taken out of the transcripts. The transcribed interviews, and any additional material that you provide during the interviews, will be identified by a research code only, and with all identifying information erased, will be kept in locked files until five years following the completion of the study, and then will be shredded. If any publications are produced from the research gathered, we will ensure that all identifying information will be omitted so that you will not be identified. The exception to this is the very unlikely event that you indicate that you might do serious harm to yourself or others, that a child is in danger of physical abuse, sexual abuse, or neglect, or a regulated health professional acted in a sexually inappropriate manner towards their patient. If that were to happen, I would inform you and appropriate mental health professionals.

In terms of direct benefit, women often express an interest in having the opportunity to talk about their experiences, and in this interview, I aim to emphasize how much I value your views and opinions and the special strengths you have. In terms of indirect benefit, a greater understanding of the factors that protect younger women, as opposed to older women from lowered quality of life after breast cancer will be valuable. As well, this research can also help other recent cancer survivors who are struggling to adjust positively after their cancer treatment.

There are no known harms associated with participation in this study. The only potential risk I have identified is that you may feel some discomfort when talking about your experiences. In this case, you may decline to participate and if you decide to participate you may skip any question, request a break, or withdraw from the study at any time. Throughout the interview, and especially before the end of the interview, I will check the way you feel about the interview. If you desire, I will provide you with counseling resources at the end of the interview. Should you decide to withdraw your permission to participate in the study, please let me know about your decision by telephoning me at the number below.

Participation in research is voluntary. You may withdraw at any time without consequence and you may skip any questions you are uncomfortable with. Should you wish further information about the study, or have any questions please email or call me.

Sincerely,

Lianne Trachtenberg, M.A., Ph.D. Candidate
youngbreastcancersurvivors@gmail.com

Niva Piran, Ph.D.
Ontario Institute for Studies in Education of the University of Toronto
niva.pira@utoronto.ca
“I acknowledge that the research procedures described above have been explained to me and that any questions that I have asked have been answered to my satisfaction. I have been informed of the alternatives to participation in this study, including the right not to participate and the right to withdraw at any time. As well, the potential harms and discomforts have been explained to me and I also understand the benefits (if any) of participating in the research study. I know that I may ask now, or in the future, any questions I have about the study or the research procedures. I have been assured that research records relating to my participation in the research will be kept confidential and that no information will be released or printed that would disclose personal identity without my permission unless required by law.”

“I hereby consent to participate.”

______________________________  The person who may be contacted
Name of Participant  about the research is:

Lianne

______________________________  who may be contacted at:
Signature  yougbreastcancersurvivors@gmail.com

______________________________  Date

______________________________
Name of person who obtained consent

______________________________
Signature
Appendix H: Interview Guide

- Thank you for agreeing to participate in the study.

- Review Consent form
  - Audio recorded
  - Confidentiality

RECORD INTERVIEW

1. Introduce self and past research.

2. What made you interested in participating in the study?
   - Validate their interests
   - Define Identity.

4. Review Demographic Information.

5. How do you currently see yourself in the world? (i.e., your sense of identity)
   - If you were going to make a list – how would you rank these roles/identities?
     - Partner, Worker, Gender, Physique, Intelligence, Endurance, Health – survivor of BC, wealth, Status, Education, Training, Achievements, Reputation, Race, Motherhood, Sexuality, Religion, Personality features…etc
       - Get details

       - A) Illness Identity (connection to your illness experience)
       - B) Gender Role Identity (connection to gender identity/role expectations)

Integration of illness experience into identity

6. Can you reflect on how the experience of self has changed or shifted from the time that you received your cancer diagnosis up until now?
   - (Anchoring self in terms of what has changed, and reflecting back on process of how they got there).
     - Partner, Worker, Gender, Physique, Intelligence, Endurance, Health – survivor of BC, wealth, Status, Education, Training, Achievements, Reputation, Race, Motherhood, Sexuality, Religion, Personality

7. How did you get there? Explore process of change. Chronologically
   - Diagnosis
   - Treatment
   - Completed treatment:
     - Months 1-3
     - Months 4-7
• Months 8-12
• Months 13+

• How has your connection to the breast cancer experience changed since your diagnosis?
  • Areas of self-growth? Areas of self-loss?
  • How is it for you to live with this? How does this impact your day-to-day life?

Integration of values that counteract traditional gender role expectations into identity

8. How do you currently see yourself as a woman in the world?

  • What expectations do you have of yourself as a woman?
  • How much do you invest in your body’s appearance?
  • Comfortable in your body?

9. Can you reflect on how the connection to your femininity or gender identity has changed since you completed treatment?

  o Months 1-3
  o Months 4-7
  o Months 8-12
  o Months 13+

  • Have these physical changes to your body had an impact on how you see yourself as a woman?

10. How does that change the way you live your daily life? Does it seem helpful or painful to cope in this way?

  • Explore the role of caregiver or nurturer?
    • Do you feel this role has changed?
    • Do you feel that you are able to take time for yourself? Needs justified?

11. Existential Shifts:

  • Carry a different perspective about the world?
  • Have you been able to find meaning after this experience?

12. Conclusion:

  • What have you learned from your journey, being a breast cancer survivor?
  • What wisdom would you pass on to other young women who have had breast cancer?
  • Is there anything else you’d like to add