RENEGOTIATING THE SELF: HOW EIGHT WOMEN DIAGNOSED WITH BREAST CANCER RE-SHAPED A SENSE OF SELF-IDENTITY

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

in

THE FACULTY OF GRADUATE STUDIES

(Counselling Psychology)

THE UNIVERSITY OF BRITISH COLUMBIA

(Vancouver)

April 2013

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Abstract

A narrative analysis was conducted to explore the research question: How do women reshape their sense of self-identify after being diagnosed with breast cancer? The diagnosis and treatment of breast cancer can leave women feeling as if their pre-cancer identity no longer fits for who they perceive themselves to be. There is a need for a better understanding of how women negotiate their experiences into a post-diagnosis self-identity. Counselling psychology is well-suited for this research because of its emphasis on helping individuals to navigate the various social, emotional, relational, and health-related concerns that women with breast cancer experience.

A social constructionist framework informed the exploration of the social and interpersonal contexts within which women experience breast cancer. Eight women participated and volunteered their time and their intimate experiences. Each semi-structured interview was audio-taped and transcribed verbatim. A holistic-content approach was used to interpret and analyze each interview in order to write an individual narrative for each participant. An across-narratives thematic analysis identified six common themes including: 1) The Future-Focused Self; 2) The “I am Not a Survivor” Self; 3) The Intentional Self; 4) The Mindful Self; 5) The Social Self; and, 6) The Self as a Woman with Breast Cancer. The themes were validated by peer and expert reviewers. Participants’ narratives and themes were then applied to a model of reshaping self-identity as a transition, in order to better understand the influences of the personal, social, and cultural contexts in which women experience breast cancer.

The resulting model holds implications for future research, theory and practice. Previous models of the breast cancer experience hypothesize about how women’s self-identities are impacted by an experience of breast cancer, while the current model explains how women move
through such a process. Counselling psychologists and healthcare professionals can use the model to identify where in the process of the cancer experience that a woman may be, and which contextual factors may be influencing her experience. Future research can expand on this model by exploring it in greater depth, and longitudinally in order to better delineate how the process unfolds.
Preface

This research was conducted with the approval of the University of British Columbia (UBC) Office of Research Ethics Behavioural Research Ethics Board (BREB), certificate number H11-03433, and from the Alberta Cancer Research Ethics Committee, certificate 25862.
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Acknowledgements

Thank you to my parents for your unconditional love, endless support, and for teaching me the values of education, perseverance, and doing what makes me happy. My sisters, Kelly, Kristen, and Brooke, Don Evanson, and my brothers-in-law, I thank you for providing me with much support and encouragement along the way. Tegan, through your loyalty, patience, and playfulness you taught me the importance of balance, and Reggie, with your boyish charm and pushy wet nose, you ensured I maintained it.

During the program I was fortunate to have met a wonderful and supportive group of colleagues. To the other members of our “dynamic trio,” Emily Koert and Dianne Westwood, I thank you for your collaborative, thoughtful, and encouraging friendships along the way. To my buddy, Trevor Olson, I greatly appreciated your moral support and friendship, as we travelled the last few years of our academic journey alongside each other.

Dr. Tom Strong, thank you for introducing me to social constructionism. Conversations with my research supervisor, Dr. Marla Buchanan, fostered further knowledge of this engaging epistemology. My sincere gratitude is expressed to you for guiding me through completion of this research with your knowledge, expertise, and belief in me. Dr. Judith Daniluk’s constructive feedback and guidance was invaluable. I am grateful to you for impelling me to more critically engage with the research question and findings. Dr. Bill Borgen, your contributions were significant in regard to prodding me to engage with theory more thoughtfully and purposefully. Thank you for your guidance.
To my many friends who offered their love, support, and patience over the years it took to complete this program and body of research. I look forward to catching up! Thank you for your encouragement.

Last, but not least, I would like to thank the women who generously shared their time and personal experiences with me so that this research could be completed. Thank you for the conversations, your trust, and belief in this research.
Dedication

For the women in this study, thank you for generously shared your time and experiences.

For my grandmother, Dorothy Johnston, although we have never met, I have always carried you in my heart.
Chapter 1: Introduction

A patient who lives with cancer finds herself in a nexus of dynamic psychosocial events. These events often result in reports of loss of productive functioning, financial strain, family stress, personal distress, stigma, and threats to former self images. Taken together, these events signal that one's identity will forcibly undergo transformation. It thus becomes imperative that patients renegotiate their identity status with family, friends, co-workers, and medical personnel (Mathieson & Stam, 1995, p. 287).

Breast cancer is the most common cancer among Canadian women. An estimated one in nine women will be diagnosed with breast cancer during her lifetime (Canadian Cancer Society, 2008). The breast cancer mortality rate has decreased by 30% since the mid-1980’s and as of 2010, the five-year survival rate for women was 87% (Canadian Cancer Statistics, 2010). The increased rates of survival have created the need for psychosocial treatments to help women cope with the ramifications of their breast cancer experience, including breast disfigurement, hair loss, changes in weight, sexual activity, loss of a sense of control, and feeling betrayed by their bodies (Ogle & Ullstrup, 2006). The disturbance to their physical appearance leaves many women feeling depersonalized and may result in a disrupted sense of identity. Furthermore, scars may serve as visible reminders of the cancer and increase the fear that it may return (Payne, 2007). The intention of this study is to answer the question: How do women re-shape their sense of self-identify after being diagnosed with breast cancer? For the purposes of this research, self-identity is defined as inclusive of a woman’s sense of self, femininity, body image, and body integrity, all of which are disrupted with the diagnosis of breast cancer (Thomas-MacLean, 2004).
**Relevant Background**

The prevailing models of inquiry into adaptation to breast cancer have included medical and cognitive models, as well as the biomedical model (Mathieson & Stam, 1995). Polivy’s (1977) seminal study appears to have set the stage for future research to identify which treatments result in better psychological adjustment. In her study she compared the body image of 15 women who had mastectomies, to 18 women who had biopsies, and a control group. This initial investigation of women’s body image concluded that while women with mastectomies initially report higher self-esteem than those who underwent biopsies, months later the trend was reversed. In many respects, psychosocial research has continued along the same vein of inquiry since Polivy’s study, striving to identify patterns of distress based on specific treatments, and expanding to include the interactions of family adaptation and the role of social support, and resulting psychosocial sequelae (Andrykowski, Lykins, & Floyd, 2008; Mathieson & Stam, 1995).

Medical models have focused on applying symptoms of psychopathology to psychiatric criteria in order to determine if a patient may benefit from psychotherapy and or pharmacotherapy. Though this approach may result in women getting the needed support, it comes at the cost of women who experience psychosocial distress being labeled as pathological (Mathieson & Stam, 1995). In addition, symptoms of depression may be reflective of an expected level of distress, yet depressive symptoms such as a lack of motivation and poor concentration may be mistaken for non-adherence to cancer treatment (Agarwala & Riba 2010).

Cognitive models of adaptation seemingly imply that a woman’s reaction to having cancer is a personal problem that can be resolved through adopting appropriate strategies (Mathieson & Stam, 1995). As much of the research focuses on reducing depressive
symptomatology, the results provide little understanding of how to foster positive psychological responses (Andrykowski, et al., 2008). As such, there is a recognized need for the development of strategies to enhance psychological outcomes for women living with breast cancer specifically, given that for many women, the alteration of body appearance results in a disruption of their sense of self and identity (McCann, Illingworth, Wengstrom, Hubbard, & Kearney, 2010).

The clinical study of breast cancer is problematic as many of the psychosocial changes and challenges that women face are not immediately apparent in clinical practice (Dow & Lafferty, 2000). Between 30-40% of women treated with chemotherapy experience distress for up to 20 years post diagnosis, with 5% meeting diagnostic criteria for post-traumatic stress disorder (Kornblith, et al., 2003). Distress can range from sadness to clinical depression and spiritual crisis, and often requires the collaborative support of a multidisciplinary team, including counselling psychologists (Dizon, 2009). With increasing rates of survivorship and the realization that the experience of breast cancer extends years beyond medical treatment, research and treatment focus must broaden to encompass women’s long-term needs (Dow, Ferrell, Leigh, Ly & Gulasekaram, 1996; McCann, et al., 2010). One of the most persistent problems faced by women with breast cancer is an altered body image, and changed sense of self, both of which have lasting influences on health and well-being (Schmid-Buchi, Halfens, Dassen & van den Borne, 2008).

Although research has investigated the effects of breast cancer on body image, the impact and personal experience of changes to appearance is not well documented, and likely underestimated (Rumsey & Harcourt, 2005). The prevailing medical and cognitive models adopt individualistic perspectives of illness, whereby medical approaches look to pathologize and
classify women according to their emotional responses, and cognitive models seek to rectify problematic responses by exerting cognitive control over the accompanying thoughts and feelings (Mathieson & Stam, 1995). What these models lack though, is the recognition of and appreciation for the individual ways that women differentially interact with the social and cultural norms (Hall, 1998).

In an example of a social perspective, Williams (1996) articulates a theory from which to understand the ways that women practically and symbolically navigate the process of realigning the body, self, and society in the context of illness. From this perspective, the healthy woman is one who is embodied. In this state her body is largely taken for granted and unproblematic, providing a means by which she acts in the social and material world. Upon becoming ill she may feel betrayed by her body, resulting in feelings of disembodiment and alienation from the body she once knew (Williams). Involvement in the medical system often creates further divides as she comes to know her body in technical medical jargon terms, stripping away the social context within which both her sense of self and body reside (Mishler, 1989). Eager to approximate the sense of embodiment she previously experienced, she endeavors toward a state of re-embodiment. Priel et al. (1991) contend that in order to achieve re-embodiment, she must find meaning in her experiences. Crafting a new narrative allows her to shift from the passive role of a patient, merely receiving treatment, to the active role of author, using her own language to reclaim her experience of her body (Frank, 1995). Depending on the nature of illness and possibility of reoccurrence, she may find herself continually oscillating between disembodiment and re-embodiment (Williams, 1996).
Purpose of the Study

Women’s post-diagnosis identities may fluctuate as they experience their bodily limits brush up against the boundaries of health and illness, and the possibility of reoccurrence (Kleinman, 1988). It is within these spaces that women negotiate their identities and form their sense of self-identity. However, given the dominant negative medicalization of their experiences, women lack alternative ways in which to frame and understand their experiences (Thomas-MacLean, 2004).

Psychosocial oncology research to date has neglected to investigate the ways in which women with breast cancer may achieve an integrated sense of self-identity, yet this process is a key indicator of well-being post treatment (Ogle & Ullstrup, 2006). Interventions are needed to help women integrate their experiences of breast cancer into their self-identity, and to encourage and enhance self-esteem (Pelusi, 2006). However, before this can happen it is imperative to understand how women integrate their experiences of breast cancer and treatment into their self-identity. An increased understanding of women’s integration of experiences is necessary to highlight ways in which psychosocial treatment can reframe cancer management, promote personal empowerment, positive decision-making, and coping (Ogle & Ullstrup, 2006).

Therefore, the purpose of this study is to interview women who self identify as having integrated their experiences of breast cancer into their self-identity, in order to address the question: How do women re-shape their sense of self-identify after being diagnosed with breast cancer?”

Significance of the Study

Once diagnosed with breast cancer, a woman’s pre-cancer identity may no longer fit for her, as she begins to recognize that the changes in her physical health extend into her social and relational spheres (Mathieson & Stam, 1995). There is a recognized need to better understand
how women negotiate the changes to self after being diagnosed with, and receiving treatment for breast cancer (McCann, et al., 2010). Yet to my knowledge, the psychosocial research on the long-term needs of women with breast cancer has surprisingly negligible contributions from counselling psychologists.

The proposed research will contribute to psychosocial oncology research and practice by hearing women’s stories and identifying the ways in which they are able to negotiate an integrated post-diagnosis understanding and experience of self. The response to cancer is individual and can have ongoing significance in women’s lives. A deeper understanding of the multiplicity of responses women experience can be harnessed by analysing the narratives of women diagnosed with breast cancer. From this, it is hoped that future research and treatment implications will be identified in order that counselling psychologists can better meet the needs of these women, particularly those who are identified as struggling with negotiating the differences between their pre- and post-diagnosed self-identity.

Proposed Methodology

The stories people tell are important not only because they offer an unmatched window into subjective experience, but also because they are part of the image people have of themselves. These narrative self representations exert enormous power. They shape how we conduct our lives, how we come to terms with pain, what we are able to appropriate of our own experience, and what we disown. (Ochberg 1988, p.173-174)

Narrative theory recognizes a mutually informing relationship between the self and social interaction. Through the stories individuals share, they come to interpret the actions of themselves and of others. These understandings then come to shape the ways in which they understand the world and themselves within it (Murray, 2003). Narratives then, are individuals’ socially constructed accounts, which emerge from, and are negotiated through, ongoing social interactions (Mathieson & Stam, 1995).
As a methodological approach, narrative research is not just a process of eliciting stories from participants, but includes the careful evaluation and analysis of such accounts (Overcash, 2003). Narrative methodology falls under the umbrella of social constructionism. It is a form of inquiry that is primarily focused on “explicating the processes by which people come to describe, explain, or otherwise account for the world (including themselves) in which they live” (Gergen, 1985, p. 266).

In a foundational article, Bury (1982) suggests that an experience of illness creates a biographic disruption in a life that has otherwise been ongoing. At such a point those with illness may be forced to change the ways they view, plan, and evaluate their lives (Charmaz, 1992). If they are fortunate, and the diagnosis is acute, it may take only a temporary significance; however, a diagnosis of a chronic illness can shake the very foundation of one’s life as living conditions can become quite dramatically and qualitatively changed. In critique of Bury’s work, Williams (2000) emphasizes that while for some illness, chronic or acute, can have severe consequences, for others such an experience can be seen as a normal, perhaps even an expected part of life. Here, what needs to be attended to, is the individually attributed meaning and context, as the meaning of any event can only be understood in regard to its temporal and spatial relationship to other events (Somers, 1994). Women’s individual responses to a diagnosis of breast cancer are heavily influenced by their personal understandings and interactions within their social and cultural contexts (Hall, 1998).

The proposed research will entail a narrative analysis of interviews of women’s experiences of re-shaping a re-integrated sense of self-identity, post diagnosis and treatment of breast cancer. Women’s sense of self-identity is constructed through social expectations, ideals, and norms about femininity and sexuality (Shilling, 1993) and as such, it is necessarily important
to consider the social and interpersonal contexts of the experiences of women with breast cancer. Narrative methodology is well suited for the research question as it regards identity development as occurring through the stories individuals tell themselves and others, as they shape and maintain their sense of self (Murray, 2003).

**Theoretical Framework**

Social constructionism forms the theoretical framework for this study. Social constructionism extends the biomedical model by taking into account the dynamic interplay between individuals and the relationships, settings, and contexts in which they are involved (Gergen, 1984). This is of importance because when understandings of women’s experiences of breast cancer are only attributed to the cancer itself, as in the biomedical model, other essential elements of the experience are missed. These missed components then run the risk of not being legitimized as a clinical concern (Kleinman, 1988). These elements can include the psychological experience, including associated thoughts and feelings, the relational experiences, and the social and environmental experiences. Therefore a comprehensive framework is required to understand and appreciate the entirety of the experience, which extends beyond the physical.
Chapter 2: Literature Review

The research in psychosocial oncology is expansive. This chapter starts by providing an overview of the literature describing women’s psychosocial experiences of breast cancer, and the impact of breast cancer treatment on women’s body image. These first two sections identify the complexity of an experience of breast cancer, while the following section explores some of the literature on possible post-diagnosis identities for women, and the ways in which this literature is limited. The discussion then turns to some of the theoretical conceptualizations of how women might re-shape their pre-diagnosis identities to create a post-diagnosis identity. This section ends with a brief rationale for choosing the construct “re-shaping” to explore the process of how women move from a pre- to a post-diagnosis self-identity. After exploring some of the limitations of this research, the chapter will then provide an overview of the socially constructed ways in which women’s self-identities are shaped. It is important to have an understanding of social constructionism in order to develop an appreciation of the social, cultural and relational influences on self-identity development. Lastly, social constructionist, and specifically narrative approaches to research are discussed. The history and contributions of illness narratives will be highlighted to speak the rationale for the choice of narrative methodology to address the research question.

Psychosocial Oncology Research

Developing a treatment-based framework for women with breast cancer and their relatives, Schmid-Buchi, Halfens, Dassen, and van den Borne (2008) conducted a review of 20 articles addressing the psychosocial needs of women with breast cancer and the needs of their relatives. The majority of the articles that were reviewed were from samples of convenience and while they predominantly represented research from the United States and Australia, they did
include three from the United Kingdom, and one Canadian study. This is an important consideration as generalizability of the results rests on the assumption that American, Australian, British and Canadian cultures are the same. However, research on breast cancer has indicated that discrepancies among seemingly similar cultures exist and may be attributable to the differing ways in which countries provide healthcare (Fallbjork, Karlsson, Salander, & Rasmussen, 2010).

Of the psychosocial issues identified, the most persistent and enduring problems included fatigue, menopausal symptoms, and impaired sexuality and body image all of which negatively impact health and well-being. The psychosocial needs of women varied according to age and the woman’s developmental life stage at the point of diagnosis. This finding is consistent with the notion that each life stage includes specific goals and tasks at the biological, personal, and social level (Rowland, 1989).

The psychosocial needs of younger women, defined by women under the age of fifty (Avis, Crawford, & Breaden, 2003) have been identified as distinct from those of older women. Issues of fertility have been identified as particularly problematic for younger women who may have not yet given consideration to their fertility and the future prospect of having children (Dow & Kuhn, 2004). Chemotherapy may result in premature menopause, and women who are able to maintain their fertility may have to wait a few years after treatment before trying to get pregnant. By further delaying pregnancy there may be a reduced chance of getting pregnant (Dow & Kuhn), and the possibility of getting pregnant may raise questions as to whether it is fair to the children, given the woman’s life threatening illness (Avis, et al., 2005). For young mothers diagnosed with breast cancer, there is very real fear that they may die while their children are still young, leaving them to grow up motherless (Breaden, 2003). Communication problems in
relationships may develop as partners discuss whether or not to have kids and what will happen to the family should the woman die (Avis et al.).

Relational issues are further complicated by the physical changes women experience as a result of adjunctive therapies such as Tamoxifen and Aromatase Inhibitors (Als), which interfere with the production of estrogen and can put women in early menopause. Sexuality may negatively impacted by symptoms such as thinning of the vaginal walls and decreased vaginal lubrication (Pelusi, 2006). Women may be hesitant to address such issues for fear of being perceived as concerned about less meaningful things when there may be the presumption that they should be lucky to have survived (Ogle & Ullstrup, 2006). These issues may not be addressed by healthcare providers who may also feel hesitant to bring them up (Esplen, 2007), or who neglect issues of intimacy as they focus on concerns about menopause or fertility (Barsky-Reese, Keef, Somers, & Abernethy, 2010). This can leave little place for women to discuss these significant issues and experience acknowledgement of their emotional experience related to these and other losses.

To look at the psychosocial needs of women across the lifespan, Cimprich, Ronis, and Martinez-Ramos (2002) randomly drew the names of 105 women from an American tumour registry. The women, all diagnosed with breast cancer, were categorized into one of three groups by age of diagnosis, namely younger women diagnosed before the age of 45, middle-aged women diagnosed between ages 45-65, and older women, diagnosed after the age of 65. Each participant completed a quality of life survey that they received in the mail. In regard to physical well-being, older women reported poorest quality of life, while middle-aged women scored the highest. The women diagnosed at an older age reported more fatigue, aches, pains, and feelings of uselessness and uncertainty. However, social well-being was reported higher by the older
group than the younger group. This finding was corroborated and expanded on by the research of Thewes, Butow, Girgis, and Pendlebury’s (2004) who concluded that younger women experienced a greater sense of isolation, perceiving support groups as catering primarily to older women, and recognizing that same-aged peers were not in a life phase where they were dealing with the reality of their own mortality. Interestingly though, the group of women diagnosed at a younger age also reported having made more positive life changes as a result of the breast cancer experience. Although not statistically significant, overall quality of life was reported highest by the women who had been diagnosed at mid-life.

As evident in the literature, the psychosocial implications for women are complex and dependent upon several interacting variables. Julia Rowland (1989) co-edited the groundbreaking text, *Handbook of Psychooncology: Psychological Care of the Patient with Cancer*, in which she proposed a developmental model of psychosocial adaptation. Rowland suggested there are five common disruptions experienced by people diagnosed with cancer. These include (1) the social experience and alterations in interpersonal relationships; (2) a disruption in one’s ability to be independent, as the cancer can create a dependency on others for caregiving; (3) achievement disruption, which occurs when the activities in which one was engaged prior to the diagnosis need to be put on hold in the service of the cancer; (4) the disruption to one’s body-sexual image and integrity, and; (5) and existential disruption, where one is now faced with their mortality. The level of disruption in any area may be influenced by an individual’s stage of life.

The complexity of psychosocial responses to an experience of breast cancer can be appreciated from the literature reviewed. It appears that the closest the biomedical research in oncology has come to studying the impact of breast cancer treatment on a woman’s self-identity
is in regard to how it affects her body image. The discussion turns now to review some of the ways in which the impact of cancer on body image been researched.

**Breast Cancer and Body Image**

Polivy (1977) was one of the first to compare resulting body image satisfaction after varying surgeries for breast cancer treatment. Her sample included 15 women who had mastectomies, 18 women who had biopsies, and 11 women used as a surgical control group. The women in the control group were age matched to the women in the mastectomy group, and had been admitted for non-cancer related surgeries. On the first day after the surgery, 6 days after the surgery, and 6 to 11 months after the surgery, all participants completed a questionnaire measuring body image, self-concept, and total self-image. Surprisingly Polivy found that immediately after surgery, women with biopsies showed a greater decline in body and self-image than did women with mastectomies. However, after several months (approximately 6 to 11 months), the pattern was reversed. Polivy concluded that women with mastectomies must have initially used denial to bolster their self-esteem and body image in the face of illness, but over the course of a few months their denial was replaced by the reality of their loss.

It is commonly accepted that treatment choice is impacted by concerns about body image, with women who opt for conservative surgeries such as lumpectomies, experiencing less body image alteration (Fobair et al., 2006; Margolis et al., 1989). However, despite having less altered body images, some women who have undergone conservative surgery report an increased fear of cancer reoccurrence, and worry that their bodies will fail them again (Pelusi, 2006). This is in contrast to women who have had mastectomies and experience a sense of relief that they have been through the worst (Ogle & Ullstrup, 2006). However, the experience of mastectomy has been associated with a higher degree of depression and suicidal ideation (Margolis et al.).
To better understand how investment in body image impacts recovery, Carver et al. (1998) followed 66 women from pre-surgery, to 1 week, and then 3, 6, and 12 months post-surgery. The women completed measures at 3, 6, and 12 month follow-ups. These scales included psychosexual and emotional adjustment, measures of body image, disruption of activities, and alienation from self. In their study, they distinguished between body image and “concern over body image”, focusing on the latter which emphasizes the importance of body image to the patient. Poorer adjustment was found to be associated with women who valued their physical appearance, considered themselves highly feminine and associated their breasts with their femininity and attractiveness.

The psychological aspects of patient satisfaction with breast cancer surgery were assessed by following 577 women post-surgery (Al-Ghazal, Fallowfield & Blamey, 2000). The average age of all women was 52 years. Forty-four percent of women had wide local excision, 35% had mastectomy, and 21% had breast reconstruction. At follow-up each completed a measure of depression and anxiety, body image scale, and a measure of self-esteem. Women who have had immediate reconstructive surgery experienced less body image distress when compared with women who delay the process. It is hypothesized that this may be accounted for by not having to be faced with the self-consciousness of not having a breast (Al-Ghazal, et al.). While this research suggests immediate reconstruction leads to better psychosocial adaptation, as the participants were not randomly assigned to the varying conditions, it is difficult to tell if there were pre-existing personality differences that may have attributed to the women’s treatment choices.
In contrast, Mock’s (1993) research on body image in breast cancer indicated that women who delayed their reconstructive surgery had slightly higher measures of body image than those who had reconstruction immediately after a mastectomy. Participants were 257 women, all two years post-surgery. The women had either mastectomy without reconstruction (n=62), immediate reconstruction (n=58), delayed reconstruction (n=47) or conservation surgery (n=90). Scales competed at follow-up included the body image scale, a measure of self-concept, and a scale of self-criticism. Positive correlations between self-concept and body-image support the view that body image is an integral component of self-concept.

The conflicting results between the two studies described above may speak to the reasons why women choose reconstruction. Women who choose this option for aesthetic reasons may be more pleased with the results versus women whose choice reflected their desire to improve sexual relations or experience their bodies as feeling whole (Carver et al., 1998). The reconstructed breast may not look or feel like the pre-operative breast and as such may fail to meet the expectations of some women (Ogle & Ullstrap, 2005).

From the research reviewed thus far, there are clearly no distinct profiles from which to determine the types of women who will benefit from a particular type of treatment. Further, the implications of breast cancer treatment on body image extend far beyond the partial or total removal and reconstruction of the breast. White (2000) has critiqued the psychosocial literature on body image in oncology as focusing too narrowly on body image as a unidimensional construct, often dichotomizing it as either positive or negative, or secure versus insecure, and missing the complexity and multiplicity of dimensions in between. Also critiquing the research within the traditional biomedical model Radley (2000) contends that the impact of breast cancer on the body is more than a physical substrate that can be accurately captured and measured. He
argues that as psychologists conducting health research utilizing quasi-experimental designs, a focus on coping and recovery is emphasized, neglecting issues of vulnerability and healing, and thereby missing the more personal components of the experience.

Recently, journalist Thandi Fletcher (2012) ran a six-part series, *Battle Scars*, in major newspapers across Western Canada. Through this medium she documented in their own words, women’s experiences of breast cancer and treatment. Terri, one of the women spoke about her reconstructive surgery helping her to feel whole again, while Julie, who is awaiting her second reconstructive surgery as her first one failed, acknowledged that she will never be the same. After a double mastectomy and reconstruction Lorna rejoiced, “I have a marvelous silhouette—for my age!” Kerrie described herself as a ‘previvor’, opting for a preventative double mastectomy and immediate reconstruction upon learning that she was a carrier for the genetic mutation in BRCA2, which she stated would increase her chances of getting breast cancer to 85%. Patti, while not diminishing the importance of reconstruction to some women, shared how she also had a preventative double mastectomy, but opted to not have a reconstruction. Though the intent of these stories was to convey the dire need in Canada for more resources for women who, at times have had to wait years for breast reconstruction, it also highlights the individual ways in which women respond to, and make sense of their experiences. The following section will discuss aspects of literature that attempt to address some of the ways that women may make sense of who they are after an experience of breast cancer.

**Possible Post-Diagnosis Identities**

“I woke up, still alive. Does that mean ‘cured’?”


In the body image literature surveyed previously, the focus was primarily on the amputation, conservation, and reconstruction of a woman’s breast and how it interacts with her
subjective sense of body image. However, as recognized in the literature, this narrow approach to research misses the experience of what it is like to live inside a body that is faced with a life threatening illness (Fallowfield & Hall, 1991).

In recognition of the experience of cancer, the notion of “survivor” was first introduced to cancer discourse in 1985 by Dr. Fitzhugh Mullan as he described his own experiences of cancer (Kaiser, 2008; Kolata, 2004), and with that, a new zeitgeist was born. Dr. Mullan helped establish the National Coalition for Cancer Survivorship (NCCS) which defined survivorship as starting at diagnosis and lasting the remainder of life. However, despite this definition, over two decades later, controversy still swirls as to what defines a survivor, and multiple definitions have accrued (Bell & Ristovski-Slijepcevic, 2013; Khan, Rose, & Evans, 2013). For example, to some people it is not the point of diagnosis, but rather the end of active treatment that demarcates the beginning of survivorship (Khan, et al.). The term has also been extended to include family, friends, and care-givers, all of whom are also impacted by the experience of cancer and survivorship (Ganz, 2005).

Seeking to understand the degree to which women associate themselves with the survivor identity upon completion of treatment, Kaiser (2008) conducted in-depth interviews with 39 women who were 3-18 months post treatment for breast cancer. Using grounded theory she identified that some women accepted the identity, while others rejected it suggesting that their ‘battle’ had not been ‘heroic’ enough, that they had not been close enough to death to warrant the title, or that reoccurrence could bring the cancer back. Some women provided their own altered meaning of survivor in order to better fit with their experiences. Why some women would accept the identity while others refuted it could not be discerned, though Kaiser asserts that it was not
related to disease stage or type of treatment. To account for such differences a better model of life after cancer is required.

The end of active treatment can be a challenging time for women as they have less contact with health-care providers and must take on more active roles in self-monitoring (Fredette, 1995). In the transition from being a breast cancer ‘patient’ to a ‘survivor’, women experience feelings of vulnerability and fear of reoccurrence. However, this time is also marked by positive behavioural changes, and a perceived sense of increased emotional strength. (Allen, Svdatti, & Levy, 2009).

In a seminal study, Cohen et al. (1998) interviewed twenty women who had experienced lumpectomies or mastectomies. Through a hermeneutic phenomenological analysis they derived three themes of major aspects of the body that were important to the breast cancer experience. These included the body as symbolic and social expression, the body, including physical symptoms and sensations, as a way of being in the world, and the awareness of the existential and mortal being of the body. Though the themes in this study may not necessarily generalize to all women who experience breast cancer, they do elucidate that the impact of an experience of breast cancer on body image extends beyond the removal and possible reconstruction of the breast. The loss of a breast has also been identified with the loss of a functional breast, the loss of femininity in the gendered breast, the loss of pleasure in the sexualized breast, and the adoption of a medicalized breast, as it becomes referenced to and discussed in regard to the treatments and procedures necessary to treat it (Langellier & Sullivan, 1988). Multiple factors act on a woman’s post-surgical self including the social and cultural influences and meanings of the body, and her realized sense of the possibility of death.
The impact of breast cancer treatment on a woman’s sense of self was further investigated by Bertero and Wilmoth (2007), in a meta-method and meta-synthesis. The outcomes of 30 qualitative research studies conducted between 1990 and 2003 were integrated. Hermeneutics guided the analysis of the experiences of 795 women across four countries. Four themes were identified including: “(1) awareness of one’s own mortality, (2) living with an uncertain certainty, (3) attachment validation, and (4) redefinition of the Self” (p.196). Of most interest to the current study is how women redefined themselves, which occurred in three ways, the first of which was through changes in the way they viewed their own bodies. No longer perceiving themselves as ‘normal’ the women were further challenged by no longer viewing themselves as complete. Secondly, they described the impact on physical function which was limited by lymphedema, and the perceived and real difficulties with sexual function. As a result of the first two changes, the women also identified questioning their femininity, as well as questioning if they were still attractive and still ‘woman enough’ (p. 200). Bertero and Wilmoth (2007) concluded that how successfully a woman adapts to her diagnosis and treatment is dependent on the response of her physical body as well as her emotional well-being. Therefore, psychosocial support is most effective when it can help her to acknowledge all changes to self.

While crucial to developing a deeper understanding of how women perceive themselves after breast cancer diagnosis and treatment, these studies leave unanswered what women do with a sense of post-diagnosis self. I turn now to some of the literature that identifies some processes by which women may move from pre- to post-diagnostic and treatment selves.

**The Re-Shaping of Self-Identity**

Suddenly illness arrives, uninvited, unexplained. I found myself caught between life and death, light and dark, banished to an unknown place – between night and day . . . The arrival of illness interrupted my cycle of life, displacing its normal parts. (Petrone 2001, p.12)
Chronic illness can disrupt an individual’s life, thereby disrupting the individual’s sense of identity as subsequently changing the patient’s relationship with self, body, and world (Hyden, 1997; Bury, 1982). Such an experience calls for the reconstruction of one’s life story in order to make meaning of the events that have disturbed the patient’s life course. Coining the term “autopathography,” Couser (2000, p.5) explores illness narratives as a means to counter predominant biomedical and cultural discourses which may lean toward the stigmatization and marginalization that often accompanies illness. This occurs as ‘everyday’ people are given the opportunity to voice and author their own experiences and stories (Fraser, 2003). From this perspective one can see the social and cultural constructs involved in the illness experience, and the ways in which suffering has been transformed and expressed (Hyden, 1997). It also gives the opportunity to explore some of the ways in which cultural and social influences impact women, for example as they choose to either get reconstructive surgery and pass as ‘normal’ or choose to remain breastless.

In research on the experiences of women during treatment for breast cancer, particularly the impact of mastectomy on body-image, Piot-Ziegler, Sassi, Raffoul, and Delaloye (2010) conducted interviews with 19 women between the ages of 37 and 62. Nine of the women were scheduled for immediate reconstructive surgery and the remaining 10 had no plan at the time. Although the impact of mastectomy on identity was not their initial focus, Piot-Ziegler and colleagues recognized how closely the theme of identity was related to discourses of the body.

The women in the study by Piot-Ziegler et al. (2010) were interviewed either just before or just after their mastectomies. Using a thematic analysis they likened to phenomenological analysis, five main themes were identified. Most relevant to the current study, were the themes of the loss of breast challenging women’s identities and relationships with others, as well as the
theme of re-evaluating existential priorities and needing to ‘re-position’ (p.500) themselves as the cancer provided them with a greater understanding of life. For example, in describing a “deep identity crisis,” one participant shared that losing her breast gave her “the impression that [she was] losing [her] true self” (Piot-Ziegler et al., 2010, p. 494). Another spoke about her ‘fractured’ sense of self, where one sense of self is active and publically accessible, and the other is hidden away from others, and even from herself.

The ‘loss’ and ‘fracturing’ of self and the need to ‘re-position’ oneself within one’s own life allude to the complexity of an experience of breast cancer. Attempting to understand the complexity of the experience is further challenged by the multiplicity of ways that different concepts have been used throughout the literature to describe the same phenomenon, namely the lived experience of breast cancer. In recognition of this, Arman and Rehnsfeldt (2003) conducted a phenomenological analysis of fourteen studies in the nursing literature on body image and breast cancer, between the years of 1990 and 2000. Identified in their research was a common theme of a ‘turning point’, which they described as occurring after diagnosis when the consequences of breast cancer on a woman’s life are realized. Turning points were described as an adjustment, transition, transcendence, transformation, and meaning-making.

In a landmark study, Taylor (1983) drew from her intensive interviews with 78 women (demographics not provided) with breast cancer and laid the foundation for a cognitive theory on adjustment to life-threatening experiences. In this she proposed that adjustment occurs when, in the face of a personal tragedy, individuals employ cognitive adaptive efforts to return to or surpass prior levels of psychological functioning. Specifically, adjustment occurs through a search for meaning, attempting to gain mastery by exerting behavioural control, and attempting to enhance the self by making downward social comparisons.
Studying the adjustment process for women with breast cancer, Taylor (2000) employed her theory of cognitive adaption (Taylor, 1983) and conducted a grounded analysis of nineteen women, ages 39 to 70 and their experiences of breast cancer and search for positive meaning. Taylor described the resulting transformation as a “basic social-psychospiritual” (p. 783) process. Specifically she described the process as encountering darkness through the diagnosis. Such darkness is then converted by looking at the experience in a larger context, for example through one’s faith. Encountering light is experienced by identifying meanings, and finally reflecting light occurs by learning from the experience, appreciating it, and even embracing it. From this Taylor suggests that helping professionals can encourage women to transform the experience of breast cancer by imbuing it with significance and positive meaning. Women may be encouraged to question, “what have I learned from this illness? How will I let this illness make me a better person?” (p. 787).

An ability to make meaning of an experience of breast cancer has been associated with better psychosocial outcome (Lepore, 2001; Moadel et al., 1999). However, what might happen should a woman not be able to identify how her illness can ‘make her a better person’ (Taylor, 2000, p.78)? Looking at self-transformation as a factor of self-esteem and well-being for women post treatment for breast cancer, Carpenter, Brockopp and Andrykowski (1999) had sixty participants, aged 35 to 77, and 3 to 54 months post-treatment, partake in a semi-structured interview and complete scales on self-esteem and well-being. In their narrative and statistical analysis they identified over 25% of the women as ‘stuck’ (p. 1406) in the process of transforming from their pre- to post-treatment selves. This experience was associated with feelings of lacking courage and support, lacking clear expectations, and being unwilling or unable to process their experiences of breast cancer. Women in this category were consistently
lower in self-esteem and well-being, as compared to the two other groups of women who identified positive and minimal transformations.

The experience of chronic illness on one’s sense of self has also been conceptualized as a disruption in personal biography and expected life trajectory (Bury, 1982). Assumptions and behaviors of everyday life that are taken for granted are disrupted such that one must re-think their personal biography and self-concept. This results in the mobilization of resources to face the newly altered situation.

Utilizing Bury’s (1982) framework to guide analysis, Hubbard and Forbat (2012) conducted an interpretive analysis of the written account of forty men and women who had been diagnosed with different types of cancer, thirty of whom identified as being free of cancer at the time of the study. Fifteen of the participants were women who had been diagnosed with breast cancer. Participants each wrote up to two pages of their experiences of living with cancer, identifying what was better, worse, and what had stayed the same.

The analysis identified that cancer is perceived as an ongoing physical and psychological disruption, a persistent threat, creating a heightened sense of mortality, and yet also contributing to positive changes to self. The implications of chronic illness on an individual’s biographical self have been suggested as having continuity and flow (Faircloth, Boylstein, Rittman, Young, & Gubrium, 2003), and being temporary or permanent (Charmaz, 1983). Hubbard and Forbat (2012) concluded from their analysis that the experience of cancer on identity is not simple enough to categorize as biographical flow or biographical disruption, but rather the impact of the changes take different meaning in people’s lives at different points in time. Some of these changes can be managed successfully, while others have a more profound or permanent impact.
How these changes are managed is not explained nor does this research explicate how the women managed the disruption in self.

Bury’s (1982) influential framework has been scrutinized for not accounting for the biological and physical realities of a chronic illness experience. It is argued that they are just as important as they are impinged on the self, act as cues for the necessity of identity reconstruction, and also act as limiting factors in regard to what actions an individual can and cannot take (Kelly & Field, 1996). For example, the stage of cancer may limit what options may be available for a women, with regard to treatment type and reconstructive options.

In her research on chronic illness and identity, Charmaz (1995; 2000; 2002) provides a conceptually developed analysis. According to Charmaz (2000) an individual’s illness experience encompasses, “metaphor and meaning, moral judgments and ethical dilemma, identity questions and reconstruction of self, daily struggles and persistent troubles” (p. 277). The taken for granted assumptions and life meanings are challenged and life becomes uncertain. Though perception of self may be shaken, it is not lost. Retained aspects of self and connection with the past are significant for the reconstruction of self-identity (Corbin & Strauss, 1987). Adaption occurs when the life and self are altered to accommodate the changes brought about by illness, in order that self and body can be unified (Charmaz, 1995).

The reviewed research has been informative for the current study in regard to identifying identity related issues in women with breast cancer. Left unexamined though, are the ways that women may adjust, cope, transition, or transform after breast cancer treatment. Numerous terms have been applied to describe the changes that a self experiences after diagnosis of cancer. Among these are reformulation of self (Morse & Carter, 1996), reconstructing the self (O’Connor, Wicker, & Germino, 1990), identity reconstitution (Corbin & Strauss, 1987),
adjustment (Taylor, 1983), and biographical disruption (Bury, 1982) to name a few. Often times these terms are not explicitly defined (Carpenter, et al., 1999). For the purposes of this study, the experience of moving from a pre- to a post-diagnosis sense of self-identity is conceptualized as ‘re-shaping’. This term was chosen because consistent with the social constructionist underpinnings of this study, re-shaping implies a fluid and fluctuating process, as new challenges and changes are continually experienced (Kralik, 2002).

**Social Constructionism**

Social constructionism is an epistemological position that seeks to explicate the processes people use to explain and account for themselves and the world (Gergen, 1985). From this perspective it is claimed that all that an individual knows and takes for granted as truth has been taught to them by others. Although there are varying stances on how the self is constructed by social influences, each shares a primacy of personal meaning, which is interpersonally negotiated from experiences within the social, political, historical and relational realms individuals live in (Polkinghorne, 1998).

**Social Constructions of the Self**

Each of the following perspectives has been conceived by several different theorists, however due to limited space, only a few will be discussed. To help exemplify the differing ways in which the self has been constructed, each will be applied to an example of a woman with breast cancer, and how she may come to understand her self and her experience from within that perspective.

McAdams (1996) life story model of identity is an example of the psychosocial perspective, whereby one’s life narrative is seen as an evolving, internalized process. Self-agency is exercised through self-reflection and consciousness. According to McAdams,
narratives are crafted in adolescence, once individuals have the cognitive tools necessary to engage in an active process of constructing identity. This is done by using the information they have gathered from their childhood. Narratives, and thereby identity, change over the course of development, as new information is gathered and incorporated. Narratives are regarded as cognitive structures that are created by the desire for a cohesive sense of self (Smith & Sparkes, 2008). For a woman with breast cancer there may be a need to find ways to integrate notions of self as sick, self as a patient, or self as breast-less, into her previously defined ways of understanding herself.

An inter-subjective perspective of self emphasizes the ways in which culture shapes individuals’ personal beliefs, influencing their thoughts and the language through which they express them (Bruner, 2002). Culture shapes basic psychological functioning. An example of this is symbolic interactionism, which according to Mead (1934) argues that individuals are born as private subjects and the processes of higher thought are developed as they come to experience others, and then mentally take on the role of those others. In this perspective, nothing exists outside of an individual’s understanding and knowledge of it. There is no objective reality outside of an individual’s own subjective understandings of reality. Narratives, or the stories individuals tell themselves, are akin to cognitive structures of the ways in which individuals come to understand the world (Smith & Sparkes, 2008). A woman whose hair grows in differently after chemotherapy may find that others no longer immediately recognize her. As a result she may find herself feeling invisible and lost, no longer recognized by others the way she once was. She may also not relate to this new self-image.

The storied perspective of self shares with the inter-subjective perspective the notion that the self does not exist outside of the context of relational and social matrices (Smith & Sparkes,
However they differ in that while the inter-subjective perspective sees thoughts as internal stories, the storied perspective regards thoughts as social actions (Smith & Sparkes). Culture provides the scope of repertoires available from which to assemble a personal story. These repertoires include the dominant narratives or discourses, which exemplify an accepted or predominant way of thinking and being (Somers, 1994). In each context individuals may draw from the dominant narratives in different ways, to actively author a story of self that is conducive to the particular context in which it is being told (Taylor, 2005). Ocuk (2005) gives the example of a woman, who through conversation with her husband, comes to feel comfortable around him without needing to wear her wig. However, due to her son’s discomfort with her baldness she ensures she wears her wig when he spending time with him in order to portray the image that she was the same mom he had always known her to be.

The dialogic perspective also suggests that people are culturally immersed; however it contends that they only exist in relation to each other. Culture speaks through the stories individuals tell (Smith & Sparkes, 2008). An individual’s internal dialogue is comprised of the words that they have heard from others, taken in, and appropriated with their own expressive and semantic intentions (Bakhtin, 1981). According to Hermans (2001), the words that individuals hear from other people then come to occupy positions within the multi-voiced self.

As the self becomes populated with the ideas, intentions, and voices of others, a more dominant or active voice ultimately decides which dialogic perspective will be audibly spoken. Upon self-reflection individuals can determine how they have adopted the voices and ideas of culture and others, into how they have come to understand themselves. To demonstrate this perspective, Ocuk (2005) describes a woman who wore a wig to work out of her concern that customers would not feel comfortable around her otherwise. By internalizing the thoughts and
feelings of others, she found she needed to present herself in a socially acceptable way, so as to make others comfortable.

Finally, drawing mostly from Gergen’s work (1999), from the performative perspective, social relatedness holds precedence over individual, interior and lived experiences. Therefore, notions such as self, narratives, and identity cannot be understood apart from their social and relational context and processes. Influenced by Foucauldian thought, identity is a discursive action, rather than an internal cognitive structure. In each interaction individuals’ identities are “performed in relationships,” and “talked into being” (Smith & Sparkes, 2008, p. 25). Through the social interchange, meanings of words are shared and negotiated between both parties as they come to a place of shared understanding. This shared understanding is one that is specific to the moment it was negotiated, and may look different if negotiated at a different time, in a different place, or by different people (Gergen 1994). Based on this perspective, a woman with breast cancer may need to adjust how she presents herself in the social context, as different contexts and audiences assume different meanings. For example if she were to wear a baseball hat to cover her baldness, it may not stand out as much at a sporting event, as it would in a restaurant. She may also have to decide how choosing not to wear a hat may be interpreted in each scenario, as going bald on a school campus may give the impression that she is a radical feminist, whereas going bald at a restaurant may indicate to others that she has cancer.

The boundaries between the varying perspectives of self are quite blurred. However, a general understanding of how the self is shaped by the social world is important to the research question. Particularly it is essential to appreciate the social and relational influences that women diagnosed with breast cancer must negotiate as they realign their post-surgical bodies and new sense of self-identity within the social contexts in which they live (Williams, 1996).
Social Constructionism and Narrative Inquiry

In her own experience of breast cancer, the American Poet, Audrey Lorde (1980) openly decried the necessity of the use of a prosthesis after mastectomy. She criticized social attitudes toward women claiming they objectified and depersonalized women’s bodies. In contest to social influence she wrote, “women have been programmed to view our bodies only in terms of how they look and feel to others, rather than how they feel to ourselves, and how we wish to use them’’ (p. 64).

Social constructionism regards the body as being as much of a social and cultural creation, as it is a physical one (Synnott, 1993). In Western society, the female breast is laden with notions of physical attractiveness, sexuality, femininity and nurturance (Spence, 2001). Naturally the experience of breast cancer requires a woman to have higher levels of body consciousness, which means needing to confront the symbolic significance of her new body and identity after medical treatment (Ogle & Ullstrup, 2006). Goffman’s (1963) work on stigma speaks to what a woman may experience when she recognizes a gap between her actual social identity, and how she perceives herself or believes others to perceive her. Concerned that she may not measure up to societal expectations, she may come to see herself as tainted. This is of particular concern for women who equate their breasts with their womanliness (Mock, 1993).

Research within this epistemological stance represents a shift away from studying the content of the breast cancer experience, to the process of the experience, and how it is perceived by women themselves. Within an objectivist framework, the body and self have real properties that can be accurately or inaccurately perceived by the rational mind. Misperceptions of the self are seen as “real” cognitive structures or schemas that can be measured (Blood, 2005). This is antithetical to the social constructionist perspective which affirms that there is no self waiting to
be discovered and perceived, but rather it is multiple, and continually being created and re-created through the social and relational context (Gergen, 1994).

Narrative inquiry provides a research approach that fits within the social constructionist perspective and that appreciates the multiplicity of selves. Narratives, or the stories individuals tell, create portholes into their subjective experiences and invite the listener into the image they hold of themselves (Ochberg, 1988). These self stories provide a framework through which individuals experience the social world and give structure to how they live their lives; how they contend with their joys and pains, and shape what they take up and what they eschew as they integrate their experiences into their senses of self (Hyden, 1997; Somer, 1994).

Given the complexity of breast cancer experiences and social constructionism’s emphasis on the self as created through social milieu, narrative is well suited to study how women re-shape their self-identities post treatment for breast cancer. The use of narrative is being increasingly used in healthcare research (Carlick & Biley, 2004). In the following section I will review some of the foundational contributions to the study of narratives of illness, as well as discuss some of the contributions they have provided to the psychosocial research in breast cancer.

**Illness Narratives**

The stories people convey reveal their life histories and it can become feasible to understand where they have been, where they are now, and where they hope to be in the future (Carlick & Biley, 2004). Through the telling of their story, individuals can develop a greater understanding of self. The telling of stories can also lead to greater emotional insight and personal growth (Heiney, 1995).

Frank (1998) proposed three structures of narrative stories in the study of illness, which he claimed provide, “the skeletons on which many stories of illness are fleshed out” (p. 200). He
described the first of these as the *restitution story*, when an individual may objectively describe the treatments received without reflecting on the personal experience. In the *chaotic story*, the telling of the experience lacks coherence and feels never ending. The teller moves from topic to topic with no resolution or conclusion. Finally, the *quest story* is one where the illness is seen as a quest and something from which valuable things can be learned. Frank gives the example of a quest story where the teller recognizes new qualities of self and attributes them to the experience of illness.

Narrative researchers in cancer care have found that narratives contribute to ways of coping from both problem-focused and emotion-focused perspectives (Holmes, 2000; Hyden, 1997), as well as enhancing motivation by either re-engaging in former goals, or establishing new ones (Carlick & Biley, 2004). In addition, patients with cancer have found narrative research helpful to organize their experiences, identify areas where they may have felt stuck, and explore their personal values and the possibility of needing to re-evaluate them (Carlick & Biley, 2004).

To understand some of the ways that women have responded to the changes and challenges of breast cancer, Hall (1998) analyzed the narratives of 20 women, 5 of whom had experienced a reoccurrence of cancer, while the remaining women had been cancer free for at least 5 years. Though the method by which Hall analyzed the narratives was not explicated, her analysis found that women’s familial, social, and cultural relations impacted the ways in which the women made sense of their experiences, and how they navigated them. Women who were more influenced by social and cultural norms allowed the medical system to determine the course their treatment would take, whereas women less persuaded by norms were more likely to agentically choose their own course of treatment, for example refusing reconstructive surgery, to
the bafflement of the treating doctors. This is not to imply that one reaction is necessarily better than another, but merely illuminates some of the ways in which self-narratives are differentially impacted by how an individual interacts with the social and cultural norms. As evidenced in Hall’s research, treatment choice, response to treatment, and satisfaction with treatment outcome are all heavily weighted by how a woman’s understanding of self and self-narrative is shaped by the context in which she lives.
Chapter 3: Methodology

*But in order to make you understand, to tell you my life, I must tell you a story*

Virginia Woolf

Researchers have yet to understand how women might integrate and make meaning of their experiences of self-identity after being diagnosed with, and treated for, breast cancer. As such, the purpose of this study is to hear the stories of women who have been diagnosed with breast cancer, and who have self-identified as having been able to come to a place of re-shaping a sense of self-identity. Specifically, the research question is: **How do women re-shape their sense of self-identify after being diagnosed with breast cancer?** It is not the intention of this research to evaluate if the women’s ways of re-shaping their sense of self is positive or negative. Rather, the objective is to understand the processes by which the women identify as having re-shaped their self-identity, regardless of how they might qualify it.

Narrative inquiry has taken root in the varying fields of sociology, anthropology, feminism, and sociolinguistics (Chase, 2005). Each has influenced how narrative is defined, recorded and analyzed, ranging from humanistic and person-centred approaches concerned with individual stories, to perceiving narrative as fluid, multiple, and contradictory, consisting of conscious and unconscious meanings and embedded in contexts of power. The latter tradition takes particular interest in how the language and subjectivity of the story-teller is influenced by social contexts. In this way, the narrator is described by the story as much as he or she is describing it (Squire, Andrews, & Tamboukou, 2008). However, the delineations between types of narrative are not that clear and as different disciplines take up narrative, new approaches are continually produced (Creswell, Hanson, Plano Clark, & Morales, 2007).
While the variety within the field of narrative can be exciting and liberating, for researchers attempting narrative inquiry for the first time, the looseness of what constitutes narrative and how best to analyze and represent the data can be intimidating. Part of the confusion stems not only from a lack of agreement on the definition of narrative, but also the use of the term without defining what is meant by it (Lieblich, Tuval-Mashiach, & Zilber, 1998; Squire, et al., 2008). Narrative has been defined as a coherent account of an experienced or expected event, providing structure and plot to a series of events which through the telling, the narrator establishes a sense of meaning and order to the multitude of details (Murray, 2003). Narrative has also been more loosely defined as models of processes in process. Specifically, narrative involves analyzing the meaning-making processes that a self undergoes as it makes sense of its experiences (Josselson, 1995).

Narrative has been likened to a family of approaches replete with its own commonalities, disagreements, and arguments (Riessman, 2008). Despite the discrepancies, the majority of scholars agree that narratives, in all forms, share a primary interest in how experiences are understood, and the ways in which meaning is constructed and communicated (Chase, 1995).

Narrative Methodology

_We Live in Stories, not Statistics_ (Gilbert, 2002, p. 223)

History of Narrative Research

Regarded as an “epistemological other” to the social sciences, narrative was often associated with the humanities and historians as a form of “story-telling” (Somers, 1994). Contemporary use of narrative within the social sciences developed as a response to positivist empiricism (Squire et al., 2008). However, initial interest was only to the extent that narratives could generate knowledge about what they represented, as if they were somehow akin to a
window pane, providing an unobstructed view of an accurate account and “ultimate truth” (Riessman, 1993). As western sociology and psychology began taking interest in narrative, emphasis was placed on person-centred approaches, biographies, case-studies, and life histories (Squire, et al.). Simultaneously, academic developments including the structuralist movement in Russia followed by poststructuralism in France, viewed narrative as a study of story content and structure (Squire, et al.). Approaches such as psychoanalysis (Lacan, 1977) and deconstructionism (Derrida, 1977) were introduced in the late 1970’s and broadened the topic of inquiry from that of the individual, to the social relations and formations that shaped language and subjectivity.

Specific to the use of narrative in studies of illness, the late 1970’s saw medicine using narrative as an interpretive tool, to ‘read’ the patient (Hyden, 1997). However, similar to the recognition that grand-narratives can no longer account for experience and knowledge in an increasingly polycentric and fragmented world (Lyotard, 1984), medicine has also faced doubt that it could account for all illness and cures (Hyden). Works such as Frank’s (1995) *The Wounded Storyteller*, constituted a paradigmatic shift in research, providing a way to view illness experiences and suffering through the lens of a social reality, apart from the ways in which biomedicine understood and represented illness (Hyden).

In his seminal research, *The Illness Narratives*, Kleinman (1988) also presented a rationale for the use of narrative to broaden current conceptualizations of illness experiences. He cited German phenomenologist, Plessner in describing how the experience of illness creates awareness that individuals both are their bodies, and have their bodies. Namely, when an individual is sick they are their sick body, and they also recognize that they have a sick body. The sick body is distinct from their self, and they can observe it somewhat objectively, as if it
belonged to someone else. The distinction of having a sick body that can be observed and experienced as external to the self has been noted in the research in breast cancer. Specifically, some women will objectify their body as if it is separate from self, referring to their breast as “it” or “they” (Waskul & van der Riet, 2002). According to Plessner, the space between an individual’s immediate embodied experience of illness as a physiological process, and the experience of self as a human being, becomes populated by the cultural meanings, symbols, and values of health and illness. In this way the illness experience takes on meaning because of the way that the relationship between body and self is mediated by culture.

Challenges can arise however, when culture and society do not have an agreed upon framework through which to perceive a particular illness experience (Kleinman, 1988). In situations such as this the tendency is to turn toward recognized health professionals to provide guidance as cultural authorities. Often missed by these cultural authorities however are understandings of the illness experience that fall outside of the physical (i.e., emotional, relational, occupational implications of the illness) and as such important aspects are left unacknowledged, the result of which can increase suffering. Kleinman recognized that these “missed aspects” of the experience are not easily captured by quantitative measures and rating scales. He asserts that narrative inquiry can contribute to a better understanding of the meaning of an illness experience, and how such meaning is ascribed. By having more comprehensive understanding of meaning-making after illness, informed therapeutic treatment interventions can be better developed.

**Why Narrative for this Topic?**

The stories individuals tell are shaped by culture as it influences how they come to see and experience their world and how they come to understand their place within it. It is through
the telling of their stories that their experiences are meaningfully organized (Berger, 1997). As a methodology, narrative presents an opportunity to understand the processes by which stories organize experiences, by analyzing both spoken and unspoken language (Riessman, 1990). It also provides the means through which to understand the often complex interactions between individuals, groups, and societies (Riessman, 1993).

Narrative has been hailed as having a primary function in the construction and maintenance of self-identity (Burr, 2003; De St. Aubin, Wandrei, Skerven, & Coppillo, 2006; Gergen & Gergen, 1983; Hiles & Cermak, 2008; McAdams, 1993). Self-identity is crafted through a process of adopting and adapting cultural meanings, values, myths, and stories (Polkinghorne, 1991). The resulting self-identity is fluid and thus open to change as new cultural artefacts are encountered, or new meaning is placed upon previously known cultural artefacts (McAdams, 1996). For the purposes of this research, self-identity is defined as inclusive of a woman’s sense of self, femininity, body image, and body integrity, all of which are disrupted with the diagnosis of breast cancer (Thomas-MacLean, 2004).

It is widely acknowledged in the literature that the experience of breast cancer is replete with psychosocial sequelae (Andrykowski, Lykins, & Floyd, 2008) and the objectification and fragmentation of the breast from a woman’s sense of self (Fisher, O’Connor, Guilfoyle, & Maasen, 2007; Langellier & Sullivan, 1998). To date, research has focused on identifying areas of distress and ways to reduce symptomatology, yet less is known about enhancing psychological outcomes, specific to the disrupted sense of self (McCann, et al., 2010).

Women diagnosed with breast cancer experience a disrupted sense of self (Little, 2002). This experience is influenced by women’s relationships with family, friends, and medical professionals, as well as the limited varying discourses from which they can draw as they seek to
make sense of, and personalize their experiences (Little, 2002). Extending Kleinman’s (1988) previously discussed theory as a means to conceptualize the research issue; the limited social and cultural discourses available leave women with little from which to make meaning of the gap they experience between the physical experience of breast cancer, and the experience of being a woman with breast cancer.

Social Constructionism: The main tenets

Narrative falls under a social constructionist epistemology, which arose in the late 80’s as a reaction to post-positivism, with the introduction of the work of various French philosophers (Squire, Andrews, & Tamboukou, 2008). Generally, social constructionists conceive of this philosophy as a psychological metatheory, which regards human activity as comprised of historicity, context, and sociolinguistics (Hibberd, 2005). Social constructionism has been influenced by several developments in the 20th century including the narrative turn, which emphasized the role of stories in expressing lived experiences (Berger & Quinney, 2004), the dialogic turn, suggesting that psychological phenomena and meaning are best understood through a focus on language (Harre, 2009), and the linguistic turn, which viewed realities as being structured by the language by which it is described (Neimeyer, 1998).

In light of all of these paradigms, it is not surprising that it can be difficult to grasp the complexities of social constructionism. Difficult to define, it is not so much a singular concept as much as it is a group of assumptions about the processes involved in how something comes to be socially understood and accepted (Gergen, 1985). Burr (2003) espouses that a stance of social constructionism necessitates the adoption of numerous critical stances including: questioning individual’s taken-for granted assumptions about themselves and their world; recognizing that their understandings of things are culturally and historically specific; an appreciation that
knowledge is something that is constructed between people, through social processes as individuals negotiate and come to agree or disagree on what something ‘is’; and finally, that social action and knowledge are inextricably linked, as social agreement determines what constitutes ‘knowledge’, and knowledge then influences how people act accordingly.

There is a continuum of positions upon which one can perch in declaring a stance of social constructionism. The extremes range from a focus on the micro analysis of language use in social interactions, to the macro analysis of social and linguistic structures that provide a framework for our psychological and social lives (Burr, 1995). Narrative methodology falls along the range of social constructionist research.

Specifically, narrative analysis can provide an understanding of how each woman has made sense of her experiences by drawing on cultural resources. Before further discussing the intricacies of analysis, one must first develop an appreciation for the main tenets of social constructionism, namely language, identity, power, and agency (Burr, 2003).

Role of Language and Context

*The limits of my language mean the limits of my world*

(Wittgenstein, 1981; p. 149)

Language is highly contextually bound. Adopting a Foucauldian view of language, the meaning of text cannot be understood if it is not located within the broader social and material context in which it occurs (Neimeyer, 1998; Phillips & Hardy, 2002). Until words and actions are socially accepted as meaningful, they are rendered empty and non-constitutive of language (Gergen, 1997). Therefore language is not reflective of reality, but rather creates it. As something comes to be accepted or rejected as significant, individuals talk things into and out of being, and
partake in a social action that not only constructs the shape society takes, but also has implications for what comes to be accepted as knowledge (Burr, 1995).

As mentioned previously, social constructionists assert that individuals’ assumptions about the world cannot be taken for granted, and that “language is not transparent” (Burr, 1998, p. 48). Language is regarded as a pre-cursor to thought, providing the building blocks for the construction of the self. It is through being taught language that things come into existence, and individuals begin to construct their worlds (Burr). Through conversational negotiations with others, individuals come to a place of agreement on what a particular term means. Often the words selected are not chosen because they best represent the thing that is being spoken of, but rather because they best convey the thing. As individuals search for ways to describe and define their experiences they recognize what Bakhtin (1981) coined, the ‘unfinalizability’ of the word. As context gives language meaning, and context is always being socially constructed, the meaning of language is therefore also always being constructed and as such is contestable.

**Identity Development**

*Humans are storytelling organisms, who, individually and socially, lead storied lives*

(Connelly & Clandinin, 1990; p. 2)

The self as described in social constructionism is one that is fluid, in flux, and a product of the social interactions and language by which it is described. Language provides a major conduit for the construction and re-construction of identity. As individuals’ experiences of self is given meaning by language, and such meanings and language are in flux, then so too are their experiences and identities prone to infinite meanings and multiple interpretations and transformations (Burr, 2003). As such, the self will change dependent on its purpose and contextual circumstances. In narrative, identity is constituted by both content and form as
individuals’ self-stories imitate their lives and provide a means by which to present their internal realities to the external world. Equally as influential, the outside world also shapes how they come to understand their internal experiences (Lieblich, et al., 1998). In recognizing the dynamic interplay between internal and external realities, both of these conceptualizations of self reflect the Bakhtinian perspective of a dialogical self, whereby different people with whom individuals interact come to take up a ‘voice’, or different aspect of self, within the internal dialogue of their minds (Morson & Emerson, 1992). Bakhtin coined the term *polyphony* to account for individuals’ multiplicity of selves, which are created through their interactions with others, and which foster voices with whom they sustain inner dialogues, depending on the specific context and subject at hand. Borrowing Bakhtin’s notions, Hermans, Kempen, and van Loon (1992) suggested that these inner dialogues, though imaginal, play a central role in daily life. These dialogues co-exist with actual dialogues, with others in social interactions, and become interwoven into the narrative constructions of how individuals come to understand themselves and the world in which they live.

**Power**

*Each word tastes of the context and contexts in which it has lived its socially charged life; all words and forms are populated by intentions* (Bakhtin, 1981; p. 293)

Discourse can be defined as a set of stories, representations, statements, and meanings that have come to be accepted as an agreed upon and particular way of viewing an event (Burr, 2003). Discourses come to represent these stories and meanings as much as they are represented by them. As with all social constructions, there can be more than one version of discourse, dependent upon the language, perspectives, and meanings from which a discourse has been constituted. In this way of thinking, speaking is regarded as more than verbal, non-verbal and
written text, but also as material things such as objects, buildings, and clothing, as all are imbued with meaning and therefore contribute to the manifestation of discourse (Burr, 1999).

Discourses regulate knowledge and are therefore intimately linked to both knowledge and power. To Foucault, power is not something that can be possessed, but rather it is an effect of discourse. As individuals draw upon particular discourses which permit their actions to be viewed in a favourable way, they are also drawing upon and exercising power (Burr, 2003). Therefore, to be able to understand how particular institutions have been constructed, it is necessary to look at the broader context, including the forces acting to maintain the fields as they are, and those that exist outside of them.

Institutional fields are dependent upon macro-cultural discourses and discursively position themselves in support of particular identities (Phillips & Hardy, 2002). As individuals take up certain discourses they may or may not be aware of the various parties or institutions involved, and the ways in which each has different stakes in how identity is defined and discussed. Inadvertently, through the implications of knowledge and power embedded in individuals’ actions, they may bestow power upon such institutions. In the context of breast cancer this can be seen by hospitals, encouraging women to take on powerless illness identities and become the ‘good patient’ (Agarwala & Riba, 2010). To cancer agencies and the general public these women are seen as ‘survivors’ (Kaiser, 2008). However, friends and family are eager to see the women ‘as they were’, encouraging them to get back to the way they were so life can resume as normal (Ucok, 2005). Each of these social contexts has an investment in how the women take up their identities, for if women do not return to others as they were, these others may be forced to acknowledge the reality of the situation and adjust accordingly. This is not something everyone is willing or ready to do.
With this discursive position of power in mind, it can be understood that as women take up their identities they not only shape social understandings of breast cancer, but they also contribute to the power that the various parties hold in how they come to understand themselves. This perspective can therefore cast light on how women’s voices may become lost in their experiences, how their voices may be found, and how women may become empowered or threatened.

**Agency**

*Any close listening to the postmodern chorus reveals a polyphony of voices—not all of which are singing in the same key* (Neimeyer, 1995, p. 30)

As with much of social constructionism, the construct of agency has been debated, both between theorists in the field, and those outside of it (Burr, 2003). If nothing exists outside of discourse, then all of reality, the physical material world, and our own bodies and health, are reduced to nothing outside of the effects of language. To many, this thought does not sit well. Are pain and joy, death and birth, not real? Would individuals cease to exist if we did not have language to define themselves?

While questions such as those raised above have ignited a flurry of contentious discussions, Burr (1998) has argued that the confusion stems from the varying ways in which ‘reality’ has been construed. Suggesting that critics dispute the idea that constructionists regard the world and materiality as figments of imagination, thereby making such constructions less trustworthy, Burr firmly states that such a claim was never made by constructionists, and yet the debate continues. In response, some theorists have called for a more moderate social construction, one where material and discursive agency and social constraints are recognized (Burkitt, 1999; Martin & Sugarman, 1997; Neimeyer, 1998). An adoption of a moderate
approach is also the position of the proposed research, in recognition of the both the biology and agency of the women.

**Positioning the Researcher**

Within the social constructionist epistemology, ontology is regarded as comprised of multiple, socially constructed, subjective realities (Ponterotto, 2005). I situate myself within this paradigm and accordingly, believe that there is no objective truth or reality that can be known, observed, or discovered. Rather, it is something that is co-constructed between individuals. Specifically, through the relationship between the researcher and the participant, the meaning that the participant has made of her experiences emerges as the participant’s storied experience is discussed (Haverkamp & Young, 2007).

In addition to the rationale for choosing narrative as described above in the section, *Why Narrative*, I also chose narrative because of its epistemological stance. I was introduced to social constructionism during my master’s research and found that the main tenets made intuitive sense to me. I can recall being a small child and questioning language and why particular things were named what they were, and who got to decide that we as a society should call them that. As such narrative does not feel like a worldview that I have challenged myself to understand but rather one that fit with the worldview I have always had.

Although alternate methodologies were considered, they were not appropriate for the particular research question, nor did they resonate with my own world view. Two such methodologies were phenomenology and grounded theory. As phenomenology seeks to reduce personal experiences to an underlying universal essence (Creswell, et al., 2007), it was perceived to be inappropriate as it is antithetical to my constructionist beliefs that we create meaning from our experiences, rather than seek to uncover a universal meaning. Without going into depth in
the evolution of grounded theory and the resulting typologies and inherent tensions (Hallberg, 2006), I felt that grounded theory was at epistemological odds with the research question. Specifically, in my limited understanding of grounded theory, the purpose of the methodology is to generate a theory that best explains the experience under study (Creswell, et al., 2007). This approach was perceived as somewhat presumptuous and reductionist for the current research question, as it is yet to be known how women who have breast cancer re-establish their sense of self-identity, and if there are unifying themes that could be woven into a singular theoretical explanation.

Being that I relate so readily with social constructionism, I am aware that my own worldview, thoughts, values, and beliefs are inextricably interspersed throughout my interactions with my participants, from the initial wording of the research question, to the last email confirming their approval of the final narrative. In order to acknowledge this influence, I maintained a research journal where I reflexively wrote about my own experiences, thoughts, and emotional reactions to the research throughout the process. A high level of self-awareness on my part was required in order to ensure that the integrity of each participant’s story was maintained. In this way I attempted to conduct an interview that was an actual account of each participant’s own reflections and recollections as they shared them, and not generated by my own biases or expectations (Polkinghorne, 2005).

**Researcher Presumptions and Expectations**

As I began thinking about and working on this research I engaged in a process of self-reflection, questioning my interest in the topic, and attempting to uncover my own biases and expectations in conducting this research. Morrow (2005) argues that reviewing the literature prior to engaging in research is a way to mitigate researchers’ biases by deepening their
understandings of the phenomenon under study. In commencing this research I consulted the literature for a preliminary understanding of how women’s experiences of breast cancer have been previously researched and represented. My presuppositions regarding women’s experiences of re-shaping their self-identities after being diagnosed with breast cancer were influenced by an introductory literature review, my personal and clinical experiences, and my social constructionist worldview.

Given the complexity of an experience of breast cancer and the diversity of ways that women cope (Avis, et al., 2004), I expected that women would identify as having experienced a change in their self-identities and understandings of self. Drawing on the literature on identity development (Smith & Sparkes, 2008) and particularly the theories on how illness impacts a sense of self (Arman & Rehnsfeldt, 2003) I anticipated that women would identify as having gone through a process to negotiate their experiences into their pre-existing self-identities. Based on my own experiences and clinical work, I assumed that the women would be able to articulate the changes in self by comparing their current understandings of self to prior understandings of self. I anticipated that there may be some differences in coping amongst women of different ages and with varying diagnoses and treatment, however I expected that there would be also be similarities in the process. Further, I recognized that duration of time since treatment, and type of treatment sought could influence self-identity. Despite these things, I anticipated that women who identify as having re-shaped their self-identity would have similarities in their processes.

In addition, my previously described social constructionist worldview also had the capacity to impose itself on the participants’ meanings and stories, as I value the role of relationship and social surroundings in influencing self-perception. While wanting to explore these possible influences in the lives of participants, it was also imperative that I not presume
them to be more influential than the participants identified them. As I approached my research topic I was aware of these biases and worked to ensure that they were not unknowingly imposed on the research. This was achieved through employment of multiple strategies in effort toward researcher reflexivity (see Morrow, 2005, for review). Reflexivity, as defined by Rennie (2004), is “self-awareness and agency within that self-awareness” (p. 183). In order to be better aware of my own experiences and to ensure they were not inadvertently imposed on the research, I sought frequent consultation with my supervisor and had her regularly review my work. In addition I engaged in member checks with the participants to ensure that the written narratives honored their experiences as they had shared them (Lincoln & Guba, 1985). Lastly, the resulting themes were reviewed by expert and peer reviewers.

**Conducting the Narrative Inquiry**

**Criteria for Selection of Participants**

Participants were included based on the following criteria: (1) females 25 years or older who were living in the Greater Vancouver or Edmonton area; (2) having been diagnosed with breast cancer; (3) agreeing to participate in the study and being available for at least one interview; and (4) identifying as having re-shaped their sense of self-identity after being diagnosed with breast cancer. For the purposes of the study there were no requirements as to the duration of time since treatment, and the type of treatment sought. The only interested persons who would have been excluded from participating in the study were those who did not meet the inclusion criteria, or who had been advised by her therapist not to participate. All respondents who met the inclusion criteria and were available for an interview were included.

The age of 25 was chosen for the minimum age of participation, as women younger are often regarded as still sorting out education and career goals (Arnett & Galambos, 2003). In
addition, in his often cited article, Arnett (2000) proposes that prior to 25; women are still in the process of identity development and preparation for adult roles in family, career, and life in general. As such, it was determined that women over the age of 25 would be more likely to have completed these developmental tasks.

**Participant Recruitment**

Ethical clearance was received from UBC’s Behavioral Research Ethics Board (BREB), certificate H11-03433, and from the Alberta Cancer Research Ethics Committee (certificate 25862). Participants were recruited via word of mouth through peers and colleagues, as well as through the Cross Cancer Institute in Edmonton Alberta. Colleagues who were aware of my research offered to circulate my recruitment poster (see Appendix A) in order to generate public awareness of my study.

In qualitative research there is no predetermined number of participants that are required to complete a study. The purpose of qualitative research is not generalizability. Rather, it becomes a question of ‘saturation,’ which speaks to data adequacy, and the goal to continue gathering data until new information is no longer obtained (Morse, 1995). However, saturation has been seen as problematic, possibly oversimplified, and in and of itself, not sufficient (Bowen, 2008).

Although the actual process of thematic analysis will be described in detail below, it is important to note here how the emergence of themes during the data collection phase was important in determining saturation, and the number of interviews that would be required. Themes were identified throughout the research process by reviewing my journal and notes taken during each interview, as I began to see relationships and core concepts within and across the data (Bowen, 2008). As sub themes emerged I created tables to compare them, and over the
course of the interviews, larger more encompassing themes emerged. During this process some subthemes were also ruled out, as there was either no larger overarching theme identified, or there were not enough participants speaking to a particular concept to deem it as significant to the research. By engaging in this process I was able to identify ways in which the data were related, and gaps where further information was required. In both instances where further information was needed, a follow-up email was sent to each participant in order to gather more information about how and when she was diagnosed. This was done at the time of the member checks in order to obtain the necessary demographic information. At this level of analysis self-reflection was also crucial to help identify if my biases and expectations were imposed on the data.

Engaging in this process also helped me establish an audit trail, in order to elucidate how the final themes and subthemes were derived (Lincoln & Guba, 1985). As the interviews were conducted general themes began to emerge. After the sixth interview it became apparent that thematic patterns were becoming highlighted. A seventh and eighth interview confirmed the themes without adding new ones. As such it was determined that eight interviews would be sufficient to support the themes as outlined in the following chapter.

**Data Collection Procedures**

Upon receiving ethical approval I conducted a pilot interview with a woman who had heard about my research by word of mouth. The use of a pilot study in qualitative research can help to determine if the interview questions will provide the data to answer the research question (Maxwell, 2008). Although this pilot interview was not a full pilot study, it allowed me to feel confident that the reflection questions and orienting statement were worded in such a way that they would elicit data to answer the research question. As this was a woman I had not previously
known, and because the data resulting from her interview was consistent with the data from the subsequent interviews, her data was included in the final write-up.

The psychologists at the Cross Cancer Institute in Edmonton (the Cross) invited me to make a brief presentation to their breast cancer support group, in order for possible participants to ask me questions about the study and the process of participation. I was contacted by women who had heard about my study through friends, or from their psychologists at the Cross. Each woman either contacted me by phone or email, at which point I emailed them more information about the study (see Recruitment Script; Appendix B). Upon reviewing the recruitment script, which includes the selection criteria and explanation as to what participation entails, some women declined either due to scheduling difficulties, or feeling that they did not best suit the selection criteria. Of the women who chose to participate, a phone-call was arranged to discuss their participation further and answer any questions they may have had. The phone call also provided me with an opportunity to begin building rapport with the women. The participants were also emailed a series of questions for reflection in an effort to help prepare them for the interview, (see Reflection Questions; Appendix C), as well as an orientating statement (see Appendix D).

A face-to-face interview was scheduled based on each participants’ availability. A confidential place of their choosing was arranged for the interview. Recruitment spanned from February to October, 2012, in order to accommodate everyone’s schedule. Upon meeting with the women, informed consent was verbally reviewed and signed (see Informed Consent, Appendix E). Participants recruited through the Cross signed the Alberta Health Consent Form (see Appendix F). The process of obtaining informed consent included reviewing the limits of confidentiality, and addressing how the data gathered from the interview would be safely stored.
Each participant was aware that the digital audio recording of their interview would be stored in a password protected file on my computer. Any questions that the participants had were answered prior to commencing the interview. Once the participants were ready to commence the interview, my dictaphone was turned on in order to obtain an audio recording.

For some participants, the reflection questions served as a starting point, while others chose to start by simply telling their story starting with when they were first diagnosed. The reflection questions were also used when necessary to further explore a particular topic, or when a participant had difficulty telling her story and discussing her personal meaning. The focus of the interview was less on the accuracy of the participants’ exact recall of their experiences, and more so on the ways in which each woman individually made meaning of her experiences (Polkinghorne, 2005). To this end I recognized that my responses were crucial in the co-creation of each woman’s story. As such, I attempted to be aware of and manage my influence on the process, in effort to ensure that my responses facilitated the participant to produce a thicker, deeper account of her experiences (Polkinghorne). The interviews ranged from 90-120 minutes.

Midway through the research I was awarded some research funds with which I could hire a transcriptionist. At this time my ethics through BREB was again revised, so that informed consent now included the use of a 3\textsuperscript{rd} party to transcribe the interviews. A private company was retained to conduct the transcription. They were requested to sign an Oath of Confidentiality (See Appendix G) and I was provided with their own Confidentiality Agreement (See Appendix H). Participants enrolled in the study after the use of the transcriptionist were made aware of this service and given the choice to opt to have me personally transcribe their interview. All interviews were labelled with the participant’s chosen pseudonym. In querying how the transcript service would handle the data they stated that once a transcript was given to me, all
corresponding audio files would be deleted from their system. As a failsafe, files were assigned an expiration date upon upload, and any file that might have been missed once complete, was automatically deleted from the system on expiration.

During the recruitment phase I was contacted by two women who had heard about my study from friends, and wanted to participate despite living outside of the Greater Vancouver and Edmonton areas. Each of these women requested to be included and interviewed via Skype. At this time an amendment was made to my ethics approval from BREB in order to secure ethical consent to conduct interviews via Skype.

Wary of interviewing via Skype, I consulted the literature only to find that little research has been conducted using this medium in qualitative research. In an article arguing the advantages of telephone interviews, Holt (2010) listed ideological, methodological and practical reasons as to why telephone interviews may in fact be more favourable than face-to-face. However, as she articulates, one of main critiques is the loss of non-verbal aspects of communication and interpersonal interaction. In a more recent article, Hanna (2012) addresses Holt’s presuppositions and extends them to interviews via Skype. In his article he argues that the use of Skype can preserve the traditional benefits of a face-to-face interview, while also profiting from the advantages of telephone interviews as suggested by Holt. Specifically, through the use of video with Skype, some of the lost non-verbal aspects of the qualitative interview can be retained.

The advantages of the two studies discussed above predominantly spoke to the convenience of phone and Skype interviews, with a primary emphasis on the convenience of the interview being conducted from the home of the researcher and of the participant. This was not of concern for my research. However, I did note some benefits to the use of Skype that I had not
previously considered. At one point a participant forgot about our agreed upon meeting time. By quickly calling and emailing her, we were able to reschedule for later that day without the inconvenience of either of us having physically travelled to the agreed upon interview location. In addition, I noticed that there were times when the participant seemed less focused on the webcam, giving the sense that my presence was not as obvious to her as she spoke at length about her experience. It made me question if somehow not having had me in the room allowed her to stay in her story more, with less awareness or concern with how I may have been responding.

In addition to the research addressed above, I also reflected on my own personal experiences to address the hesitancy I experienced with using Skype. For additional learning in my doctoral studies I completed an online course through Interprofessional Psychosocial Oncology Distance Education. During this course I had the experience of completing a group project with students across Canada, using on the telephone and email as our medium for communication. Initially this sounded quite challenging; however, in the end we were all amazed at how easy it was to facilitate our work. In addition, I have provided parenting consultations over the telephone for the past five and half years, during which time I have spoken over 1500 parents across Canada. Although doing a qualitative interview requires different goals and skills than phone counselling and counselling in general (Polkinghorne, 2005), I believe that my above discussed experiences have provided me with the experience to know that it is possible to establish rapport over the telephone. As such, I felt that the added benefit of the video component in Skype would only further facilitate the research relationship development. The women who were interviewed via Skype were notified that although Skype was recording the audio and video
components of the interview, only the audio portion would be given to the transcriber to transcribe.

As previously described, I knew I had reached saturation when themes and subthemes continually emerged from each interview, without new themes or subthemes being added. At the completion of all interviews the participants were notified that I would be in contact in order to share each of their narratives with them for their review. The process of constructing the narratives will be described below.

**The Process of Analysis**

The initial two interviews were transcribed verbatim by myself. They were reviewed by my research supervisor in order to ensure that I was not inadvertently leading the participants. Once I received the small research fund, the services of a professional transcriber were retained to transcribe the remaining interviews. All interviews were transcribed verbatim.

It is important to note that analysis of the data begins with transcribing the interview (Lapadat & Lindsay, 1999). By having the interviews transcribed by someone else, I ran the risk of missing the initial step in the preliminary analysis of the data, thereby causing me to be one-step removed from it. In attempt to ensure that this was not the case, I took extra care in reviewing the transcripts that I did not transcribe. I did this by reading each transcript as I listened to the interview, in order to ensure that it had been transcribed verbatim. To immerse myself back into the interview so as to begin analysis, I listened to the interviews multiple times while reading the transcripts and reviewing my notes taken during each interview.

When sharing their experiences, individuals describe them as a succession of stories, not all of which are always coherent (Murray, 2003). Bruner (1990) identified two ways of knowing, the first of which he defined as *paradigmatic cognition*, which he describes is the traditional,
logical, and scientific mode. This is differed from narrative cognition, which he presupposes is a means to arrange diverse elements of a particular action into a unified whole, whereby each element is related to the central function of the action. As Bruner (1990) described, “people do not deal with the world event by event or with text sentence by sentence. They frame events and sentences in larger structures” (p. 64). Given this perspective, the stories that each participant shared during the interview needed to be organized into a larger more clear and coherent narrative.

In order to do this, I drew on Polkinghorne’s (1995) expansion of Bruner’s (1990) epistemology the first of which he labeled “narrative analysis,” and defined as the process of researchers gathering information from the participants and then organizing it into a coherent story. He distinguishes this from “analysis of narratives” (p. 12), which is the equivalent of Bruner’s paradigmatic cognition. Polkinghorne defines this as the process of identifying patterns and creating descriptions of themes that resonate across the participants’ stories. Accordingly, I employed two different levels of analysis, “narrative analysis,” in which I developed narratives from the transcribed interviews, and an “analysis of narratives,” in which I identified patterns of themes across the narratives. Each of these will be discussed in turn below.

**Narrative Analysis**

The process of narrative analysis essentially begins with the first few interviews, after which the content was examined by myself and my research supervisor, in order to ensure that it was speaking to the purpose of the research (Rubin & Rubin, 2005). At this point I modified my questions to ensure that they would better elicit the experience under study.

Upon completion of the transcriptions, I began the process of narrative analysis, which as defined by Polkinghorne, (1995) is meant to, “order experience by seeing individual things as
belonging to a category,” and essentially order the elements of each individual interview into a story. Polkinghorne argues that in order for narratives to be derived from transcripts, a plot is required in order to: 1) demarcate the beginning and end of the story; 2) determine what needs to be included; 3) order the events that the participant shares; 4) help elucidate the meaning that each of the events has contributed to the story as an integrated whole.

In order to identify the plot and organize each transcript into an integrated story, I needed to listen to each interview multiple times while reading the transcript, in order to re-immure myself in each interview. I also read the notes I made during and after each interview. I worked sequentially on each individual interview, and following Polkinghorne’s (1995) four purposes of narrative analysis as described above, I plotted an outline from each transcript. Through my multiple listenings and readings I then began to expand on and refine the headings of the outline until I had a coherent narrative that captured the elements of each participant’s individual experiences as she shared them.

In writing the narratives I attempted to be selective with my use of quotes in order to ensure that I was accurately capturing the meaning the participant was conveying, without being too cumbersome for the reader. As well, to facilitate the ease of reading, intrusive elements of the speakers’ quotes were removed, except where doing so changed the speaker’s meaning. Examples of intrusive elements include sounds of speech such as “ah” and “um,” as well as words such as “like”, and “you know” (Kleinman, 1988).

After a narrative was completed, I sent it to my research supervisor for her review, in order to determine if I had written it coherently, as well as to ensure that I hadn’t inadvertently missed something, or over or under emphasized any particular part. The narrative was then sent to the participant for her review. Each participant was also asked to consider specific questions
when reviewing her narrative. These questions will be discussed in the section below titled, “Evaluating Narratives.”

**Analysis of Narratives**

Once each of the narratives had been completed and reviewed by each participant I began the process of analysing all of the narratives in order to identify patterns and create descriptions of themes that resonated across all the participants’ stories. Polkinghorne (1995) describes this process as an inductive and recursive movement from the identified common elements to the categories that have been proposed by the researcher. By repeatedly moving back and forth between the two, the categories were refined until they most accurately captured the particular instances of the emerging categories.

Lieblich et al, (1998) provide a more detailed reading of the process for this type of analysis, which they have termed, categorical-content analysis. Employing the four steps outlined in this form of analysis, I re-read all of the narratives and organized all sections of each narrative that addressed the research question, into a separate document. As part of the second step, I began the process of defining the content categories. For this I read through all of the selected texts and began to define overarching themes that emerged. Through additional readings themes were refined, altered, added, and removed.

In step three I again re-read the narratives and the previously identified sections of the texts, and began assigning them to the content categories I had just defined. This too was an iterative process as the texts selected helped refine the categories, and the refined categories helped identify appropriate text. Once the main categories were identified as meta-themes, smaller content domains under each larger theme were identified. I then sent the themes and
subthemes to my research supervisor for verification. Each of these themes and subthemes are described in Chapter 4.

**Evaluating Narratives**

Many have questioned how best to evaluate qualitative research, and unfortunately the narrative study of lives and stories do not fit into neat boxes that have been scientifically calculated and calibrated (Philaretou & Allen, 2006). In some ways, the notion of needing criteria by which to evaluate narrative is antithetical to the interpretative nature of narrative research, which supports multiplicity and the idea that narratives can be read, and understood in a multitude of ways (Lieblich, et al., 1998). However, that is not to say that in narrative research, anything goes.

According to Morse, Barrett, Mayan, Olson, and Spiers, (2002) trustworthiness is the qualitative equivalent of the quantitative notion of rigor, without which, research loses its utility. While rigor and trustworthiness may be recognized as synonyms, the use of parallel terminology further divides qualitative and quantitative research. Morse et al. assert that researchers should not rely upon reviewers to ensure trustworthiness, but should execute self-correcting verification strategies built into the methodology.

Maintaining trustworthiness throughout the conduction of a study becomes somewhat challenging as there is no agreed upon canonical way in which to validate interpretive work. Some procedures may better fit particular research questions over others (Riessman, 1993). In light of this, I employed the criteria as suggested by two narrative theorists, Lieblich et al. (1998) and Riessman to inform the trustworthiness of this study. These include coherence, comprehensiveness, resonance, and pragmatic value, each of which will be described below.
**Member Checking**

In effort to minimize the influence of myself as the researcher on the narratives and resulting themes, I employed several different modalities. Each participant was emailed a list of questions that address the four criteria as listed above. She was asked to reflect on the questions as she reviewed her personal narrative, and email me with her thoughts and comments. This process of member checking is a valuable way of determining if the data analysis and subsequent narrative is congruent with each woman’s individual experiences (Curtin & Fossey, 2007).

Additionally, two peer reviewers were given the same questions to reflect on as they reviewed the resulting themes of the analysis of the narratives. Both of the peer reviewers were women who had identified as being interested in participating in the study, but due to time constraints were unfortunately unable to do so. The themes were also reviewed by two professional reviewers who are registered doctoral level female psychologists, and who actively work in psychosocial setting and provide therapy for women who have been diagnosed with breast cancer. The expert and professional reviewers were asked to comment on the same questions as the participants in their review of their narratives. The wording of the questions was slightly changed for the professional reviewers in order to reflect that they would be answering from the position of a practitioner, and not a woman having gone through breast cancer. The questions asked of participant are listed below, while the questions asked of the peer and expert reviewers can be found in Appendix I. Lastly, I also maintained a research journal and will share my personal reflections below. Each of the criteria will be discussed in turn. I have included the comments of the participants, as well as the peer and expert reviewers, in order to explicate how I strove toward ensuring trustworthiness of the study.
Coherence

The criteria of coherence asks whether the narrative is as “thick” as possible (Riessman, 1993), and creates a deep and meaningful impression (Lieblich et al., 1998). In effort toward gaining a rich description of the participants’ experiences, and achieving a greater depth of my interpretation, I emailed each participant her narrative and asked her to comment on the following: Does this narrative portray your experience as you understand it? You can add more information for clarity and delete phrases that you do not want to include.

In response, all participants stated that their own narrative portrayed their experiences. Several participants wanted to make little changes regarding wording in order for ease of reading and to tighten up their quotes. As an example, Nine wrote that she was surprised by her quotes, and said, “do I really say ‘like’ that much?!” Maeve replied, “reading it feels familiar and a reflection of how I feel and how I see what happened and how I am living my life now in comparison to how my life was before diagnosis.”

One participant (Trish) took her time in replying as she carefully reviewed the narrative and reflected on her experience of the interview and reading the narrative. In her response email she stated, “I have just completed reading your report for the third time and I think you did a very good job in understanding me.” Another participant (Ruby) also replied that that her narrative represented her experiences, and for her it was “cool to see what has come together.” She also commented that she appreciated my inclusion of her poems.

Both peer reviewers remarked that they found the themes to be coherent. However, the expert reviewers offered suggestions as to ways to make the titles of the themes more succinct. One expert reviewer also requested clarification as to the types of groups that the women attended.
Comprehensiveness

Comprehensiveness refers to the quality of the interview and the subsequent analysis (Lieblich et al., 1998). One way in which this can be attained is to include several quotations from the interview in order that the reader can make his or her own interpretations of the data. In addition to including numerous quotes from the interviews, I asked each of the participants the following in the follow up email: **Is the narrative comprehensive of your experiences? Or are there important pieces missing? Has anything changed or come to mind since we met?** It was important to get feedback from the participants to ensure that the story reflected their experiences, and how they understood them, rather than of my own interpretations. In her response Trish stated that although the first draft of the narrative was accurate and comprehensive, it was missing an important piece of the interview that she wanted to have acknowledged. She replied that she wished for future research to focus on how men perceive women whose bodies have been physically changed due to breast cancer, whether by lumpectomy or mastectomies. She shared, “We survivors (I hate this word, but use it as an identifier) yearn to see where we stand as a desirable woman.” In response to Trish’s request, I included this in my final draft of her narrative.

The peer reviewers both commented that they found the descriptions of the themes to be comprehensive. One of them wrote, “Although there is some commonality between themes/subthemes, as you mentioned, how you described them creates differentiation.” The other peer reviewer stated that she had just finished her allopathic treatment and was “very curious about the findings of alternative remedies and their help in recovery.” An expert reviewer suggested that she would like to see more inclusion of participant comments in each of the subthemes. In response to this I added one more participant’s voice to each section.
Resonance

It was important to know that the narratives resonated with the participants and adequately captured the depth and meaning of their experiences as they had described them. To this end I asked each participant the following question: Does this narrative accurately portray your experiences as you shared them? You may have reflected on things since we met, or as you read this, so please feel free to add those things as well. Again, a common theme in the participants’ responses was that their narratives resonated with them.

Kathleen shared, “I see the narrative as helpful to other women. It sounds hopeful and proactive, while not negating the reality of a horrible experience.” She felt that her narrative, while speaking to the things she did to help herself get through the experience, was reflective of the whole experience, and did not negate the challenges that she experienced despite having found ways of coping. Trish shared that reading the narrative was challenging for her because in reading it she realized how vulnerable she had made herself in the interview by sharing things she had never previously verbalized. In her response to the above question she replied:

I had to step back and ask myself was I being honest with my narrative? The entire experience was more difficult than I thought it would be. I do not regret participating in the study knowing that my values can hopefully help other women with their personal reflection; hence, accepting the "new" body image.

Through self-reflection and introspection, Trish was able to identify that despite the somewhat difficult process; ultimately the narrative did more than resonate with her. Specifically she stated that her narrative, “cements my faith that my body is visually O.K. and nothing to hide.”

On a whole, both peer reviewers replied that the themes resonated with their own experiences; however, one peer reviewer stated that she could not comment on the theme about the role of groups as it is only now that she can actually consider attending them. She wrote that
she had tried to attend a group within the first three months after her radiation. She described how it had been recommended by her therapist; however, she stated, “I found it very intense, way above what I could handle at the time. It turned me off and I have not tried any other group sessions since then. I am now ready for them one year later.” The second peer reviewer wrote that she identifies with the word survivor and she was surprised to read that not everyone who has gone through cancer identifies with the term.

This second peer reviewer also added that the themes did not speak to a large part of her own experience, which was acceptance of her true self. She wrote:

Through my journey, including losing my hair and having surgery on my breasts, I came to appreciate that who I truly was, is not dependent on what I looked like. My looks did not make me who I was. Whereas before cancer my identity depended to a large degree on my looks, particularly my long brown hair, going through cancer helped me realize that who I was being for myself, others, the world was what was ultimately important.

She was also surprised to read that several of the women in the study reported worrying less, as her experience caused her to worry more. Of particular concern for her were her finances and concern about whether she would be able to pay her mortgage. It was surprising and saddening for her to read how women’s sexuality was impacted by the breast cancer. She shared, “I want women to feel good about themselves no matter what they look like, and no matter what men think.” Lastly, she wrote that she identified with the importance of finding a purpose. Although she already knew her purpose before the cancer, for her, “it was a matter of staying connected to that.” Both expert reviewers commented that these themes were reflective of what they have heard from the women they have worked with in their clinical practice.

**Pragmatic Value**

According to Riessmann (1993) pragmatic value of a study is determined by how much it becomes the basis for future studies. Given this definition, it would be difficult to argue the value
of this study using this criterion. However, she suggests four ways in which others can determine the trustworthiness of a study. These include making the research process and interpretations visible to readers, and making the primary data available to other researchers. In response to this, the full narratives are included in the body of my research, in order that readers can follow how the main themes were derived from the narratives.

In addition, I felt that it was important to know what, if anything the participants felt that they had gained from the interview process. In the validation email I asked: **What if anything do you see that this research process added to your life? Are there any benefits that you can identify by having participated in this research process? Do you see this narrative as being helpful to other women? If so, why?**

A common theme resonating within the participants’ responses was a sense of hoping that these stories would be helpful to other women, but also appreciating the uniqueness of every woman’s experience. One participant (Nine) summarized this well when she replied:

> I think that this process has helped me to look back and see how what has happened to me, has shaped who I am now and how things around me have changed. If you hadn't asked me those questions and forced me to look back at things and reflect I don't think I would have some of the perspective that I have now. So yes I think that would be a definite benefit. I think this narrative is helpful - it is always comforting to know someone else has gone through this I think. Everyone has a different path but the information that every story provides is indeed helpful I believe.

Trish also spoke about the value of sharing her story and how she hopes that doing so will help to evoke a social change. She shared:

> Yes, I do think the narrative would help others take an honest look at their own feelings and learn not to judge our selves by our body’s image. That is not to say that our image is not important; but rather that there is a lot more to a person than having the ideal breasts. My views about changing the way others see "us" is a long process; however, every time it is repeated, we get a tiny bit closer to making that change.
Each peer reviewer replied that although they see the themes as potentially helpful to other women, it is important to remember that each woman’s experience is unique. With that in mind, however; one reviewer added that she believes that despite the differences between women, hearing these themes could, “make other women realize that they are not alone in their experiences as they journey on their road to recovery.”

The expert reviewers also reported that that they regard the themes as having potential value for women diagnosed with breast cancer and in the process of re-shaping their sense of self. One of the reviewers spoke to the clinical application she found in the “schematic” of the themes and the different ways that the participants re-shaped their self-identities. She shared that in her clinical work she has used Julia Rowland’s (1989) developmental schematic as a way to assess how a client’s current developmental life phase may be impacted by a cancer diagnosis. She stated:

Anytime you come up with a schematic that can be used clinically it’s helpful, because it gives you something you can hold in your mind as you ask yourself, how does this particular woman fit with these themes? Or does she not fit in? And what is that about for her? It’s good to keep in mind when doing a clinical interview, and particularly for interns. It has coherence, and is based on real issues that have been triangulated.

With the schematic that resulted from the narrative analysis a therapist can “hold in mind” how women’s different senses of self (i.e. relational self, intimate self) may or may not have been impacted by the breast cancer, and how they have addressed it.

**Ethical Considerations**

The participants were invited to reflect on and share their experiences of breast cancer, and how it has related to their resulting sense of self. Parts of their participation had the potential to remind them of challenging experiences during their lives, which could have affected them emotionally. Although their courage to share their stories was acknowledged and respected, it
was also explained to them that the purpose of the study was not a form of personal counselling. Participants were given information on local counselling resources in their area in the event that their participation in the study brought about something that they would benefit from discussing further in counselling (see Informed Consent, Appendix E; Alberta Health Consent Form, Appendix F).

It is not only the participant’s involvement in the study that could raise concerns, but also that of the researcher. A research relationship develops between the researcher and participants, which naturally influences what the participant is willing to share, dependent on how comfortable she is. Furthermore, the researcher’s own subjectivity, social location, theoretical framework of understanding, and worldview will influence what is chosen to be included in the final document (Riessman, 2003). In acknowledgement of this, I made an effort to make explicit my own biases and assumptions, as described above, and I also maintained regular consultation with my research supervisor. The member check as described above also functioned to prevent my own lens from being implicitly transposed on the participants’ stories.

During the process of consent, I explained the research question and the purpose of the study. This was done in effort to gain informed consent, including giving the participants’ an awareness of how they could expect their stories to be used (Smyth & Murray, 2000). Based on this it was also explained that the analysis may not be as reflective of their actual stories, as much as it may be reflective of what the analysis has located within their stories.

In true social constructionist tradition, each story and each analysis has the potential for multiple interpretations, as each reader takes from it what is meaningful to him or her (Murray & Smythe, 2000). While I will acknowledge my own interpretations of the stories, the final interpretation will always be that of the reader (Ellis, 2004).
Chapter 4: Results

Eight women generously volunteered their time and personal experiences by inviting me into their homes and into a very intimate and challenging time in their lives. As will be described in the individual narratives, each participant was at a different point in her life when she was diagnosed. Each diagnosis was different, as was each treatment approach, and each woman’s experience. The interviews were transcribed and transformed into narratives that each woman helped co-create as she offered her feedback and reflections, in effort to ensure that the final product was one that was reflective of her experiences as she had shared them with me.

Listening to the experiences of these women revealed eight very unique life stories, that while in many ways were incomparable, shared several commonalities. Six themes each with subthemes emerged from the collective narratives. These themes were then reviewed by two women who were external to the study, and had also been diagnosed with breast cancer, as well as two registered psychologists who counsel women going through such experiences.

In presenting the narratives I never questioned that each narrative needed to be included in the main document in its entirety. I felt that this was imperative for two reasons. Firstly, an option may have been to provide a brief summary of each participant in the body of the document and append the entire narrative. However, this felt incongruent as the narrative is the crux of the research and not supplemental or adjunct information to be referred to by the curious reader. In addition it struck me as disingenuous to ask these women to share such sensitive experiences for the sake of the research, but then reduce it down to brief summaries in order to keep the results chapter from seemingly unwieldy. Secondly, consistent with my social constructionist worldview, I believe that something cannot be fully appreciated or understood if it is stripped from the context in which it was experienced (Burr, 2003). In this way a woman’s
experiences are not something that can be isolated and objectively understood. Rather, it needs to be interpreted through the context in which she underwent the experience and made meaning of it, based on her social, cultural, relational and contextual surroundings. Each of the participants chose their own pseudonym except for three who requested that I create one for them.

**Individual Narratives**

**Kathleen**

But I'm still me. I didn't feel as if I had intrinsically, the me hadn't intrinsically changed. I didn't feel diminished and I think, from talking to a lot of other women, they feel diminished. And that's as if it's their fault and, you know, and losing a breast makes them less of a person, less of a woman.

(Kathleen: age 57 at diagnosis in fall 2007, married, 2 adult children, 1 grand-daughter, Caucasian, mastectomy, chemotherapy and radiation, 5 yr course of tamoxifen, ending in April 2013, 5.5yr post diagnosis at interview)

After a routine mammogram picked up something unusual, Kathleen was called back for an ultrasound and biopsy. It was the fall of 2007 when she was diagnosed with breast cancer in her left breast. Kathleen was 57. Unfortunately because the primary tumor could not be located, it was determined best that she have her entire left breast and 14 surrounding lymph nodes removed. She recalled when she and her husband found out the results, “I can remember, I just sat there and I was holding his hand and I just had tears rolling down my face, going yes, no, numb really.”

She described never being able to forget telling their two adult daughters of her diagnosis. Her eldest daughter had been quite involved with the ‘Run for the Cure’ and was more aware of breast cancer than Kathleen was. Her daughter’s response was “oh, mum, not you,” which was quickly followed with reassurance that cancer is not “a death sentence” and that survival rates are high.
After being diagnosed Kathleen returned to her office to pass along her client files to her colleagues. As a travel agent in the same office for 13 years, it was a difficult for her to see her peers so concerned. She recalled that, “they felt so bad for me but I felt bad for them 'cause they didn't really know what to say, and they're all women, you know.”

Within a month Kathleen had her mastectomy and then began six treatments of chemotherapy followed by radiation. Her treatment was challenging as it was during that time that her brother passed away and because she was on chemotherapy, she could not attend his funeral in England. Years later, this is still a source of pain for her.

Finally after a year of treatment Kathleen was able to return to work on a part-time basis, until a detached retina ultimately lead to her official retirement 2 years after her diagnosis. Kathleen was saddened as she explained her non-event transition to retirement. It was anticlimactic. There was no party and no formal marking of the end of her 20 years of working in the industry. As Kathleen described this she shared that she felt like she lost her “main identity” when she was forced to retire. However, throughout the telling of her story, there became apparent several ways in which she crafted new identities throughout her experience of breast cancer.

Kathleen described herself in terms of her relationships with family and with her faith. When sharing the changes she has noticed about her self, the following themes were noted; a greater sense of appreciation, changes in priorities, changes in her relationship with God, and changes within herself. Each of these will be discussed in turn below.

**An Attitude of Gratitude**

I'm actually happier with my body now that I have the time to concentrate on doing all my exercise. Like I'm in multiple fitness classes at the moment, I'm working really hard at it and I feel better in myself, even with only one breast, than I did before I got the breast cancer.
Kathleen shared that when speaking about her mastectomy with her doctor, the possibility of reconstructive surgery was never posed. She then reflected that even if it was presented as an option, she might have only considered it if she was younger. In discussing this, she described that all of her life she had been “overweight” and shared that as a result her body “had not always been [her] best friend.” However, this has shifted since being diagnosed and as she has learned more about her body and how to take care of it.

Prior to the cancer Kathleen explained that she would come home from work, “have something to eat and flop in front of the TV.” However, upon taking a course on various issues related to breast cancer and treatment, Kathleen became aware of the importance of nutrition and the role of fat cells in the production of estrogen. Given that her type of cancer was estrogen dependent, she became determined to exercise and lose weight.

Kathleen half joked as she shared that she was “always a selfish person,” but since being diagnosed and retired, she has “no problem just spending time going out for walks and cooking healthier meals and just spending more time simply on me than I did before.” She described herself as “a lot more conscious of what I put into my body than I was before and I'm, you know, I value it more.”

Previous to her diagnosis Kathleen shared that she had not “clued in to the benefit of actually exercising,” whereas now she is enrolled in multiple different exercise classes throughout the week. In describing the benefits she gains from exercise she stated:

I like that feeling of being out and moving and learning what my body's actually capable of, even though I've got some impediments with my joints hurting and stuff. I'm a lot more aware . . . so that's a change.
Increased awareness of, and appreciation for her body are only some of the benefits Kathleen has noted from her regular exercise. While exercising she has also noticed that she is “very much in the moment.” She shared:

I think that's part of why I like it actually. I'm very present in the moment when I'm doing these exercise classes. I'm just very conscious of enjoying being able to do it and I enjoy listening to the music and the whole experience. My mind doesn't think about anything else.

A Change in Priorities

In addition to the “quietering in [her] mind,” and the balance between “the body and the mind” that she experiences while exercising, Kathleen also commented on changes in her relationships as a result of her newly found appreciation for physical activity. Prior to her diagnosis her “main identity” had been that of travel agent. She shared that in social settings she had always been “the travel agent”, and the person that people would come up to for travel and accommodation advice. Kathleen lamented, “I don’t get asked that so much anymore, and it was really hard to let that go, the social side of work, all of that.” However, since being diagnosed new friendships have formed as a result of her new interests. She shared that she has “developed relationships with other survivors” as a result of her participation in an annual run training group through the “Running Room Survivor Clinic.” She expressed that the Run for the Cure is an empowering event because everyone is so “bright and chipper.” She appreciates being able to distinguish the runners who are breast cancer survivors because their shirts are different from the other participants. She proudly shared, “I raised $2000 all by myself!”

In regard to seeking the support of other women who had also been diagnosed with breast cancer, Kathleen shared that she never sought out a formal group. However, she did attend an informational group that she inadvertently heard about, and that she found “tremendously helpful.” The topics covered a variety of things including nutrition, how to wear a prosthesis, and
chemotherapy side effects. She is sure to tell any woman she meets who is also going through breast cancer to attend the group. Kathleen also sought out an online email support group. Although she did not post her own story, she found much support in reading the journeys of other women.

During the interview Kathleen reflected that the nature of her relationships have also somewhat changed as a result of her focus on physical activities. She shared that prior to the diagnosis she would have met a friend for coffee, whereas now she would be more inclined to say, “let's go for a walk around the lake and then we'll go to such-and-such for coffee.” For her this is a “big change” as opposed to her visits with friends having previously been “completely sedentary.”

As Kathleen has adjusted to being at home now instead of going to work, she has noticed her priorities shifting. During the time of her treatment her daughter went through a stressful pregnancy and Kathleen became a grandparent for the first time. Although initially she “didn’t really want to be a grandparent,” she now identifies that aside from her exercise, her “main focus” is her granddaughter. Through her relationship with her granddaughter Kathleen found that she has “reconnected with the mother [she] was when [she] had small children.” She described that becoming a “granny” has brought “out a different person” in her. For Kathleen this has been a positive experience because it has reminded her of some of the things that she had forgotten that she was “pretty good at.”

**Rethinking Relationship with God**

In general my prayers are more thankful for things that I have rather than asking for things that I don't have. I actually thank God for things more than I did, so I'm more aware of my blessings than I was before, when you just take them for granted.
Before her mastectomy, Kathleen felt a tug from her Catholic upbringing to go see her priest and go to confession. Although she had raised her children Catholic she shared that they did not attend church often, typically going twice a year. She was driven by the thought, “I could die on the table here [during surgery]. So I had better go and make my peace.” Kathleen was given the sacrament of the sick and told that the parish would pray for her. The priest also acknowledged that her childhood education by nuns in a convent in England had given her a “good dose of Catholic guilt.” Kathleen felt relieved to have gone and shared that she has attended mass every Sunday since “without fail.”

Kathleen believes that “any kind of near death experience makes people rethink their relationship with the higher power, whatever they believe it is.” For her the initial experience of going to the priest for confession not only renewed her relationship with her faith, but has also given her a greater sense of peace with the prospect of dying. She shared, “I feel like I’ve got something to hang onto to keep me sane going through it somehow.”

As mentioned in the quote in the opening of this section, Kathleen has also developed a greater sense of gratitude for things in life that she otherwise may not have paid attention to. Our interview was conducted on her patio during a heat wave and midway through she shared:

I'm just looking at these trees, you know. . . I've never been much of a person for sitting outside, to be honest. And over the last few years I sit outside an awful lot more and I just really appreciate nature a lot more.

**Changes Within**

Kathleen shared that she does not believe that the loss of her breast has had a large impact on how she feels about herself. When reflecting on how the medical decision for a mastectomy affected her, she paused and stated:

I accepted that pretty quickly, that was not hard for me to accept. And it didn't affect the way I saw myself too much; that's not to say it wasn't hard. I mean having a shower, I'd
just cry my eyes out in the shower, but that was because of the whole thing, yeah. I mean I did miss my breast, that's for sure, but don't miss it now. It's fine, don't care.

Although she described losing part of her body as “horrible,” she went on to explain how in the morning she will put in her prosthesis, and look in the mirror to see if her “nipples line up,” and without much of a second thought, go about her day. While at the pool during her regular aqua fit classes, she does not make an effort to hide her mastectomy unless there are children around. She stated that she is not self-conscious about other women seeing her scars, and if anything she is okay for them to notice, “because every woman needs to be aware” of the reality of breast cancer.

The impression that Kathleen gave was not so much that the loss of her breast was inconsequential, but perhaps rather that her focus was more so on other changes that she was noticing about herself. She described:

I think I'm pretty confident now. I think maybe I'm a little bit more confident than I was before, maybe that's changed. I mean I was pretty confident but maybe more so. Then again I think it's a getting older thing. You don't take shit from people when you get older.

Age was something that Katherine referenced at different points throughout the interview. She reflected that her acceptance of the loss of her breast may be accounted for by her having been older, having breast fed her children, and not needing her breasts “in the same way.” She empathized with the stories she has heard of younger women whose husbands left them because they could not cope with their wives’ cancer. In the same breath she shared how she was fortunate for having had a “supportive family” and a husband who said, “it doesn’t matter, it doesn’t change who you are.”

The experience was not just impacted by her age, but also gave her a sense of feeling older. She shared that she perceives her younger friends as having more respect for her and
seeing her as wiser as a result of “having gone through breast cancer.” Kathleen also sees herself as more “experienced” and feels older as a result. The impact though, is one of appreciating what she now knows that she is capable of handling. Through the cancer, losing her brother during the chemotherapy, and then having had the detached retina, Kathleen feels “stronger” and believes that she can “deal with things better” than she could prior to her diagnosis. From the way Kathleen spoke, it appeared as though she is more aware of what she is capable of, as she knows that she “can deal with things now.”

The way in which Kathleen coped with the breast cancer diagnosis was also influenced by a diagnosis of facial melanoma years prior. When surgery could not initially remove all of the cancer, she realized that she “got to the point where I don't care what I look like as long as I'm still alive.” Also influential was her acceptance of the diagnosis. Although initially questioning why this was happening to her, she shared that ultimately:

I never had that why me thing at the time when I was diagnosed. I never really had that why me, why me, why me. ... it was more, well, why not me? ... I was quite accepting that I was one of the nine that was going to, every ... one in nine gets breast cancer at some point in their life. And I was just, oh, shit, it's me, you know? It wasn't, it was just oh, bloody hell, and it’s me, oh, drat.

However, despite her acceptance of the diagnosis and loss of her breast, and in light of the changes she has appreciated about herself since being diagnosed, Kathleen is still naturally greatly impacted by the entire experience. She described herself as being “aggressive” about doing what she can to minimize the risk of reoccurrence, this includes maintaining regular check-ups, continuing with her varying exercise activities, and watching her food intake to try to reduce her weight. She recalled a recent experience of going to the dentist and having x-rays taken. Wearing the heavy radiation vest, laying back in the chair in a vulnerable position, and sitting in the room alone while the pictures were taken, she experienced a moment of panic as
memories of her radiation treatments flooded back. She laughed as she explained that through her tears she had apologized to the dentist. She then paused and thoughtfully stated, “I suppose all of these things stay with you forever.”

**Maeve**

My sense of self has completely changed as well. I immediately I had more confidence . . . I used to worry a lot and right after I was diagnosed, I know I had one, maybe two bad sleeps but I started sleeping better. I stop worrying about a lot of the things I had been worrying about.

(Maeve: age 38 at diagnosis in Jan 2010, dating, no children, Caucasian, bilateral mastectomy and immediate reconstruction April 2010, hormone therapy until Dec 2011, chose to end it 3.5 yr premature, 3yr post diagnosis at time of interview)

Maeve noticed a lump in her breast 6 months prior to her diagnosis, and not thinking much of it figured that similar to other lumps she had previously, this one would come and go with her cycle. When the lump didn’t disappear, she saw her doctor and assumed that because the lump was not going away it would likely need to be removed. She recalled walking into her appointment and hearing her doctor state, “I guess you figured out by now that you have a small breast cancer.” Her reply was “no!” A biopsy confirmed a cancerous tumor in her left breast. Maeve had just turned 38. There was no family history of breast cancer. She found herself thinking, “How did that just happen, like how did I just become somebody with breast cancer?”

A mastectomy was recommended for her left breast, and a dimple on her right breast posed the question of whether a lumpectomy on that breast would be necessary. Maeve laughed as she shared, “when it came down to the decision I just kind of said take them both and get me a pair that match, and if you can make them pretty that would be great.” In retrospect, she reflected that she “didn’t know anything.” She figured, “I’m going to have a little bit of radiation and then we’re all going to move on and this is going to be wrapped up in about six weeks or a month.”
Instead, it was 2 ½ months after her diagnosis, on April 1st, 2010, that Maeve had a bilateral mastectomy and immediate reconstruction.

In describing who she is as a person, and what she believes defines her, she described herself now juxtaposed to who she was prior to her diagnosis. She shared, “I’m a social worker, I’m an educator, and I’m my dog’s caregiver. I’m an awesome auntie... I’m a dreamer.” The following sections are organized to reflect the themes that stood out as Maeve shared how the diagnosis of breast cancer has impacted how she experiences her sense of self.

**Earning the Cancer Badge**

And then they told me I didn’t have to do chemo and while I was relieved and felt like I could breathe again there was also another part of me that questioned how do you get your cancer patient identity without doing chemo?... It’s almost like I didn’t get my cancer badge because I didn’t do chemo.

Maeve was a part of a clinical trial that did DNA testing of her tumor and determined that chemotherapy was not necessary. She spoke about the tension she felt between her relief from not having to do chemotherapy, while feeling that without doing it, she wouldn’t be able to take the identity of cancer patient. In reflecting on what was contributing to her idea that she had to have chemotherapy to be seen as a cancer patient she shared that in part it was not having had cancer in her family. Only one friend of hers prior to her diagnosis had cancer, and that friend underwent chemotherapy. Maeve recalled, “I just thought that’s kind of what everybody did.” Until this time, in Maeve’s mind, cancer had been equated with chemotherapy.

Initially this gave Maeve the experience of thinking, “it was almost like I hadn’t suffered enough because I didn’t do chemo. Like, you know, losing both my breasts and my fertility and I actually lost my job in the course of it.” However, as she learned more about cancer treatment she realized that although her “cancer experience was different” than she had expected, she had still “suffered enough”, even if she did not have to do chemotherapy, and did not have to lose her
hair. She had earned her badge. She noted that this was still a challenge for her a year and a half after her diagnosis, when she moved from across the country. In her new hometown she would not have been part of the medical trial, and likely would have done chemotherapy. Meeting women in her new town who are her age and going through chemotherapy and losing their hair, she is reminded of her initial internal turmoil.

This also brought about awareness for Maeve that prior to her diagnosis she was always engaged in physical training, for example, training for marathons and triathlons, in order to prove that she could train for and complete such challenging physical feats. Now having had cancer she shared that she no longer feels that need to challenge herself. She shared, “things don’t get much harder” than cancer, and that she doesn’t “need to prove it to myself or anyone else that I’m strong and vulnerable.”

**Letting Go of Control and Letting Help In**

The whole letting go and being comfortable in the unknown. And that’s actually one thing I’ve carried with me and not worrying, I don’t worry nearly so much about the future or about things working out or not working out or if I’m doing the right thing.

When Maeve first met with her oncologist she came armed with a list of questions. She described herself as having tried to “project manage” her way through the treatment decisions. As she presented the doctor with all of her concerns regarding the side effects, for example osteoporosis, the doctor said, “your bones might be the last thing you need to worry about.” She reflected that 5 minutes into the appointment, “all of the questions were irrelevant.”

Through the experience of breast cancer Maeve also learned to “let go” and worry less. Shortly after being diagnosed she realized that the things that she had been worrying about prior “didn’t really seem to matter that much.” She also quickly recognized that she had to learn “how to ask for help and how to receive it,” particularly when she realized that there would be times
when she would not be able to do things for herself. Part of learning how to ask for help also meant learning to advocate for herself. She identified this when speaking about the “gaps in communication” between doctors, and reflected on how challenging it would be for someone whose first language was not English. Her newfound sense of advocacy proved helpful for her a year after her surgery when she moved across the country, and had to navigate herself through a new medical system.

**The Role of Teacher**

One of my natural skills is as a teacher. I took on the role of teacher. And so as I was learning things about the medical system or science or the crazy things they could do to my body to make this better I was teaching people about it.

Learning to let go of her worries allowed Maeve to free herself from concern about what other people may think of her and her decisions. In sharing this she reflected on a sense of “confidence that came with the breast cancer,” and stated, “I gained a purpose that also got me some credibility which was interesting.” Part of the credibility that Maeve spoke of was by becoming a teacher and helping others to better understand breast cancer. In doing this she shared:

I actually became quite public about it and that became part of my teaching role. To de-mystify it a little bit and I’ll show them the scars rather than, rather try to explain them and or have them not ask me and wonder.

**Giving People an Opportunity to Show Love: Changes in relationships**

It gave people the avenue to be nice and to tell me that they loved me in a way that they hadn’t had either an avenue or permission before. I don’t think people loved me any more or any less. I just think a door got opened where we had permission to do that now. And particularly people who weren’t my family, we could say I love you and it didn’t come out of left field. It was actually an appropriate thing to say and to express.

In reflecting on the changes she noted in her relationships, Maeve shared that people were more willing to emotionally express themselves toward her, and she was more expressive
herself, “much more willing to do the I love you’s.” Her growing openness in relationships was met with her increased self-confidence, and she became more “intentional” about her relationships, and who she would spend time with.

This aspect of change came into being as Maeve was coping with her diagnosis and subsequent surgeries. She noticed which of her friends were willing to “step up” and found that if people were not “adding” to her life, then she was less willing to put “energy into those relationships.” She was particularly tested by a few friends who did not necessarily agree with how she was coping with her diagnosis. She shared that her attitude toward them was, “if you’re upset about me go and deal with it, somewhere else, but I can’t take on dealing with you and my stuff right now.” Through these relationships Maeve learned how to set boundaries. Before she would have just “avoided” someone if they upset her, whereas now she is more willing to share why she is upset, and let go of unhealthy relationships. In making these changes, Maeve noticed that she is less bothered by “rejection,” from others, and that while it may still cause emotional “scars,” she feels better able to deal with them.

Familial relationships were also impacted by Maeve’s experience of breast cancer. She shared that a few months after her own diagnosis, her mom was subsequently diagnosed with breast cancer. Within two years of her diagnosis, her father became quite ill and passed away, and her sister-in-law also passed away due to mental illness. When reflecting on how her family coped during this time, she shared a sense that her family saw her “crisis was over, and we were now focused on my dad’s crisis and then my mom’s crisis. But the thing was my crisis wasn’t actually over. So we had some negotiating to do around that.”

The negotiating appeared to focus on her relationship with her mom, who wanted to see Maeve as “all better.” For a significant time her mother would not talk about Maeve’s cancer.
She remarked, “I think that was just part of the not knowing how to deal with it ongoingly. That it’s a permanent thing for me, I will always have had cancer.” She recalled her mom wanting to move beyond Maeve’s experience as she said things such as, “you’re feeling better, you’re feeling ok right?” as if somehow forgetting it would help it go away. In response Maeve found herself drawing on her newfound confidence and advocating for herself. She would respond to her mom, “its not over and that’s just the way it is. . . And I don’t know how we deal with it now.” Maeve shared that she thinks the weight she gained as a result of the steroids she had to take was what legitimized her experience for her mom and allowed her mom to be “empathetic because she could see it.”

April Fool’s Boobs

I suppose I am kind of disassociated from it in a lot of ways that it doesn’t necessarily represent me or represent my image of myself either before cancer or after. And that may come from weight issues, body image issues, a sense of pride in it in my body.

In her humorous way, she shared, “I always like to say that I got new boobs on April Fool’s Day.” However, in discussing her “new boobs” in a more serious manner, she shared, “my breasts are fairly de-sexualized to me just because they don’t feel the same, they don’t look the same, they don’t react the same.” While this has raised many thoughts for her, one that she spoke of was how her future relationships are also likely to be impacted by the breast cancer. She ponders, “when do you tell somebody; a) that you had cancer and b) that you had a double mastectomy?” This becomes more complicated for Maeve as her breasts don’t “play into” her own pleasure, as they would for a partner.

When first seeing her reconstructed breasts Maeve did not know what to expect. She shared,

Everyone seemed pretty pleased with it, the plastic surgeon was pleased and the general surgeon was pleased and my family doctor was pleased and my oncologist complimented
the work. I guess, I didn’t have an image of what they would look like after so I took on everyone else’s opinions. I guess they are good and that they turned out well given the circumstance.

Although she felt that the reconstruction had gone as well as could be expected, she felt frustration with the medical community for only focusing on her breasts. With every doctor she saw she expressed concern over the weight gain that the steroids were causing. Each attempt was met with an unempathic, “you know, that’s too bad, it’s a side effect.” Feeling that the medical community only saw her body as “parts,” Maeve finally made the decision for herself to quit taking the medication.

**Loving my Body Much More than Before**

And I also used to do marathons to prove that I could. And now that my body has done cancer I don’t have to prove anything. It just is, right? And I try to treat it much better than I used to and I try to love it much more than I used to.

Despite being initially “pissed off” at her body for getting cancer, Maeve’s focus shifted to feeling “proud” of her body for how well it healed. She tries to exercise grace with her body, taking care of it and respecting it more than she did before the diagnosis. She described the impact of her new found respect has that she has for her body, “I think about it daily and the choices I make every day now about what I eat or when I go to sleep or exercise or the people I spend time with it, all relates to the cancer.” For Maeve this has resulted in changes in how she eats, recognizing that she isn’t “invincible,” and therefore ensuring that she gets enough sleep.

Her love and appreciation of her body has not been without challenge. Looking in the mirror she finds that the image she sees is not what she pictured in her head at all. Even when she moves her body she finds that her breasts do not shift in the same manner as before.

Maeve was told that 6 to 8 weeks post-surgery she would be able to return to her yoga practice and swimming. She shared, “I was really excited about that because it was going to be
one of my milestones that I was better.” However, upon resuming her previous activities, she found that her body did not move the way it used to. In part this was because the stomach tissue used to create her breasts has changed her sensations and strength both in her chest and stomach. A particular yoga pose that highlighted this for her was her favorite one called “bow.” Before surgery, in this pose she would lay on her stomach, reach backward to grab her legs and rock back and forth on her stomach. While doing this she could feel the pulse of her stomach against the floor below. After surgery, she no longer has that sensation. She shared that losing that really made her sad. Within her sadness she found that she had to “re-learn [yoga] and find different comforts in it.”

An Attitude of Gratitude

But I did have cancer and then that just becomes part of the big great story of what my life is. And because I had cancer I’m more appreciative and I’m also more purposeful. I have a great life . . . otherwise it just would have been, you know, an ordinary life. . . I’m just happier. Yeah, I’m just happier.

Since being diagnosed, Maeve has found that she has a greater appreciation for the things that life has to offer, whether it’s “really good oatmeal for breakfast,” or her friendships and the opportunities that come her way. She described her life as “definitely more modest” than before her diagnosis, but shared that she is also the “most content” that she has ever been. Without the cancer her life would have been “ordinary,” but with the cancer she has an experience that people are “interested” in her and her life. During the interview she reflected that without the cancer, we would not have had the opportunity to meet and discuss her experiences, so even within that experience she found gratitude.

Redirecting Maternal Desires

I love watching how he just has no hang ups about anything. He’ll walk up to anybody and expect to be loved and if they don’t love him he moves on. And, you know, his feelings aren’t hurt, he just keeps going. And I kind of think that’s sometimes the way I
need to be. . . I don’t think I’ll ever be without a dog now. And he’s a huge, huge gift from the whole thing.

Due to her cancer medication, Maeve went into early menopause. She described this as a “big thing” for her, as she was still hoping to have children. The adjustment for her was, “how was I still going to be maternal and not have children?” Although she has since come out of menopause, she questions if her body at this point could handle having kids, and whether becoming a mother would still be the right thing for her.

Still left with a maternal desire, Maeve adopted a dog. Almost immediately after being diagnosed, she and her sister began looking for the perfect dog for her. Though initially the incentive was to give Maeve a reason to have to get out and exercise, she quickly found that she assumed “the identity of dog owner.” She reflected, “I’m always surprised at how much my dog comes up in these kinds of identity conversations.” Though a “huge part” of her “maternal energy” goes toward her dog, she has also taken on an integral role with her nephews, which was a huge impetus for her decision to move across the country, in order to be closer to family.

Tata to the Tatas Party: Humour and other ways of coping

So, I can make a lot of jokes about it. But yoga was one place where I didn’t make a joke out of it and . . . when you’re sitting in yoga and you just look inside or you just, you know, focus on your breath. And so I use that a lot. I remember using it when I had the MRI; I used it when I had a CAT scan. . . Just that focusing on my breath and closing my eyes and knowing how to do it and having it feel familiar because I’d practiced it already.

Maeve used humour to diffuse the situation and cope with her diagnosis. She recalled writing an email to her friends saying, “I wish I was telling you I was running away to join the circus . . . instead I’m telling you I have breast cancer.” She shared that in part she used the humour as a way to deflect and a way to avoid having to “deal with what’s real.” It was also a way of trying to control other people’s reaction. She shared, “if I laughed about it then they would laugh and I didn’t have to deal with how upset they were. I didn’t have to deal with them
feeling bad for me . . . I don’t have to deal with their fear.” The weekend before her surgery she had a big party. Calling it the “Tata to the Tatas party” she said she just wanted time with friends, and “good food, good booze and dancing in the living room.”

However, Maeve wasn’t always joking about her diagnosis. She described yoga as being one of the few places where she let herself cry. She believed that her experience of yoga prior to the diagnosis “served” her well because she could draw a sense of quiet that she had found within. “The quiet” she described as her ability to focus on her breath and be present to the moment. Within this she found “reserves of strength,” and also a place to connect with her emotions. Once she was healed from her surgery and able to return to her prior yoga practice, she found that, as previously described, her body did not move the same way, and did not have the same upper strength that she once had. Yoga then became a place where she could “mourn” the physical changes, and “even mourn the experience of yoga.”

Writing also served an important role for Maeve in “putting [her] life back together.” In describing this process she shared:

Writing was a way for me to explore my survivor identity in a way intentional way. Because it takes me longer to write than to talk, my written words have more thought behind them. Putting my story into written words somehow made it more real. My thoughts, when in paper were literally tangible. And because they were on paper I didn't have to hold them in my head, I was free to move onto other thoughts, without fear of losing older parts of my story. Because my story is written I can revisit it if I want and I am free to re-write it. Putting my life back together was a form of re-authoring my identity... the result at this point is a self, which I feel is more congruent then before I had cancer.

Her hope is to write a story about her experience at some point, for no other reason than for her to just have it. She shared that having the narrative from our interview, “is and will be a treasure on my 'cancer-journey' map.”
Cancer is not a Gift

I didn’t expect the putting my life back together after to be so hard. I thought I could just jump right back into my life and I couldn’t. I tried, I tried and tried and tried. But I couldn’t.

Since being diagnosed, Maeve moved back home to be near family, and shifted her career focus back toward what she had always wanted to do. Currently she is enrolled in a master of Social Work Program, and a PhD is on her “radar.” Jokingly she stated, “if I’m not having kids I’m going to have a whole lot of degrees,” and in the same breath, in a more serious tone she shared, “the priorities shift, you just find different ones.”

Maeve shared that she hates the “whole gift of cancer thing because it’s not a gift I would give anybody.” However, in the time that she has spent reflecting on “why” she got cancer, she has identified that perhaps it was to “slow” her down, and teach her to appreciate things more. These things she identified as including her life, her relationships, and the “stuff” she gets to do more, including being a “social worker”, an “educator”, “Bradley [her dog’s] caregiver”, an “awesome auntie,” and a “dreamer.”

Though not a gift, the mark that cancer has left in her life is indelible. She shared:

I’m getting further from it, but I still won’t say that it is in the past. I wouldn’t say it’s in the past yet. . . It’ll never be in the past because I’ll always be somebody who had cancer and I’ll always be somebody who doesn’t have breasts and someone who has a scar on my stomach and needs to go to bed early and eat well and general take exceptional care of myself. I am motivated but with the knowledge that I am not invincible.

Nine

I asked my husband this morning and he said I'll send you some stuff when I get to the office this morning. And then he was like I don't think I can, I think I'm too close to it. . . he thinks I'm the same. And I was like really? Think of the Nine before and the Nine now but like that's him, and he'll love me whatever. But I know I'm different, I'll never feel...the same...about myself, as a woman, ever, because the reconstruction they'll salvage some stuff, but I'll never have a spectacular chest. And as a woman, that's a huge thing.
Nine, Afrikaans for Nina, was 37 years old in March of 2010 when she noticed a lump in her left breast. She is married and the mother of three young boys under the age of twelve. Reassured by the doctor that it was just fibrous, it wasn’t until November of that year that she again went to her doctor with her concerns, insisting that “something was not right.” By this point her cancer was quite advanced, and in December she was diagnosed with Grade III breast cancer, which she stated was the most aggressive and common in younger women.

Although she had been aware of a history of breast cancer in her family, she had never envisioned it could happen to her. As a wife and mother of three young boys she found herself thinking that this couldn’t be happening to her. Christmas plans were already booked and so the family went on their ski holiday and upon returning she started chemotherapy.

Treatment started with eight rounds of chemotherapy and was followed by a mastectomy and immediate reconstruction, which she described as rare in her city due to the high rate of infection. She shared that as she and her physician discussed the mastectomy, she knew she had to have the immediate reconstruction because she did not want to wake up and see herself with only one breast. Although the weeks leading up to the surgery were difficult, she recalled feeling that the process was not as bad as she had anticipated, and that ultimately she was quite pleased with the result of the reconstruction. By the fall of 2011 Nine began radiation and after 5 weeks it became too much for her skin, and resulted in a third degree burn and staph infection. Nine became quite sick and due to the infection, her reconstructed breast had to be removed. She awoke from the surgery devastated, and “exactly where [she] hadn’t wanted to be”. Initially getting fitted for the prosthesis was a stressful experience, but over time she found that she did
not even think about it as she dresses each morning. In part she thinks some of this acceptance may have stemmed from knowing that she would be having a second reconstructive surgery. Despite her growing comfort with her mastectomy scar and prosthesis, it wasn’t until February of 2012 that at her husband’s insistence, she let him see her scar. At the time of the interview Nine had just received a “green light” on her scans indicating that she was cancer free and would undergo her second reconstructive surgery in the late summer or early fall of 2012.

When asked how she would define herself she stated that she is a mom first, then a wife, friend, and an active woman. She resolutely stated that she is still all of those things, and then went on to share that although she is definitely not who she was before the cancer and that it is harder for her to describe who she is now. The sections below are organized into themes of how the different areas of her life were impacted by, and had an impact on, her experience of breast cancer.

Family and Striving for Normalcy

A theme that became quite evident early on in the interview was the sense of normalcy Nine strove to maintain for her family, despite the challenges she was facing. Once her diagnosis was confirmed, she recalled her husband and her telling their three young boys (aged 9, 7, and 3 at the time) about her diagnosis, and an hour later the family was out the door to another hockey game or practice. She described this as the best way for them to handle her diagnosis, and how imperative it was that the boys be impacted as little as possible.

Until receiving the positive news of her clean scans, Nine felt extra pressure to enjoy every minute with her boys, fearful that she may not have much time left to be alive with them. She described that on their family holiday a few months ago she found herself engaging in activities with the boys that she would otherwise not have done. She became animated as she
shared that since receiving the scans she continues to do more things with her boys, but now with less of a pressured feeling, and more so out of desire.

Part of what motivated Nine to maintain the normalcy within the home was having watched her mother-in-law go through chemotherapy and pass away from cancer, which she described as awful. For Nine it was really important to maintain her physical appearance as best as she could to spare her husband from having to watch her be affected by the cancer as his mother had been.

Maintaining normalcy also meant forcing herself to get out of bed on the mornings that the chemotherapy was wearing her down. She needed to pack her sons’ lunches and see them off to school. She reflected that in retrospect, her efforts to maintain her routine were likely beneficial for her. She shared, “if I had stayed home, and in my misery, I would have not been in a very good place.”

Although Nine described herself as someone for whom it is important to do things on her own, she could feel the chemotherapy wearing her down. As neighbours dropped off meals and offered to help her with the kids, she found herself more willing to accept their help. She described that her husband had seen accepting the help from others as pity, and she shared that it took a while but she was finally able to help him to see that she needed the help and wasn’t able to do all of the things for the family that she used to be able to do. It was during this time that she noticed her willingness to receive help, and realized that even if she could do things on her own, she did not necessarily have to. Upon beginning to physically feel better, she also recognized a growing willingness to help others. She shared that before the diagnosis she would have been so caught up in her own schedule that she would not have thought to offer to help friends. Upon
reflecting on this she indicated that this change came about not only by wanting to give back what she had received, but also by a sense of feeling less dictated by her own schedule.

Despite her efforts to maintain normalcy, she recognized that much had changed. She hesitated and said that she is not the same person as she used to be, despite believing that her family will always think of her as the same person. In saying this, she almost scoffed and quickly acknowledged that to herself, she is “totally not the same.”

Social Self

Nine described herself as living in an affluent suburb of a metropolitan city, where pressure to ‘keep up with the Jones’” is the norm. Unaware of how much her husband had disclosure to others about her health condition, and how much others in their community knew, Nine found herself feeling increased pressure to “look good” in public. She was particularly concerned with not wanting to look tired. When going for runs through her neighbourhood, while waiting for her second reconstructive surgery, she felt self-conscious of her chest, and struggled to find appropriate clothing that would hide her missing breast. Her husband in an effort to support her said “Who cares?” – but to Nine this was not comforting, as she cared.

Friends also made efforts to console her. She shared an example of her best friend speaking about her own breasts and stating “mine are all saggy and I wouldn’t care”, implying to Nine that perhaps losing her breast was a good thing. She further indicated that while Nine had the one breast removed and redone, why not have had the other one too? For Nine again this was not helpful, sharing that she does not think any woman can really understand the experienced until they go through it themselves.
**Physical Self**

To Nine losing her hair at the time of chemotherapy was initially the “biggest thing,” in retrospect she reflected that having gone through both of her subsequent surgeries and the necessity of multiple upcoming surgeries, she confidently stated that losing her hair was in fact nothing.

During her chemotherapy she wore wigs of different styles, lengths, colors, and cuts and would have to make conscious efforts to remember which wig she had worn to which son’s hockey game, so as to not confuse people or alert them as to her diagnosis. She recalled running into a fellow hockey mom at a grocery store, where the other woman was caught off guard by seeing Nine with a radically different hair style and color.

Even away from the neighbourhood and hockey games where she strove to maintain her pre-diagnosis physical self, she still felt self-conscious while away on holiday. Recently while in Hawaii she found herself faced with a greater awareness of how she looked in a bathing suit, worried about whether people could tell if she was wearing a prosthesis, and if it was sufficiently covered by her swimwear.

Along with the physical changes, Nine also felt challenged by the loss of physical strength. She lamented that just prior to her second surgery she had been doing bootcamp classes; however, upon returning from surgery she was disheartened to find herself starting back at the beginning despite the gains she had made.

After the removal of her reconstructed breast, Nine shielded her chest from her husband for four months, describing herself as ‘creeped’ out by the scars, and needing time in order for her to be ready for him to see it. Although she was unable to articulate how or why she became
ready for him to see it, she seemed to better know why she hadn’t been ready, sharing that somehow time allowed her to accept it.

Challenged by trying to wear something sexy for her husband, she found herself in a mess of tears. “So much of what defines a woman I’ve lost” Nine thoughtfully shared. “I'll never feel sexy like attractive or you know anything remotely like that,” she said as she described how her scars and prosthesis limit the lingerie she can wear. Her husband she said, does not seem to understand, as he was more focused on function and having Nine do whatever needed to be done to ensure that she could be there as his wife and mother for their children. In sharing this Nine reflected that perhaps her husband’s lack of understanding and apparent indifference to the changes in her physical body was good for her, as she felt she would have been devastated if he had been repulsed. Although she still finds herself struggling with some of these issues, she shared that “it’s getting easier to spin around and come back out of it.”

When initially discussing the options with her surgeon, Nine stated, “when we talked about the mastectomy, I just knew in my head I had to have the reconstruction. I didn't want to wake up and not have anything.” However, a year and a half later, having been through the chemotherapy, radiation, and subsequent loss of her reconstructed breast, Nine found herself reflecting:

I don't even care about the reconstruction. I don't even care if I get another breast because I'm more worried about is it in my liver, is it in my bones, why does my stomach hurt? That was when I was like wow I must have just totally accepted living with this prosthesis and if I had to spend the next year with that, then that was my reality. So it wasn't until I think around that time that I had accepted what had happened with the infection and accepted that this is who I am for now.

This was a rather big shift for Nine and she shared that she felt that she really could not reflect back on the experience until she was given the clean scans last month. Since then she shared, “now all I think about is last year and how I've changed, and how things are different now.”
Part of what Nine found helpful in this process was her focus on keeping as active as she could, maintaining her running throughout, and starting yoga during her chemotherapy. In both activities she found that she could “block everything out and focus on the breathing…my mind is not really where it usually is, it’s just sort of empty.” She was animated as she shared that yoga gave her peace, “for an hour and a half, I don’t have breast cancer.”

Nine’s baths also offered reprieve from the cancer. Although she referred to them as her “awful place” during chemotherapy, she found that she could use her bath time to cry, think about how difficult things were, and ultimately leave those negative feelings and worries there as she got out of the tub and focused on the upcoming weekend, or whatever else was going on at the time.

**Self as a Cancer Patient**

Although Nine didn’t explicitly define herself as a cancer patient, throughout the interview she described what it was like for her to be a patient receiving cancer therapy. She shared that the chemotherapy brought darkness in waves and during those periods she would remind herself that tomorrow she would feel better. In this she found that maintaining a focus on knowing that the chemo would eventually end helped her to get through it.

Earlier in her treatment Nine attempted to join a support group but found that she could not relate to the rest of the women as they are 30 years older than her on average. She recalled the first meeting when a nutritionist made her feel like she had “eaten her way to cancer.” She vowed never to go back to that group but recently joined a different group that she feels would have benefited her at the earlier stages of her treatment. She laughed as she described almost feeling guilty about attending now that she has received her clean scans and is feeling stronger about things, as many of the women are really struggling in the earlier stages of their treatment.
Nine opted to be a part of a clinical trial through the cancer centre, and often has to fill out forms to comment on her symptoms. She laughed as she recalled having to answer a question about her current level of pain as the only pain she felt was in her thighs from an intense exercise class the previous day. When she shared this with the nurse the nurse also laughed and said “I don’t think we have a form for that.”

In the past few months Nine has started receiving counselling at the local cancer centre, at the suggestion of her surgeon who saw her struggling to let herself look at the surgical site where her reconstructed breast had been removed. Through counselling, Nine came to call her experiences of running, yoga, and being in the bath as ‘being in the moment’, and she stated:

I think I would have had to do that, if I hadn’t I would have had to go on an antidepressant or something for sure because I think just as a person, you can’t deal with all of that stuff in your mind and not have some sort of a release solace or a pill.

Counselling also helped her acknowledge the changes she is experiencing, for example allowing herself to feel her feelings without getting ‘stuck’ on them.

Several times throughout the interview she described feeling that it had been time that had helped her to gain perspective on things, stating “it’s something you have to go through in your head. It didn’t matter what people told me.” In addition to time, the recent news of her clean scans has also helped her to come to a greater place of acceptance. She described:

It's better now, but I'm in a different phase than I was in last year, …those scans were a big deal, … and it's not like, like I'm cancer free now, but I'm by no means cured. It's not like it cannot come back, so I have a greater sense of peace, and when I leave yoga now, it stays longer.

When asked what seemed to stand out as significant in her process, Nine stated that in addition to the physical changes, she has a loss of naivety or carefreeness, in that she feels less confident planning for the future. This loss has also allowed her to better appreciate the present moment. She described this as also being a “process of acceptance in who I am now.”
Ruby Tuesday

After cancer came
I went on a pilgrimage
and got my life back

I love my life now
more than before this disease
got me back on track

I am free of fear
and I am free of anger
and I forgive all

My life is better
and will never be the same
as it was before

~Ruby~

(Ruby: age 47 at diagnosis in Aug 2009, single, no children, Caucasian, lumpectomy in August 2011, continues with alternative treatments to present, 3.5yr post diagnosis at time of interview)

For years Ruby’s psychic had told her she would find a lump in her left breast, and while it would cause her concern, it would be nothing to worry about. Occasionally she would check only her left breast, and in August of 2009, at the age of 47, she found a lump. She recalled feeling frustrated by the whole diagnostic process as her doctor was out of town and it was up to her to coordinate her own care and appointments. Her results were delivered in what felt to her like a very dismissive and nonchalant manner, as the doctor said, “Oh well, I guess you know already that it’s cancer.” Ruby was angry and in a 3 day novel contest she unleashed her emotions in a book titled, Calling all Angels. “I got all of my emotions out because I was mad and all kinds of emotions were coming up that I was not sure what to do with.” Ruby was then scheduled to meet with a surgeon whom she referred to as, “Dr. Death,” who was yet another cold professional. When her own doctor returned, Ruby met with a second surgeon whom she felt was much more compassionate and willing to hear which route of treatment she wanted to
take. Together they created a plan and a lumpectomy was booked, and then Ruby left town. She emailed her surgeon and said, ‘I am in Costa Rica. I won’t be back for six months. I am not coming for surgery’ . . . and I didn’t.”

From the beginning it was important for Ruby to do things in her own way. She had seen her mom go through breast cancer, and ultimately pass away 5 years ago from a secondary cancer, and she vowed that unlike her mother, she would not go the Western treatment route. In describing her choice to try alternate approaches to Western medicine, she stated:

I was mad at the system and the way that I was treated. It is just part of my personality - I wanted to prove it can be done – that you can recover by using alternative approaches. So that was what I’d hoped to do.

It was also important for Ruby that people respect her choice, and those that couldn’t she stopped communicating with. For her it was important to be seen as being well.

I didn’t want to be associated with cancer, the disease or with my mother’s illness. I didn’t want people going up to my father and saying, “Oh, is Ruby okay?” Or get that look that overly sympathetic look people can give you, “Are you alright?” Just treat me normal, I am alive, I am doing things, I am existing. I didn’t want to be put into this ‘C’ category or to be treated different.

As a result, she told very few people, stating, “I know people’s perception of cancer and I didn’t want that associated with me.”

In Costa Rica, Ruby found that the diagnosis made her question herself. “It was not that I was going to die, it just made me rethink what is important to me? Where do I want to be? What is valid? What am I doing here?” She described herself as always having been productive and creative, but now with more of a focus. “I feel more centered. I feel I understand my mission in life. I am on my path.” Themes that stood out as Ruby described herself since being diagnosed were an increased sense of being centred and connected, feeling more focused, and maintaining balance, each of which will be discussed in turn below.
Finding Centre and Creating Connection

It got me back on track and it made me even more centered. I was spiritual before. I was fit and I was eating really well. I am still doing all of those things but on a higher level and also with clarity and with more purpose. So that is the main part of the change for me.

Part of what helped Ruby to feel more centered within herself was her realization that she had been using coffee and wine to self-regulate, in a way that she described as similar to the drug use of women in the downtown East Side of Vancouver. She had been working on a documentary with these women, and was passionate about her work. She would start her day with a coffee, which she stated, “makes me almost aggressive and really wired and I get a lot done, so it is like a cocaine high for the downtown East Side women. Then heroin brings them down, so at night it was like my wine.”

In Costa Rica she learned a specific meditation practice and came to realize that when she drank wine it would take her days afterward to be able to “get that connection, that tapping into…I don’t like to use the word ‘God’ that much because who is God to whoever? But to whatever higher power, spirit, whatever is out there.” When she abstained from drinking she also found that she was able to tap into a psychic power that she recognized she had since childhood, but that she had not focused on using.

She described that the greater sense of connection she discovered by keeping her body and mind clear of toxins, through choosing raw foods, and avoiding caffeine and alcohol was a good shift for her. This year on her 50th birthday she decided, “no more drinking. I have spent enough of my life, over half of my life drinking and being numb, so let’s at least give myself the other half or at least have some years of clarity.”

Ruby also found clarity through her meditation practice which helped her to connect with her spirit guides and receive “divine information and knowledge,” as well as the realization that
things will happen, “if you allow them to unfold naturally.” This awareness allowed her to be more open to change and to trust that things happen for a reason and trust the synchronicity. “So I am very aware of that and I have used that a lot through this process of healing to make sure the right people come to me and they do.”

Examples of the right people coming to her include when she met someone who introduced her to German New Medicine, which links the cause of disease to an unhealed emotional trauma, as well as coming across a shamanic healer who connected her cancer to love and her relationship with her mother. Ruby became aware of the emotional trauma of the loss of her mom to cancer a few years prior. Meditating in a cave in India one evening, she found herself connecting with her mom’s spirit, and through this realized that she had to forgive her mom, truly forgive her, and release her emotions around her mom and the lack of nurturing that she felt from their relationship.

Ruby described an experience with a kinesiologist in Costa Rica, whom she referred to as a witch doctor, and who through their work together, facilitated Ruby in gaining the clarity she needed to recognize her life purpose. “Through the different modalities like meditating and putting the pieces together, and also being open to receive the information, it became clear.”

**Finding Focus and Connecting with Purpose**

I am doing what I am asked to do. I am here, I know my mission. So I am doing things in life that help that happen, being focused on them rather than not being focused or being caught up in the past or the future.

Ruby shared that she discovered two missions in her life, for which she “had a vague idea before but now it is not just knowing, it is doing.” The *doing* of her mission comes with new issues. She described:

There is almost a sense of urgency for it, perhaps partly because I just turned 50 this year, so I am thinking, “okay, there are certain things I want to get done and let’s do them”. So
I have had this extra sense of urgency but yet I don’t want that. I want to do things peacefully and mindfully and yet I am still a Capricorn and very goal oriented.

The mission that Ruby discussed was a desire to get to a place of ascension, enlightenment, and an overall sense of striving “for more than just living.” The urgency that she felt stemmed from a prior belief that “I had lots of time to do what I needed to do and now I realize that you don’t always. So that is different”. Prior to her diagnosis she shared that she “wasn’t so focused on [her] mission before and completing it.”

Ruby’s change in focus and purpose has reformed her perspective about her career as well. She described herself prior to the diagnosis as drawn to the “macabre and the underground world.” She had immersed herself in creating a documentary on life on the downtown East Side, and stated, “I just wanted to understand what that existence was about.” Looking back now she reflected:

I wasn’t necessarily on the right path when I was doing those projects. At the same time they are all good. I learned from all of them but it is one thing doing a project to do a project, it is another to do it from a place of your mission and to help people and doing it from a place of love and from your heart and with good intentions. I believe I did this to some degree yet my approach with all my projects now is with this sense of passion for the project and I consider how it can help others as well as myself in the greater picture.

The shift in her from wanting to do a project from “a place of love,” was affirmed when a friend recently lent her a book called *Beast*, and she realized, “I just don’t want this in my life right now.” Instead, she found herself now drawn to things that make her feel good, and she ensures that she laughs every day.

Ruby’s recognition of her purpose and urgency has made her more mindful to not “waste time.” These things have also impacted her on a relational level, as she shared, “I don’t have light conversations. I don’t do light chit-chat with people. It bores me and it doesn’t do anything for me . . . it is not worth my time to waste on fluff.” Relationships also shifted as she set
boundaries with people who did not support her, and chose to surround herself by positivity, even asking her father to be more positive. When her good friend found out about her diagnosis and began to worry, Ruby shared that she “had to train her; I had to teach her how to treat me and to treat herself, because worrying is not good for anyone’s health, mine or hers.”

Choosing the Lumpectomy

In India this woman who was a medium . . . said this really cool line that always stuck with me, she said, “surrender isn’t giving up, it is giving in.” That made sense to me. I didn’t want to feel like I was giving up on the idea that I could do it on my own and I wanted to prove that to my doctor too, I want to show that it can be done and I know it can be done.

After 6 months in Costa Rica, Ruby returned to Canada for a short time before heading to India for 6 months, and then on to Malaysia for 2 months, and Thailand for 3 months. In each country she continually sought out alternate healing modalities until excruciating sciatic pain and the warmer weather of Canadian summer drew her home.

Despite her terrible pain, she recalled a sense of relief that she was no longer focusing on cancer, but rather the intensity of her discomfort. She scheduled to see her doctor for the first time in 2 years and they conducted several diagnostics and ruled out the possibility that the pain was a sign of the cancer having spread. However, despite her best efforts, the lump in her left breast had grown. Interestingly, although the lump was larger, it was not as large as would have been expected given the time that had passed since diagnosis. Her surgeon commented, “you are doing something right because normally the tumour doubles in size every three months, and she said, yours hasn’t.” For Ruby this was a validation of her decision to have gone the alternate route.

At this point, however; a lumpectomy was again put on the table as the best route to go. Before Ruby relented, she stated that she “took charge of everything” and researched aspects of
the surgery, negotiating with her surgeon about where the scars would be, and even speaking to
the anaesthesiologist to choose the anaesthetic. “Once I decided to do the lumpectomy I just put
my head around it and I thought; let’s visualize it going perfect and it went really well.” Ruby
experienced a shift from stating that she wanted “all of my body parts that I was born with”, to
realizing that “I like my body so I am comfortable in my body so it’s . . . it is pretty minor. I
think; so what? I have a scar and one breast is different than the other. My body is still intact.”

As soon as she awoke from the surgery she recalled feeling pushed by the attending
professional trying to convince her to take pain killers that would ease the pain and also make
her sleepy. Ruby adamantly refused and chose a cold pack that her surgeon suggested instead
and within hours she and a friend were out shopping together. She shared that she found the
process much easier than anticipated, particularly when she reflected back on her mother’s
experience of breast cancer, mastectomy, and chemotherapy.

Although Ruby realizes that her breasts are no longer symmetrical, she shared that it is
“ok”. “I am not concerned with cosmetics. I could change things if I wanted to but it doesn’t
matter too much to me.” Instead, she sees her scars as “cool because they are a story. They are an
atlas; they are part of your map. So this is part of my map now.”

*Maintaining Balance, Taking Control, and Putting Self-Learning into Practice*

It doesn’t have to be a tough road. I love my life. I love where I am at. I love that I know
what I am doing here. I feel well. I have great friends and it doesn’t have to take such a
big part of you - the disease. It doesn’t have to take so much of your spirit.

Pervasive throughout Ruby’s story was a strong belief that she could be well. She stated
this clearly when she said, “I believe that you can get rid of cancer without doing it the Western
way. I know you can.” Her journey brought her to many different healing modalities including a
kineasiologist, shamen, Ayurvedic doctors, an indigenous bush doctor, cranial sacral massage,
ozone therapy, vitamin C intravenous, and different dietary approaches. An integral part of her continued healing included starting each day with meditation, yoga, and yogic breathing. “It gives me peace and it gives me balance. If I don’t do it I feel out of. It keeps me balanced and I deal with whatever comes up in an easier manner.”

Although she had initially been very angry at her diagnosis, she shared that now “I don’t let things bother me as much or I don’t get so angry because it is just a waste of energy.” Reflecting on changes in her emotions she shared:

I am softer than I used to be. I was pretty hard . . . I think I don’t come across so edgy as I used to. I allow myself to show emotions more . . . to love people more easily and to express it.

These changes require ongoing balance for Ruby, particularly as she experiences personal change on her long sabbaticals away from family, but upon returning her family expects her to be the way she was before leaving. “I am different and they try to almost bring me back to where I was. I am not there anymore and I don’t live in the past.”

Another thing that Ruby recognizes is that her thoughts of cancer have somewhat lessened. “It took so much of my mind space which could have been used for better things. The more you focus on something the bigger it gets. So if you are going to focus, focus on being well, on healing.” This recognition, however; is met with the very real possibility of the cancer returning. She recalled one of the few times when she attended a breast cancer support group and a woman who had been cancer free for 10 years was fearful of her upcoming mammogram. She shared; “I look forward to being free of the thoughts around it though it is still a conscious thing.”

Ruby’s friend was diagnosed with cancer two weeks before her. Her immediate thought was if it had been her who was diagnosed, she would research and find out what her options
were, and that is something that she did and continues to do. She started a website where she posted the information she had found through research and her own experiences. Her posts and personal writing have also been instrumental in her journey. “My writing is therapeutic. It is a way for me to express my emotions and thoughts and to process them. It is also a way for me to communicate to others.”

With a history of conducting research for her work, she feels compelled to share what she has learned with other women who are on a similar journey. Her commitment to sharing her experiences has created a feeling that she needs “to be well, to be proof that healing from a disease is a mind, body, spirit connection not just dealing with the disease of the body.

The few breast cancer support groups that she attended served as an impetus to want to share about the methods, diet and supplements she had researched and incorporated into her life. In the group she had been disheartened by the ways in which “so many women were doing exactly what their Western doctors told them.” Ruby wanted her website and Facebook page to “help and inspire others to create a mind body spirit balance on their path to wellness.”

In describing how her “journey” has impacted her, she shared that it has, “helped me feel empowered with knowledge and understanding of how to maintain my well being . . . We have an idea of how our life will unfold yet life may have other plans for us.” Upon reflection she shared that her purpose has become more important to her than her goals, and that she is “more open to things unfolding rather than making them happen.”

Ruby also shared that her experience dealing with cancer “gave me permission to do whatever I want,” and by doing what she wanted, she was able to travel to places she had always wanted to go, and met different healers and have experiences that have helped her connect with her sense of purpose. She shared that even before being diagnosed, she had never had a fear of
dying, but rather a sense that, “I want to make sure that I do what I need to do before I die. I now focus on my purpose in life rather than my goals. These are some of the things that have changed for me.”

It is interesting what brings us back to our path. In a way a dis-ease can be a blessing if it gets us back on track and back to re-member our mission on earth. So for this I am grateful because my mission has been re-presented to me.

The ultimate gift really.

~Ruby~

**Sharon**

The sense of self, for me is the body, mind, spirit and emotions. And what it, what the diagnosis did, and the whole healing experience, what it did was it defined each of those more so within me, so looking back, it wasn’t at the time, but looking back, it was a good thing.

(Sharon: age 43 at diagnosis, divorced, no children, Caucasian, lumpectomy, alternative treatment ended Dec 2005, 7.5yr post diagnosis at time of interview)

Sharon was diagnosed with stage II breast cancer in her right breast when she was 43 years old. Two years previous she had found a tiny lump the size of a pea in her breast. At the time she was told by her doctor that it was likely a cyst. Given the option to aspirate it, Sharon chose not to, and over the next two years became aware of it growing larger. Upon speaking to her female naturopath, she was advised to seek a second opinion. Her diagnosis was confirmed
after an ultrasound, mammogram, and needle biopsy. At this point the cancer had also spread to her lymph nodes.

When Sharon reflected on who she was prior to being diagnosed she shared that she believes she held a lot of suppressed anger from her childhood, and was “half-heartedly living my life…just merely existing in it,” essentially, “just going with the flow.” She described this as moving through her life without fully participating in it, or being the person who she now realizes herself to be. For her, life based on what she thought she should do, rather than what she actually wanted to do. She stated that she was repressing her emotions and “shutting down little parts of myself.” For example, she was working at a job that she didn’t like, that required her to engage with the public in a way that didn’t always allow her to say the things that she felt needed to be said. She was also in a long-term marriage that had “no real relationship to it.” In retrospect, she now feels that when she was shutting down her emotions, she was also shutting down her immune system, and her entire body.

Reflecting on her process, she found it difficult to describe as she struggled to find the words to explain it. However, what was clear to her was knowing that her life has “drastically” changed since her diagnosis. She described a shift that took place within her very early in the process. Her lumpectomy was scheduled one week after her diagnosis and she recalled not having much time to do anything or ask anyone any questions beforehand. However, after the surgery she took some time to look for healing modalities as alternatives to chemotherapy. In her first appointment with her oncologist she recalled struggling to get answers to her questions, and feeling as though she was being “pushed” to do chemotherapy. She described a strong feeling “of what felt right, and what felt wrong, and that felt wrong. So I started really early on to listen to that, and that grew stronger as I went through the experience.” For Sharon this initiated a process
of what she described as “establishing” a sense of self, which she suggested includes a willingness to be different than the norm. She defined her self, as body, mind, emotions, and spirit, each of which became more distinct, and yet integrated as a whole, throughout her process. Each of the four components will be discussed in turn below in regard to how she perceives each as having contributed to her healing.

**Bringing the Body Back to Balance**

So there were a lot of things that I needed to address, as well as finding a way to heal, or finding ways to bringing the body back or the being back to balance. And I didn’t know how. And I began and I learned how as I went through it. So my sense of self…was anchored I think during the process of the healing.

Sharon’s first interaction with her oncologist confirmed to her that she did not want to go the traditional Western medicine route of chemotherapy and radiation following her lumpectomy. Instead, she sought out alternate healing at an integrated health clinic. During this time she “craved” for someone to talk to who was doing the same treatment as her, and so she sought the support of local breast cancer groups. However, in the groups, she felt herself silenced and:

being shut down in front of the group…I thought it was a *breast cancer support group*, but it wasn’t….I realized much later…it was not a breast cancer support group; it was a chemotherapy support group. And I went ohhh why didn’t they tell me that then?

Despite feeling disconnected from the group due to her treatment choices, and her dismay that she thought the groups were for “supporting someone through what they call breast cancer,” she shared that she continued to attend “once in a while to kind of show them that I was still alive. It seemed the belief at that time, anyone not doing mainstream treatments, didn't survive.

**Quieting the Mind and Releasing Emotion**

The mind had a tendency to rule, but it’s only one of four equal parts the mind needed to take its place, it’s one of *four* components shall we say, it’s the mind, the body, spirit and emotions. Equal parts.
Prior to her diagnosis, she described her mind as the ‘ruler’ dictating her decisions and path in life. At times when she had thought about quitting her job, “the mind would say, we’ve got a mortgage to pay, we have to do this, what else are we going to do, we’re here now, just do it, just shut up and do it.” In her mind she also described recalling her mother’s words: “my mom’s words would come to my mind saying you made your bed now lie in it and I was like ok, well, I guess I’m doing this then for the rest of my life.”

She described a process of channeling, or automatic writing, which she explained, is different than regular writing where “the dominant hand is used to write your mind’s ideas.” In automatic writing, the non-dominant hand is used and she shared, “if I sit in a meditative state for a few moments or for a little while then words come through and they aren’t coming directly from my mind.” She shared that words would come to her and she “would have to often look up the word in the dictionary, and it was amazing the perfectness of the messages.” However, before being able to receive such messages, she said, “the mind had to be quieted. I would do a little writing, writing with my opposite hand and then I would read it and it was amazing and then a second later the mind would kick in and say 'oh brother you just made it up'. And this was constant throughout it. It wasn’t all this feeling of bliss throughout my period of healing. It was these battles.”

Part of what Sharon also battled was a tendency toward depression and negative thinking. She described that to tackle this she needed to “change her mind.” However, first, she needed “the mind” to be “willing to believe that it could.” Maintaining a focus of “moving forward in life,” and to cope with the inner battles of her mind, she absorbed herself in positive CDs, books, and courses.
Through the automatic writing she learned that she had to release the emotions from her past, but first she needed to learn how. Upon completing her healing protocols, which she described as intravenous vitamin C and herbs, she took training in how to release suppressed emotions. She became animated as she shared that this training helped her to realize all the emotions that she had pent up, which then became her focus, and ultimately created a shift in her career as she went to become trained as a practitioner in emotional release. Ultimately she learned to use her emotions as a guide, as opposed to previously shutting them down because as she stated, “no one wants to get anyone angry.”

The Dark Night of the Soul

Most people don’t want to go through it, but when you do; it’s amazing what happens after. It’s kind of like how I described writing about it, kind of like going to the place where your soul lives.

During her healing process Sharon experienced a dark period where for three days she did not leave her room. Sitting alone with her thoughts, she found herself in a deeply reflective and meditative state until days later when she said, “I woke up feeling happy….first time ever. That was always my goal in life, to be happy, to find happiness…and I found it.” In this dark place she had learned to connect with her inner self and by doing so, strengthened it by actually paying attention to it, and as she said, “the more we use it the stronger it gets. It’s like a muscle.”

Sharon was somewhat hesitant as she shared that learning to sit in a meditative state allowed her to connect with her “angels and guides.” Part of her concern in sharing this piece of her experience is the awareness that others may see it as “far-fetched.” However, out of self-protection, she chose to share it with people whom she knows will understand and appreciate this piece of her experience.
Prior to her diagnosis she had known about spiritual resources, but “did not know how to connect with them personally, until her experience of cancer.” These resources have now become a source of strength for her and through this process she learned how to recognize her emotions, and acknowledge them, without necessarily staying in them. Instead, she finds that she can use the emotion as a sign of something that needs to be released, so that she does not get bogged down or find herself “rehashing the past.”

**Authenticity**

It’s like there is no real old you and new you. It’s just like some of the stuff that’s not needed has fallen away and the basic core of the person is just more clear and authentic.

Although Sharon stated that she did not have a strong sense of her self both before and after the diagnosis, she had a sense that some of the “stuff” that was not needed within her self, had “fallen away” and was taking a less central role in her life. Some of the “stuff” included thoughts and emotions that she can recognized as unhelpful or unhealthy, and as a result of this process, more readily released herself from getting caught up within them. Sharon likened the process of becoming a more “clear and authentic” person to the process of learning a new language where you may find yourself suddenly speaking it, without a full appreciation for all of the individual words you had to learn along the way.

Other changes that Sharon has noted include less willingness to participate in idle chit-chat just for the sake of filling time, and more patience with daily annoyances, such as people talking loudly on their cell phones in small public spaces. As a result, she shared that, “it’s taken me a while to re-balance into society, because I would rather just sit here, know what happens here and just be quiet about it.”

The process though, Sharon recognizes, is one that continues and is never really done. She finds that she continues to experience constant tests and triggers, such as difficult emotions, but what is different now is that she is better prepared to “clear it out as it comes up….You can’t stay in it.” As a result she feels more empowered when facing a challenging situation and
determining for herself how she would like to handle it. As she shared, “throughout the diagnosis I really had to step into my power and step into my thoughts and feelings and opinions about what I was and was not going to do.”

Toward the end of her healing experience, Sharon’s medical leave at work was coming to an end when she was offered a buy out that allowed her to quit her job. She said that this is when “life began” and she was able not just from the financial perspective, but finally with a sense of internal permission to herself, to move into a more meaningful career. At present Sharon is an emotional release specialist. As she eloquently states on her website:

Through guided introspection-like meditation, our inner wisdom leads us to where the stuck emotions and memories are stored. As we truly forgive, our bodies and minds are able to release the blocked energy. This is the training I have immersed myself into.

**Tommy**

I am a 76 year old woman in pretty good health (so says my doctor).

I’m a Lutheran deaconess (51 years), most of my ministry being with marginalized people (children, the aged, some in poverty, etc.). Married in 1996 and widowed three years later. My closest relative is a niece in St. Louis, Mo. who spent time with me the last two summers, the first when I had cancer and now while my broken arms have been healing. I am a baptized child of God, and it is my faith that has sustained me through difficult times and isolated places.

I’m an introvert (ISFJ) – a “stabilizer” (SJ). I have a strong personality, and am competent in writing and in theological teaching. I am a low-energy person, but since chemo and radiation in 2011, I have even less energy and stamina, always wanting a nap (but don’t always give in). I’m active in my church and community, but I’m not as enthusiastic as I used to be. I have become more reclusive, I think, but still want to be, and try to be, involved.

While dealing with chemo and radiation, I was very adamant that I did not want to be invalid, and so I pushed myself to be involved in my usual activities, even if somewhat curtailed. I spent much time lying on the sofa and not caring much about anything. At the same time I continued to instruct a seniors’ Tai Chi class weekly, for my own good as well as for that of the class. I think that both my faith in Christ and my self-reliant nature have helped me to keep a hold on my life and cope with what comes. I want to be active, but I also give myself permission to slow down and take time to rest my body and mind.
Tommy heard about my research through a friend of hers. The above quote is how she introduced herself to me when initially inquiring about participating in an interview with me. She was 74 years old when she stood in the mirror one day and noticed the nipple on her right breast was somewhat inverted. Her first thought was, “oh that means cancer probably.” Tommy’s thought was confirmed by a mammogram. She described a family history of cancer and stated, “So I just kind of expected it. . . I was kind of stoic I guess, and the doctor seemed more emotional than I did when he told me I had cancer.” A partial mastectomy was followed by chemotherapy and radiation. Throughout Tommy’s telling of her experiences, the themes of how she described herself in the above block quote were prominent. These include her need not to be seen as in-valid, her faith, her competence and strong personality, and her relationship with her husband. Each of these will be discussed in turn below.

“Aren’t you well?” Being seen as valid

I’ve seen that that’s kind of what happens when people, particularly when people have had cancer, they’re kind of counted as out of the loop because they’re not capable of continuing their life. And so it was important for me to continue my life and to stay as normal as possible, so that’s what I worked on.

For Tommy it was important that not everyone knew of her diagnosis. She recalled several instances of people asking her if she “was well,” which she perceived as them saying, “are you still sick?” when in fact she identified that there were several days when she was not sick. When asked this question, she wondered, “do you not think I should be [well]?” To her pastor she once replied, “yeah, are you well?” hoping that he might get the intimation that she did not want to be asked that question. She recalled a time when someone came up to her in front of a group of people and said, “Oh Tommy, it’s so good to see you. Are you well? Oh of
course you’re not well. Why would I even ask you that?” Tommy was taken aback. She had not realized that this person even knew about her diagnosis, and thinking to herself that it was a “dumb thing” for the person to have said, she replied, “yeah I’m very well,” and left as quickly as possible.

In response to these questions Tommy would repeatedly respond, “I’m fine,” which she believes helped those around her to know that she was “ok,” and not to ask her if she was “well.” Gradually the question became, “how are you?” which to Tommy, was much more acceptable.

Tommy interpreted the question, “are you well,” as people’s general understanding that “cancer is a death sentence,” and a sense of pity for her. Her perception of how people with cancer are treated is that it is like:

Having people think that you’re not capable of being anything except a cancer patient, that you can’t be a normal person and do the things that you need to do or the things that you like to do because you’re a sicko.

The desire to be seen as “normal” and not as “in-valid” motivated Tommy to continue with her pre-diagnosis life as much as possible. She shared:

I think it’s important for me to be who I am and not who I think other people expect me to be; my value is from within me, not from what others think. Therefore I had to determine who I wanted to know about my diagnosis.

She chose to tell her pastor and colleagues at the church office, because for her it was, “a very comforting kind of thing, to have them have that knowledge,” so that she could speak with them whenever she needed. Her preference was to not share it with her acquaintances at church because she did not want to discuss her personal life with them, although she was aware that there was “some gossip.”
A Baptised Child of God

Experience maybe, life experience. I think that and my real trust that God will get me through the things that I need to get through.

Tommy described her faith as the "basis” for her life. During her treatments she maintained contact with the church as much as was possible. However, unfortunately due to complications during her treatment, she contracted an infection resulting in low white blood cells. To reduce the risk of further infection she had to minimize contact with others. Not one to miss church, Tommy would arrive for the service a little late, listen from the vestibule, and then leave just before service ended.

During the interview Tommy recalled a few Christian books that she had read that have influenced her coping. Most significantly were two authors who shared their own experiences of realizing when they could not handle their own life circumstances and, as such had to ask God to do it for them. Almost incredulously Tommy shared:

And so I tried that a couple of times and by golly, when I let go of it, things began to have some kind of resolution. It might not have been what I would have wanted, but it was a resolution that would work.

At times of struggle Tommy has found herself, “just trusting that God is there for me and [believing that] God has plans for my life.” When she looks at her life in retrospect she can see how well “everything just fell into place all the way.” This seems to offer Tommy peace and strength, which she describes as God’s presence during challenging times. Specifically she stated:

I don’t think God stops things from happening. There’ll always be valleys, and they help one to grow. God is always with us, never leaves us out there all alone. Therefore, there’ll always be mountaintops and reasons for rejoicing. So with cancer, as with other hard things, I just ask what God has in store for me. . . That’s peace for me. And that’s strength for my daily life.
Tommy draws on this peace and strength, particularly when she finds herself getting “upset about stuff,” and thinking about the possibility of the cancer coming back. Knowing what to expect with cancer and cancer treatment has also appeared to help Tommy manage the thought of reoccurrence.

She also shared a book that she recently read which was written by a pastor about his experience of cancer, and the concept of “when caregivers must become care receivers and being able to accept help.” This was particularly poignant for Tommy as she acknowledged, “there were times when I would rather have something not get done than to ask somebody to help, but now I’m willing to ask somebody to help with things.” This is a shift that Tommy continues to struggle with as it butts up against her desire to be independent and self-reliant. She laughed as she admitted:

And so I’m still working on that. I struggle with that. Letting other people do things is part of that struggle. And I don’t have to be right all the time. Even if I am, I don’t have to let everybody know it.

One of her initial experiences of letting go was when early in her treatment and decided to refrain from acting as a Stephen Minister. In this role she is meant to provide support and pastoral counselling. She shared, “I didn’t know if I would have the energy for it and I didn’t know if it would be a good idea for me to be helping somebody else when I myself was in need of help.” This continues to shift for Tommy and she has recently recommended that her Stephen Ministry group study the book on caregivers accepting help.

**Learning to Say Yes Less**

Well I don’t have to prove anything. And if I don’t make things happen, somebody else will. And I realize that I’m beginning to depend on other people to do some of the things that I think need to be done, but I don’t have to do it all.
When first diagnosed, Tommy said one of her first thoughts was, “Well I’ve got to find somebody who knows something about it.” Unfortunately the local Cancer Association was unable to connect her with someone, and so Tommy sought someone else on her own. She chose to confide in one of the women with whom she does Tai Chi. This woman had previously spoken to Tommy about her own cancer experience and her first response was one of support. She accompanied Tommy to her first few treatment appointments. A parish nurse also attended Tommy’s appointments and kept notes for her.

Unfortunately throughout her treatments there were several complications due to the number of side-effects Tommy experienced. Her niece, not too many years her junior, came to stay with her, and for Tommy this was a struggle as she prefers to be “self-reliant.” Tommy described that she would allow her niece to help her with the “minimal amount,” and would oblige her when she would “push” Tommy to keep getting out of the house. Tommy described, “she would say ‘I need to get some tea.’ And so we would go shopping and she’d get some tea,” and then Tommy laughingly shared, “when she left I took all these teas over to the church.” Quickly Tommy added, “but I would do the driving!”

The above examples explain how Tommy has come to accept help by virtue of needing support during her treatment, and also being somewhat physically limited by the treatments. However, she also believes that her acceptance has been impacted by her age. She shared a story of a women 10 years her senior who refuses to accept that she is aging and may be “pushing” herself to do things she shouldn’t. Tommy on the other hand does not feel bothered by saying that she feels “too old” to do something. She laughed as she shared that she will tell herself, “You know you don’t have to do everything. I mean you’re old enough now that you don’t have to do everything.”
The shift in realizing that she does not have to do everything was a major theme for Tommy. She described that she has adopted an “I don’t care attitude,” where she recognizes that it’s not that she doesn’t care, but rather that she doesn’t “take things quite as seriously” or see “everything as important.” For Tommy this has not just meant accepting help, as previously discussed, but it includes letting go of the need to do things, just because she can do them, neither of which was necessarily easy for this self-defined “competent “woman with a “strong personality.”” As she stated, “I think I have to decide what is important for me and what is not and what I can say let somebody else do.” This has resulted in a decreased sense of responsibility to get things done, and a simplifying of the things she chooses to do. She used the metaphor of being a “one-pot person,” which she laughed as she described means putting meat and vegetables in one pot and cooking it altogether.

However, it is not that Tommy has chosen to no longer engage in varying activities, but rather that she is more selective about what she will commit to. For her this was a move toward “saying yes less” when asked to partake in varying activities. She is still regularly involved with her church, and does volunteer clowning at the local hospital. Twice in the interview she spoke about the idea of providing support to people through the Cancer Clinic, but as she shared, she doesn’t quite have the desire to follow through on that thought, and is not sure why.

Tommy described a woman at her church who emailed the list-serve looking for information for her mother who was recently diagnosed with breast cancer. She decided to reply to the email because she had found it helpful to speak with people who “have had the same kind of problem.” Her main recommendation was to “have a group of people to talk to.” Although Tommy herself did not identify as having a group of people to talk with, she stated that she had a “slate of people,” each of whom she could turn to if she needed support.
Tommy also found support within by reflecting on previous adversities that she had overcome. She shared:

I’ve learned that when there’s a problem and I have to deal with the problem, I become a little stronger because something else is going to come up ahead and is probably going to be harder and so I’m going to have to deal with that. . . I just gain a little strength every time that I have to deal with things.

Lastly, another theme in Tommy’s ability to accept less responsibility was her choice to continue teaching Tai Chi, as she described “for [her] own good, and the good of the class”. Throughout her treatments she missed only 2 classes. Though initially she had not really told anyone of her medical status, by the end she had shared with the entire group and they were commenting on her increased ability. As Tommy described how each movement in Tai Chi is intentional, I likened it to mindfulness, to which she replied, “Well I think that’s probably true. . . It is also a relaxer. When I do a set, I get lost in my own world.”

**Widowed for Twenty-Two Years**

I was 50 years old when I got married, so I wasn’t a sweet young thing; and I was fat. And my husband thought that I was pretty great. And he was a doctor and he understood how surgery and illness and other things change a person’s life, and so he and I just accepted each other as we were. . . And I think about that still. I mean he’s been dead for 22 years, but I still think about what he would think of me, because I think he can still see what I’m doing. . . I think that that kind of makes a difference, that when I married him I gained a confidence of being a woman that I’d never had before. And I don’t think this has taken that away from me.

More difficult than the cancer, Tommy identified the loss of her husband after only three years of marriage as the worst thing that has ever happened to her. Although she did not speak at length of her husband, twenty-two years after that loss, he still has influence on how she coped with her diagnosis and treatment of her breast cancer.

When reflecting on how she perceived her body herself she shared that she had “wondered” how she might feel after the partial mastectomy. She described that, “one looks like
an eggplant and one looks like a pear,” and ultimately she does not believe that it has not made that much of a difference to her. She shared that she does find herself wondering about younger women who may be, “pushed aside by their husband because they don’t have that perfect body anymore.”

Tommy’s recognition of struggles specific to younger women with breast cancer was part of what prompted her to want to do the interview. She shared that, “cancer may be different for people who are older who, you know, they’ve lived a big part of their life and they’ve accomplished things in their lives.”

When discussing how her thoughts on cancer have changed, she shared that once the treatment decision was made she found herself thinking about the cancer less. She reflected, “I live with the knowledge that it can come fast.” She reiterated that for her, “the important thing is to be able to continue with life and be as normal as possible.” While she does have thoughts about it reoccurring she does not allow herself to “hold” onto those thoughts, or get stuck in them. For Tommy, “you can either worry about what’s coming up ahead or you can try to deal with what you have to deal with today.” She recognizes that she still does both.

**Tracy**

(Tracy: age 42 at diagnosis, divorced, 1 teen daughter, born in Dubai, of Pakistani decent, lumpectomy and chemotherapy, treatment ended June 2008, 5.5yr post diagnosis at time of interview)

It was September 2007 and Tracy was 42 years old when she was diagnosed with stage 3 breast cancer in one breast. Seven months prior to her diagnosis she had been for her annual mammogram and was told “nothing showed up.”

In the months between her mammogram and diagnosis she went on holiday to Pakistan. It was the middle of summer and desperate to ward off the heat, Tracy found herself showering
more than usual. During this time she found a painful lump near her breast but chalked it up to the heat and ignored it. She shared, “we don’t do self-exams I guess in our culture at all, that’s not something we grew up with.” When she developed a persistent cough a friend suggested that she go to the local cancer hospital. Reluctantly she obliged and recalled, “there was a young doctor and he just did an exam and he wrote something down on a piece of paper, asked me to do some tests. I didn’t do any.” Tracy did not even bother to read the note that the doctor had written on the paper.

When she returned to Canada she saw her own doctor for an ultrasound and was then sent for a biopsy. Assuming the results would be normal, she was taken aback when her doctor said, “you’ve got cancer . . . and you need to tell me what to do.” Tracy wasn’t even sure of what options she had. Her doctor gave her a booklet to read, and she thought to herself, “so it’s a lumpectomy or a mastectomy, I never heard the words before in my life.”

And so I’m sitting there crying, I’m thinking ‘am I going to die?’ and then I have to drive home. I mean I love my doctor. She’s really nice. . . But it’s just that I guess they get so used to telling patients that.

Tracy had one night to decide and when she met with her doctor the next day she learned that her odds of reoccurrence were the same regardless of which option she chose. She thought, “if it’s the same then I’ll have a lumpectomy. I still didn’t know what that meant, like how much they would be taking out and stuff like that.” The lumpectomy was scheduled for 2 weeks later. Chemotherapy did not start until just before Christmas. It was somewhere in this time that Tracy read the note the doctor in Pakistan had written which read, “100% malignancy.”

As Tracy spoke about her experience she described it in terms of her relationship with her family, herself, and her faith. Each of these will be described below in regard to how each shaped and was shaped by her experience of breast cancer.
Family

It was just like there was nobody inside me. And what bothered me was people would look at me and say “But you look fine.” And I [replied] “Do you even know what’s going on inside me? Do you have any idea?” “Oh but you look fine.”

Tracy felt dismissed by others who told her that she looked “fine”, when she knew that she did not look like herself, and certainly did not feel like herself. Her father lived in a care home nearby, but she felt that she could not let him see her sick, as she knew it would “bother him.” She laughed as she described that in part it was also because her dad wears a lot of aftershave and because she had lost her nose hair, she was hypersensitive to smells that otherwise would not have bothered her. She would wait until she was having a “good day” and then ask someone to bring him to her for a visit.

While Tracy found herself less able to connect with her dad during this time, her relationship with her siblings grew. Half a world apart, she was in close contact with her brother in Pakistan and her sister in the Middle East during her chemotherapy. She shared, “family became very important to me. Like you know I would just long and yearn to talk to them and see them. And yeah, so family is I think really that helped me a lot.” Since she has been well, she has found that she and her siblings have drifted, “we kind of all got busy with our own lives again.” Despite this though, Tracy identified that the strength she received from them during her illness has resulted in a greater appreciation for family. This is one of the few changes within herself that she articulated.

Tracy shared that it was always her priority to be a mother. During her treatment her daughter was taking her last semester of high school and so Tracy felt that she could not rely on her. As a single mom, she found herself worrying about her daughter, particularly as the father is not in their lives. With the weight of worry on her mind, she shared, “I think at some point you
do start feeling sorry for your own self too. There is self-pity.” Just as quickly however, she shared “but you have to get out of it because otherwise you just keep on going down.” When asked to clarify how she believes that she was able to keep from going down, she shared it was by, “thinking of the people you cherish in your life and live for others, not yourself.”

**Relationship with Herself**

It’s like I used to always tell people it was like I’m here; this is my body, but it’s like within me there is nobody. It’s like empty. I’m empty on the inside. And I really felt that. It was like my – I don’t know how to explain that really. It’s like you’ve lost your soul. And I was literally like you say hollow; I was hollow on the inside. So I really don’t know how else to explain that.

Tracy described herself as “going through the motions” as she struggled through chemo. Reportedly she was part of the 0.2% that cannot handle chemotherapy, but as she said, she had no alternative. On three times the normal amount of steroids, she “became like a big elephant. . . I was massive.” She recalled that she would look at herself in the mirror “and throw up, I hated myself that much. Like just looking at myself I could throw up.” She was angry. For 6 months she took herself to chemo, and brought herself home. Pointing to the couch on which she sat during the interview she said, “This was where I lived, on this couch, for six months.” She felt like the chemo “flattened” her out, “like I said, it was me here but it wasn’t me on the inside. There was nobody inside. It had just gone.”

Feeling empty and alone, she could not help but to ask herself what she had done to deserve the cancer. She was offered counselling and group support by the cancer centre, but she shared, “they said do yoga and those kinds of things. I don’t believe in those, in meditation and yoga, so I didn’t take that counsel.” She described how the chemotherapy impacted her sense of self:

You lose your self-confidence when your hair falls out. You know you have no self-worth. And I used to, you know, literally feel that I was good for nobody because I mean
I can’t help myself, I can’t help anybody else. You do really feel that you’re worthless at that stage. . .

Compounding her feelings of self-worth were cultural ideals that a woman has less worth if she has had cancer because there is the fear of reoccurrence, “we don’t know what’s going to come.” In addition, due to pain in her uterus, Tracy had a preventative hysterectomy in 2010. She explained, “you’ve got a piece of your breast taken out and . . . a hysterectomy . . . which man is going to want to have. . . they want perfect wives, perfect women who have had no problems.” The cultural rejection is painful. Having been single since her husband left her at 8 months pregnant, and now that her daughter is a young adult, Tracy would have liked to have sought out a new relationship, “maybe a friend even, like a companion,” but now that she no longer feels it is possible.

Her decrease in self-worth was met with a loss of self-confidence, which makes her second guess her decisions. She described, “I was very confident as a young person. I was very confident, travelled the world, did everything. But it makes you second guess everything that you say and do.” Living with the fear of reoccurrence she questions if she should make long-term plans. Through this she has come to “take every day as it comes.”

Although her confidence has slowly come back since the chemotherapy, she identifies that it is not what it used to be. She has lost her “arrogance” and confidence and recognizes that despite whatever gains she makes, “there is still an emptiness because you’re never going to be the same as before.”

**Faith**

I don’t think I’m strong. It’s just that, in spite of everything, I think my faith was paramount in my life. My faith was strong. It went down, but then it would go on up again. But I don’t think you’re strong, I think you just kind of go through the motions.
Going to church had been an important part of Tracy’s life, but when she was ill she was not able to attend. During her treatments her church held their annual conference. Never having missed one before, Tracy was determined to go. Unable to fit into her clothes due to the weight gain from steroids, and feeling unlike herself, she shared, “I put on a wig and I thought ‘oh gosh’; I hated it. And I put that on and I went and I sat right on top so that nobody would see me.”

As Tracy shared, her faith was paramount in her life. During her chemotherapy there came a time when she was “really, really down.” Despite how much she tried, she was unable to pray. Her friends from church continued to encourage her. At times she would find herself in a pool of tears, trying to talk to God. Somehow, she continued trying, and as time passed, through that experience, she ultimately recognized a sense of having had her faith “renewed” by her experience of cancer.

In her experience she also found answers to the one question she had always asked herself, “why did I move to Canada?” Not one to usually question things in her life, her decision to move to Canada on her own with her then 7 year old daughter, to Canada on their own, was something she had always questioned. In hindsight now, she believes that the cancer was the reason that God brought her here. She believes that had she stayed in Dubai, she would have died. “No one would have been able to pay my bills.” Despite the challenge that the cancer created in her life, it also brought her clarity on a decision that she had been questioning herself about for over 14 years.

When Tracy was finally able to return to church and to the Sunday School class that she taught, she was told by the mother of one of her students who was only 5 or 6 at the time, that
“he prayed for you every night.” Tracy was touched. “I thought that was so special that he, in his own way, was just praying for me. And that was really, really, really touching.”

Tracy’s experience gave her an understanding of and appreciation for what people may go through when they cope with cancer. It highlighted to her the importance of needing “someone strong to stand by them,” which she did not identify herself as having had. Her compassion has led her to pray for people that she knows are going through cancer. She described this as:

I think just having a desire to pray more for people who were sick . . . That was like a big focus for me, if I knew somebody was ill, just keep praying for them . . . [before] I would once in a while, but it wasn’t a passionate prayer for people. That became a very big thing in my life. It still is, like if I know somebody is ill I want to help them as much as I can. I don’t know how but just be there for them.

When reflecting on her experience, she quietly but confidently shared, “if people are going through something they have to have a desire to come out of it.” For Tracy it was her strong desire to one day meet her grandchildren that she believes pulled her through. Toward the end of the interview Tracy shared that if she could tell anything to other women going through the experience it would be:

Just tell them to hold on to something, anything that’s in their life, anything. . . But if there is anything in their lives, whether it is their grandchildren or something that they can – that’ll give them the desire to get out of it and to get better.

**Trish**

So it’s something every one of us, every one of us has that black line in our life. You have the line before children, after children, before marriage and after [marriage], but we have this big black line that says before cancer and after cancer. That’s there universally for all of us.

(Trish: age 46 at diagnosis, married, 5 children aged 14-20, Caucasian, mastectomy, chemotherapy, radiation, reconstruction not possible, treatment ended Dec 2004, 9yr post diagnosis at time of interview)
Trish was 46 years old, married, and a mother to 5 children, when she found what felt like a “hard quarter” just below her collarbone. Living in the US at the time, she opted to get “decent” private insurance before having the lump checked. It was January 2004 when a mammogram confirmed that there was something in her breast. An ultrasound was immediately scheduled. Trish, who had been speaking so quickly and passionately, softened her voice and said, “it was so awful, Dawn, because they told me right there on the ultrasound table, even before a biopsy.” While lying on the table, she was told, “I’m so sorry but I see cancer in three quadrants of your breast and I’m afraid you’re not going to have the option of having a lumpectomy.”

She was in shock. Tears started welling as the biopsy was conducted. It was stage three breast cancer. It was a Friday evening and she called her husband to share the news. When she arrived home two hours later, her husband and 5 kids, aged 14 to 20 were sitting in the family room waiting. She listened to her kids telling her that they wanted to support her, and shared, “I’m a mum, I have to take care of the family and I’m just going to downplay it. ‘Get out of here, it’s Friday night, get lost, I know you’re there for me, of course.’”

Appointments were scheduled with the surgeon and the plastic surgeon and the process of reconstruction was discussed. Trish opted to go for a C cup as she had always wanted larger breasts. The mastectomy and immediate reconstruction were scheduled for one month away. However, upon awakening from her surgery, she was informed that the assumption that lymph nodes were not involved was incorrect, and she would require chemotherapy and radiation. This prevented them from being able to do the immediate reconstruction.

During the year of her treatment she recalled being angry and feeling like she did not have the energy to focus on her faith. She stated, “during that one year I was being selfish. It
was like, you know what? I've got enough on my plate.” After a year though, she felt the longing for the church community, the familiarity of the church hymns, and the “really good coffee cakes after church,” and returned back to her church community.

Trish completed her treatment protocol and when her skin had healed, she went to the doctor to discuss her reconstruction. She recalled being told, “no, I’m sorry, I guess we didn’t make that clear to you. You cannot have…an implant put in because your skin has been radiated so badly that the chances of your body rejecting it are probably over 50%.” One option was the DIEP reconstruction, where skin, fat, and blood vessels, are taken from the stomach to form the breast, however; Trish had too little fat on her midsection to qualify. The only remaining option was a major surgery to pull skin from her back down over her shoulder to form the breast.

She was shocked. Not only had she never been asked if she wanted reconstruction, she had never been told that having it may not be an option. “I guess I hadn’t thought about it . . . it was assumed by your medical staff and by everybody that you’re going to want a breast reconstruction. It’s just assumed; it’s not even asked.” Hearing her options and the risk of complications, Trish decided, “I don’t want to do it. After a year of all that stuff you don’t want to go back there. You don’t want to see any more doctors; that’s it, I don’t need it.”

When asked to describe who she is as a person, she shared that she is an individual, who appreciates her independence, is comfortable in her own skin, and who values “being productive and experiencing new things.”

**Being an Independent Individual**

I am the only person I know that will show the public the repercussions of having one breast; hence, no bra, no reconstructive surgery and I do not avoid tight blouses. Strangers will come up to me and hug me out of the blue, and tell me how brave I am. Yet, there are many more that scorn the depiction and feel I am not being faithful to the image of women. It certainly is a personal choice.
The above quote was from the first email that Trish sent me, requesting to be a part of the study. She referred to it as the “rebel” in her, but despite having been fitted for a prosthesis, she has chosen not to wear it. She tried it a few times but felt that it was too cumbersome, too fake. In her experience, “most women will wear prosthesis or have it done - so I’m kind of a rarity like that.”

When she first moved to the West Coast of Canada she was told by locals to check out a local nudist beach. Being one who is up for adventure she set out on her own, vowing to not take her clothes off. Upon arriving, however; she decided it would be “ok” to just take her top off, and by the afternoon she was wading naked in the water. She described that despite the unspoken rule to not gawk at others, she felt “like an exhibitionist:”

I mean, if I had two breasts and a woman walked by with a mastectomy, oh my God, I would definitely look. And I would think to myself also though, ‘That’s pretty brave of her to do that’, so I think it’s also filling part of my need to feel like it’s okay and I’m okay to do this. I don’t know.

In further discussing her “need to feel like its okay,” she shared:

You can get over it for yourself but the public is never going to get over it; the public will never, never look at me without a breast and say that’s the norm, that’s okay. You’re a freak, you are; people will look at you. That’s okay. The more I do it the less I care about it anymore; you know, really, but I will stand out and I still wear those tight T-shirts sometimes.

For Trish it seemed that part of what is helping her feel “okay” is her willingness to not hide her mastectomy from the public. Prominent throughout the interview was her desire to “educate people out there by saying, ‘you know what, look, this is breast cancer, this is what breast cancer is about’.” Hearing the stories of the women in her support group Trish is moved to want to “desensitize” people to the sight of one breasted women, in the hope that one day implants will not be the norm. She reflected on her own diagnostic process when it was so
readily assumed by her doctor that she would want a reconstruction, that she did not even think about it or question it herself.

Despite her need for independence, a significant part of her story involves being in, and facilitating a breast cancer support group. Her first experience of a support group was just after she was diagnosed and she lost her job as the company she worked for decided to downsize. Not one to sit idle, Trish found herself with more time on her hands. With one month until her surgery, and several questions about the process, she decided to seek out a support group.

Several times she stated that the group provided her support that she could only get from other women who were going through or had been through the experience. She recalled wondering if she should buy a ticket for an upcoming concert, so she checked in to get opinions from the group. “How am I going to feel after my second chemo treatment? Everybody in the group said, ‘You go girl, you go, you get that ticket, life goes on’. You need to hear that . . . and that was much more valuable than reading about it in a book.”

Trish continued in that group until 2008 when the family moved to Vancouver. She stated that she didn’t necessarily need the support of a breast cancer group, but she sought one out as a way to meet other women. To her surprise, however; there was no support group. A year later when she again lost her job she thought, “Aah, let’s get that support group going’ because I know it helps people; it really helped me a lot.”

Not long after starting her own support group, the Canadian Cancer Association became aware of what she was doing and offered her and her co-facilitator training in group facilitation, as well as a place within the local cancer centre to run their group. Trish was thrilled. Unfortunately, shortly after, the funding dried up. Trish and her co-facilitator were determined to keep the group going as she shared, “it’s better to have a group . . . somebody who knows you
only because they have been diagnosed with breast cancer too. So that’s why I think a support group is really, really, really helpful.” Trish beamed with pride and happiness as she shared that the group will be celebrating their 3rd anniversary in one month.

In the group Trish hears many women’s stories. She shared that what appears to be a common theme for the women is a sense of wanting to “better” themselves, by making healthier lifestyle choices in desperation to ward off a reoccurrence. She stated:

I don’t do anything dangerous. I do smoke cigarettes every now and then. I do like my wine. But a lot of these women give up wine, they give up really good stuff, meat; they don’t eat any red meat anymore. My God, I couldn’t give up a steak; I love my steaks.

Trish shared that she experiences guilt for not having made an effort to take up “good habits” yet just as quickly she stated, “I’m sorry. I like my vices, sorry.” To Trish the prospect of “sacrificing some of the things that I really, really like just to give myself an extra year,” was not worth it. Her parents had passed away at the age of 67 and she has always felt that if she can live to “even that age then that’s okay”. In further reflection she shared:

Do I really want to sacrifice some of the things that I really, really like just to give myself an extra year? No, not really... You know, I did good while I was here; I had fun while I was here. I raised five kids, they're doing good. That’s it; I don’t need to live forever.

Being Comfortable in Her Own Skin

I’ve always been very comfortable in my own skin, Dawn, and I didn’t wear a bra; I never wore a bra, so now I’m going to wear a bra and stick a rubber thing in there? I don’t think so. So I don’t wear a prosthesis.

Trish shared a story that she has never previously told anyone. A few years ago, she noticed that a local strip club was holding a fundraiser for breast cancer and she thought to herself, “and why shouldn’t they? They appreciate breasts more than anybody, right?” To Trish this was an opportunity to humanize breast cancer. She stated:
If we’re ever going to kill, get rid of breast cancer, you’ve got to look and see that this is what breast cancer is. It’s not just a word and a pink ribbon, but it’s a breast with a big scar next to it.

So, she called the club and told them that she would be “happy to get up on stage and show you what breast cancer is.” She recalled standing on stage with her top off and having men throw money at her. She shared, “oh my God, it was awesome; it was so fucking awesome. And then I put on my clothes and I went home and didn’t tell anybody what I did!” For Trish it was an opportunity, a “learning moment” for men to see what breast cancer really is in reality.

Yet despite the confidence it may have taken Trish to get on stage, she still experiences fear of being judged and no longer being seen as attractive. She shared, “you’re still a woman and you still want men to look at you and they’re not going to look at you with one breast. If they see one breast now they’re going to look at you as a freak.” Although she believes that women may be less quick to judge, she questions if women would think, “Why would she do that? Why would she not wear a prosthesis?”

Her concern about being seen as a “freak” was part of what lead to her first statement to me when we sat down to interview. Almost immediately she shared her, “desire to see a study done with male participants gauging their attitudes toward breast cancer, and dating women without breasts.” She went on to explain:

Maybe my view that breasts are paramount to men is false. . . .We survivors (I hate this word, but use it as an identifier) yearn to see where we stand as desirable women. Please pass on this [research] suggestion to your fellow scholars.

This was no passing statement and several times during the interview Trish mentioned the personal importance of the study she has proposed for two reasons. Firstly, from her experiences of facilitating the support group, she has listened to numerous women’s concerns about being socially accepted. This is of particular concern for single women who may fear rejection and
question how to go about broaching the topic with potential suitors. The second reason for Trish is that although she is married, she, like many other women, has always appreciated when she would draw male attention. She shared that for her, walking down the street and receiving male attention is flattering. She stated, “If somebody whistles, that’s a compliment, I’m sorry!” The resounding theme in women’s stories of concern that males may no longer find them attractive, or that single women may have a harder time finding partners, is what has created her longing to have research done to determine men’s perspectives on body altering breast cancer treatments.

Within the stories of the support group, Trish has also found that she and the women in her support group are all more likely to look at another woman’s chest with envy. She recalled feeling it was insensitive to see women who accentuate their chests. She emphatically stated, “How many pink runs are we going to have where people aren’t aware that there is breast cancer out there?”

Yet not everyone Trish encounters leaves her feeling judged. She recalled a concert she attended where she was “boogying” alone in a sheer shirt when a woman came up to her and stated how proud she was of Trish. Though neither of them spoke about why the woman was proud, to Trish it was obvious that it was because she was not hiding her one breasted chest. At her church she has also experienced people coming up to both her, and her husband, telling them how brave they think she is. Trish reflected that for her, this is validating and provides her with a source of strength. She shared, “so I guess I’m trying to make myself feel better too, like I’m brave, I’m strong, I can do this.”

**Being Productive and Open to New Things**

I think, like I said, you get that bucket list going. Not that I really have a bucket list... I think we do run with the clock a little bit though. I think I am a little bit more energetic because I’m fighting the clock, because I know I might not have a long life; it’s very
possible because the cancer might come back, I had a bad cancer. I could be dead in five years so I do tend to like grasp everything I can.

Trish had a zest for life before the diagnosis and during the interview her passion was almost contagious. She has always been one to look for ways that she can better her community and the people around her. What has changed for her though is an increased sense of urgency and desire to use her time more wisely.

She described the fear that she and the other women live with, and how they will always “be looking for that extra bump and lump.” However, as time has passed and she has moved further from the diagnosis, she has found that she slowly began to think about it less and less with each day. She equated it to a smoker trying to quit and slowly over time losing the urge.

Despite the fear that remains Trish does not want to live her life “miserable” or in constant anxiety. Instead she described, “I live for the day, I do; I really do live for the day,” and in doing so, she finds she is better able to “smell the flowers a lot more, notice the colors on the trees, notice people’s expressions.” Trish believes that her ability to balance her fear with living life regardless came from her mom, who when she had a problem would ask her, “‘can you control it’? ‘No’. ‘Then don’t worry about it, move on, just move on’.” From her mom Trish learned acceptance and that, “you can either think that life is crappy and then you die, or life is great and then you die. It’s all a matter of attitude and I think my attitude has always been very positive.”

An important part of who Trish is as a person is her desire to find ways to contribute to making the world a better place. She described a few of her philanthropic endeavors over the years, and one for which she volunteered to serve drinks stood out as most explicitly capturing her belief that life is what you make it. She shared:
You only have one shot at being here, and I’m not trying to impress anybody but I want to make us all a little bit better or happier or more comfortable. I’m not a selfish person so I just want to help, you know? You only have a short time here and it isn’t all about you, and if you don’t have money too there are a lot of ways you can enjoy the gala without paying for the gala, just because you’re serving the drinks, right?

In addition to her desire to help others, Trish has a passion to provide valuable information to the women in her support group, and educate others about the reality of breast cancer. She recalled a time after she had lost her hair to chemo and wore a baseball cap to her son’s school. A teacher caught her in the hallway and demanded she take it off in respect for the school’s no hat policy. Trish quickly pulled off her hat knowing the teacher would be embarrassed once she realized why Trish was wearing the cap, and she was. For Trish this was an opportunity, even if a small one, to create some awareness of, and sensitivity to the needs of women with breast cancer.

Finally, as mentioned in the opening quote for this section, Trish noticed the development of an informal bucket-list. Shortly after her treatment was completed, she found a group of hot air ballooners with whom she could volunteer for 3 mornings with the hope of getting a ride. Hot air ballooning had been a long held dream of Trish’s and after 3 consecutive mornings of starting at 4am, she was finally offered the chance to go up. From her description she enjoyed the women with whom she volunteered as much as she did the ride itself. They “initiated” her into the group by catching her off guard and getting everyone to throw champagne on her. Upon parting from the group she was told, “oh, you can’t tell anybody about the initiation rights, okay”? I said, ‘Okay’. I told everybody!”

Trish shared that part of what has prompted her “bucket list,” was an awakening sense of needing to “get more done,” and the realization that she “can’t take life for granted anymore.” She shared that her sense of urgency is maintained by her personality and constant drive to be
busy, but that it is balanced by her sense of acceptance that, “if I die tomorrow that’s okay too; I’ve had a fun time; fun while it lasted.”

For Trish it has been important to get what she can out of life, and while her mention of her family was few in comparison to the other topics discussed, it was obvious that they have also played a significant role in how she has negotiated her experiences of breast cancer. As an actively engaged mom, Trish formed strong relationships with her children, and they have remained supportive of her throughout this process. She shared that she “taught” the neighborhood about breast cancer, when her kids’ friends would come over and see her gardening in a tank top without her prosthesis. Despite her openness and willingness to use her experience to educate others, Trish ensures that she does not inadvertently embarrass her kids, for example by telling them of her experience of taking her top off at the local strip club, or by wearing too tight of a shirt while with them in public.

She believes that her relationship with her husband has been relatively unaffected as he has been supportive of her throughout the process. She shared that they had not really been sexually active prior to her diagnosis and that this remains unchanged. She did reflect though, that if they were to be intimate, she would prefer to wear a tight shirt, as she would personally find it “sexier” than her bare chest. Even as she spoke about her own experience with her husband, the importance and influence of her support group shone through. A strong theme for Trish was her compassion toward women who are seeking new relationships, and worry about when to tell their new partner, and whether they would be accepted. She shared that if she was single she would be reluctant to enter a new relationship “because of the one breast.”

Trish will continue facilitating the support group until she feels “burned out” and finds that it’s time for her to pass on the reins. For her it’s an important thing to do as she sees the
women benefit so much, and also because she feels that it’s “the responsibility of everybody to give back to their community in any way you can.”

Outline of Common Meta Themes and Subthemes

An across narrative thematic content analysis was conducted in which six common themes and subthemes emerged. These were identified as:

1. The Future Focused Self
   - The Importance of Purpose
     - Maintaining normalcy
     - Establishing new activities and roles
     - Learning more about health

2. The “I am Not a Survivor” Self
   - Rejection of the survivor label

3. The Intentional Self
   - Changes in Control Needs
     - Letting go of control and finding acceptance
     - Taking control where previously there was none
   - Simplifying and Reprioritizing Life
     - Recognizing own desires
     - Realizing from desire and not obligation

4. The Mindful Self
   - Being Present in the Moment
     - Yoga, other physical activities, and writing
     - Finding clarity, purpose, and appreciation
• Letting go of Worry
  o Acceptance
  o Taking it day by day

5. The Social Self
• Relational Self
  o Setting boundaries
  o Spending less time on the less meaningful
• Intimate Self
  o Intimate relationships not a large focus
  o Self-acceptance before partner’s acceptance

6. The Self as a Woman with Breast Cancer
• The Role of Support Groups
  o Why go?
  o Why not?
• Altruism
  o Sharing personal experiences with other women individually
  o Sharing personal experiences and results of personal research with
  larger audiences

Common Themes across the Narratives
Each of the main themes was represented to a greater or lesser degree, and in varying
ways, within most if not all of the participants’ narratives. In order to identify some of the
different ways in which each theme was represented, subthemes were identified. Even when
participants acknowledged the same subtheme, their individual expression of it varied. It is
important to recognize that the themes did not occur in isolation. However, for the purpose of illustrating the many ways that the women re-established a sense of self, delineations have been demarcated where possible. As such, slight overlap among the themes and subthemes may be evident.

Despite the numerous challenges each woman faced, the importance of finding a purpose and a reason to keep moving forward was unanimous. The ways by which each woman found her purpose were varied. This theme will be discussed first followed by the remaining themes in no particular order.

**Theme One: The Future Focused Self**

*The Importance of Purpose*

Throughout all of the women’s stories resounded a need to find something to keep them moving forward and focused on recovery. Tracy spoke of it most directly when reflecting on what helped her, and what she would want to share with other women going through a similar experience. She stated, “Just tell them to hold on to something, anything that’s in their life, anything . . . that will give them the desire to get out of it and to get better.” Though the ways that each of the women found her focus varied, each of the women placed similar importance on the need to find a purpose.

Maintaining normalcy was imperative for several of the women and this is what helped to keep them focused on moving forward. “Normalcy” meant striving to continue participating in the activities that they engaged in prior to their diagnosis. For Nine this entailed a focus on maintaining routines as much as possible for her family. She stated:

I would think every day I have to get out of bed today because they need their lunch packed, or they’ll wonder why I’m not seeing them to the bus, so I had to be that way. . . if I didn’t have that, maybe I would just be this little ball in bed still.
For Tommy, normalcy was a matter of continuing to function in her role within her church as much as she could. Some of the women also identified that it was also important not to be seen as “sick.” Although there were times throughout the treatment that they may have felt sick, there was a sense of not wanting to take on, or be identified with that role.

For some women, finding a purpose or something to keep them focused on moving forward meant adopting new activities, and new roles. Maeve returned to school and became a first time dog owner. She initially adopted her dog to ensure that she went “outside at least once a day,” but quickly realized that she would be out more often than that. She shared, “I don’t think I’ll ever be without a dog now. And he’s a huge, huge gift from the whole thing.” Trish created a “bucket list” to encourage her to use her time wisely and do some of the things that she had always wanted to do. She talked about “fighting the clock, because I know I might not have a long life. . . I could be dead in five years so I do tend to grasp everything I can.” For her the focus became one of wanting to ensure she made the most out of her life’s time. Kathleen focused on her granddaughter and Tracy focused on her desire for grandchildren in the future. For Kathleen the role of grandmother reminded her of what she was already capable of and some of the things that she was already “good at.” Ruby and Sharon spoke of a similar focus which was their belief that they could heal themselves from the cancer. They were each driven by a desire to learn more about alternative treatments and healing modalities.

Almost all of the women began to place greater emphasis on caring for their bodies and being more conscious of food choices, learning about supplements and healthy nutrition. For each woman there was a sense of wanting to do more than “just live” as Ruby shared. Overall, through the above identified ways, each woman’s desire to live with a sense of future was what gave her focus and purpose to keep moving forward.
**Theme Two: The “I am Not a Survivor” Self**

Only one of the women identified with the word “survivor,” stating that with the chemotherapy she felt like she’d been “through the mill” and as a result felt “empowered” and much like a survivor. However, the remainder of the women adamantly asserted that they did not identify with this word. Trish did not hesitate to say that of the women she has met through her support group, “none of us like that word.” Ruby explained that she does not associate with the word survivor because to her it means, “somebody that got thrown out of the Titanic and given a buoy to be brought in. They are a survivor. For me it is like, I wasn’t drowning.” Nine did not feel that the word survivor captures enough of an experience of breast cancer. She said, “I just think it’s more about what the process does to you as a person and everything that comes along with it . . . and how you reshape your life because of that.” Sharon, who had done alternative treatments stated:

> I don’t relate to what I’ve heard over the years of being a breast cancer survivor. I don’t. What that means to me is a chemotherapy survivor, nothing to do with breast cancer, or nothing to do with surviving breast cancer; it has to do with surviving chemotherapy.

The above sentiments were reiterated throughout the women’s narratives as they questioned, “When do you become a survivor?” and suggested that a survivor is “someone who is just getting by.” Some of the women questioned if such a word was necessary, while others offered alternatives such as, “graduate,” “healed from breast cancer,” “and “c-free.” For some of the women there was a prevailing sense that it’s more about having survived the process of cancer treatment than the cancer itself. Rather than focusing on whether they were a survivor, there was a sense of the need to focus on how these women could “reshape” their lives in the aftermath of cancer’s assault. Despite the above arguments and dislike for the word, the women
acknowledged using “survivor,” given it seemed to be what “people know,” while not capturing the whole of a breast cancer experience.

Theme Three: The Intentional Self

Changes in the Need for Control

Paradoxically, control was a predominant theme, both relinquishing and maintaining it, and at times taking control where initially there was none. In these ways, control was perceived as something that was empowering, either by letting it go and breaking freeing oneself from whatever they were trying to hold on to, or by taking control and feeling encouraged to do things differently.

For several of the women letting go of control allowed them to be better able to accept help, although this was not without struggle. Self-reliant natures, the desire for independence, and the need not to be seen as sick challenged some of the women as they faced the normative realization of tasks they would not be able to manage during treatment. Maeve shared that she had to, “learn to ask for help and how to receive it,” and Nine spoke about having to learn that it was “okay” to accept help. Tommy commented, “I think that there were times when I would rather have something not get done than to ask somebody to help, but now I’m willing to ask somebody to help with things.” Nine shared, “I just realized I don't have to do it all anymore.” Ultimately the women had to shift their self-reliant natures to accept themselves as needing help, and being okay with that.

Learning to let go of the need for control was both influenced by, and resulted in, an increased ability to accept things as they are. Maeve spoke of this when she realized that she could not “project manage” her way through her treatment, and needed to let go of the need to control all aspects her treatment. This allowed her to better accept the fact that she had breast
cancer. For Tommy and Nine, accepting that they needed help during their treatment allowed them to release some of their need to control things in other areas of their lives as described above. For them this resulted in increased comfort with selecting what they wanted to do, and relinquishing the need to continue doing all things just because they could physically.

On the other end of the control continuum was a theme of learning to take control. This was apparent even among the women who had learned to let go of the perceived need for control. When these women lost control in some areas of their lives, they found other areas where they could exert more control. For some of them taking control meant arming themselves with as much knowledge as they could about alternative healing options, and choosing for themselves what their treatment would include. Stepping into this role allowed for a greater sense of empowerment.

**Simplifying and Reprioritizing Life**

Changes in priorities were evident in nearly all of the narratives as the women began to identify what was important to them. Whether it was feeling less concerned about things needing to be perfect, or being perceived as “selfish” by putting her own needs first, each woman spoke to new insights into her own needs and desires. Within this was a common thread of not feeling as externally influenced by their social surroundings, and the desire to please others. For some women this meant giving themselves permission to travel, and focus on the things that made them feel good such as healthy food and exercise. Kathleen reported that the cancer made her more “selfish” saying she now focused more on doing things that make her feel good. She stated, “I have no problem just spending time going out for walks and cooking healthier meals and just spending more time simply on me than I did before.” Ruby believed that the cancer gave her permission to travel on a whim and live a less traditional life. She shared, “it is almost like I had
an excuse to live that way because I was not well, and my father could understand that.” There was also an increased ability to say no to things that they did not want to do, and an ability to act with more intention in the things that they did want to do. When talking about feeling less “wrapped up in my own little schedule”, Nine shared, “I just don't get as irritated or stressed out about those things like I used before. . . I'm much more casual about stuff.”

As previously mentioned, letting go of the need to control and creating room for a willingness to receive assistance created new space for some of the women to accept help, even if they perceived themselves not needing it. This also enabled a shift in priorities as they realized that they had been doing things, not necessarily out of desire, but rather from a perceived sense of having to do them. One woman even noted that she now has developed a desire to help others – a desire that she had not previously recognized or noticed. Feeling less driven by the clock and more by what is better for her at the time, she became aware of a growing willingness to go out of her way for others.

**Theme Four: The Mindful Self**

**Being Present in the Moment**

Almost all of the participants in this study spoke about an increased ability to be present in the moment. Kathleen described it as an experience of “the quieting of the mind,” when she does not have to think about anything. Nine shared that in her practice of staying in the present moment she finds some reprieve. During those moments she noted, “I don’t have breast cancer.”

For several of the women, the experience of being present focused and not thinking or worrying about anything else, came through the experience of exercise, with several of them noting the benefits of yoga. Yoga allowed the women to focus on their breath and their body postures and create a space where the cancer was not forefront in their minds. Similar
experiences were also described in the practice of Tai Chi, running, and swimming. Meditation and writing were described by some as providing a sense of peace within – helping them to gain clarity and connect with what Ruby described as, “a sense of purpose.” Sharon described writing as a means to get “information and guidance” from her intuitive self, and spiritual guides, as she learned to “quiet” her critical mind, and connect with her emotions. The benefits of these practices allowed several of the women to develop a greater appreciation of little things, “to smell the flowers a lot more, notice the colours on the trees, notice people’s expressions” as Trish described, and to feel “at one with the universe,” as Kathleen described.

**Letting Go of Worry**

A few of the women identified that they had never been “into worrying,” and so for them it came more naturally to not find themselves worrying about the future. Others identified that their relationship with worry was changed by the diagnosis as they found themselves worrying less. Specifically, when speaking about their ability to let go of the need to control, they also spoke of a greater ability to accept things as they were. The acceptance made it easier to not worry as much, and to just take things as they came. Often times this was referred to as “taking it day by day” or “living for the day.”

The avenues by which each woman arrived at her ability to let go of worry somewhat varied. Again, for some women worrying was never really a concern for them. Others identified that letting go of the need for control helped to reduce their propensity toward worrying. Maeve described this as learning to be “comfortable in the unknown.” She shared, “And that’s actually one thing I’ve carried with me and not worrying, I don’t worry nearly so much about the future or about things working out or not working out or if I’m doing the right thing.”
For other women learning to be present in the current moment was instrumental to quelling anxiety. Nine described that when she is in yoga she experiences “a little bit of peace” that she hadn’t previously experienced. During her yoga classes she described that she can, “shut everything out . . . for an hour and half, I don’t have breast cancer. It’s not the first thought on my mind.” Though her worries may come back, she has found that at least for a little while she can let go of some worries, she can experience a “greater sense of peace.” This was reiterated by Kathleen who described that when she does yoga or works out, she finds herself “present in the moment,” where her mind “doesn’t think about anything else.”

For some participants letting go of worry came through an increased faith in their spiritual and religious beliefs. Through their experiences the women identified: a greater trust that things would work out, a deeper sense of faith and belief that God had a plan, an increased awareness of their own inner strengths for having gone through the breast cancer experience, and a lessened fear of death. Kathleen described this when she spoke about her reawakened sense of a spiritual self and her Catholic faith. She described:

It’s not that I want to [die] or anything. I'm more peaceful with it if it should happen sooner rather than later. But that's not to say I wouldn't react with fear or anything as well, but I feel like I've got something to hang onto to keep me sane going through it somehow.

Theme Five: The Social Self

Relational Self

Setting boundaries in interpersonal relationships was another important theme across all of the narratives. The women identified changes in their relationships as they began to evaluate which relationships were contributing to their well-being and which were detracting from it. For some women this meant the loss of friendships as they chose to surround themselves with the friends who were supportive of them, their treatment decisions, and how they chose to cope with
the process. Other women identified choosing to spend less time with people whom they perceived as negative, or who had certain unwanted expectations of how them.

Changes in relationships were also influenced by an expressed desire to focus more on the meaningful and less on the superfluous or superficial. Again this was attained through the women asserting their needs more clearly, and learning to say no to the things that they did not want to do. Expectations of others and society were less influential and the women found themselves less distracted by and less engaged in meaningless conversations and “chit-chat.” Reflecting on changes in some of her relationships Ruby commented:

I like to think that I don’t waste my time as much. . . I don’t do light chit chat with people. It bores me and it doesn’t do anything for me . . . it is not worth my time to waste on fluff.

**Intimate Self**

Intimate relationships with others were not a significant focus in any of the women’s stories. However, Trish was adamant that research on men’s perceptions of women’s bodies after physically altering surgeries is a necessity. Her desire for this research was fuelled by the shared belief in her support group that a woman’s sexuality is defined by her physical body and particularly her breasts. Without breasts, or with surgically-altered breasts, a woman must therefore be seen as less sexual. From her perspective it will only be after hearing that men are accepting of women’s bodies post-surgery, that women may come to accept themselves more readily. However, this was in contrast to the theme that emerged from other participants’ narratives. Other women expressed a sense of needing to take their time to get accustomed to their bodies themselves, regardless of their partners’ acceptance. Several of the women commented on wanting to shield their body and scars from their partner, and needing to do so until they came to a place of personal comfort with themselves. For some women this took the
form of avoiding intimacy, while others covered their chests with clothing while being intimate. Maeve shared how she kept a shirt on while being intimate, but when her partner acknowledged that wearing her shirt might not be comfortable for her, she was somewhat relieved. She took this as an indication that he would be ok with it, and ended up taking her shirt off. Nine described how she knew when she was ready for her partner to see her scar. She shared:

   It wasn't bugging me as much anymore when he came in the room I wasn't leaping to cover with my shirt anymore. I knew I wasn't ready for him to see it in the beginning. That much I knew . . . it's still really gross looking but I guess you get used to it. Time allows you to accept it.

Theme Six: The Self as a Woman with Breast Cancer

The Role of Support Groups

Throughout the women’s narratives arose a common thread that upon diagnosis each had a desire to connect with a woman who had already been through a breast cancer experience. By speaking with others, the women wanted to know what they could expect from the medical system and from treatment. Typically the women were able to identify within their own social circles, a woman who had been through breast cancer treatment. Not all of the women were able to locate local support groups, or were made aware of different types of groups offered in their area. The women who were able to attend groups identified that they wished they had known about available groups sooner after diagnosis. For these women the ability to learn from other women’s experiences was quite valuable. Educational groups were also identified as helpful in order to prepare women for after surgery care.

Despite the benefits that some experienced, the majority of women either did not attend a group, or attended only one or two times. Kathleen described that her initial few group experiences were helpful as they taught her about prostheses, side effects, and nutrition. She shared: “It was incredibly helpful because that gap of trying to get over the surgery . . . so
anybody I hear about who’s diagnosed now, I tell them about the group.” However, once she knew what to “expect” from her treatment, she described herself as “alright” and no longer felt the need to attend a support or educational group. Maeve also described that she attended one or two groups, but once she got into her “own routine” with her treatment, she also no longer felt the need for group support.

An interesting subtheme for some of the participants was a sense of needing to attend a support group for the benefit of the other group members. For Sharon it was a matter of wanting to be an example that alternate treatments are effective. She described: “I just went once in a while to kind of show them that I was still alive.” Nine shared that she continued to attend a cancer support group in order to demonstrate that there is hope and that things get better once active treatment is completed. She described a tension that she experiences as she has moved through treatment and finds herself in a happier mental space. However, she does not want to seem too “happy-ish” as she recognizes that some of the women are really struggling. Despite feeling that she may not need to attend for herself, she shared: “I hope maybe they're getting something from me . . . You know, to give them a different perspective.”

Due to issues of timing and not knowing what to expect from groups, the prevalent perspective among the majority of the participants was that they did not find groups to be the most effective way of obtaining the type of support that they needed during treatment. In their narratives the women emphasized the importance and value of the support they received from their faith and churches, family and friends, other women who had been through breast cancer, and informational resources including alternative treatment.
Growing Desire to Help Other Women

Within each woman’s story was a desire to help others, specifically other women who have been diagnosed with breast cancer. Some of the women talked about how they had reached out and shared their breast cancer experiences with another woman as a means to offer her support and encouragement. Even when it meant going beyond their “comfort zone” and sharing their personal experiences, the women saw this as a way to hopefully make the challenging process easier for others who may be just starting treatment. Tracy shared that part of her motivation to participate in the research was the hope that her story could help others – “even if just one person” – by hearing how she managed to get through such a difficult experience in her own life.

Other women spoke about the ways they are intentionally seeking to share their experiences and knowledge with a more women. Blogs, websites, and books they authored or published, and the desire to write about their own stories was an underlying theme. For the women who actively sought alternative healing and learned more about nutrition and different supplements, their desire was to keep updating their websites and save other women going through cancer, from the hours of work that they had to put in when they first started their quest for knowledge. Ruby believes that learning from each other’s experiences is part of what life is about. For her it is important to share her information in a “sisterly way” in the hope that it will help other women going through breast cancer.

Another subtheme was the desire to educate others, whether reaching numerous people through a group atmosphere, or informally with friends and family members. Within the stories this took several forms as some women shared a desire to not hide the results of their surgeries, and to share them with other women who have been diagnosed and are considering their surgical
options. Some of the participants were willing to show other women their chests and postsurgical scars in the hope of educating the public to develop a better understanding of what breast cancer is, and what it really means for women. Maeve referred to this as wanting to “demystify” breast cancer. Trish shared that her desire comes from wanting the public to know that breast cancer is “not just a word and a pink ribbon, but it’s a breast with a big scar next to it.”

**Summative Reflections**

Finding my own identity as a cancer survivor . . . there’s so much to rebuild after cancer. Everything changes, and the way you look at everything, and the way that everybody looks at you seems to change too. There’s a lot of adjusting to do. (Maeve)

The diagnosis of breast cancer necessarily catalyzed the women in this study into a new experience of themselves. Schlossberg (1981) described adaptation to transition as:

A dynamic process, (defined as an event or non-event that alters the individual’s perception of self and of the world, that demands a change in assumptions or behaviour, and that may lead to either growth or deterioration) a movement through the various stages of a particular transition (p. 15).

Through Schlossberg’s (2005) lens, transition can be seen as a “moving in,” “moving through,” and “moving out” (p. 44) of a particular experience, which appears to describe the process the women in this study went through in terms of re-shaping their self-identities after being diagnosed with, and treated for breast cancer. This identity transition for the women in this study did not follow a linear course. The process for each woman was shaped by the individual, interpersonal, and contextual realities of her life. Below, I have attempted to provide an overview of the process of identity reconstruction following breast cancer, based on the stories of the women in this study, and the factors that seemed influential in facilitating their movement through this transition.
Moving In

Tommy recalled that her doctor was more emotional than she was, when she was diagnosed. At the age of 74, and knowing she had a family history of cancer, she said she had been “expecting it for years.” Kathleen was 57 and recollected a conversation with God when she accepted the diagnosis and thought if one in nine women is diagnosed then, “why not me?” Maeve on the other hand was 38 when diagnosed. In shock she thought, “how did this happen? How did I just become somebody with breast cancer?” Age at diagnosis, as well as personal history, seemed to play a role in the women’s response to a diagnosis of breast cancer.

Indeed, Kathleen reflected on how her experience of breast cancer and a mastectomy had likely been influenced by her age and past experiences. She reported that a prior diagnosis of facial melanoma left her thinking, “I'd gotten to the point where I don't care what I look like as long as I'm still alive.” Tommy also reflected on how age had shaped her experience of breast cancer. She shared:

I thought well maybe it would be good to talk with you, because I’m older. And cancer may be different for people who are older who, you know, they’ve lived a big part of their life and they’ve accomplished things in their lives.

For Maeve however, the diagnosis and subsequent treatment meant early menopause and giving up her desire for children. She questioned, “How was I still going to be maternal and not have children?” The women’s reactions exemplify the influence of life phase and development, and prior experience, on how a woman might respond to a diagnosis of breast cancer, as she finds herself “moving into” an experience of re-shaping her self-identity.

Moving Through

A general theme of “quieting the mind” and self-reflection appeared to follow the diagnosis and perhaps initiate the “moving through” process. For Ruby it was three days of
immersing herself in a writing contest and unleashing her emotions on the pages as she wrote. Sharon spent three solitary days in silence and darkness, and when she emerged she found that her rage had turned to happiness. She described, “for the first time ever. That was always my goal in life, to be happy, to find happiness, and I found it.” Trish’s reflective process came through taking a year off of church during her treatment. “Pissed off” and “angry,” though not at the church or God, she remembered feeling:

I don’t need to make this sacrifice to be good right now. Right now I need to just take care of me . . . having faith takes effort . . . during that one year I was being selfish. I’ve got enough on my plate.

After her sabbatical, she felt drawn back by the church community and fellowship. Nine and Maeve found their quietness in yoga, as did Kathleen.

The quietness each woman found was expressed in different ways. Diminished influence of social expectations allowed the women to experience shifts in their priorities, and gave them room to learn to act from desire and not obligation. Shifts in their relationships were experienced as they identified as wanting to spend less time on less meaningful things and relationships. They learned to accept help and relinquish control, yet also learned to take control as they became more active in their treatment planning. The women balked at social constructions that identified or defined them as survivors, stating that the notion of survivor “has [more] to do with surviving chemotherapy,” and surviving “all that other crap that came with it.” They questioned, “when do we become a survivor?” and “what did I do that was brave? I just did it. I had no choice.” Ultimately, post-treatment, when they reflected back on their experiences, there was a sense of having done more than “just survive.”

Two significant aspects in being able to move through this phase of the transition included the need to keep focused on the future, and identifying a purpose. Nine described her
desire to maintain normalcy for her family, while Maeve changed careers and adopted a puppy to learn new ways to funnel her maternal energy. Sharon and Ruby focused on their beliefs that they could heal, and spent time researching alternative treatments. Faith served as a source of strength and focus and purpose for Trish, Tommy, and Kathleen.

The women in this study were aware of the important symbolic significance of breasts in our cultural perceptions of femininity. Tracy, the only woman of ethnic minority in the current study, spoke about her lumpectomy as making her less of a woman when viewed through the lens of her culture. Trish spoke about feeling less sexy with only one breast, yet wearing it as a “badge” to desensitize the public to breast cancer. She lamented, “It’s so sad that breasts are so important, you know the image. . .” The women particularly empathised with the plight of single women navigating the social world after breast cancer treatment. That said, part of the process of re-defining themselves, was coming to a place of bodily self-acceptance. It is also important to acknowledge that for the majority of women in this study, changes in their inter- and intra-personal worlds were described as being more significant to them, than the physical changes to their bodies that resulted from their cancer treatments.

Moving Out

Although identity development is an ongoing process (Murray, 2003), by participating in this study the women indicated that they had “moved out” of the initial experience of having to negotiate a post-diagnosis self-identity. Each woman had a personal conceptualization of how her sense of self was re-shaped and changed by the transition into becoming a woman who had experienced breast cancer. Ruby and Maeve described how they are more willing to express and share their emotions, “much more willing to do the I love you’s” Sharon and Ruby described a sense of being on the right “path in life,” having less negative thoughts, and being more agentic
in life choices. Sharon defined this as a process of “climbing into my sense of self” and “becoming more of myself.” Tracy and Nine referred to a loss of “carefreeness” and “arrogance,” resulting in an apprehension to plan too far into the future. As a result Nine noticed, “I appreciate things more, I don’t take things for granted.” Trish also spoke to not taking things for granted anymore, and creating a bucket list so that she can “live life to the fullest.” Kathleen makes more time to do the things that make her feel good, like exercise and healthy cooking. Tommy, like Nine, acknowledged a greater awareness that she does not have to do everything herself, and that it is “okay” to ask for, and receive help.

Summary

Multiple lenses were required to understand the personal, social, and cultural factors that influenced transition as each woman re-shaped her self-identity. “Quieting the mind” appeared to help the women to identify what was important to them. This helped them to identify their purpose or focus. From a personal perspective Tracy described her faith as “paramount” to her process. Kathleen re-discovered her faith in her process. She described her faith as giving her a sense of peace and “something to hang onto to keep me sane going through it.” Tommy’s faith was also influential to helping her move through the process. Yet, she described that equally as helpful were her past experiences and challenges, which provided her with a source of strength. She stated, “I just gain a little strength every time that I have to deal with things.”

From the social perspective, Tracy and Nine described how having children gave them a reason to keep moving forward, even during times when it might have felt easier to give up. Nine’s desire to maintain normalcy for her children helped her to stay in a routine and keep a future focus. Maeve and Ruby stopped investing in unsupportive friendships and strengthened
interpersonal boundaries with family and friends. It appeared that shifts in relationships helped the women to identify their own desires, as they felt less influenced by social expectations.

Social constructions of what it means to be a cancer patient prodded Tommy, Ruby, and Nine to limit who they told about their diagnosis, in an effort not to be seen as un-well. Social understandings of what it means to be a survivor appeared to push the women toward forging their own understandings of self, as they did not want to be identified and defined by a construct that they do not feel captures the entirety of their experiences.

Cultural conceptions of femininity and sexuality also influenced the women. Tracy, a single woman, identified that in her culture, men want “perfect wives, perfect women who don’t have problems.” She further stated that women are regarded as less feminine after breast cancer surgery. This was in contrast to Kathleen, who in the context of a supportive husband, does not feel like less of a woman. Trish, also married to a supportive husband, identified moments where she feels sexy being one-breasted, yet she also described instances where her self-confidence is challenged by cultural expectations around what is “normal.” She stated, “it’s not right; it’s not part of the sexual experience to have one breast. It’s a freaky thing and I think that's how men would perceive it.” Though having identified other ways that her self-identity has been re-shaped, her own experiences of being a woman with one breast continue to be a process of negotiation for Trish.

The words of Sharon and Kathleen seem to capture the experience of identity reconstruction following breast cancer:

Like there is no real old you and new you. It’s just like some of the stuff that’s not needed has fallen away and the basic core of the person is just more clear and authentic. (Sharon)

But I'm still me. I didn't feel as if I had intrinsically, the me hadn't intrinsically changed. I didn't feel diminished. (Kathleen)
Personal Reflections

Since the first conceptualization of this study I have struggled with which constructs to use and how to ask the research question. I was wary of wording the research question in an evaluative way or one that indicated that I only wanted to speak with women who had positive experiences.

I intentionally chose not to use the word “survivor,” in my writing because I did not want to label women as something with which they may not identify. Since immersing myself in the literature, I paused when I read about “breast cancer survivors.” Where is the woman in that? Are they not women who have breast cancer? I’ve always chosen to put the person before the particular condition, diagnosis, or disease that I’m speaking about. I struggle when I hear colleagues refer to their eating disorder client or borderline patient. I ensure that I see the client as an individual. I wanted my participants to know and feel that.

In preparation for my first interviews I was nervous as the experience of breast cancer is not one with which I have had immediate experience. I wanted the women to hear my empathy and feel my genuine interest in them as people. I wanted them to know that this was more than a research interview for me; this was me as a woman sitting down to hear their stories from a place of deep caring.

During an initial interview a participant shared how old she was when she was diagnosed. At the time her diagnosis she was not much older than I am now. Reflecting afterwards I was emotionally affected by that. Her cancer had not come about because of anything she did or did not do. There is a history of breast cancer in my family, and I am aware that I am not immune to the possibility of one day being diagnosed with it myself.
In the final writing stages of this document I visited one of my participant’s websites where she had posted a picture of a beautiful bright air balloon just taking flight. I was almost moved to tears. I recalled another participant sharing that her diagnosis of cancer had motivated her to do things she had always wanted to do. On the top of her list was going on a hot air balloon ride. She had spoken with such passion as she had described the exhilaration of being able to fulfill that dream. In some way I felt it was synchronistic to see the balloon from one woman’s story, on the personal website of another participant. Somehow it spoke to me about the common themes I had found threaded through the narratives of the eight different women. I am continually reminded of how grateful I am for these women and their generosity. I want my research to do their experiences justice.
Chapter 5: Discussion

The purpose of this study was to explore, **how women who have been diagnosed with breast cancer, re-shaped their self-identity post diagnosis**. Narrative interviews were conducted with eight women, all of whom had been previously diagnosed with breast cancer, and all of whom self-identified as having re-shaped their sense of self-identity since diagnosis. Self-identity for the purposes of the research was defined as inclusive of a woman’s sense of self, femininity, body image, and body integrity, all of which are disrupted with the diagnosis of breast cancer (Thomas-MacLean, 2004). However, at the beginning of each interview each woman was asked how she would describe or define herself.

The women’s interviews were transcribed and written into narratives which they each reviewed to ensure their narrative closely resonated with their experiences as they had shared them. Through an analysis of all the narratives, the following themes emerged, *The Future Focused Self*, *The “I am Not a Survivor” Self*, *The Intentional Self*, *The Mindful Self*, *The Social Self*, and *The Self as a Woman with Breast Cancer*. The significance of these themes as they relate to counselling theory, counselling practice, and future research, will be discussed below.

This chapter closes with an acknowledgement of the limitations of this research.

**Theoretical Implications**

At the end of Chapter 4, Schlossberg’s (2005) model of transition was applied to the women’s narratives in order to better explicate the process of re-shaping self-identity. The resulting model elucidates how each woman’s process was influenced by the personal, social, and cultural contexts in which she lived. After the women coped with their initial experience of being diagnosed, they “moved in” to the process of negotiating a new self-identity. Their
experiences were influenced by personal factors including their pre-diagnosis self-identities, their age and developmental phase, and prior life experiences.

The “quieting of the mind” appeared an integral step toward entering the “moving through” phase of the process. During this phase the women experienced the need for a purpose or something to keep them focused on the future. They acknowledged feeling less influenced by social expectations and a realization of their own desires. They spent less time and energy on less meaningful things and relationships. They reported a greater ability to let go of the need for control, resulting in a greater sense of acceptance. For some women there was an increased sense of control as each took command over her own treatment regime.

Cultural influences were also discussed as the women shared how they were influenced by social constructions of femininity, sexuality, and being a breast cancer survivor. By participating in the study each woman identified that she was in the “moving out” phase, thereby having re-shaped her self-identity since being diagnosed.

The application of a transition framework to the women’s experiences results in a model of the process by which women re-shape their self-identity post-diagnosis of breast cancer. In Chapter 2 several prior models of a re-shaping process were discussed in regard to identifying some of the identity related issues that women experience (for a review see Kralik, Visentin, and Van Loon, 2006). The current model adds to and builds on the prevailing models by more explicitly describing how women transition to and re-shape self-identity after a breast cancer diagnosis and treatment.

With a process of re-shaping articulated in the above described model, the discussion now turns to focus more explicitly to the different themes that the women identified as integral to the process. Within the theme of The Future Focused Self, the participants described activities
that helped to keep them moving forward each day. This was achieved by maintaining a sense of normalcy and routine, finding purpose in new activities and roles, and maintaining the belief that they could heal. One woman described this as a process of finding something to hold on to that would give her the “desire to get better,” while another shared how she now focuses on the future by continuing to “grasp” everything she can from life.

The finding that having hope may positively impact women’s abilities to reshape their self-identity was unanticipated. This suggests that hope contributes to re-shaping a post-diagnosis view of self. Hope has been defined by Stephenson (1991) as “a process of anticipation that involves the interaction of thinking, acting, feeling, and relating, and is directed toward a future fulfillment that is personally meaningful” (p. 1459). Purpose and hope include the realization of personal values, establishment of goals, being agentic, and finding self-acceptance (Baumeister, Vohs, & Snyder, 2002).

Although the participants did not necessarily define their need for purpose as finding or maintaining hope, throughout their stories they identified personal ways in which they participated in what could be regarded as a process of maintaining hope. Little et al. (2002) refer to these as ‘anchor points,’ which are defined as ways that cancer patients are able to resolve a disrupted sense of self by identifying beliefs, values, relationships, and roles they can hold onto despite the challenges they face.

Hope is a significant resource that mediates a person’s ability to cope with stressful and life threatening circumstances (Chi, 2007). Specific to patients with cancer, hope has been found to increase positive adjustment, (Oncology Nursing Society, 2009) and positively impact quality of life (Fitzgerald, 2007). Maintaining hope and a purpose of life are associated with happiness and a desire for life (Wnuk, Marcinkowski & Fobair, 2012). According to Rustøen, Cooper, &
Miaskowski (2010), hope mediates psychological distress and serves as an important resource to positively affect the individual’s view of self and possibility for the future.

Psychological adjustment to an experience of cancer can be maximized by developing a preservation of hope (McGee, 1984; Owen, 1989). Furthermore an ability to accept a diagnosis of cancer, engage in treatment, and plan for the future may all be adversely impacted by a loss of hope (Owen, 1989). The current study illustrates how women with breast cancer used the construct of hope as a coping mechanism, even without the explicit awareness that they are doing so. Although the women in this study did not label their desire to maintain a focus on the future as a means to establish or sustain hope, it appears that it may have had that effect. Each woman described finding a personally meaningful way to maintain a focus on the future. This was of particular significance in helping the women to keep moving forward, even during times of challenge.

Seven of the participants reported that they did not identify with the identity of ‘survivor.’ Those that used the word stated that they did so only because it is a word that is socially understood. In the theme, The “I am Not a Survivor Self,” the women suggested alternative words such as “c-free”, “free”, and “graduate.” Maeve explained that she is “smarter and wiser for having taken the [cancer] course” and shared, “you know, a lot of times just being is the accomplishment.”

The responses of the participants in the current study stood in contrast to the recent findings of Documet, Trauth, Key, Flatt, and Jernigan (2012) who studied women’s perceptions of breast cancer. Open-ended interviews were conducted with 112 women, aged 34 to 81, who had been diagnosed with breast cancer between 1.5, and 53 years prior. A thematic analysis revealed three major themes, the first of which was that a survivorship identity was realized
through a defining moment. Specifically, the women reported feeling “back to normal,” and as one participant shared, “everything was fine and I just moved on with my life.” This suggested a “completion of a process” once survivorship was attained.

The women in this study did not echo these sentiments. Rather, they reported a sense that even though they made efforts to maintain normalcy, there was no going “back to normal.” There was an appreciation that normal as it was, no longer exists, and thus needed to be newly negotiated. Additionally, numerous times the participants reported that the process of creating an integrated self-identity was one that continued to be ongoing, as opposed to Documet et al.’s (2012) finding that the women experienced it as a “completion of a process.”

Documet and colleagues (2012) described themes two and three as the meaning and benefits of survivorship. Even though the participants in the current research may not have the same perception of survivorship as those in the study by Document et al., they did report several of the same benefits of survivorship experiences. These included “new outlooks” through an increased appreciation of time and taking on new roles and activities, the desire to “help others” who are coping with breast cancer, a “new appreciation for life,” “improved relationships” by being more authentic and intentional in relationships, “self-improvement,” and “increased attention to health.”

What could account for women identifying with the benefits, or outcomes, of the survivorship experience without identifying as survivors? Attaching the label of ‘survivor’ is problematic as not all women perceive it as positive (Kaiser, 2008; Park, Bharadwaj, & Blank, 2011; Zebrack, 2000). Can women have positive views of survivorship when they dislike the word survivor? Women’s perceptions of survivorship is of importance as it has been suggested that, “it is intuitive that a positive meaning of survivorship should facilitate healthy adjustment
by producing feelings of pride and social worth” (Kaiser, 2008, p. 81). Additionally, positive views of survivorship have been associated with less risk of psychological distress (Helgeson, 2011; Kissane, 2000). However, the women in the current study did not identify ‘survivorship’ as positive, and yet did identify as having been able to re-shape a post-diagnosis self-identity.

The current research builds on existing conceptualizations of survivorship and suggests that it is not a woman’s identification with the word ‘survivor’ that reflects how she will fare post-diagnosis, but rather her identification with what the concept of ‘survivor’ means to her personally, regardless of what it is termed.

The Mindful Self was described by seven of the participants as an increased ability to be present in the moment. Kathleen described it most concisely as the “quieting of the mind.” Silencing the mind allowed the women to shut out “critical thoughts,” better “connect with emotions,” and find an “inner sense of peace.” Additional benefits included creating a sense of mental clarity, and connecting with a greater “sense of purpose.”

The described sense of “quiet” was found in physical activities like running, swimming, yoga, and Tai Chi, as well as meditation and writing. While all of the activities resulted in similar benefits, the women suggested additional advantages of the physical movement of swimming and running, and yoga in particular. Half of the women described benefits of yoga as providing a reprieve, and a “sense of peace.” For the duration of the yoga practice, the women stated that they did not think about their cancer. Focusing on the breath provided a distraction for the mind.

An increased ability to let go of worrying was another subtheme of The Mindful Self. Through other subthemes of letting go of the need for control, and finding greater acceptance, the women found that they did not worry as much. This allowed them a greater ability to be in the present moment, to “live for the day,” and to “take it day by day.”
Mindfulness has been defined as “present-moment awareness of experience as it is, without judgment or analysis” (Garland, Carlson, Cook, Lansdell, & Speca, 2007, p. 7). A common practice of mindfulness is meditation, where attention is focused on the internal stimuli of thoughts, sensations and feelings (Bishop, et al., 2004). Although only four of the participants explicitly acknowledged a practice of mindfulness, seven of them described ways in which they engage in mindful practices including yoga, meditation, taking time to notice and appreciate little things throughout the day, for example the changing colors of leaves in the fall, and, “the expression on people’s faces” when walking down the street.

The benefits of mindfulness as identified by the participants have already been described in the literature. These include feeling less anxious and worrying less (Garland, et al., 2007), increased tolerance of undesirable aspects of self, including physical changes to the body (Bonadonna, 2000), and a greater ability to cope with strong emotions (Lengacher et al., 2009). Most explicitly, mindfulness has been integrated into supportive therapies for people coping with cancer through a program called Mindfulness Based Stress Reduction (MBSR).

MBSR groups for women with breast cancer have been associated with finding ways to cope with cancer, resulting in decreased anxiety and isolation, increased self-acceptance and self-care, and an overall sense of letting go of the cancer (Weitz, Fisher, & Lachman, 2012). The practice of mindfulness in MBSR has also been associated with a greater connection to self, specifically by facilitating an awareness of habitual ways of reacting to thoughts, feelings, and circumstances, resulting in feelings of empowerment to be able to choose alternate ways of responding (Hoffman, Ersser, & Hopkinson, 2012).

Changing from being responsive to circumstances rather than being reactive (Dobkin & Zhao, 2011; Hoffman, et al., 2012), speaks somewhat to a recent article in which I proposed that
mindfulness, as offered through MBSR, may hold promise for helping couples cope with the changes women experience to their self-identities (Johnston, 2012). Employing the five facets of mindfulness, delineated by Baer et al. (2006) as a framework, I attempted to explicate how the practice of mindfulness may help women to become aware of their thoughts, feelings, sensations, and internalized beliefs. Without attaching meaning or judgment the women could label their experiences and acknowledge them as just experiences in a particular moment, without mindlessly acting on them or responding to them (Bishop et al., 2004). As an example, Maeve described that when practicing yoga she became aware of the physical changes in her body as a result of her surgeries, and she became angry. By acknowledging that anger and allowing herself to not judge it, she described that she was able to recognize and experience underlying feelings of sadness and loss. Through the continued practice of yoga, and her growing ability to be present to her experiences, she found herself closer to a stance of acceptance of her post-surgical body, and appreciation for all that it had been through.

Although the intent of the current study was not to test the theoretical proposal that mindfulness may help women re-shape their sense of self (Johnston, 2012), seven of the participants did speak to mindfulness as being integral to the construction of their post-diagnosis self-identity, as supported by Maeve’s yoga experience. This suggests that MBSR may hold promise for women diagnosed with breast cancer that is beyond reducing distress, and into the realm of identity reconstruction.

Interestingly, two of the participants described how the mindful practice of yoga helped them to recognize and begin to process their grief. One of the women described how various yoga postures brought to her awareness, the physical changes in her body that resulted from her surgery. Not being able to hold some of the postures as she had been able to do before being
diagnosed brought about grief for the way her body used to be. Yoga became one of the few places where she would let herself cry, and she described it as, “a place to mourn.” A second participant also described getting in touch with her grief though yoga. Upon ending a class one day her instructor told them to hug themselves and let their bodies know how much they were loved. She recalled thinking, “I don’t love a single thing about my body right now as tears proceeded to stream down my face.” She shared that this experience was an “eye opener to know that I actually disliked so much about my body in that moment.”

The practice of yoga by people diagnosed with cancer contributes to a willingness to pay positive attention to one’s body, an ability to regain bodily awareness, increased self-esteem, and an ability to recognize and process emotions (van Uden-Kraan, Chinapaw, Drossaert, Verdonck-de Leeuw, & Buffart, 2013). Though only two women in the current study spoke in-depth about their practice of yoga, their experiences suggest that yoga may facilitate an ability to process emotions, specific to the grief of self-specified losses.

A subtheme within The Social Self was how the women described their sexual sense of self. It is of interest to note that for the majority of the participants, their perceptions of themselves sexually was not a large focus. Three of the participants who were single expressed concern about how and when to tell a new partner about their bodies, and worried about acceptance. Half of the women expressed that regardless of their partners’ support and acceptance of their post-surgical bodies, it was more important that they were comfortable with their bodies themselves. This was in contrast to two of the participants who suggested that their partner’s acceptance was sufficient for them to still feel desirable. Tracy was the only participant from a minority group and she described cultural issues that prevented her from feeling as if a man from her culture would ever perceive her as a whole woman as a result of her lumpectomy.
Within a few of the women’s stories there were also discrepancies as to how comfortable the women were with their bodies. For example, Trish, the participant whose time since diagnosis was the longest of the participants, described her inhibition to be sexually engaged as a result of her mastectomy, yet she also adamantly stated, “I will stand out and I still wear those tight T-shirts sometimes . . . the more I do it the less I care about it.”

Given that sexuality has been so central to well-being (Van der Riet, 1998) it is interesting that it was not featured more prominently in their stories. Developmental life phases can impact the nature of sexuality, for example, by taking on different significance for women who are partnered versus those who are dating, and for women who have had children and those who desire children (Ussher, Perz, & Gilbert, 2013). The lack of emphasis on sexuality found in the research narratives may be an artifact of the research process, it may also indicate that women are not used to talking about the impact of breast cancer on their sexuality, which may be perpetuated by the help of healthcare professionals’ reluctance to address such issues (Esplen, 2007; Ussher, et al.). Additionally, the varying ways that the women expressed feeling about their bodies and sexualities may indicate that even more than other senses of self (relational, social), women’s sexual selves continue to be negotiated post-diagnosis. Lastly, a sense of sexual and intimate self may not be as forefront to women with breast cancer as might be expected given the emphasis placed on it in the literature, as well as social and cultural perceptions of what it means to be a woman. This expands current conceptualizations of how breast cancer is experienced by suggesting that as challenging as it can be for women and their sexuality and femininity, such challenges are not inherently problematic for all women or to the same degree for each woman (Daniluk, 1998).
Also within the theme of *The Social Self*, the majority of the participants described a sense of having less desire to partake in trivial conversations and feeling less influenced by social expectations. This is in contrast to experiencing a deepening of relationships as has been described throughout the literature as part of an experience of breast cancer (Ganz, Coscarelli, Fred, Kahn, Polinksy, et al., 1997). The participants in the current study spoke to setting boundaries in interpersonal relationships, and a growing awareness of wanting to act from their own desire and not social obligation.

Acting from desire was also noted in the research narratives in the theme of *The Intentional Self*, as the women expressed a growing ability to put their own needs first, and as Kathleen said, “be selfish.” For some women this meant doing things that they had always wanted to do. These shifts have also been identified in the literature as an altered sense of priorities (Knobf, 2007; Mols, Vingerhoets, Coegergh, & van de Polle-Franse, 2009).

Two of the older participants questioned if the changes they noted in themselves were due to the cancer, age, retiring, or were likely to have happened anyway. Tommy stated that part of her incentive to volunteer for the study was to share her experience of being an older woman with cancer. She stated, “cancer may be different for people who are older who, you know, they’ve lived a big part of their life and they’ve accomplished things in their lives.” Giving a specific example, Kathleen shared how her previous diagnosis of facial melanoma years prior impacted her experience of breast cancer. She stated, “I got to the point where I don't care what I look like as long as I'm still alive.” Within the literature on breast cancer, older women have reported having more life experiences to draw from which may better prepare them with coping strategies to manage the sequelae (Knobf, 2007).
A growing desire to help other women going through breast cancer was reported by the majority of the women in the study in the theme, *The Self as a Woman with Breast Cancer*. Sharing personal stories has been identified with an affective benefit and instilling hope (Harper Chelf, Deshler, Hillman, & Durazo-Aruz, 2000). There is a large body of literature suggesting that openness about one’s illness appears to decrease the negative effects of the illness on well-being (Chaudoir & Fischer, 2010). The desire to support others and seeing themselves as having something to offer is an important part of the identity reconstruction process (Little, et al., 2002). Women’s desires to share their stories with others may signal the re-shaping and acceptance of their post-diagnosis self-identities.

Lastly, in reviewing the participants’ responses to the member check questions, a new theme arose regarding the value each found in sharing and reading her own story. Tracy shared that through the process she developed a new respect for counsellors and what they have to offer. She stated, “I never believed in speaking openly about what I went through, simply because people didn’t care to listen. It felt really good to be able to express my feelings in this process.” Reading her own story reminded Maeve of how far she had progressed in her process. She wrote:

I love having this written down and as a 'snapshot' of where I am in my reflection on my illness. Reading the narrative is a reminder for me to continue to be intentional about the lessons I have learned and continue to incorporate in my life. The narrative is a sort of 'letter' to myself.

Nine also spoke about how the process of sharing her story and how reading it affected her understanding of her own experiences. She shared a shift in perspective and said:

I think that this process has helped me to look back and see how what has happened to me has shaped who I am now and how things around me have changed. If you hadn't asked me those questions and forced me to look back at things reflect I don't think I would have some of the perspective that I have now.
Ruby expressed that although she has already spent much time reflecting on, and writing about her experiences, the interview and subsequent written narrative added another element:

It just helped me realize how I feel. I had to focus on your questions and that allowed me to consider the effects of this whole process - from diagnosis till now. I had to re-evaluate my feelings and thoughts about it all. I already have done this by thinking about it, writing about it and making a website and Facebook page, yet your questions allowed me to give it extra focus all at one time like creating a synopsis to a story that is already written. Just that it helps me to realize how I feel about it all. I may be able to use some of my thoughts from the interview for writing in the future.

A narrative perspective on meaning-making is defined as an attempt to assimilate a stressor by constructing a self-narrative that is coherent – one that provides a sense of continuity between who one once was, and who they are now (Neimeyer & Anderson, 2002). In each of these responses, the women described how the process of participating in the research and reflecting on their sense of self-identity further impacted how they view themselves and their experiences. Trish replied that she found that the interview and narrative “solidified things,” and “forced” her to ask herself if she had been “honest” with her narrative, ultimately deciding that she had.

Being reminded of the differences between how she felt about herself immediately after diagnosis, and how she felt about herself at the time of the interview, helped Maeve feel motivated to continue with her process of integrating past experiences into her “life learning.” As Nine revisited her experiences, she recognized having a new perspective on them, and for Ruby, reviewing her story helped her realize how she feels about herself and her experiences now as opposed to pre-diagnosis. These thoughts as shared by the participants speak to the idea that meanings are fluid and continually being revised (Murray, 2003), but furthermore they also address some of the theoretical conceptualizations of processes that women undergo when integrating their experiences of cancer, as discussed in Chapter 2.
Specifically, the ways in which the participants realized their self-identities as influenced by previous understandings of self speaks to the fluid nature by which self-identity post-diagnosis is experienced. This lends support to the definition of transition as defined by Kralik (2002) who proposed transitions as a fluid process when new challenges are experienced. Furthermore, the necessity of reconstructing a valued self-identity is imperative in a transition (Kralik et al., 2006). During the interviews, several of the participants indicated that their understandings and self-identities continue to change and shift. For some, the thought of starting new relationships challenged their current sense of self, as each was faced with having to decide if, when, and how to tell their new partners about their cancer experience. The women’s re-conceptualization of self after reading their narratives also provides support for the notion of re-shaping self-identity as a process that is nonlinear and recurrent as new experiences, successes, and challenges are faced (Kralik, 2002).

Identity reconstruction has also been implicated as an important outcome in meaning-making. This is thought to occur when an individual experiences a shift in their biographical narrative after a particular experience (Gillies & Neimeyer, 2006). Specific to cancer, identity reconstruction occurs when a revised self-identity arises from negotiating the experience of cancer into the pre-diagnosis sense of self (Zebrack, 2000). As the excerpts from the participants’ reactions to reading their narratives indicate, meaning-making was and continues to be an important part of the ways in which they reconstruct and re-shape their self-identities.

**Implications for Counselling**

Each of the participants and peer and expert reviewers indicated that the outcomes of this research may hold implications for other women working through this experience; however, they also each emphasized the uniqueness of the experience. In addition, each participant addressed
that the passage of time was an important component to being able to sort through their experiences and begin to make sense of them. Therefore it is important that women be reminded of the individual nature of an experience of breast cancer.

The proposed model of re-shaping self-identity as a transition demonstrates that multiple lenses are required through which to view women’s experiences of breast cancer, and determine how best to support them. Identifying if they are in the “moving in” or “moving through” phase can help therapists better discern which strategies may be most useful to them and when. For example, a woman having come to accept her diagnosis of breast cancer may not be sure of what to do next. This may signal that she is entering the “moving through” phase, and that she may benefit from being taught mindfulness skills in order to “quiet the mind.” Therapists could also help women identify ways that they can integrate aspects of mindfulness into the activities in which she already participates. As mindfulness appeared to be the first part of the “moving through” process this would be a crucial first step. Women in the “moving through” phase may also benefit from support with identifying a sense of purpose or future focus, and exploring how their social and familial relationships are impacting their experience. Discussions about if and how they perceive influences of cultural expectations and norms of femininity and sexuality may also be fruitful as the women seek to develop their own understandings of their experiences.

At some point during the research, each of the women in this study spoke about the value of the research process in helping her to construct new stories and understandings of her experiences. As Nine shared, “If you hadn't asked me those questions and forced me to look back at things and reflect, I don't think I would have some of the perspective that I have now.”

Women diagnosed with breast cancer can benefit from being asked questions such as how they perceived themselves before the diagnosis, how they experience themselves in the present, and
how their sense of self-identity has shifted since being diagnosed. Hearing and perhaps reading their stories can help women identify post-diagnosis identities and the ways in which they were shaped. These types of dialogues can also facilitate meaning-making, which is an integral part of re-shaping identity (Gillies & Neimeyer, 2006).

Taking on the identity of a survivor has been associated with reduced psychological distress (Documet et al., 2012), however not all women, including those in the current study, perceive the notion of survivor as something positive or with which they wish to identify (Kaiser, 2008; Park, et al., 2011; Zebrack, 2000). Awareness of the implicit meaning of constructs is essential (Bell, 2013), as is the importance of not assuming the meaning of language for the client. Therefore, asking women how they view survivorship may give false impressions of how at risk they are for psychological distress. Rather, it is imperative that practitioners understand how individual women perceive life after diagnosis.

The current research highlights women’s sexuality as a continued area of negotiation for women post-diagnosis. As has already been acknowledged in the literature (Esplen, 2007; Ussher, et al., 2013) counseling psychologists and healthcare professionals working in psychosocial oncology must assess women’s needs, thoughts, and feelings in regard to sexuality post-diagnosis. While it is important to be open to discussing such issues with women, as is exemplified in the current study, it is just as imperative to not over assume the importance of the physical changes to how women’s sexuality and femininity is affected.

“[T]he hopeful person is on the boundary between old formulations of the self and new formulations not yet born” (Barnard, 1995, p. 50). Hope is associated with less psychological distress among people with cancer (Wnuk et al., 2012) and as the current study suggests, it can also play a significant role in helping women re-shape their post-diagnosis self-identity. Through
the women’s research narratives, hope was found in the activities and roles in which they were already participating.

Hope can be a way of thinking, a way of feeling, acting, and relating (Stephenson, 1991). According to Larsen and Stege (2010a) hope can function as a verb, noun, adjective, or adverb, and is therefore an active process. Implicit uses of hope, such as the activities expressed by the participants of the current study, have been linked with fostering client change in psychotherapy (Larsen & Stege, 2010b). Therapists can assess women’s readiness for hope-focused dialogues and once hope is identified and women’s awareness of hope is raised, therapists can use therapeutic hope focused interventions in order to foster hope (see Larsen, Edey, & Lemay, 2007 for a review). Helping professionals can help women identify their sense of purpose and what keeps them focused on the future, thereby helping them identify hope and ultimately identifying new ways of conceiving of their self-identity.

Lastly, the women also identified that information on local support, educational, and psychotherapy groups would have been helpful to have received earlier in the process and that they had very different experiences while attending groups. One peer reviewer said it was only a year after treatment that she could consider attending any group. This reviewer’s first experience of a support group was during her radiation treatments and she perceived it as emotionally too soon for her. Two participants shared their experiences of attending a support group after having received a few rounds of chemotherapy. They perceived the group as supporting women through the chemotherapy process and given that they already knew what to expect, they did not see the necessity to attend. Two other participants were disappointed with their first experiences of a support group because they perceived it as predominantly for women who were taking medical treatment, while the participants had chosen alternative therapies.
Given the mixed experiences reported of educational, supportive, and psychotherapy groups, women’s expectations and understandings of the different groups need to be clarified. With experience and training in facilitating groups, counseling psychologists can contribute to group experiences by meeting with women individually prior to starting groups to assess group readiness. This can help them to make informed choices about which groups may be most appropriate and when in their process they may be most receptive to the benefits of participating in a particular group.

Limitations

Inherent to research conducted via narrative methodology, the presented research is exploratory in nature and has limitations with regard to generalizability (Lieblich et al., 1998; Riessman, 1993). The participants presented themselves as middle class Caucasian females, except for one woman who was born in Dubai. At the time of the interview each woman was three to six years post treatment, except for one woman who was awaiting her second reconstructive surgery, as her first one had failed. They ranged from 37 to 74 at the age of diagnosis, and the stage of cancer, and prescribed cancer treatments were all varied. Across four different major metropolitan areas the women chose different treatments, ranging from lumpectomy to double mastectomy and immediate reconstruction, while some augmented alternative medicine. Three of the women were married, two were single, two were divorced and one was widowed. Half of the women did not have children, and the number of children for the other half ranged from one to five. Despite the multiplicity of ways in which the participants varied, they shared several commonalities in their experiences.

In addition, all of the women volunteered to participate, which may somewhat obscure the identified themes, as they were each comfortable enough and had the time to share their
stories and desire to contribute to research and future treatment for other women. Women less likely or less able to volunteer may have found other ways of going through this process, and it is possible that the resulting themes may have been less likely to resonate with them. Additionally, as identified by all of the women, and the external peer and expert reviewers, there is an appreciation of the individual nature of the experience, and as such, these themes will not necessarily resonate with all women.

The ability to describe ones’ self-identity and the process of re-shaping may have been limited by the women’s current levels of consciousness and or unconsciousness about their experiences. During the interviewing process it was evident that some of the women had spent more time thinking about how the cancer had impacted their sense of self. As most women noted, reviewing their narratives after their interview impacted their current understandings of self. For these reasons the narratives and resulting themes represent a snap-shot of where the women were in their process when they participated. In this way the meanings made, and self-identities re-shaped, are likely to change over time (Murray, 2003).

The research and findings may also be limited by the wording of the research question. “Self-identity” and “re-shape” are only two constructs used throughout the literature pertaining to the same or similar issues, and they are not even always clearly defined (Carpenter, et al., 1999). In an effort to establish the participants’ understanding of self-identity each interview began by asking them how they would describe themselves, such as roles they fulfill, or activities in which they participate. For some women this was easier than others, and again may reflect their level of awareness about such issues (Polkinghorne, 2005). It may also have restricted some women from participating as they were unclear of what the research was about.
The research may also be limited by myself as the researcher. The nature of my interactions with the participants may have influenced their sharing of their stories, as I identified more with some women and some pieces of their stories more than others. Although I attempted to remain objective but engaged, I was aware of how much my empathy influenced the interviews and subsequent analyses. Narrative interviewing may start with a few general questions, after which the participant is encouraged to give a narrative account of their experiences (Murray, 2003). My responses and follow-up questions may have helped some women to delve deeper into their experiences, while inadvertently leading some women off topic (Murray; Polkinghorne, 2005). In Chapter 3 I discussed the number of ways that I attempted to ensure the trustworthiness of the research, and that the narratives represented the women’s experiences as they shared them. However, I am cognizant that my influence was ultimately unavoidable given the co-constructive nature of narrative inquiry (Haverkamp & Young, 2007).

**Implications for Future Research**

The passage of time is an essential component to understanding how a process unfolds (Kralik, at al., 2006). The current study was retrospective in design thereby relying on the participants’ abilities to reflect back on how they would have described their pre-diagnosis self-identities. Future research should employ longitudinal designs with multiple measures and interviews could attempt to document the process of self-identity re-shaping, and seek to better understand the model of re-shaping self-identity as a transition that resulted from the current study. Use of a grounded theory study could also be employed to answer the research question and develop a mid-range theory (Corbin & Strauss, 1990).

The sample of women in this study was small. In addition the women varied in age and developmental life stages, diagnosis, and treatment. A study with a larger and more homogenous
sample could broaden understandings of the re-shaping process and establish if women of similar ages employ similar strategies. This is of particular concern given that women in different life stages have varying developmental needs (Avis et al., 2004).

Future research agendas could employ specific interventions based on the common themes that were located in the participants’ research narratives. This could entail using interviews and varying questionnaires as pre- and post-measures for women participating in MBSR groups. The inclusion of such measures would lend to a better understanding of the ways in which mindfulness influences self-identity. Qualitative methodologies including grounded theory could be utilized to focus on women’s personal experiences of meaning-making and hope-focused therapies. Such an approach could provide a deeper understanding of the processes by which these two interventions help to shape self-identity.

As suggested by the current research and the literature, the marital status of women impacts self-identity (Ussher, et al., 2013). In example the single women in this study expressed concern over if, when, and how to tell new partners about their breast cancer. Future research could focus on how married versus single women re-shape their self-identities and if different strategies are employed. Such an approach could assist toward tailoring interventions to better meet the needs of these two distinct groups.

Lastly it is important to recognize the significance of cultural influence on self-identity development. In the current study seven of the eight participants were of Caucasian decent. The one participant who was not Caucasian spoke about the influence of her cultural beliefs on how she experiences herself after diagnosis and treatment. Given Canada’s increasingly diverse population (Statistics Canada, 2006) it is imperative that psychosocial healthcare professionals are sensitive to different cultural responses and coping (Knobf, 2007). By broadening research
activities in the proposed areas, a more comprehensive foundation can be developed from which to identify and further develop psychosocial interventions that capitalize on ways in which women can re-shape their self-identities post-diagnosis.

**Conclusion**

The experience of cancer needs to be integrated into a person’s understanding of self (Mathieson & Stam, 1995). Post-diagnosis identities may strongly influence well-being (Brennan, 2001). However, research to date reveals little about how post-diagnosis identities are formed (Park et al., 2011). Understanding how people make sense of their post-diagnosis identities can help to tailor practice in a client-centred way, and provide context to foster further integration of self-identity (Park, Zlateva, & Blank, 2009).

The role of counsellors and counselling psychologists is to support women as they move from diagnosis into treatment, during treatment, and into life post-treatment (Tighe, Molassiotis, Morris, & Richardson, 2011). Through their generous contributions of their time, and most significantly their personal and intimate experiences of breast cancer, the women who participated in this study benefited counselling researchers and practitioners, as they attempt to find ways to support women in re-shaping post-diagnosis identities. The themes in the participants’ narratives that were identified as instrumental in their processes were reviewed and validated by peer and expert reviewers, who also generously donated their time. The participants’ narratives and themes were then applied to a model of re-shaping self-identity as a transition in order to better understand the influences of the personal, social, and cultural contexts in which women experience breast cancer. The resulting model adds to theory by describing a process that though previously acknowledged (Kralik, et al., 2006), has not explained how women move through it. Counselling implications can be drawn from the model
as it helps professionals identify where in the process a woman may be, and which contextual factors may be influencing her experience. In example women making sense of their diagnosis may be most influenced by their personal history of experiences, current age, and developmental life phase. Future research can expand on this model by exploring it in greater depth, and longitudinally in order to better delineate how the process unfolds.

This current research is important not just to help individual women living with breast cancer, but also to contribute to the shifting social narrative of what it means to be diagnosed with cancer. Within the current psychosocial frameworks and interventions there is the presumption of an obligation on women to find growth and benefit in their experiences (Bell, 2012). As the literature on survivorship grows, so too does the awareness of the pressures on women to find benefit in their experiences. In advancement of a discourse that does not inadvertently silence or shame women who are unable to identify growth as a result of breast cancer, the current study identified ways that women can negotiate and feel re-shaped by an experience of breast cancer, in such a way that is not evaluated as positive or negative.
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Appendices

Appendix A: Recruitment Poster

Have you been diagnosed with breast cancer?

Has the experience of breast cancer re-shaped your sense of self?

Would you like to participate in research exploring the experience of re-shaping the self?

Criteria for participation:
- Must be at least 25 years of age
- Must have been diagnosed with breast cancer
- Must feel that the experience of the breast cancer influenced/shaped your sense of self, for example how you feel about yourself (your body, mind, spirit, relationships with others).

Your participation will include:
- A face-to-face interview & follow-up interview (each 60-90 min)

Benefits of this study include:
- Contributing your experiences and knowledge to psychosocial understandings of how women re-establish a sense of self after having been diagnosed with breast cancer.
- Contributing to the development of psychological theory and counselling practice for women through the breast cancer experience

For more information please contact Dawn Johnston:
xx@xxxx.com
(###) ####-#####
Appendix B: Recruitment Script

Introduction
Thank you for expressing interest regarding the research project that I am conducting, which has been approved by the University of British Columbia’s Behavioral Research Ethics Board. I am completing my dissertation for a Doctorate of Philosophy of Science degree in Counselling Psychology in the Division of Counselling Psychology at the University of British Columbia. I am interested in looking at the lived experience of women who have been diagnosed with breast cancer and self identify as having re-shaped a sense of self, post diagnosis.

Purpose of the Research
Are you interested in finding out more?
The purpose of this research is to better understand how women diagnosed with breast cancer re-negotiate a sense of self-identity. For many women, the diagnosis of breast cancer challenges the ways that they think about themselves, their bodies, their sense of femininity and sexuality. It is the hope of this research that through sharing your experiences with me, we will be able to identify ways in which you were able to re-establish a sense of self since being diagnosed. The insights gained may help identify themes that other women who are coping with breast cancer may experience. This can not only lend to new awareness in the realm of cancer care and psychology, but also has the potential to inform ways in which psychology can support women going through the experience of breast cancer.

If YES:
What will I be asked to do?
Before commencing I will email you a copy of the informed consent that you would need to review. I will also provide you with a few questions that may be helpful for you to begin thinking about as you prepare for our interview. Two weeks later we would schedule a time to meet to review the letter of consent in person, and address any questions or concerns you may have. If you agreed to participate and sign the letter of consent, we would begin the interview which would last approximately 60-90 minutes. The interview would be audiotaped so that afterwards I could transcribe it write into a personal narrative of your experiences. I would then email you the narrative to get your feedback on whether it reflects your experiences. You would have two weeks to review your narrative and contact me with any suggestions as to what should be added, deleted or changed so as to ensure it resonates with your experience. Should you require more time than that, we can negotiate something that is more suitable for your schedule. Once I have analyzed the narratives of all participants, we would schedule a second interview. This meeting, referred to as a member check, will be conducted, so as to provide you with the opportunity to review the analysis’ resulting identified themes, and metaphors. This is done in effort to determine if the derived themes accurately capture your experiences as you shared them. This final verification process will require approximately another 60 -90 minutes of your time.
Do I Have to Participate?
Participation is completely voluntary and you may choose to withdraw from the study at any time without penalty. You may also choose to not to discuss certain experiences, in order to self-monitor the extent of your self-disclosure.

What about my privacy?
Participation is entirely anonymous and confidential and as such, your name and any identifying information will be kept private. As the sole researcher of the study only my supervisor, Dr. Marla Buchanan, and I will have access to your name and contact information, and your confidentiality will be maintained at all times. Due to the nature of the information discussed in this study, if the research data is subpoenaed by a court of law and if you disclose the physical harm or potential for harm to yourself, children, or another person, I would be legally obliged to disclose this information to the appropriate authorities (e.g., child protection or law enforcement officials).

Please note, if at any point you choose to withdraw from participating, only the information gathered up until the point of your withdrawal will be retained for use in the final write-up of the study.

If you choose to participate I will personally analyze your narrative and conduct all correspondence with you. Your name will not appear on any report of the results and any identifying information in your story (e.g., geographic locations, third parties) will be removed. You will be given the option of choosing a pseudonym (i.e., a pen name to refer to you) that will be used in all transcripts, final the write-up, and any academic or non-academic presentations or publications. All data (e.g., hard copy of your narrative, audio copy of the interview) will be kept in a locked filing cabinet in my office, and data stored on my computer will be protected by a password. Data will be stored for five years, at which time it will be permanently erased, shredded, and destroyed.

What are the risks and benefits of participating?
This study will invite you to reflect on your lived experience of realizing that your pre-diagnosed sense of self has not been a good fit with your emerging sense of self post-medical treatment, asking how you navigated such an experience to further develop and reconstruct your present sense of self. This may remind you of some challenging times in your life that have touched you emotionally. While I appreciate and respect the emotional impact of such a process, our time together is not a form of personal counselling. If something we have discussed continues to upset you after your participation, the following sites are available for free and low-cost counselling:

Counselling Services Available in the Vancouver Area:
- New Westminster Counselling Centre: (###) ###-#### (up to 8 months free counselling sessions)
- Brookswood Counselling: (###) ###-#### (sliding fee scale and ongoing counselling service)
- Fraser River Counselling Centre: (###) ###-#### ($10/session, fee can be waived
Counselling Services Available in the Edmonton Area:

- Psychosocial and Spiritual Resources - Alberta Health Services: (###) ###-#### (No charge)
- The Hope Foundation of Alberta: (###) ###-#### (sliding fee scale)
- University of Alberta - Faculty of Education-Clinical Services: (###) ###-#### (one-time fee of $50)

Personal benefits of your participation may include continual growth and reflection upon the process of identity formation and psychological well-being. Additionally, your narrative will be recorded in the final write-up of this study, as well as potentially my final dissertation, and possible academic and non-academic publications. By your participation you will be contributing to the research and applied community of counselling and breast cancer research.

What is the next step?
Please contact me at the phone number or email below, and I will send you a copy of the Informed Consent form attach to read over, and maintain a copy for your reference. I will be in contact in two weeks time to arrange a convenient time for the face-to-face meeting. Please do not hesitate to contact me if you have any questions or concerns. Two copies of the Informed Consent form will be provided to you at the time of the face-to-face meeting. Both copies will need to be signed and one copy will be for your own reference and the other for me.

If you have any further questions, please do not hesitate to contact me.

If NO:
I thank you kindly for your consideration and greatly appreciate your time and interest. Any further questions/concerns, or a change in mind about participating, can be directed to me via e-mail (my address is indicated below) or phone (see number below).

Thank you for your kind consideration,

Dawn Johnston
PhD. Student, Counselling Psychology
Division of Counselling Psychology
University of British Columbia
E-mail: xxx@xxxx.com
Phone: (###) ###-####

if necessary)
Appendix C : Reflection Questions

Sample Questions for Reflection Prior to Interview

I want to ask you to tell me the story of how you became who you are now. The best way to do this is to describe who you were before you were diagnosed, and who you are now. You can take your time in doing this, and also give details, because for me everything is of interest that is important to you.

In order to tell me your story it may help to reflect on some questions before meeting for our interview. It may be helpful to draw a picture or write about who you are, revisit journals kept during this particular time period, or to speak with friends, family, and others who may have been a part of your life during this period.

Below are some questions which may be helpful in recalling the experience:

- How does who you are now compare to who you were before the diagnosis?
  (For example: what is different/same in your life, how you see yourself, the world, your relationships etc.)

- When you think of yourself, how would you describe you?
  - Who am I?

- How was your sense of self impacted by the experience of breast cancer?
  - Ex. In what ways do you see yourself as different from the way you saw yourself prior to being diagnosed?

For example, if you were to introduce yourself to someone how might you describe yourself? Some women may think of themselves in regard to their roles/relationships/hobbies/activities.

- How do you understand yourself?
  - What helps you to know who you are?

You may have already answered this question by answering the first question.

It may be helpful to think about yourself in regard to the things such as your roles/relationships/hobbies/activities, or your physical/sexual/social/feminine/spiritual/emotional self.

- What has contributed to you developing a new sense of self?
- How did you know when you had reconstructed/negotiated a sense of self?
What were the signs of a new sense of self being constructed? When did you notice the signs?

- Is there anything currently happening in your life that may change or challenge your sense of self?

- Does this process seem complete to you or is it ongoing?
  - Ex. Do you need to work to maintain your sense of self and if so, what helps you be able to do so?

- What, if anything stands out as most significant to how you understand yourself since being diagnosed?

- Is there anything else that you would like to add? Anything else that you think may be important for me to know or for us to talk about?
Appendix D : Orienting Statement

I want to ask you to tell me the story of how you became who you are now. The best way to do this is to describe who you were before you were diagnosed, and who you are now. You can take your time in doing this, and also give details, because for me everything is of interest that is important to you.
Appendix E: Informed Consent

THE UNIVERSITY OF BRITISH COLUMBIA

Consent Form
Reconstructing the Self: How women diagnosed with breast cancer re-negotiate a sense of self.

Principal Investigator:
Dr. Marla Buchanan
Associate Professor, Registered Psychologist
Department of Educational and Counselling Psychology, and Special Education
Faculty of Education, UBC
###-###-####

Co-Investigator(s):
Dawn Johnston
Counselling Psychology Doctoral Student
Department of Educational and Counselling Psychology, and Special Education
Faculty of Education, UBC
###-###-####

This research is for Dawn Johnston’s doctoral dissertation, for which Dr. Marla Buchanan is the research supervisor.

Purpose:
The purpose of this study is to better understand how women who have been diagnosed with breast cancer develop a new sense of self, as a result of their experiences. A narrative analysis will be done on women’s narratives, in order to identify metaphorical themes and social and relational influences that have acted on how they have come to understand themselves.

Study Procedures:
Upon expressing interest in participating in this study, you will be given a copy of this consent form to review, as well as some reflection questions to help you think back on your experiences since being diagnosed.
Should you agree to participate in this study, you will meet with the Dawn Johnston, the Co-Principal Investigator for 60-90 minutes, to discuss the purpose of the study, informed consent, and address any questions or concerns you may have. Once you have given consent to participate, the interview will begin. The interview will be audio-taped and will consist of the same reflection questions you were given to review initially.

A narrative of your story will then be transcribed either by Dawn Johnston (Co-Investigator) or a transcriptionist, who will not have access to any of your personal or identifying information. The interview transcript will then be analyzed by Dawn Johnston (Co-Investigator) in order to identify themes. You will be emailed a copy of the narrative and themes in order to review for accuracy and appropriateness, and to discuss any changes that you may wish to make. You will have 2 weeks to review your narrative and contact the researcher with any changes.

Once Dawn Johnston (Co-Investigator) has had a chance to interview and analyze the narratives of all participants, you would then be invited to a second 60-90 minute meeting with Dawn, in order to give you the summary of themes, and provide you the opportunity to comment on if the themes are resonate with your experiences as you have shared them.

The resulting study may be used in academic and non-academic, publications and presentations. You will be given the opportunity to give consent to whether or not your narrative may used in the future, and you will be given the chance to determine whether all or portions of your narrative can be included. Any questions you have regarding the procedures may be directed to the co-investigator.

**Potential Risks:**
As you are being invited to reflect on and share your experience of breast cancer, and how it has related to your psychological and spiritual well-being, parts of your participation may remind you of challenging times during your life that may affect you emotionally. Although your courage to share your story is acknowledged and respected, the purpose of the study is not a form of personal counselling. In the event that your participation in the study raises something that you would like to discuss further in counselling, or if you feel emotional distress as a consequence of your participation in the study, you may approach any of the counselling resources listed below:

**Counselling Services Available in the Vancouver Area:**
- New Westminster Counselling Centre – Phone (###) ###-#### (up to 8 months free counselling sessions)
- Brookswood Counselling – Phone (###) ###-#### (sliding fee scale and ongoing counselling service)
- Fraser River Counselling Centre– Phone (###) ###-#### ($10/session, this fee can be waived if necessary)
Counselling Services Available in the Edmonton Area:
- Psychosocial and Spiritual Resources - Alberta Health Services - Phone (###)-####-#### (no charge)
- The Hope Foundation of Alberta - Phone (###) ####-#### (sliding fee scale)
- University of Alberta - Faculty of Education - Clinical Services - Phone (###) ####-#### (one-time fee of $50)

Potential Benefits:
Personal benefits from your participation may include continual growth and reflection as you develop your spiritual identity in the process of your own psychological well-being.

Additionally, your experiences will be anonymously recorded in the final write-up of my (Dawn Johnston, Co-Investigator) final doctoral research document and, potentially, in future academic and non-academic publications. By this, you will have the opportunity to contribute to the field of counselling and as well to the breast cancer community and research.

Confidentiality:
All documents will be identified only by your chosen pseudonym and kept in a locked filing cabinet and data stored on my computer will be protected by a password. Data will be safely stored for five years, at which time it will be permanently erased, shredded, and destroyed. You will not be identified by name in any reports of the completed study and your pseudonym will be used in reference to you in all transcripts, the final write-up, and future publications or presentations.

Only the Principal Investigator Dr. Marla Buchanan, and Co-Investigator, Dawn Johnston, will have access to your personal information. Your confidentiality will be maintained at all times. However, due to the nature of the information discussed in this study, there are two possible conditions when confidentiality would not exist:

1.) If the research data is subpoenaed by a court of law, and
2.) If you disclose the physical harm or potential for harm to yourself or another person, or the neglect or abuse of children.

In that case, there is a legal obligation to disclose this information to the appropriate authorities (e.g., child protection or law enforcement officials) and you would be invited you to join in this process.

Remuneration/Compensation:
In order to defray the costs of transportation and parking costs you will reimbursed for any costs incurred as a result of your participation in this study.

Contact for information about the study:
If you have any questions or desire further information with respect to this study, you may contact the Principal Investigator, Dr. Marla Buchanan at (###) ###-####, or Co-Investigator, Dawn Johnston at (###) ###-####.
Contact for concerns about the rights of research subjects:
If you have any concerns about your treatment or rights as a research subject, you may contact the Research Subject Information Line in the UBC Office of Research Services at (###) ###-#### or if long distance e-mail to RSIL@ors.ubc.ca.

Consent

Your participation in this study is entirely voluntary and you may refuse to participate or withdraw from the study at any time without any penalty.

Your signature below indicates that you have received a copy of this consent form for your own records.

Your signature indicates that you consent to participate in this study.

_________________________________
Participant’s Name (please write)

____________________________________
Participant’s Signature __________________

Date

The signature of a Witness is not required for behavioural research.

Using this pseudonym, I grant permission to be quoted: Yes: ___ No: ___

The pseudonym I choose for myself is:

____________________________________________________

I give permission for parts of my narrative to be used in future academic and non-academic publications and presentations: Yes: ___ No: ___

I give permission for my entire narrative to be used in future academic and non-academic publications and presentations: Yes: ___ No: ___

I am aware that a transcriptionist may be employed by Dawn Johnston to transcribe my interview and that this person will not have access to my personal and identifying information and I give my consent for this: Yes: ___ No: ___
Appendix F : Informed Consent for Alberta Health Services

How women diagnosed with breast cancer
re-negotiate a sense of self

CONSENT FORM

This form is part of the process of informed consent. It is designed to explain this research study and what will happen to you if you choose to be in this study.

If you would like to know more about something mentioned in this consent form, or have any questions at anytime regarding this research study, please be sure to ask Dawn Johnston, the Co-Principal Investigator. Read this consent form carefully to make sure you understand all the information it provides. You will get a copy of this consent form to keep. You do not have to take part in this study and your care does not depend on whether or not you take part.

Your participation in this study is entirely voluntary. Please take your time to make your decision. It is recommended that you discuss with your friends and/or family about whether to participate in this study.

“WHY IS THIS STUDY BEING DONE?”

You are being invited to take part in this study because you have been diagnosed with breast cancer.

This study is being done because currently there is no research on how women re-develop a sense of self after having been diagnosed with breast cancer. In order to develop appropriate and effective counseling and psychological treatments for women, it is important that psychologists understand this process.

This research is for Dawn Johnston’s doctoral dissertation, for which Dr. Marla Buchanan, is the research supervisor.

“WHAT DO WE HOPE TO LEARN?”

We hope to learn ways that psychology can help women better cope with the experience of being diagnosed with breast cancer.

The purpose of this study is to identify ways in which psychologists and professional counselors can help the growing number of breast cancer survivors to better cope with the experience of breast cancer, specific to the ways in which breast cancer disrupts a woman’s sense of self.
“WHAT WILL MY PARTICIPATION INVOLVE?”

Upon expressing interest in participating in this study, you will be given a copy of this consent form to review, as well as some reflection questions to help you think back on your experiences since being diagnosed.

Should you agree to participate in this study, you will meet with the Dawn Johnston, the Co-Principal Investigator for two face to face meetings. The first meeting will last 60-120 minutes, to discuss the purpose of the study, informed consent, and address any questions or concerns you may have. Once you have given consent to participate, the interview will begin. The interview will be audio-taped and will consist of the same reflection questions you were given to review initially.

A narrative of your story will then be transcribed and analyzed, in order to identify themes. Dawn Johnston, the Co-Principal Investigator will then transcribe your narrative and analyze it for themes. You will be emailed a copy of the narrative and themes in order to review for accuracy and appropriateness, and to discuss any changes that you may wish to make. You will have 2 weeks to review your narrative and contact the researcher with any changes.

Once Dawn Johnston (Co-Principal Investigator) has had a chance to interview and analyze the narratives of all participants, you would then be invited to a second 60-90 minute meeting with Dawn, in order to give you the summary of themes, and provide you the opportunity to comment on how reflective the themes are of your experiences as you have shared them.

The resulting study may be used in academic and non-academic, publications and presentations. You will be given the opportunity to give consent to whether or not your narrative may used in the future, and you will be given the chance to determine whether all or portions of your narrative can be included.

“How Many People Will Take Part In This Study?”

About 6-10 people will take part in this study at the Cross Cancer Institute, as well participants who will be recruited through clinical counselors and psychologists in Vancouver.

“How Long Will I Be Involved In The Study?”

The total amount of time required of you is approximately 2 to 3 1/2 hours.

“What Are My Responsibilities?”

You must be willing to attend up to two face-to-face meetings with Dawn Johnston (Co-Principal Investigator) each of which will be scheduled at a time and place of your convenience.
“WHAT ARE MY ALTERNATIVES?”

You may choose not to participate in this study.

“ARE THERE ANY BENEFITS TO PARTICIPATING IN THIS STUDY?”

Participation in this study may or may not be of personal benefit to you. However, based on the results of this study, it is hoped that, in the long-term, patient care can be improved.

Personal benefits from your participation may include continual growth and reflection as you continue to develop a sense of self-identity in the process of your own psychological well-being.

Additionally, your experiences will be anonymously recorded in the final write-up of Dawn Johnston’s (Co-Principal Investigator) doctoral research document and, potentially, in future academic and non-academic publications. By this, you will have the opportunity to contribute to the field of counseling psychology and as well to the breast cancer community and research.

“CAN I WITHDRAW FROM THIS STUDY?”

Taking part in this study is voluntary; you may withdraw from the study at any time if you wish to do so. If you choose to withdraw you will have the opportunity to determine if your data that has already been collected can be a part of the final project, or if you would prefer for it to be permanently destroyed.

“ARE THERE COSTS TO ME FOR TAKING PART IN THIS STUDY?”

You will not have to pay for your participation in this study.

You will be reimbursed for reasonable, out-of-pocket expenses related to your participation in this study, for example for transportation to the interview and parking costs.

“WILL MY PERSONAL INFORMATION BE KEPT CONFIDENTIAL?”

Identifiable health and personal information will be collected from you during this study. This information may be used by the researchers who are carrying out this study. Any research proposal to use information that identifies you for a purpose other than this study must be approved in advance by the Alberta Cancer Research Ethics Committee.

Direct access to your personal information that is collected for this study will be restricted to the researchers who are directly involved in this study except in the following circumstances:
1) If the research data is subpoenaed by a court of law, and
2) If you disclose the physical harm or potential for harm to yourself or another person, or the neglect or abuse of children.

In that case, there is a legal obligation to disclose this information to the appropriate authorities (e.g., child protection or law enforcement officials) and you would be invited to join in this process.

Your personal and identifiable health information will not be shared with anyone other than the researchers who are directly involved in this study. Any disclosure of your identifiable health information to another individual or organization not listed here will need the approval of the Alberta Cancer Research Ethics Committee. You will be given a pseudonym (i.e., a pen name by which I will refer to you) that will be used in all transcripts, the final write-up, and any academic or non-academic presentations or publications. All data with identifiable information (e.g., the signed consent form with your name on it, as well as the key indicating which pseudonym you have been assigned) will be kept in a locked filing cabinet in Dr. Turner’s office at the Cross Cancer Institute. Only your de-identified material will be allowed out of the Cross Cancer Institute, and data will be protected by a password. Data will be stored for five years, at which time it will be permanently erased, shredded, and destroyed. Data will be safely stored for five years, at which time it will be permanently erased, shredded, and destroyed. You will not be identified by name in any reports of the completed study and the pseudonym you will be assigned will be used in reference to you in all transcripts, the final write-up, and future publications or presentations.

The researchers who are directly involved in your study may share information about you with other researchers, but you will not be identified in that shared information except by the pseudonym that you are assigned. The key that indicates which pseudonym you have be assigned will be kept secure by the researchers directly involved with your study and will not be released.

Although absolute confidentiality can never be guaranteed, Alberta Health Services will make every effort to keep your identifiable health information confidential, and to follow the ethical and legal rules about collecting, using and disclosing this information in accordance with the Alberta Health Information Act and other regulatory requirements.

The information collected during this study will be used in analyses and will be published and/or presented to the scientific community at meetings and in journals, but your identity will remain confidential.

“WHO DO I CALL IF I HAVE QUESTIONS OR PROBLEMS?”

As you are being invited to reflect on and share your experience of breast cancer, and how it has related to your psychological and spiritual well-being, parts of your participation may remind you of challenging times during your life that may affect you
emotionally. Although your courage to share your story is acknowledged and respected, the purpose of the study is not a form of personal counselling. In the event that your participation in the study raises something that you would like to discuss further in counselling, or if you feel emotional distress as a consequence of your participation in the study, you may approach any of the counselling resources listed below:

**Counselling Services Available in the Edmonton Area:**
- Psychosocial and Spiritual Resources - Alberta Health Services - Phone (###) ###-#### (no charge)
- The Hope Foundation of Alberta - Phone (###) ###-#### (sliding fee scale)
- University of Alberta - Faculty of Education - Clinical Services - Phone (###) ###-#### (one-time fee of $50)

If you have any questions or desire further information with respect to the study, you may contact the Co-Principal Investigator, Dawn Johnston at (###) ###-####, or the Co-Investigator, Dr. Marla Buchanan, at (###) ###-####.
Appendix G : Oath of Confidentiality

Confidentiality Agreement

**Project Title:** Reconstructing the Self: How women diagnosed with breast cancer re-negotiate a sense of self.

I, _____________________________, the *transcriber* have been hired to *transcribe audio recorded material.*

I agree to -

1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., computer files, tapes, transcripts) with anyone other than the *Researcher.*

2. keep all research information in any form or format (e.g., computer files, tapes, transcripts) secure while it is in my possession.

3. return all research information in any form or format (e.g., computer files, tapes, transcripts) to the *Researcher* when I have completed the research tasks.

4. after consulting with the *Researcher,* erase or destroy all research information in any form or format regarding this research project that is not returnable to the *Researcher* (e.g., information stored on computer hard drive).

*Transcriber*

________________________________________   ___________________________________________   __________________________
(Print Name)   (Signature)   (Date)

*Researcher*

________________________________________   ___________________________________________   __________________________
(Print Name)   (Signature)   (Date)
Appendix H: Confidentiality Agreement

Confidentiality Agreement

Project Title: Reconstructing the Self: How women diagnosed with breast cancer re-negotiate a sense of self.

1. The transcriber have been hired to transcribe audio recorded material.

I agree to:

1. keep all the research information shared with me confidential by not discussing or sharing the research information in any form or format (e.g., computer files, tapes, transcripts) with anyone other than the Researcher.

2. keep all research information in any form or format (e.g., computer files, tapes, transcripts) secure while it is in my possession.

3. return all research information in any form or format (e.g., computer files, tapes, transcripts) to the Researcher when I have completed the research tasks.

4. after consulting with the Researcher, erase or destroy all research information in any form or format regarding this research project that is not returnable to the Researcher (e.g., information stored on computer hard drive).

Transcriber

(Please sign here)

Date:

Researcher

(Please sign here)

Date:

Version: May 7, 2012
Appendix I : Questions asked of Peer and Expert Reviewers

Questions asked of Peer Reviewers:

1. Are the descriptions of the themes coherent?
2. Are the descriptions of the varying themes and subthemes comprehensive? Are there enough details and content?
3. In light of your own experiences, are these themes an accurate reflection of how women might re-shape their sense of self identity after being diagnosed with breast cancer?
4. Do you think that these findings might be helpful to other women diagnosed with breast cancer?

Questions asked of Expert Reviewers:

As you review these themes, I ask that you please keep in mind the following questions:

1. Are the descriptions of the themes coherent?
2. Is the description of the varying themes and subthemes comprehensive? Are there enough details and content?
3. In light of your expertise on this topic both with research and practice, are these themes an accurate reflection of how women might re-shape their sense of self identity after being diagnosed with breast cancer?
4. Are the findings helpful to other women diagnosed with breast cancer, or to counsellors working with women with breast cancer, or researchers in this field?