“Continuing a Normal Life as a Normal Person”: A Hermeneutic Phenomenological Study on the Reconstruction of Self Identity of Chinese Women Within the Lived Experience of Breast Cancer Survivorship

by

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Breast cancer incidence in Chinese women is rising in North America. However, a critical review of the empirical research reveals a clear under-representation of the breast cancer survivorship experiences of ethnic minority women, particularly those of Chinese origin. A breast cancer diagnosis not only disrupts a woman’s everyday life but also, and more importantly, her self-identity: who she was before the cancer diagnosis and who she becomes after the diagnosis.

The purpose of this study was to understand the lived survivorship experience of Chinese women with breast cancer, in particular the way they reconstruct their self-identity while living under the constant threat of premature mortality.

A hermeneutic phenomenology was employed to illuminate the essence of the lived experience. A purposeful sample of 24 Chinese women was recruited, and audiotaped face-to-face semi-structured interviews were conducted in English or Mandarin. An iterative process was carried out to identify themes and interwoven them into the four existentials of lifeworld to lend structural meaning to the lived experience.

The self-identity of Chinese women living with breast cancer did not fit the current combative survivor identity and narrative as represented in the North America media. Rather, a
‘quiet’, modest and practical narrative underscoring the Chinese virtues of self-reliance, endurance, and social responsibility and harmony characterized their lived experience and self-identity. They endured unexpected major life events and accepted what life offers in an effort to move on with their lives of being a normal person again.

An understanding of the way Chinese women manage the impact of breast cancer and their survivorship experience will significantly contribute to building our knowledge about this minority population within the Canadian context. In turn, this understanding will support health care professionals with the development of culturally sensitive psychosocial/supportive care services to maximize adaptation and recovery.
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CHAPTER 1
INTRODUCTION

While the science of survival attempts to understand the disease itself, the art of survival attempts to understand the human experience of that disease. (Leigh, 1992, p.1475)

1.1 Introduction to the Problem

Cancer is increasingly viewed as a curable disease for many and a chronic illness for others (Aziz & Rowland, 2003; Hewitt, Greenfield, & Stovall, 2006). As women with breast cancer are living longer, greater attention is being paid to the art of their survivorship experience. Artists, however, paint the canvass of survivorship without employing a full spectrum of available colours, thus resulting in narrower interpretation of the lived survivorship experience, including the images and identity of breast cancer survivors. A good understanding of survivorship as a lived experience necessitates distinguishing between public discourse and personal experiences of survivorship. The current discourse on survivorship is commonly characterized by the use of militaristic metaphors or heroic narratives and the assumption that all women embrace the 'survivor' identity as part of their recovery process. While the term “survivor” has broad application and various interpretations, the dominant images and identity of breast cancer survivors are often portrayed in media by middle-class Caucasian women as fighters, thrivers, or champions (Kaiser, 2008; President's Cancer Panel, 2004). They have overcome breast cancer and are openly honored and celebrated as triumphant, happy, healthy and feminine “survivors”. These dominant survivors’ images and identity are promoted and reinforced.
in various breast cancer fund raising events, such as the annual “Run for the Cure” (Kaiser, 2008).

Current extant psychosocial oncology and survivorship literature on breast cancer concentrate primarily on the experiences of Caucasian populations, while those of ethnic minority groups remain glaringly under-represented. In fact, the influence of the wider social context on survivorship experience is rarely identified as an important variable in research designs. Although there are universal experiences that unify women living with breast cancer, there also exist distinct survivorship differences based on social factors\(^1\) such as gender, ethnicity, culture, race and social class (American Cancer Society, 2009; Carver, Smith, Petronis, & Antoni, 2006), which represent a broader spectrum of colours on the canvas. Furthermore, the extent to which women of colour, including Asian women, identify with or reject the current dominant survivor identity and discourse is not well understood (Kaiser, 2008).

Breast cancer is a life-threatening illness and life-altering experience that not only disrupts the fabric of daily life, but also alters a woman’s self-identity\(^2\): who she was

\(^1\) Other social factors including sexual orientation are beyond the scope of this paper.

\(^2\) Historically, ‘self and identity’ have been conceptualized from diverse theoretical perspectives. It is a complex and multidimensional concept that is constantly evolving (Groome & Edwardson, 1996; Purdie, Tripcony, Boulton-Lewis, Fanshawe, & Gunstone, 2000). For this paper, ‘self-identity’ is employed as an interrelating concept based on Sökefeld’s (1999) reasoning that it is difficult to conceptualize individuals embracing a plurality of identities without referring to a self. He argues that there can be no identities without selves and there is a need to conceive of acting self \textit{in addition} to its identities. Self is based not only on having a physical body (Baumeister & Muraven, 1996), but also as having a reflexive sense that enables the person to distinguish self-consciously between himself or herself and everything else (Sökefeld, 1999); identity is an extension of the self. Identity or identities is a process of ‘becoming’ or ‘being’, never final or fixed (Jenkins, 2004). Thus, self is the object we act toward (based on reflexivity) and identity is the naming of that self, the name we call ourselves (Charon, 2004). Therefore, ‘self-identity’ concerns both who we are and what we think of who we are and is influenced by social structures within a cultural context (Purdie et al., 2000).
before the cancer diagnosis, who she is during treatment and who she becomes post-treatment. Studies on the effects of illness on self-identity from other diseases (Asbring, 2001; Bury, 1982; Charmaz, 1983, 1987; Corbin & Strauss, 1987; Fife, 1994) suggest individuals undergo a process whereby they come to terms with the physical and identity changes brought upon by their illness, which results in the redefinition of their self-identity and the creation of a partially new identity based on a novel situation (Corbin & Strauss, 1987). Although this process of change is supported in survivorship literature where, regardless of ethnocultural background, the breast cancer survivorship experience may result in positive transformation, personal growth or gains (Breaden, 1997; Fredette, 1995; Gaudine, Sturge-Jacobs, & Kennedy, 2003; Ho, Chan, & Ho, 2004; Pelusi, 1997; Vachon, 2001), little is known about the way these individuals deconstruct their previous self-identity and reconstruct a new self-identity as they attempt to restore a sense of life purpose and meaning (Fife, 1994; Kaiser, 2008). In fact, concepts such as social context, reconstruction and self-identity have received minimal attention in the survivorship literature. There exists a particular dearth of knowledge on how Chinese women living in Canada reconstruct their self-identities within these contexts of breast cancer survivorship.

1.2 Background of the Study

Cancer is a life threatening disease that does not discriminate by colour, race, culture, ethnic origin or social class. Among the increasing rates of cancer worldwide (American Cancer Society, 2009b; Seer Surveillance Epidemiology and End Results,
2009), breast cancer remains the most frequent diagnosis in women (Althuis, Dozier, Anderson, Devesa, & Brinton, 2005; Canadian Cancer Society, 2009). The mortality rate for breast cancer has, however, declined steadily since 1986 and is reported to be at its lowest since 1950; in Ontario, it is estimated that 88% of women are expected to survive the disease 5 years following diagnosis (Canadian Cancer Society, 2009) and overall are one of the more rapidly increasing population of survivors (Pelusi, 1997; President's Cancer Panel, 2004). A large number of studies have investigated the survivorship experience of women with breast cancer (Allen, Savadatti, & Levy Gurmankin, 2009; Ashing-Giwa, 1999; Ashing-Giwa et al., 2004; Carver et al., 2005; Dorval, Maunsell, Deschênes, Brisson, & Mâsse, 1998; Ferrell, 1996; Ferrell & Dow, 1996; Ferrell et al., 1996; Ganz et al., 2002; Hassey-Dow & Laffery, 2000; Holzner et al., 2001; Kaiser, 2008; Parry, 2008; Tomich & Helgeson, 2002); it is in fact, studied more often than other types of cancers, with a particular focus on the psychological and emotional impact on these women. The majority of studies, however, predominantly concentrate on middle to upper class American Caucasian survivors (Ashing-Giwa, 1999; Ashing-Giwa & Ganz, 1997; Aziz & Rowland, 2002), which raises concerns around acceptance of their experience as universal and the consequent negation of the influence of other important social factors, such as culture, on the illness experience.

Culture plays an important role in women’s health and their illness experience and influences their health beliefs and practices (Kleinman, 1988). Within the Chinese

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3 This study focuses primarily on the quality of life and survivorship experiences of women with breast cancer, not men with breast cancer. Men diagnosed with breast cancer have distinct gender needs and issues, which remain unexplored.
culture, self-sufficiency, self-sacrifice and face-saving are dominant values with respect to social responsibility and public family image, and to maintain harmonious interpersonal relations as a mean to preserving social order. These values influence the attitude of Chinese women towards their illness, their identity formation and the meanings they ascribe to breast cancer; in turn, these meanings shape the manner in which women experience breast cancer: how they respond to screening and treatment options, as well as the strategies they employ to cope with and make sense of their breast cancer illness and prevent recurrence (Anderson et al., 2003; Bilodeau & Degner, 1996; Fitch, Grey, Franssen, & Johnson, 2000; Klawiter, 2004; Kwok & Sullivan, 2006; Lam & Fielding, 2003; Wong-Kim, Sun, & DeMattos, 2003; Yeo et al., 2005). In a descriptive phenomenological study, Fu and colleagues (2008) found that Chinese women’s adjustment to breast cancer reflected deep rooted Chinese historical, social and cultural influences. To lessen the impact of cancer on others, these women kept the news of their cancer illness to themselves and internalized their feelings and thoughts in efforts to maintain harmony within and outside the family.

While the science of survival has made tremendous strides in the understanding of the disease itself, lesser progress has been made to understand the art of survival of ethnic minority populations, in particular, those of Chinese origin. Psychosocial oncology and survivorship literature is replete with the survivorship experience of Caucasian women (Aziz & Rowland, 2002, 2003), however, that of Chinese women with breast cancer remains largely unexplored in the US and Canada. Thus, there is a dearth of literature that specifically addresses questions such as: What are the long-term effects of breast cancer
treatment on the lives of Chinese women and their families? What influence do Chinese cultural values and beliefs have on the meaning and management of their illness, in particular the way they reconstruct their self-identity? What are their perceptions of the ‘survivor’ identity? Do they embrace or reject it? Completion of active cancer treatment does not signal the end of the cancer experience; most women who complete adjuvant therapy continue to struggle with the challenges of their illness across physical, psychological, social and existential domains, all of which affect their overall quality of life and survivorship experience (Ferrell & Dow, 1996; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998). Mullan (1985) refers to the period following adjuvant therapy as the “extended survival phase” of cancer, a period of watchful waiting with periodic examinations while an individual attempts to build a bridge between life as a patient and life under the constant fear of premature death. The fear of recurrence is likened to the sword of Damocles that continues to hang over persons diagnosed with cancer and their families for the rest of their lives (Muzzin, Anderson, Figueredo, & Gudelis, 1994) and is a reality that cannot be avoided (Mullan, 1984).

A life-threatening illness profoundly disrupts everyday life and threatens an individual’s ‘integrity of self’ (Charmaz, 1995). It challenges a person's way of living previously taken for granted, ways of interacting with others and ways of knowing one’s self (Charmaz, 2000). As Kleinman (1988) states, breast cancer is “a culturally marked illness, a dominant societal symbol that, once applied to a person, spoils radically the individual’s identity and is not easily removed” (p.22). Breast cancer challenges a
woman’s taken-for-granted assumption of the healthy functioning body\(^4\) and the unity between the body and self (Charmaz, 1995). The suddenness of a cancer diagnosis, the intensity of cancer treatments and the fear of premature death all threaten a woman’s confidence and self-identity. Breast cancer forces identity changes not only from having to endure the long-term physical and psychosocial effects of the disease, but also from inevitable existential questions about life’s meaning. Ultimately this results in a significant restructuring of one’s life, relationships, expectations and goals, as well as reconstruction of a new self-identity. Reconstruction is viewed as a fluid and continually evolving process that may occur throughout the illness trajectory. For women with breast cancer, however, existential questions about the meanings of their illness experience and their self-identity – who they were and who they have become - usually arise closer to or on completion of treatment, when less attention is directed towards getting through the treatments and more on getting on with life. This restructuring of life and reconstruction of self-identity transcends ethnocultural, racial and class boundaries (Anderson, Blue, & Lau, 1991).

The effects of illness on the self-identity of cancer patients remain unexplored. While literature is replete with the effects of chronic illnesses on self-identity, there is no acknowledgment of the social factors that shape a person’s reconstruction of new self-identity following a life threatening cancer diagnosis. In particular, there is a dearth of knowledge on how ethnic minority women reconstruct their self-identities within the social context of breast cancer survivorship. As the second largest immigrant group in

\(^4\) The concept of health is defined in terms of the absence of disease or injury (Evans & Stoddart, 1994).
Canada, an understanding of the quality of life and survivorship experiences of Chinese women with breast cancer is crucial and demands attention in psychosocial and survivorship oncology literature. The understanding on how they see themselves, who they want to become and how they wish others to see them are important factors that impact their quality of life.

1.3 Rationale for the Study

Canada is a culturally diverse nation. According to the 2006 Census Canada, over 5 million individuals in Canada are identified as members of the ethnic minority population, and 58% of the 1.1 million immigrants who arrived in Canada between 2001 and 2006 were from Asian countries; the Chinese are the second largest visible minority group in Canada (Statistics Canada, 2006). The incidence of breast cancer in Chinese women is on the rise (Facione, Giancarlo, & Chan, 2000; Kim, Ashing-Giwa, Kagawa-Singer, & Tejero, 2006). While there is an absence of Canadian statistics on ethnic women with breast cancer, US figures show that between 1992-2002, the overall breast cancer incidence in Asian American women/Pacific Islanders increased at a rate of 1.5% per year (American Cancer Society, 2006a). The adaptation of a western lifestyle has been cited as a primary reason for the higher rates among Asian and Asian American women in developed countries (Stanford, Herrinton, Schwartz, & Weiss, 1995). Chinese women living in North America for over a decade have an 80% overall higher risk for developing breast cancer than recent immigrants (Facione et al., 2000), which may be attributed to successive generations in, and acculturation to Canadian society (Facione et al., 2000; Kagawa-Singer & Maxwell, 1999). The diaspora created by the significant
migration of Chinese worldwide lends importance to the exploration of Chinese women’s health care needs and illness experiences. Despite the increasing culturally diverse landscape of Canada, few integrative theories in the domain of women’s health research incorporate the ethnoracial and sociocultural elements that shape women’s health and illness experiences (Grant & Ballem, 2000; Im & Meleis, 2001). Rather, literature is replete with biomedical theories that reduce women’s health and illness experiences into a disease or health problem (Im & Meleis, 2001). Notably, gender, ethnicity, race and social class are components rarely considered in Canadian health research and policies (Becker, 2004).

The current knowledge base on quality of life outcomes and breast cancer survivorship experiences has evolved from studies conducted primarily on Caucasian American women, manifesting a glaring absence of the psychosocial impact of breast cancer on ethnic minority women in psycho-oncology literature. With the increasing longevity of women with breast cancer, it is imperative that the voices, perspectives, concerns and survivorship experiences of ethnic minority women be heard and documented to promote their visibility in the psychosocial and survivorship oncology literature. The multitude of complex health care needs of these women and their ongoing involvement with the health care system in an economically constrained environment necessitates reconsideration of the utilization and delivery of existing services and resources. Of greater importance is the need to understand how Chinese women manage the impact of breast cancer and the experience of transformation of their lives, a crucial component for oncology social workers committed to assisting cancer survivors in their
recovery. The development of appropriate and culturally sensitive clinical psychosocial interventions throughout the illness trajectory requires health care professionals to understand and demonstrate sensitivity to the social issues of, gender, racism, ethnicity, culture and social class as well as the interactions with the health care system that influence the social construction of women’s health experiences. Thus, interventions that reflect the values of social justice and anti-racism/oppression practice require knowledge of the key influences that determine how Chinese women access appropriate health care services and reconstruct their self-identity post-treatment.

1.4 Purpose of the Study

The purpose of the study was to explore the lived survivorship experience of Chinese women with breast cancer, in particular how these women reconstruct their self-identity post-adjuvant treatment, while living under the threat of premature mortality. The findings from this research serve to broaden the interpretation of the lived survivorship experience of ethnic minority women living with breast cancer and provide direction for future research. This research focused on English-speaking and non-English-speaking (i.e. Mandarin-speaking) Chinese women living with breast cancer post-adjuvant treatment 6 months or longer, who had completed treatment and were considered disease-free.

The research question of this study was:

- What is the lived survivorship experience of Chinese women living with breast cancer?
1.5 Philosophical Underpinnings

The decision to employ hermeneutic phenomenology was steered by the fundamental principle of allowing the research question to guide the research method (Patton, 1990). Since the focus of the study was to understand a human experience or a phenomenon within the survivorship context, hermeneutic phenomenology seemed to be a natural choice as it afforded the framework to accomplish an in-depth exploration of a relatively new area of research, the lived survivorship experiences of Chinese women living with breast cancer. Hermeneutic phenomenology, or interpretative hermeneutic phenomenology, developed by Heidegger, is the study of the lived experience or the lifeworld (Creswell, 1998; Moustakas, 1994), which emphasizes historical lived experience and self-interpretation (Koch, 1995, 1999; Laverty, 2003). Heidegger believes that human experiences are embedded in social, cultural and political contexts (Lopez & Willis, 2004) and a person cannot live devoid of interpretation of human experiences (Koch, 1999; McConnell-Henry, Chapman, & Francis, 2009a). A person not only understands things intellectually or conceptually, but also experiences things in “corporeal, relational, enactive, and situational modalities” (van Manen, 1997, p.xiv). In the case of a woman, she experiences and knows things through her body, her relations with others and interactions with the things of her world (van Manen, 1997). A Chinese woman’s history or background, for example, including the culture bestowed upon her from birth and passed down, presents ways for her to understand the world and determines what counts as real (Laverty, 2003). In this study, the interplay of social factors such as gender, culture and social class is an important component to
understanding the way Chinese women reconstruct their self identity within the social context of breast cancer survivorship. This study was guided by van Manen’s (1997) hermeneutic method for data collection and analysis. Phenomenology is to recall, recollect or retrieve the essence of the lived experience. Hermeneutic phenomenology is interpretative and focuses on language and meanings; it offers the instrument to understand the structures of the human lifeworld: lived space (spatiality), lived time (temporality), lived body (corporality) and lived relations (relationality). The application of these four existentials of lifeworld facilitated an understanding of the lived survivorship experience of Chinese women with breast cancer during the distinct phase of survivorship in the cancer continuum.

The researcher’s integral involvement in the research process and intersubjective experience within interpretative research (Laverty, 2003; McConnell-Henry et al., 2009a) were also important considerations that favoured hermeneutic phenomenology. Given the shared membership with the participants, locating the researcher’s position in the research process was deemed essential in order to maintain rigor. For methodological rigor, the researcher engaged in reflexive practice throughout the research process, noting biases and assumptions as well as thoughts and emotional responses to the participants and the interview process. Rather than maintaining neutrality throughout the research process, the researcher openly acknowledged her position as an outsider, a social work clinician and doctoral student/researcher, as well as a Mandarin-speaking Chinese female insider. Through shared gender, culture, ethnicity and language, the participants and researcher intrinsically connected in co-creating an understanding and reconstruction of
meanings of their survivorship experience (Vis, 2005). A more detailed discussion of hermeneutic phenomenology is presented in Chapter 4.

1.6 Definitions of Concepts and Terms

1.6.1 Concepts of Disease and Illness

As the focus of this paper is on the lived survivorship experience of Chinese women living with breast cancer, lesser attention has been paid to the physical aspects of the disease. It is, however, necessary to distinguish between the concepts of disease and illness which, although related, differ in interpretation (Conrad, 1990). Disease is an undesirable physiological process or state. Illness, on the other hand, entails a social phenomenon that involves perceptions, behaviours and experiences that may or may not rest on a disease as a foundation (Conrad, 1990). Conrad (1990) identifies two illness perspectives: the outsiders’, etic, and the insiders’, emic. According to Conrad, etic views the illness from the objective outsider’s experience, which minimizes or ignores the subjective reality of the sufferer; it sees the patient, disease or illness as something to be affected. In contrast, emic focuses specifically on the subjective experience of living with the illness and the meanings that people attribute to it. It addresses the way people view and feel their disease has changed them and their lives, and how they adapt to the changes. This study adopts the emic view of looking at the subjective illness experiences and the meanings that Chinese women ascribe to breast cancer, and recognizes that the experiences of Caucasian women cannot be generalized to all women.
1.6.2 Concept of Breast Cancer Survivorship

Cancer survivorship is a well-used term by health care providers, researchers and patients to represent the state or process of living following a diagnosis of cancer, regardless of how long a person lives (Zebrack, 2000). It is a tumultuous experience of balancing the elation of surviving a life-threatening illness with the demands of ongoing health concerns and altered life meaning (Ferrell, 1996). The traditional biomedical model definition of cancer survival refers to the population of cancer patients who live disease-free for at least 5 years after treatment (Thewes, Butow, Girgis, & Pendlebury, 2004). For the purpose of this study, breast cancer survivorship is more broadly defined as a multidimensional concept that includes the experience of living with, through and beyond the illness post adjuvant therapy. Survivorship is not a stage or component of survival (Leigh, Boyle, Loescher, & Hoffman, 1993), but a process that is individualized, dynamic, unique, complex, multifaceted, interdependent and uncertain (Farmer & Smith, 2002). Survivorship encompasses the spiritual, psychological, physiological, sociological, vocational and sexual dimensions of cancer survivors’ lives (Ferrell, 1996) and the process of an individual’s lived experience with breast cancer (Farmer & Smith, 2002).

1.6.3 Concept of Reconstruction

Several terms are applied in the literature to describe the process whereby people integrate their cancer illness experience: restructuring, reconstituting, renegotiating, redefining and restoring. For the purpose of this paper, the locution ‘reconstruction’ was employed to describe the process whereby Chinese women integrate their breast cancer illness experience by defining and redefining their self-identity through social
interactions. The underlying assumption was that as part of the survivorship experience and recovery, identity reconstruction involved the integration of the cancer experience into one’s previous self-identity, which may lead to a new or renewed sense of self and thus change the way cancer survivors see themselves in relation to their social world (Charmaz, 2002; Zebrack, 2000). Reconstruction suggests that a cancer diagnosis initiates a new life path that extends over the remainder of one’s life, regardless of life expectancy (Zebrack, 2000). For some survivors, however, the experience may be unremarkable; they do not necessarily deny the experience but tend to minimize the impact of the disease as they resume their normal life (Vachon, 2001).

1.6.4 Concepts of Pragmatism and Practicality

Pragmatism is a philosophy defined by the doctrine that meanings of ideas or positions are sought in their practical bearings, that the function of thought is to guide action, and that truth is preeminently to be tested by the practical consequences of belief; this action translates to a practical, matter-of-fact approach to assess situations or solve problems (Merriam-Webster). For this paper, pragmatism refers to a mindset or an orientation to life that guides an individual’s actions and behaviours. An individual may or may not be consciously aware of this mindset. Pragmatism translates into thinking and behaving in a practical, matter-of-fact, or straightforward manner and takes into consideration the practical consequences of a thought or course of action.

1.6.5 Oncology Terms
Adjuvant therapy. Adjuvant therapy is a treatment method used in addition to the primary therapy to improve the chances of curing cancer. Examples of adjuvant therapy include the use of chemotherapy or radiation therapy after surgery (Canadian Cancer Society, 2009). Adjuvant therapy is commonly used to treat newly diagnosed breast cancer.

Long-term effects. Long-term effects refer to any side effects or complications from treatment for which a cancer patient must compensate; these effects begin during treatment and continue beyond the end of treatment (Aziz & Rowland, 2003).

Post-adjuvant treatment. Post-adjuvant treatment refers to a particular period of survivorship – the period following first diagnosis and treatment and prior to the development of a recurrence of cancer or death (Hewitt et al., 2006).

Survivor. A survivor in this paper refers to anyone who has been diagnosed with cancer, from the time of diagnosis to the end of life (Aziz & Rowland, 2003).

1.6.6 Qualitative Research/Phenomenological Terms

Being-in-the-world. Being-in-the-world is a Heideggerian idea that refers to the way human beings exist, act or are involved in the world, such as a man, woman, child or parent (van Manen, 1997). In other words, humans cannot abstract themselves from the world (Lopez & Willis, 2004).

Bracketing (epoche). Bracketing describes the act of suspending one’s various beliefs in the reality of the natural world in order to study the essential structures of the world (van Manen, 1997).

Dasein. Dasein refers to the entity that allows humans to wonder about their own existence and question the meaning of their Being-in-the-world (Dreyfus, 1991; McConnell-Henry et al., 2009a).

Dualism. Dualism is the idea that reality consists of two separate parts, and it is accompanied by binary thinking commonly expressed in distinctions such as good or bad, mind-body, experience-reason, and so on (Schwandt, 2007).

Essence. The term essence is derived from the Greek word ousia, which means the inner essential nature of a thing, the true being of a thing. Essence is that what makes a thing what it is rather than its being or becoming something else. Essence often refers to the ‘whatness’ of things, as opposed to their thatness (van Manen, 1997).

Hermeneutics. Hermeneutics is the theory and practice of interpretation. The word hermeneutics comes from the Greek word hermeneusin, a verb, meaning to understand or
interprets (van Manen, 1997). Traditionally, hermeneutic is the art of interpretation
(Laverty, 2003).

**Hermeneutic Phenomenology.** Hermeneutic Phenomenology is a descriptive
(phenomenological) methodology because it wants to be attentive to how things appear
and to let things speak for themselves; it is also an interpretive (hermeneutic)
methodology because it claims that there are no uninterpreted phenomena (van Manen,
1997).

**Hermeneutic Circle.** Hermeneutic Circle refers to the circular movement from the whole
to the parts, incorporating the contributions of all deconstruction and then reconstruction,
resulting in a shared understanding. By utilizing the hermeneutic circle the researcher
attempts to ’read between the lines’ and uncover the true essence of the experience
(McConnell-Henry et al., 2009a).

**Intentionality.** Intentionality indicates the inseparable connectedness of the human being
to the world (van Manen, 1997).

**Lifeworld.** A life world refers to the world of lived experience, or a “world of immediate
experience” (van Manen, 1997).

**Lived Experience.** Dilthey (1985) describes a “lived experience” as involving our
immediate, pre-reflective consciousness of life: a reflexive or self-given awareness which
is, as awareness, unaware of itself (as cited in van Manen, p.35).

**Lived Meaning.** Lived meaning refers to the way a person experiences and understands
his or her world as real and meaningful. Lived meanings describe those aspects of a
situation as experienced by the person in it (van Manen, 1997).

**Phenomenological Reduction.** Phenomenological reduction is a technical term that
describes the phenomenological device which permits us to discover what Merleau-Ponty
(1962) calls the spontaneous surge of the lifeworld. To come to an understanding of the
essential structure of something, we need to reflect on it by practicing a certain reduction
(van Manen, 1997).

**Reflexivity.** Reflexivity is defined as a process of self awareness that clarifies how one’s
beliefs have been socially constructed and how these values impact interaction and
interpretation in research settings (Gerbich, 1999).

**Repetitions.** Repetitions refer to phrases or concepts that occur and reoccur (Ryan &
Bernard, 2003).

**Theme.** Theme is the form of capturing the phenomenon one tries to understand. Theme
describes an aspect of the structure of lived experience (van Manen, 1997).
manifested in generalized statements by the informants about beliefs, attitudes, values, or sentiments (Luborsky, 1993).

Theme Analysis. Theme analysis refers to the process of recovering the theme or themes that are embodied and dramatized in the evolving meanings and imagery of the work (van Manen, 1997).

1.7 Format and Organization of the Study

The study is organized and presented in seven chapters.

Chapter Two provides a critical analysis of the existing empirical literature on breast cancer survivorship and survivor identity; it identifies the gaps in research and justifies the need for this study. A comprehensive review of research literature in psychosocial oncology and survivorship highlighted the need for further research on the survivorship experiences of ethnic minority and non-English women, in particular Chinese women living in Canada.

Chapter Three highlights three theoretical perspectives, symbolic interactionism, Charmaz’s theory on the effects of illness on self-identity and Asian American feminism, to understand the influence and intersection of social factors in shaping the lived experience of Chinese women with breast cancer. A Chinese cultural model is also offered to understand how Chinese cultural values and beliefs shape the reconstruction of their “new” self-identity. Together, they informed the exploration of the lived survivorship experience of Chinese women living with breast cancer, particularly the reconstruction of their self-identity post-adjuvant treatment.

Chapter Four presents an examination of the philosophical underpinnings of the study. To answer the research question, this study employed a hermeneutic
phenomenology to illuminate the essence of the lived survivorship experience of Chinese women living with breast cancer, in particular their reconstruction of self-identity. Key relevant phenomenological principles are presented and several explanations offered to support the use of hermeneutic method. A description of the study objective and methods used for recruitment process, sample population and pilot-testing is presented.

Chapter Five presents a detailed description of data collection, management and analysis, including transcription and translation issues and challenges. Rigor and ethical considerations in the study are also addressed.

Chapter Six describes the sample population and examines the incidental and essential themes derived from, and interwoven into the four existentials of lifeworld to lend structural meaning to the lived experience of breast cancer of Chinese women, in particular the way they reconstructed their self-identity.

Chapter Seven discusses the findings and implications for social work education, clinical practice and policy/program development, limitations of the study and direction for future research.
CHAPTER 2
REVIEW OF EMPIRICAL LITERATURE

This chapter provides a critical analysis of the existing empirical literature on breast cancer survivorship and survivor identity, identifying the gap which justified the need for this study. There were three questions that guided the review of the empirical literature: (i) What is currently known about the survivorship experience? (ii) What is currently known about ethnic minority women’s survivorship experiences? and (iii) What is missing from the current survivorship literature? The dearth of research studies on the survivorship experiences of ethnic minority women with breast cancer and its influence on self-identity, in particular Chinese women, necessitates drawing upon studies from the US, China and other international sources. A systematic search of the literature was conducted focusing on studies published between 1990 and 2009 in major electronic databases such as Medline, PubMed, CINAHL, PsychINFO, Sociological Abstracts, AnthroSource and Anthropology Plus; key search words included breast cancer, chronic illness, Chinese/Asian/Canadian women, immigrant women, survivorship, illness experience, self-identity, culture, diversity, race, ethnicity and gender.

2.1 Current Knowledge on Survivorship Experience

The basic tenet of modern medicine is to cure a disease. The post-positivist paradigm remains the dominant epistemological perspective in health research, which adopts a specific method of asking questions and obtaining answers. It assumes a tangible reality that may be controlled by a set of variables and measured independently. The aim is to create a law-like body of knowledge in the form of general truth statements that are bias free. According to this belief, every action may be explained as a result of a real cause that precedes the effect temporally (Rodwell, 1987). Randomized-controlled studies are the ‘gold standard’ for scientific enquiries
and validation. Though useful, this approach neglects to capture the health and illness experience of women, in particular ethnic minority women and non-English speaking immigrant women, who are often excluded from clinical trials and research studies due to language barriers and lack of appropriate culturally translated validated instruments. The exclusion of these women limits generalizability of findings and ascertainment of influential social factors (Ashing, Padilla, Tejero, & Kim, 2004). Non-English speaking women are systematically excluded because of the difficulty and costs associated with translation and administration (Frayne, Burns, Hardt, Rosen, & Mokowitz, 1996). As a result, research on the health and illness experiences of ethnic minority women including non-English speaking immigrant women is notably absent.

Existing studies on the impact of breast cancer on the lives of Chinese women have customarily relied largely on quantitative methodology, especially comparative analysis (Chiu, 2004). Few studies consider the subjective and qualitative experience of these women. This serious omission fails to explain how female participants construe their illness experience, restructure their lives in accommodating the altered body, reconstruct their self-identity and draw on meanings relevant to their self-perceived gender and cultural roles (Chiu, 2004).

The emotional and psychological impact of breast cancer diagnoses and subsequent cancer treatments in women are well documented in the literature: disruptions in family routines, psychosomatic conditions such as sleep disturbances, heightened feelings of depression and anxiety, fears about cancer, its treatment, recurrence and death, and concerns about their ability to cope with the illness (Allen et al., 2009; Ashing, Padilla, Tejero, & Kagawa-Singer, 2003; Ashing-Giwa & Ganz, 1997; Breaden, 1997; Fredette, 1995; Gall, de Renart, & Boonstra, 2000; Ganz et al., 2002; Gray et al., 1998; Holzner et al., 2001; Kornblith & Ligibel, 2003; Payne, Sullivan, & Massie, 1996; Tasmuth, von Smitten, Hietanen, Kataja, & Kalso, 1995). As women
are living longer, increased attention is being paid to the long-term effects of breast cancer on quality of life and survivorship. Research reflects that many survivors continue to struggle with the long-term effects years after completion of treatment, which negatively impacts their quality of life. Long-term effects include limitations in arm and shoulder function due to surgery (Cancer Care Ontario Practice Guidelines Initiative, 2004; Kornblith & Ligibel, 2003); lymphedema (Ganz, 1999; Hayes, Janda, Cornish, Battistutta, & Newman, 2008; Mak et al., 2009); fatigue (Wilmoth, Coleman, Smith, & Davis, 2004); pain (Ferrell, Hassey-Dow, Leigh, Ly, & Gulasekaram, 1995; Steegers, Wolters, Evers, Strobbe, & Wilder-Smith, 2008); premature menopause (Jansen, Miaskowski, Dodd, & Dowling, 2005; Tchen et al., 2003); cognitive impairment (Jansen et al., 2005; Tchen et al., 2003; Weis, Poppelreuter, & Bartsch, 2009); body image and sexual and reproductive concerns (Kornblith & Ligibel, 2003; Thaler-DeMers, 2001; Wilmoth et al., 2004); fear of recurrence (Allen et al., 2009; Ashing-Giwa et al., 2004; Hassey-Dow, 1990); anxiety, depression and post-traumatic stress disorder (Amir & Ramati, 2002; Levine, Eckhardt, & Targ, 2005; Luecken, Dausch, Gulla, Hong, & Compas, 2004; Smith, Redd, Peyser, & Vogl, 1999); and financial or employment difficulties (Bradley & Bednarek, 2002; Maunsell, Brisson, Dubois, Lauzier, & Fraser, 1999; Park, Park, Kim, & Sung-Gyeong, 2009; Spelten, Sprangers, & Verbeek, 2002; Stewart et al., 2001).

2.1.1 Impact on the Family

Breast cancer is a ‘family’ disease that has a devastating impact not only on the woman diagnosed with the disease, but also on her family. It alters familial relationships and social support systems, and disrupts family routines and household roles (Lewis, Ellison, & Fugate Woods, 1985). Studies on marital relationships and marital satisfaction show that a diagnosis of breast cancer may strengthen family ties and interpersonal relationships or draw them apart
(Morgan et al., 2005; Northouse & Peters-Golden, 1993; Pistrang & Barker, 1995; Sormanti & Kayser, 2000; Zahlis & Shands, 1991; Zunkel, 2002). Whereas Caucasian women primarily identify their husband as their main source of support, ethnic minority women largely depend on their family (Ashing-Giwa et al., 2004). Asian American women are expected to self-sacrifice, nurture husband and family, and promote harmony over intimacy in marital relationships; Caucasian American women, on the other hand, emphasize intimacy over harmony (Kagawa-Singer & Wellisch, 2003).

The effect of parental cancer on children is also receiving increased attention. However, most of the studies are descriptive in nature and employ self-reported measures. They focus on early stage disease or newly diagnosed parental cancer, and thus very little is known of the effects of children living with parental cancer across the survivorship continuum (Lewis, 2007). Evidence to date suggests that children’s psychosocial functioning is related to family functioning in terms of communication and expressiveness and they are more likely to internalize problems (Osborne, 2007). Of significance, adolescent daughters are affected more negatively than adolescent sons due to greater family responsibilities as well as fear of developing breast cancer themselves (Grabiak, Bender, & Puskar, 2007). Although the results are mixed, initial evidence suggests that maternal depression and adjustment is associated with increased distress in children (Osborne, 2007).

2.1.2 Emotional and Psychological Impact

A cancer diagnosis is a traumatic event for many women who are understandably overwhelmed by fears of death, disfigurement, life changes or suffering from pain. In recognition cancer as a precipitating traumatic event stressor, the modification of Diagnostic and Statistical Manual of Mental Disorders, IV (American Psychiatric Association, 1994) has promoted
research interest in the application of a Post Traumatic Stress Disorder (PTSD) framework to understand the psychosocial adjustment in cancer survivors (Levine et al., 2005; Smith et al., 1999). In a long-term follow-up study on breast cancer survivors, 5 to 15 years post adjuvant treatment, Kornblith et al. (2003) found that although most survivors recovered from their cancer diagnosis and treatment, a subset of survivors continued to experience psychological and emotional distress, including PTSD, cancer-related sexual difficulties and lymphedema. For this small set of survivors, the impact of cancer was not entirely forgotten. Even with partial PTSD, symptoms may seriously impair quality of life. For survivors who have recovered, other negative stressful life events, such as the death of a loved one, or adequacy of social support, may offset any lasting impact of cancer and supercede the importance of diagnosis in survivors’ distress.

2.1.3 Body Image and Sexuality

Breast surgery affects a woman’s body image and sexuality. The loss of a breast threatens a woman’s femininity and sexuality, particularly in an image-conscious Western society. Kornblith and Ligibel (2003) reported that many breast cancer survivors identified body image concerns as a result of surgical treatment, including psychosocial distress over scars and a reduced sense of attractiveness, which negatively affected their self-esteem, social relationships and quality of life. Some women reported difficulty finding suitable clothing and were uncomfortable in revealing clothes such as halter tops, strapless dresses and bathing suits, and thus avoided related leisure activities (e.g. going to the beach or swimming pool). Weight gain is a common occurrence in women with breast cancer on account of decreased physical activity and metabolism, and hormonal changes (Wilmoth et al., 2004). While it further contributes to deceased feelings of attractiveness and sexuality, weight gain also increases health risks such as heart disease, osteoporosis and diabetes (Wilmoth et al., 2004).
2.1.4 Impact of Chemotherapy

Chemotherapy improves long-term survival for most women with breast cancer, however, greater attention is now being paid to the impact of its toxicities on cognitive functioning. Cancer patients receiving chemotherapy report increased difficulty in their ability to remember, think and concentrate (Jansen et al., 2005; Weis et al., 2009). Symptoms described as “chemo-brain” or “chemo-fog” profoundly affects their ability to perform activities of daily living and work-related job tasks. In a study of women receiving adjuvant chemotherapy for breast cancer, Tchen and her colleagues (2003) found that most women experienced significant cognitive deterioration, fatigue and menopausal symptoms. Evidence suggests that women with chemotherapy-induced menopause endure more severe symptoms than those who experience menopause naturally, including hot flashes, cold and night sweats, mood disturbances and decreased or loss of interest in sex.

2.1.5 Fatigue

Fatigue, a major side-effect of cancer therapy, is also receiving more attention due to its debilitating effect on a person’s quality of life. Cancer-related fatigue is “a distressing persistent, subjective sense of tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning” (National Comprehensive Cancer Network, 2007). Fatigue affects a person physically, socially, emotionally and psychologically. It restricts the person’s ability to perform self-care activities (e.g. bathing), daily activities of living (e.g. housecleaning or cooking) and to engage in social activities (e.g. socializing with friends or going out for dinner); it is also positively correlated to depression and menopausal symptoms (Tchen et al., 2003; Wilmoth et al., 2004).
2.1.6 Employment and Returning to Work

Maintaining employment and returning to paid work are important aspects of community reintegration and preserving one’s quality of life. Resuming employment symbolizes a positive step towards establishing a ‘new’ normal and provides not only the much-needed financial support, but also and more importantly, self-identity (Kearney Mahar, Brintzenhofeszoc, & Shields, 2008; Maunsell et al., 1999). A person’s sense of self-worth and self-identity is largely derived from his/her occupational role (Bradley & Bednarek, 2002). In a review of literature that examined the rate of return to work and the influencing factors, Spelten and her colleagues (2002) determined that approximately 62% of cancer survivors returned to work, 74% of whom were younger than 50 years of age, and only 30% older than age 50 years. They also found that a non-supportive work environment and manual labour were the most common reasons cited for preventing return to work. Other studies that examined survivors’ experiences of return to work identified other employment-related problems, such as job loss, denial of new jobs, demotions, unwanted changes in job tasks, difficulties with employer and co-workers, changed attitudes toward their work and diminished physical capacity due to cognitive impairments, fatigue and lymphedema.

2.1.7 Insurance Coverage and Benefits

Fear of losing existing short and long-term disability benefits, health and drug benefits and life insurance coverage frequently discouraged people from pursuing job changes. As well, a diagnosis of cancer significantly decreases the potential to secure new health and life insurance policies for survivors (Stewart et al., 2001). Notably, these problems were identified in early studies among survivors treated more than 20 years ago, yet prevail today and are embedded in
women’s survivorship experiences (Maunsell et al., 1999). Research is clearly needed to determine the prevalence of these problems and to distinguish whether they are specifically associated with breast cancer or the result of extended sick leave from work (which may last up to a year) or simply a competitive job market.

2.1.8 Impact on Older and Younger Women

Recent research has found that the effects of breast cancer on quality of life are influenced by a woman’s age. Younger women, under 50 years of age, have a more aggressive disease, a higher rate of recurrence and poorer prognosis than women over 50 years of age (Sammarco, 2001). They are more likely to receive aggressive adjuvant treatments that increase the risk for developing osteoporosis (Bruning, Pit, de Jong-Bakker, van den Ende, & van Enk, 1990), diabetes (Wilmoth et al., 2004) and cardiovascular disease (Barrett-Connor & Bush, 1991). Although breast cancer survivors of all ages share common concerns, experiences and anxieties, there exist distinctive quality of life differences between younger and older women (Sammarco, 2001), including psychological distress, sexual functioning, body image concerns, relationship problems, unmet information needs and financial or vocational difficulties (Thewes, Meiser, Rickard, & Friedlander, 2003).

The long-term impact of breast cancer therapy on reproduction and sexuality are two major issues that uniquely affect young pre-menopausal survivors. It disrupts the women’s reproductive years and impacts their chances of bearing children, feelings of sexual attractiveness, enjoyment of having frequent and pleasurable sex, and the ability to have a committed relationship (Schover, 1994, 2000). They may also experience a distressing range of physiological symptoms including vaginal dryness, hot flushes, dysparuenia, mood fluctuations and short-term memory loss (Ganz, Rowland, Desmond, Meyerowitz, & Wyatt, 1998).
Compared to older women with breast cancer, younger women are particularly vulnerable to the physical and psychological sequelae of the disease (Arndt et al., 2004; Lam, Chan, Ka, & Fielding, 2007) where they experience poorer psychological adjustment, higher cancer-related PTSD, greater fear of disease recurrence, and increased disruptions to family relationships, and personal and social lives, than their older counterparts (Ferrell et al., 1996; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997; Hassey-Dow & Laffery, 2000; Mosher & Danoff-Burg, 2005; Sammarco, 2001). Furthermore, younger women also experience greater financial and vocational difficulties from loss of more days away from work and childcare problems, which also affect their quality of life (Thewes et al., 2004).

Undoubtedly, the long-term effects of cancer treatments profoundly affect all dimensions of a woman’s life, which results in a major process of deconstructing and reconstructing her self-identity as she comes to terms with the physical changes, successfully negotiates role and relationship disruptions, and accepts the altered body, the ‘new’ self-identity.

### 2.3 Current Knowledge on Ethnic Minority Women’s Survivorship Experience

Notwithstanding the considerable body of literature on the impact of breast cancer and survivorship experiences, the extent of its influence on ethnic minority women and the physical changes remain unexplored. While recognizing the importance of understanding the impact of the physical changes in these women, this paper predominantly examines the reconstruction of self-identity of Chinese women in light of the long-term effects of the illness experience. Literature on the effects of a major illness, such as breast cancer, on self-identity suggests it may result in positive transformation; however, how Chinese women accept the physical changes from the cancer treatments and how the breast cancer illness experience shapes the perception of
themselves and their illness remains unclear. Thus far, research on ethnic minority women is largely confined to epidemiological analyses of cancer risk and survival, early detection and screening, quality of life and health beliefs and practices. Emerging exploratory studies, however, have begun to focus on the lived experiences of breast cancer survivors and are inclusive of diverse samples (Ashing et al., 2003). Qualitative research offer the tools that enable discovery of new knowledge and a deeper, richer understanding of participants’ experiences through open dialogue with the researcher (Padgett, 1998). A handful of qualitative studies focused on the survivorship experiences of African American women revealed they experienced psychological distress, problems with body image, sexual, marital, rehabilitation and physical concerns, as well as employment difficulties as a result of breast cancer diagnosis and treatment (Ashing-Giwa, 1999; Ashing-Giwa & Ganz, 1997). More importantly, they found talking about their experiences to be cathartic, which lends significance to having their experiences acknowledged and validated (Ashing-Giwa & Ganz, 1997).

In one of the few studies on racial and ethnic differences in post-treatment symptoms among women, Eversley et al. (2005) found a significant association between symptoms and socioeconomic factors such as ethnicity and income. African American and Latina women experienced higher levels of pain and lymphedema compared to Caucasian and other ethnic women. Additionally, for Latina women, higher depression and fatigue, lower income, having a mastectomy and chemotherapy were predictors of high post-treatment symptom distress. The results from this study also suggest that socioeconomic factors play an important role in determining women’s ability to seek post-treatment rehabilitative care.

To date, only a few studies have investigated illness experiences and breast cancer survivorship in Asian American women (Ashing et al., 2003; Ashing et al., 2004; Ashing-Giwa
Chinese women in mainland China (Cui et al., 2004; Fu, Xu, Liu, & Haber, 2008; Li & Lambert, 2007; Lu et al., 2007), Chinese women in Hong Kong (Ching, Martinson, & Wong, 2009; Lam et al., 2007; Lam & Fielding, 2003; Lam, Fielding, Ho, Chan, & Or, 2005; Simpson, 2005), and Chinese women in Australia (Kwok & Sullivan, 2006; Yeo et al., 2005). These studies have focused primarily on cultural beliefs and health practices, treatment decision-making, information needs, disclosure, coping and adaptation, and illness experience and quality of life.

As an example, Kagawa-Singer, Wellisch and Durvasula (1997) explored the cultural impact of breast cancer on Asian (Chinese and Japanese) and Caucasian American women and found differences between the two in cultural beliefs pertaining to the central role of the family, women’s roles, self-sacrifice and the group-centered aspect of an Asian society. Specifically, Asian American women sought professional assistance for psychosocial problems at a significantly lower rate than Caucasian women, based on their cultural values of self-reliance and face-saving. In the Asian culture, accepting assistance entails an obligation to repay the favour in kind. Asian women resorted to other modes of help-seeking behavior, such as relying on their inner resources, for emotional concerns, and sought different sources of social support than Caucasian women.

Similar findings were observed in a qualitative study by Ashing-Giwa et al. (2004). In addition to common concerns shared by all women relating to health, physical well-being, recurrence or metastases, children, body image and sexual health, they also identified ethnic and cultural differences in women’s illness experiences. Whereas Caucasian women were more concerned with the loss of autonomy and loss of a breast, Asian, African and Latin women were more worried about caregiving and being a burden on their family. Cultural factors were found to
influence the way women coped with their illness and central to their coping mechanisms was their reliance on spiritual beliefs and practices. Regardless of ethnic differences, all women displayed resilience in their survivorship experience. Many African American women drew on their long legacy of resilience and survivorship. Asians and Latinas responded to their feelings of emotional displacement by relying on their inner strength and focusing on their families and household responsibilities. A large number of Caucasian women resorted to personal empowerment, individual responsibility and knowledge as their source of resilience while Asian women gained spiritual strength and support through connectedness with their family. As Chiu (2004) states, Asian women “consciously or unconsciously anchored themselves in their culture values that provided spiritual strength and power of interpretation to their health and illness” (p.182). Spirituality and religion are important components of recovery for most Asian women who tend to perceive the outcome of their illness and their fate as being in the hands of God (Ashing et al., 2003; Ashing-Giwa et al., 2004).

Li and Lambert’s study (2007) utilized a descriptive and prospective survey design to identify the coping strategies employed by Chinese women with breast cancer in mainland China and also to determine the demographic characteristics and coping strategies that were best predictors of general well-being. The findings showed that planning (thinking about how best to handle their health-care problem and making definitive plans accordingly), positive reframing (reframing their health-care situation in a different light to make it more positive), and self-distraction (doing something to distract themselves from the stress of their existing health threat) were the most commonly used coping strategies, which underscores the Chinese characteristic of working towards a “constantly striving spirit”. These Chinese women responded to their illness by engaging in productive activities or doing something helpful for themselves or others. The
best predictors of general well-being were employment status and the coping method of self-blame. Self-blame was found to be a negative predictor of general well-being and associated with psychological distress. Paid work promoted the women’s general well-being and ability to engage positive coping methods. Similar results were also reported in other studies on employment and returning to work (Bradley & Bednarek, 2002; Kearney Mahar et al., 2008).

Ching and her colleagues (2009) undertook a qualitative study to understand the psychological adjustment of Hong Kong Chinese women with breast cancer by identifying dispositional and contextual factors. The findings from this study highlighted the significance of coping and acknowledging the role of self in creating a subjective positive interpretation, which enhanced the acceptance of the disease. Reframing was a key factor in the adjustment process of these Chinese women; they reconstructed a perspective which accommodated the diagnosis and impact of breast cancer, thus enabling them to understand, predict, and continue to live and function. Furthermore, a sense of control and acquiescence to fate (a yielding approach) were important factors in aiding them to gain control of their problems through their own efforts or their social support system. Contrary to the emphasis on control of events and outcomes by North Americans, the adoption of a yielding approach by the Chinese women did not result in helplessness, hopelessness and avoidance; rather, they displayed self-confidence in their ability to endure the suffering. Self-reliance and endurance are highly valued virtues in the Chinese culture and historically the Chinese are accustomed to sustaining themselves during adversity. The findings of this study also showed that the Chinese women participants placed great trust in their health care providers and depended on them for decision-making and advice, which accentuates the Chinese cultural values of acceptance of, and deference to authority.
In another qualitative study which explored the meanings of breast cancer experience of Hong Kong Chinese women, Lam and Fielding (2003) found several influences that affected their quality of life. First of all, the interruptions imposed by breast cancer over-ride the women’s previous assumptions about life and ultimately forced them to re-organize and re-define the meanings of breast cancer. Coming to terms with breast cancer as a life threatening illness meant not only facing the threat of death, but also the possibility of social rejection and exclusion. The loss of an individual’s self-identity is secondary to the rejection of having a ‘spoiled’ identity in a collectivist culture and a society that is intolerant of differences and non-conformity. Therefore, for these Chinese women, social exclusion was a major concern.

Secondly, physical changes from the cancer treatment profoundly impacted the women’s self-identity; definitions of self are constructed and reconstructed through symbolic physical interactions with the world and others, thus any changes of the body call for major restructuring of self-identity. Despite the fact that the breast cancer experience leads to redefinition of social relationships, the questioning of life priorities and confronting possible death, consistent with Western literature, these Chinese women were nevertheless able to construe positive meanings from their illness experience.

Kwok and Sullivan’s study (2006) on Chinese Australian women also supports ethnicity and culture as important influences on women’s beliefs about cancer and helps explain their cancer screening behaviours. They interviewed 20 Chinese-Australian women and found that their image and perceived causes of cancer were thought to be products of their religious, cultural and everyday life, as opposed to the Western biomedical causes of smoking, diet, sun bathing and alcohol use. Fear, mystery, contagion and stigma were embedded in these images of
cancer; the perceived causes of cancer were identified as lifestyle, stress, environment, genes, unknown causes and destiny and were laden with cultural and social meanings.

2.3 Gaps in the Current Survivorship Literature

The long-term effects of breast cancer treatments profoundly affect all the domains of a woman’s life including her sense of self. She experiences identity struggles imposed by the late effects and undergoes a major restructuring of self-identity in adapting to the altered body. The results from the breast cancer survivorship studies on Chinese women living in the US, mainland China, Hong Kong and Australia offer significant insights into the influence of gender, ethnicity, culture and class on identity formation and survivorship experience. In a collectivist society that emphasizes social order, obedience, and harmony, pressures are exerted on a person to develop social roles that conform to established cultural values, norms and expectations. Thus, social role is a greater determinant of self-identity in the Chinese culture than in individualistic communities (Lam & Fielding, 2003; Uba, 1994). While studies on Chinese women demonstrate that their coping, acceptance and adaptation to breast cancer reflect their cultural values, beliefs and norms, little is known of the influence these values, beliefs and norms have in shaping the reconstruction of self-identity as part of the lived survivorship experience while living under the Damocles’ sword. To date, there are no reported Canadian studies on the reconstruction of self-identity of Chinese women who live with breast cancer. Reconstruction of self-identity within this ethnic population is strongly reliant on a woman’s interpretation of what others think about her, as her perception of self is significantly influenced by how she defines herself within the social world and her interactions with others (Fife, 1994). In response to the gap, this study was conducted to explore a relatively new area in-depth with the objective to understand how
Chinese women reconstruct their self-identity post-adjuvant treatment as part of the breast cancer lived survivorship experience, while living under the threat of premature mortality.
CHAPTER 3
THEORETICAL PERSPECTIVES

This chapter highlights three theoretical perspectives, symbolic interactionism, Charmaz’s theory on the effects of illness on self-identity and Asian American feminism, to understand the influence and intersection of social factors in shaping the lived experience of Chinese women with breast cancer. A Chinese cultural model is also offered to understand how Chinese cultural values and beliefs shape the reconstruction of their “new” self-identity. Together, they informed the exploration of the lived survivorship experience of Chinese women living with breast cancer, particularly the reconstruction of their self-identity post-adjuvant treatment. The conceptual framework lays the foundation for future research on the subjective perceptions of Chinese women, the symbolic meanings they attach to their ethnic, racial and class self-identities, how these perceptions are transmitted and reinforced through social interactions within the health care system and how they influence the reconstruction of their self-identity. To fully develop an integrative conceptual framework, this section summarizes symbolic interactionism and Charmaz perspectives (1983; 1987; 1994; 1995; 1999; 2000; 2002) on the effects of an illness experience on self-identity, and thereafter critically reviews their applicability specifically to women with breast cancer post-adjuvant treatment as they reintegrate into their community while living under the constant threat of premature mortality. An overview of the Chinese culture and attitudes towards health and illness is presented, and Asian American feminism discussed in relation to the influence of gender, ethnicity and race in shaping the reconstruction of self-identity of Chinese women.
3.1 Symbolic Interactionism

Jenkins (2004) defines self as “an individual’s reflexive sense of his or her own particular identity, constituted vis-à-vis others in terms of similarity and difference, without which she or he wouldn’t know who they are and hence wouldn’t be able to act” (p.27), and identity as “our understanding of who we are and who other people are, and reciprocally, other people’s understanding of themselves and others” (p.5). In other words, identity refers to a person’s location in social life (Charon, 2004). Social identity is derived from the interactions and identifications others make within community memberships, while personal identity is derived from the personal identifications that an individual makes (Hewitt, 2000). These identities are constructed through interactions and become part of the self-concept when they are internalized (Charmaz, 1994). This paper employs Charmaz’s theory on the effects of a physical illness on self-identity to understand how breast cancer affects Chinese women in reconstructing their self-identities. Charmaz’s key argument is that people experience identity struggles imposed by a physical illness and adapt their identity goals in response to the physical changes (Howard, 2000); further, these changes in identities influence and shape the evolving self (Charmaz, 1987).

While there are several perspectives on self-concept, this paper emphasizes a sociological perspective of self that is constructed through reflexive interactions with others (Charon, 2004) within the context of a life-threatening illness. In particular, a symbolic interactionist perspective is used to understand how the reconstruction of Chinese women’s self-identity is shaped by the social context of survivorship. Symbolic interactionism is a social constructionist approach to understanding how individuals construct reality through active interactions with others (Charon, 2004). It is historically rooted in the philosophy of pragmatism and heavily influenced by the work of George Herbert Mead, a philosopher and psychologist in the early twentieth century. As
a pragmatist, Mead views living things as constantly attempting to make adjustments to their environment (Blumer, 1969). Central to symbolic interactionism is the person’s social interaction with the environment (Charon, 2004). Mead argues that the person acts towards things on the basis of the meanings that it has for him, the meanings arise out of the social interactions that he has with others, and these meanings are handled, and modified through, an interpretive process used by the person in dealing with the things he encounters (Blumer, 1969). The ‘self-identity’ is constructed from these social interactions over time. In other words, the world does not tell the person what it is; rather, he actively interprets the world, understands it and decides what to do with it.

Symbolic interactionism sees the self as an object, a social construct, which is constructed through reflexive interactions with other people (Charon, 2004) and consequently is processual and not static (Charmaz, 1987); self-identity continuously changes by defining and redefining itself in social interactions. It is “an emergent structure or organization. It may shift or change as the person reflexively interprets the identifications and images that self and others confer upon him or her” (Charmaz, 1987, p.284). A Chinese woman develops symbolic meanings to objects, behaviors, herself and other people and transmits these meanings through interactions. Consequently, language plays an important part where self-identity is constructed and communicated through symbols in interactions (Howard, 2000). Cultural values, beliefs and practices are passed down from one generation to the next; they are interpreted and internalized, and influence how a person’s sees himself (self-definition), how he sees others (interpersonal perceptions) and how he thinks others see him (van Manen, 1997). As an example, a Chinese woman internalizes the culture’s emphasis on deference to authority which influences the relationship of herself to health care providers; that is, people actively shape self-entity through
their talk (Howard, 2000). The underlying assumption is that a cancer experience may result in the integration of a new and perhaps permanent identity (Zebrack, 2000). As Leigh (1992) states, “Those (people) who thrive (after cancer) are able to put life and death into perspective and consequently create a special niche for their cancer experience within their personal life history” (p.1478). Whether this sentiment applies to women of ethnic minority requires further exploration.

Another important concept in the symbolic interactionist perspective is the use of symbols, a type of social object, which are used to socialize individuals and to learn their roles in relation to others. Symbols are central to society as its culture depends on them; they are used intentionally to communicate and represent things, thus lending them significance and meaning. Language and words are two of important symbols that facilitate human thinking and communication (Charon, 2004). An individual uses words to talk to self (to think) and to communicate with others; symbolic interactionism focuses on the meaning that events hold for people and on the symbols that convey this meaning (Asbring, 2001). The Canadian health care system intentionally employs many symbols (e.g. words, actions, behaviours) to delineate the hierarchical role of a health care provider and a patient, and to communicate its expectations on the ways individuals must interact with one another. A highly valued professional status is bestowed on medical providers, while a subordinate ‘sick role’, or the role of patient, is assigned to the ill person, often creating internal tensions in those who do not want to be a patient first and a person second. When faced with a life-threatening illness, people often try to hold onto their personal and social identities which at times may not be consistent with medical objectives and treatments (Charmaz, 1987). Those who comply with medical directives are viewed as ‘good’ patients, while those who fail to comply are often seen as difficult or demanding.
A life threatened by cancer creates imbalance and disharmony, and through redefinition of meanings of illness and reconstruction of self-identity, they are able to restore a sense of life purpose and meaning (Fife, 1994). According to the symbolic interactionist perspective, cancer survivors’ well-being and adjustment may be explained in part by: 1) the ability to reconcile their ideal and actual experience; 2) successfully resolving role-specific disruptions; and 3) the positive interactions with, and positive feedback or reinforcement from, others (Zebrack, 2000). Indeed, to achieve optimal recovery, cancer survivors are challenged to reconcile their own expectations of an ideal healthy self with their actual experiences of new or different physical, existential, emotional or social capabilities. As Clark and Stovall (1996) state, “Regardless of the type of cancer or the extent of survival, all persons diagnosed with cancer must manage the enduring and complex ways in which cancer transforms the self and everyday life” (p.239); this reconstruction of self-identity is a process that happens over time.

The influence of symbolic interactionism on the effects of illness on self-identity has been well documented in several notable writings: Bury (1982), Charmaz (1983; 1987; 1994; 1995; 1999; 2000; 2002), Conrad (1987), Corbin and Strauss (1987) and Morse (1997). In the majority of studies, however, the experience of illness is conceptualized within a Western biomedical model based on chronic illnesses such as diabetes, cardio-vascular, rheumatoid arthritis and more recently, fibromyalgia (Asbring, 2001; Clarke & James, 2003; Crooks, 2007) and HIV/AIDS (Ciambrone, 2001; Wilson, 2007). Bury (1982), for instance, views a chronic illness such as rheumatoid arthritis as a disruptive event for patients. He conceptualizes illness as a “biographical disruption” that necessitates a fundamental rethinking of biography and self-concept in facing an altered condition. Activities previously performed with ease become more difficult or impossible because of the illness; there is disruption in the individual’s definition of
self with regard to the past, the present and the anticipated future. Corbin and Strauss (1987) portray “biographical accommodation” as the central process through which the ill person takes action to achieve some degree of control and balance over a life rendered discontinuous by chronic illness. This action enables continuity and meaning and rebuilding of identity. Identity reconstitution involves defining and redefining identity, and refocusing of direction and integration. Each step aims to keep important aspects of self active and in focus, draws novel aspects into the self and discovers new and unsuspected aspects of self. Therefore, for accommodation to be successful, it must take place not only in terms of illness management but also in biography.

For some individuals, a cancer experience may result in positive personal growth (Ho et al., 2004; Kayser & Sormanti, 2002), post-traumatic growth (Ho et al., 2004; Tedeschi & Calhoun, 1996; Weiss, 2002) and self-transformation or self-transcendence (Breaden, 1997; Fredette, 1995; Gaudine et al., 2003; Pelusi, 1997; Vachon, 2001). Post-traumatic growth refers to peoples’ positive perception of the changes or transformations experienced following a traumatic event or life crisis (Ho et al., 2004; Tedeschi & Calhoun, 1996). In a study of post-traumatic growth in Chinese cancer survivors, Ho et al. (2004) discovered some universal aspects that were shared by all survivors in the four domains noted in western studies, regardless of their culture or type of cancer: self, interpersonal, spiritual and life orientation. They reported improved self-confidence, greater ability to accept and express emotions, feelings of closeness to and compassion for others, better appreciation of life, stronger faith and better understanding of spiritual matters. For these individuals, therefore, a cancer diagnosis affected their sense of self, and this reflexive self enabled them to act, take initiative and reconstruct their identities through interactions to arrive at positive definitions of who they were. For others, however, a cancer
diagnosis may lead to them to view their self as “damaged” and thus identify themselves as being “damaged goods”.

Self-transcendence may lead to the reconstruction of a positive sense of self-identity and quality of life. Reed (1991) defines self-transcendence as a developmental phenomenon that involves extending one’s personal boundaries to include broader life perspectives and purposes, which in turn strengthen one’s sense of identity with the environment and results in a new sense of meaning or purpose. In other words, self-transcendence refers to an individual’s ability to find a new sense of purpose (Fife, 1994) and self-identity. Vachon (2001) argues that cancer survivorship may be a personal spiritual transformative experience and identifies the following key issues that confront cancer survivors: finding the meaning and place of cancer in one's life, dealing with the immediate and long-term side effects of treatment, relationship changes with others, and the constant threat of recurrence and/or death. In her study of breast cancer survivors, Pelusi (1997) found that surviving breast cancer evoked many feelings and concerns, the identification and acknowledgment of which enabled women to find meaning and self-growth.

Similar transformative experiences have been reported in other disease studies. Asbring (2001) contends that biographical disruption is sometimes viewed as an “identity-transformative” experience, which may bring positive changes or new insights with regard to the individual’s previous life and self in general. The results of her study on the effects of fibromyalgia on identity transformation suggest that although illnesses could involve a dramatic disruption in the biography of women and have profound consequences for their identity, particularly in relation to work and social life, many women also experience illness gains. Therefore, biographical disruption and illness experiences comprise of both losses and gains that have consequences for identity. In studying the illness experience of HIV/AIDS population, Carricaburu and Pierret
argue that identity could be ‘biographically reinforced’, that is, some aspects of identity may be reinforced post-diagnosis.

3.2 Charmaz’s Perspective on The Effects of Illness on Self-Identity

Life-changing events precipitate disruptions in a person’s daily routines and activities, sense of control and the normal process of identity formation. They lead to spiraling consequences that affect people’s practical daily lives, including the loss of productivity, financial crises and strained relationships, as well as social and psychological consequences such as stigmatization (Goffman, 1963) and engulfment (Beanlands et al., 2003); the onerous aspects of disease and treatment are so extensive that they entirely dominate the person’s sense of self. Therefore, the challenge for people who face a life-altering experience is the acceptance of the newly reconstructed self as they re-integrate into their community and resume a new ‘normal’ life while constantly living under the threat of premature death.

Of all the writings on the effects of chronic illness on self-identity, Charmaz (1983; 1987; 1994; 1995; 1999; 2000; 2002) offers the most conceptually developed analysis of illness and self-identity. Charmaz (2000) defines illness as a person’s social and subjective experience that encompasses emotions and physical sensations as well as meaning making; it transcends physical discomfort, the acknowledgement of symptoms and the need for care. It also includes, “metaphor and meaning, moral judgments and ethical dilemmas, identity questions and reconstruction of self, daily struggles and persistent troubles” (p.277). Experiencing a life-threatening illness challenges prior life meanings and assumptions, ways of living that often have been taken for granted, and ways of knowing self; life is now uncertain. The perception of one’s former self-identity crumbles, thus making the person vulnerable. However, not all aspects of self are
completely lost. Most people are able to retain some aspects of self and this connection with the past is important for reconstructing self-identity (Corbin & Strauss, 1987). Charmaz (1995) postulates that most people eventually adapt or accept the physical changes or losses imposed by their illness. She defines adaptation as the means by which people alter life and self to accommodate the physical changes which unify the body and the self accordingly. This adaptation involves three stages: 1) experiencing and defining the altered body; 2) assessing the altered body; and 3) relinquishing control over illness and accepting that one is tied to the altered body.

A life-threatening illness calls for major reconstruction of self and questioning one’s perception of who one is and what one is able to do; breast cancer forces a woman to question who she was, who she has become, and what she will be. Central to Charmaz’s work is people’s desire to return to health and to a former restored, or even a supernormal self when faced with a chronic illness. According to Charmaz (1987), people develop preferred identities as they reconstruct their lives apart from their illness, which constitute a particular identity in the identity hierarchy. Identity levels refer to implicit or explicit objectives for personal and/or social identity that chronically ill people aim to achieve. These identity levels reflect the type of selves that people wish to become, that is, their preferred identities, and thus are constructed in accordance with their hopes, desires, aspirations and dreams. Charmaz (1987) identifies four types of identity hierarchy: the supernormal identity, the restored self, a contingent personal identity and a salvaged self; the identity people choose depends on their preferred identity.

The supernormal identity values success, independence, hard work, social achievement and acclamation. People who assume this identity level are those who excel or thrive in a demanding and intensely competitive world more effectively than their healthier counterparts,
Despite the serious limitations imposed by their condition. For example, a woman with breast cancer assumes the identity of a cancer survivor and becomes a political activist and lobbyist initiating grass-root movement and activities.

The *restored self* refers to the identity level people aim for when they return to their former lives. They aim not only to reconstruct a similar physical self, but the same sense of self prior to illness. These individuals usually have taken-for-granted assumptions that recovery is a sequel to illness. Thus they believe they could and should be the same person they were in the past. For instance, a woman completing adjuvant treatment assumes she will simply resume her past activities on completion of the treatment.

A *contingent personal identity* is one that the ill person perceives as questionable and risky, but possible in the future. Such a person tends to view illness as the primary source of failure rather than attributing failure to lack of his/her own efforts. Most people typically first pursue a supernormal identity or a restored self, and failing to recognize it, aim for a contingent personal identity.

Those who aim for the identity of a *salvaged self* attempt to maintain some aspects of their past positive self-image, despite the reduced ability to function. They attempt to present themselves in the most favourable light possible as they accept their debilitating condition and loss of achieving other adult identities in the social world. They accept the restricted level of activity imposed by their illness or simply present themselves to self and others in a positive manner.

Reintegration into one’s community and resumption of a ‘new’ normal life following a life-threatening illness are steps to preserve the ‘integrity of self’ (Morse, 1997) and quality of life. The self-identity that emerges from an illness experience is dependent upon the type and
degrees of illness, the meaning of the illness experience, the timing and the sequence of the illness, and the individual’s expectation of and for the self (Charmaz, 1987; Morse, 1997). While leading “a converted life, avoiding dependency and minimizing stigma”, individuals may glide up and down the hierarchy of identities with the formation of self occurring through interactions with the social world and relationships (Morse, 1997). Self-identity, therefore, is derived from the individual’s preferred identity and from interactions with others who may confirm or deny the individual’s preferred self-identity.

Although Charmaz’s work offers a significant conceptual framework to study self-identity, her research focuses primarily on chronically ill populations; her perspective on self-identity does not consider persons facing the onset of an acute and sudden life-threatening illness such as cancer, which precipitates symptoms, behaviours, responses, disabilities and outcomes that result in an altogether different illness experience (Morse, 1997). Notably, important social factors such as gender, culture, ethnicity, race and social class are excluded from her conceptualization and thus fail to acknowledge the influences of the wider social context on the reconstruction of self-identities. In the Chinese culture, the way a person interacts with others in the group is a measure of the person’s sense of identity.

In summary, the symbolic interactionist perspective is relevant to understanding the experiences of Chinese women living with breast cancer: how this disease affects their previous perceptions of self-identity, how these perceptions might change and how new perceptions are defined and redefined in interactions with others. A major weakness of this perspective is its failure to acknowledge the broader social context that influences the reconstruction of a new identity. Research on the application of Charmaz’s theory to oncology patients within the
broader social context of survivorship is clearly needed to understand the experience of ethnic minority women who live with breast cancer and how they reconstruct their self-identity.

3.3 Chinese Cultural Model

Ethnicity refers to a group of people categorized according to common racial, national, tribal, religious, linguistic or cultural origin or background (Merriam-Webster). Ethnicity intersects with gender, class and other social factors. Health care literature clearly demonstrates that ethnicity influences people’s behaviors and plays an important role in determining the way they feel about their health and illness and how they manage medical treatments (Anderson et al., 1991). Culture is defined as a set of beliefs and practices by members of a particular group; it is rarely isolated from race and is infused with social, political and historical meanings (Anderson et al., 2003). Culture provides a blueprint to understand the world and shapes and determines people’s responses. However, cultural definitions have also been employed to account for differences and to construct groups or individuals considered as other. Stereotypical descriptions of the health practices of different ethnocultural groups illustrate the tendency to essentialize behaviours, values and beliefs in ways that ignore individuality and diversity (Anderson & Reimer Kirkham, 1998). Cultural beliefs and values influence a person’s health beliefs and practices in terms of how a person defines illness, how treatment is explained and managed, how quality of care is perceived, and how a person responds to and copes with an illness (Anderson et al., 2003; Bilodeau & Degner, 1996; Fitch et al., 2000; Klawiter, 2004; Kwok & Sullivan, 2006; Lam & Fielding, 2003; Wong-Kim et al., 2003; Yeo et al., 2005). Studies show that these beliefs and values contribute to lower cancer survival outcomes among ethnic minority groups (Ashing et al., 2003; Ashing-Giwa et al., 2004; Aziz & Rowland, 2002). To understand the significance of culture on health practices and the survivorship experiences of Chinese women living with
breast cancer, an overview of the Chinese culture is presented. It is important to note, however, that the employment of a cultural model to describe the Chinese culture is not intended to essentialize the characteristics of the Chinese culture or to ignore the issues of power and privilege in the health care domains (Johnson et al., 2004). The existing limited survivorship and health studies on Asians, in particular the Chinese, are replete with overgeneralizations and homogeneous descriptions of the Chinese culture which disregard the dynamic and lived experiences (Johnson et al., 2004). There is a clear need for investigations that incorporate a more diffused approach to cultural presentation and which address the systematic barriers that hinder access to health care services.

The Chinese culture is described as collectivist or family-centered with a strong emphasis on historical linkage to ancestors and maintenance of social harmony. Tan (1997) describes the significance of ancestral homage:

We believed that the spirits of ancestors who had passed away were still very present in the lives of the living family. Proper homage, prayer, and offerings to deceased ancestors would bring blessings. On the other hand, failure to attend properly to deceased ancestors could incur their wrath, resulting in illness among family members, or misfortune (even the future generations). (p.203)

Social harmony is the result of achieving interpersonal harmony; repression of feelings, self-control and self-discipline are Chinese values that promote and maintain interpersonal harmony (Uba, 1994).

In the Chinese culture, the etiology of illness is based on physical health and philosophical teachings (Lee, 1986; Tan, 1997). Health and sickness are viewed as societal issues which require people to look “normal” and avoid disruptions of group harmony. Disease, therefore, carries a strong moral imperative. Health for many Chinese is an equilibrium or
balance between the opposite forces of *yin* (*cold*) and *yang* (*hot*); disequilibrium or imbalance of these forces results in illness (Simpson, 2005). The significance of this balance is evident in the use of Chinese herbs, food groups and diet; certain foods are classified as either ‘hot’ or ‘cold’ and therefore, excess consumption of one kind of food group offsets the internal *chi* (*energy*) balance. Chinese herbs correct an imbalance rather than cure an ailment. The current Chinese medical practice of blending Eastern and Western medicines also underlies the significance of achieving an internal balance or constitution of the body.

Confucianism, Taoism and Buddhism are three major philosophical teachings deeply rooted in Chinese history. In particular, Confucianism has the most pervasive influence on Chinese deportment, and sets the rules and regulations for social behaviours and interactions that emphasize reciprocity and loyalty, benevolence and righteousness, self-respect, self-reliance, self-control and face-saving (Lee, 1986). Reciprocity refers to treating another person as he/she would like to be treated. Loyalty is the unquestioning allegiance and total subordination to superiors and elders. Reciprocity and loyalty are the foundations of imperialism, authoritarianism, filial piety and closely-knit family structure. This authoritarianism is manifested in the doctor-patient relationship; the Chinese, including other Asian groups, perceive themselves in an accepted hierarchical relationship to their physician, in contrast to the egalitarian doctor-patient relationship evident in Western cultures. Doctors are respected and revered and their advice is usually heeded without question, and thus patients assume the role of a ‘good’ patient. In most situations, the majority of Chinese women prefer to leave medical decision making to their physicians (Ashing et al., 2003).

Self-sufficiency, self-reliance, self-sacrifice and face-saving are highly valued in reinforcing the importance of social responsibility, especially family (filial) obligations, public
family image and maintaining harmonious interpersonal relationships. Research involving Chinese groups confirms that family needs often take precedence over individual desires (Uba, 1994). Tan (1997) describes the essence of filial piety:

If I disobeyed my parents and was unfilial to them, my own children will be unfilial to me. If I caused someone harm or suffering, I would reap the consequences of my actions later on in my life or suffer at the hands of the people I wronged in my next life. (p. 201)

These values influence the attitude of Chinese women towards their illness, identity formation and the meanings they ascribe to breast cancer. In turn, these meanings shape the manner in which women experience breast cancer, including decision making responses to prevention, screening and treatment options, as well as their strategies for coping with and making sense of breast cancer illness.

Studies reflect that Chinese women are more likely to have mastectomies than breast conserving surgeries, such as lumpectomies, based on their cultural beliefs of collectivism and safety, even though there is no survival advantage of one treatment over the other (Ashing-Giwa et al., 2004; Kagawa-Singer et al., 1997; Killoran & Moyer, 2006; Lam et al., 2005). A distinct difference in the attitude of Chinese women towards cancer compared to their Western counterparts is their view on fatalism. When a Chinese woman is diagnosed with breast cancer, she sees it as her destiny, God’s punishment, God’s plan, ‘bad karma’ or ‘bad luck’. The conviction that a person’s fate determines the occurrence of cancer extends to the strong belief that cancer is a death sentence, and this hinders Chinese women from overcoming the fear of this disease (Ashing et al., 2003; Facione et al., 2000; Wong-Kim et al., 2003). Prone to superstition, Chinese women view breast cancer screening as inviting bad luck or tempting fate to bring misfortunes to the family. These fatalist views, as well as the significance of family, play a large
part in the delay by Chinese women to access screening and treatments (Kagawa-Singer et al., 1997; Maxwell, Bastani, & Warda, 1998a, 1998b); Asian American women reflect the lowest breast cancer screening and early detection rates compared to other ethnic groups, with even lower rates reported for new immigrant women and those with lower socio-economic status (Ashing et al., 2003).

The inherent Chinese cultural virtues and values such as modesty and shyness, also account for women of this ethnic minority having less knowledge about their sexual health and sexuality; cultural taboos against talking about or touching one’s body contributes to avoidance of self-exams and screenings (Ashing et al., 2003). The emphasis on modesty further explains the low participation in screening tests, such as mammography and cervical exams (Maxwell et al., 1998a, 1998b). The female breast is less sexualized in the Chinese culture than Western culture (Kagawa-Singer et al., 1997; Lam & Fielding, 2003). Though important, the breast is less significant in maintaining self-identity than ensuring harmonious role relationships (Lam et al., 2005) and family financial security. “The Oriental way of thinking (is) placing the role of mother above the role of woman. (This) plays a big role in their attitude. The primary concern is to survive for the children, not be a beautiful woman for their husband” (Ashing, 2003, p.42). The relationship between breast cancer in Chinese women and sexual health nonetheless remains complex and warrants further research.

Public discussion of breast cancer within Chinese society is discouraged. It is viewed as a private matter to be shared only with family and otherwise avoided in order to maintain harmony in the group and face-saving; a woman’s sense of self is connected to that of her family and is the foundation for self-sacrifice (Cheung & Liu, 2004). To maintain social harmony based on collectivism and avoid bringing shame to the family, Chinese women with limited social
support display fewer help-seeking behaviors (Chiu, 2004; Kagawa-Singer et al., 1997), also in keeping with the Chinese culturally viewed virtues of self-reliance and endurance. A Chinese woman is expected to be practical and sacrifice her own sense of well-being, suffer in silence and endure psychological distress for the welfare of her family (Kagawa-Singer et al., 1997). Seeking external aid is viewed as a personal failure (Chiu, 2004), therefore Chinese women rely on themselves to cope with psychosocial concerns and engage in activities such as cleaning and cooking to take their minds off the problems (Ashing et al., 2003).

In conclusion, cultural beliefs and values influence health beliefs and practices, which in turn affect a woman’s health experience. Chinese women’s reconstruction of self-identity and their breast cancer survivorship experience are impacted by the importance placed on family as well as Confucius’ teachings. To better understand the effects of breast cancer on the self-identity of Chinese women survivors, it is necessary to integrate the Asian feminist theory with Charmaz’s theory of illness to capture the wider social context, which encompasses gender, race, ethnicity, culture and social class. The lives of Chinese women are gendered, raced and classed, and each exists within complex social interactions and relationships that have significant implications for identity formation, quality of life and health. The social constructs of gender, race and ethnicity are important determinants of women’s identity and survivorship experiences while they live in constant fear of recurrence of illness and premature mortality. “Surviving the disease is the initial challenge. Surviving the aftermath of the disease is the next major step. The ultimate challenge, though, may be to move beyond basic survival and to actually flourish in the face of adversity” (Leigh, 1992, p.1478).

3.4 Asian Feminism
Gender, race and class are all socially constructed (Brewer, 1993), and together with ethnicity, are often overlooked in health research (Anderson, 2000; Becker, 2004; Greaves et al., 2000; Im & Meleis, 2001) and illness experiences. Self-identity is not solely influenced by experiences based on gender, class and race, but also on health care ideologies. In the absence of the impact of Asian feminism in Canadian literature, Asian American feminism is employed to analyze the effect of these factors on the breast cancer survivorship experiences of Chinese women.

Application of the Asian feminist perspective to understand the unique experiences of Chinese women living with breast cancer though worthwhile, is over-simplified and over-inclusive in that it ignores the substantial differences among the various Asian subgroups. As a racial category, Asian is not representative of a homogenous group as there are many subgroups within the Asian culture (Bradshaw, 1994). The term ‘Asian’ geographically refers to peoples of East Asia, Southeast Asia and South Asia. Nonetheless, they are frequently represented in the literature as a generic group with little information on within-group differences (Tsang, 2001). Caucasian researchers often classify Chinese people as a generic category of Asians based on the assumption that each subgroup shares a common ethnicity and a common culture.

3.4.1 Ethnicity

The common practice in research literature to represent ethnic identity as essential, fixed and stable results in it being mistakenly viewed as a neutral concept rather than a social construct with distinct associated values (Tsang, 2001). Even the term ‘Chinese’ does not have fixed and stable characteristics; Chinese people are often incorrectly deemed to be a homogeneous group that share similar political ideologies and characteristics common to the Chinese culture such as
familism, filial piety and hierarchical family structure, irrespective of their country of birth or origin (Tsang, 2001). For example, not all Chinese individuals who live in Taiwan identify themselves as Chinese or identify Taiwan as their place of origin, or share similar political ideologies; some identify themselves as mainland Chinese and migrated to Taiwan with the Nationalist regime in 1949. They consider mainland China as their ancestral place of origin and see themselves as belonging to the dominant Han ethnic group. Others do not regard themselves as Chinese, but rather as native Taiwanese with a separate entity and political affiliation from mainland China (Tsang, 2001). Thus, being Chinese “involves complex processes of identification, which are site-specific, varying across different sociopolitical contexts” (Uba, 1994, p.233) with each group adopting traditional Chinese values to varying degrees.

It is also necessary to distinguish ethnic background from cultural affiliation and cultural orientation. Individuals with similar ethnic backgrounds may not internalize the same cultural elements but multiple cultural systems (Ho, 1995) and they may assume different levels of identification with a particular culture depending on the extent of acculturation, migration experiences, occupational skills, religion, primary language, income and education (Uba, 1994; Ward, 1996). For instance, Chinese people who live in Hong Kong and mainland China may share the same ethnic background, however, they internalize different elements of the Chinese culture based on historic, political, economic and social events.

3.4.2 Gender

Gender influences access to health services and illness experiences (Doyal, 2004). It is a social and cultural construct with a set of behavioural norms associated with males or females (Greaves et al., 2000; Phillips, 2005). Gender role is defined as, “behaviors, expectations, and
role sets defined by society as masculine or feminine which are embodied in the behavior appropriate to males or females” (O’Neil, 1981, p.203). Historically, female gender was defined by elite White males as the ‘other’. The concept of other was first articulated by de Beauvoir (1952) in her work on the nature of men and women where in the Western culture males were perceived as "real" and everyone else, including women, were perceived as "other". To place males at the center of attention is to focus solely on the site of dominance (Weis, 1995).

‘Othering’ is defined as, “a process that identifies those that are thought to be different from oneself or the mainstream, and it can reinforce and reproduce positions of domination and subordination” (Johnson et al., 2004, p.253), and “a process through which people construct their own identities in reference to others” (Weis, 1995, p.17). Othering’ is a form of marginalization (Johnson et al., 2004). Marginalization refers to the lack of equitable access to political, economic and social benefits and exclusion from full participation in these arenas due to membership in specific identifiable groups; it is closely related to gender (Spitzer, 2005). A consequence of the application of the concept of othering to the feminist theory and health research is that women are defined in terms of their similarity and dissimilarity to men. Furthermore, they are defined in terms of their functional significance to men rather than in terms of their own unique differences (de Beauvoir, 1952). In relation to women living with breast cancer, the cancer survivorship experience of Caucasian women has become the ‘real’ experience, while those of ethnic minority women relegated to the ‘other’.

Asian American feminism is employed to understand breast cancer survivorship within a broader social context and to determine its influence on the reconstruction of self-identity in Chinese women. Asian American feminism acknowledges Asian women as a legitimate source of knowledge and the experts on their lives. It recognizes the uniqueness of the Chinese culture
and beliefs which influence health beliefs and experiences. The history of Chinese women is distinct from those of White and African women, and their culture is grounded in the family, not the individual, as the basic unit in society. The teachings of Confucianism, Taoism, and Buddhism influence and shape Chinese women’s social position and their lives in the world. Just as there are universal experiences that unify all women living with breast cancer, there also exist distinct differences within each major ethnic group and subgroup based on their vast and diverse histories, nationalities, languages, religions, ethnicities, classes, immigration status and geographic territories (Bradshaw, 1994; Shah, 1997). As Shah (1997) states,

The reason to talk about Asian American women as a single group is because we all share the same rung on the racial hierarchy and on the gender hierarchy. It is not that our lives are so similar in substance, but that our lives are all monumentally shaped by three major driving forces in the U.S. society: racism and patriarchy most immediately, and ultimately, imperial aggression against Asia as well. And as long as those systems of distributing and exercising power continue to exist, it will continue to make sense to talk about Asian American women as a group. (p.xiii)

In recognition of women’s differences and their distinctive lived experiences, the White feminist movement emerged in the 1960s to challenge the political, social and economic marginalization of women, the hierarchy of social structures and the othering practice that supported and justified gender inequality (Finn & Jacobson, 2003). The White feminist movement rallied for women’s individual and collective sociopolitical interests and self-determination that led to a new political identity of women as well as economic and professional equality with men (Phillips & Drevdahl, 2003). In doing so, however, White women’s experiences were accepted as the voice for all women, thus relegating non-White women’s experiences to the status of other. While the White feminist movement was applauded for
pushing women’s agenda to the forefront of the sociopolitical arena, some Black feminist intellectuals challenged the notion of White women’s experiences as universal and representative of all women.

Central to the Black feminists’ criticism is that White feminism overwhelmingly represents the middle-class White female perspective that characterizes all women as a homogeneous group with universal concerns (Cheung & Liu, 2004; Collins, 2000; Phillips & Drevdahl, 2003) and experiences, and ignores their social differences. Black feminists argue that gender alone does not explain African women’s social location and experiences. In other words, gender cannot be understood if decontextualized from race and class; gender, race and class are in fact rooted historically and contextually (Brewer, 1993). Black feminists further argue that the theory and practice of White feminism fails to recognize that White women stood in a position of power as oppressors of women of color, including Asian women. This power imbalance therefore compromises any feminist theory and practice found on the simple notion of equality and also highlights class and power relations between women from different social classes (Carby, 1982). The exclusionary practice of White feminism led some Black feminist intellectuals, in conjunction with feminist writing and rethinking of the African American women at the time, to identify the “polyvocality of multiple social locations that are historically missing from analyses of oppression and exploitation in traditional feminism” (Brewer, 1993, p.13) and to interject race, ethnicity and class into feminist discussions (Phillips & Drevdahl, 2003). Black feminists argue that the social construction of African womanhood is inextricably linked to racial hierarchy (Brewer, 1993), and the historical and cultural experiences of African American women is crucial to their self-identity; thus an understanding of these experiences is essential in any analysis of their lives (Brewer, 1993). As Dominelli (1997) argues, “It
(feminism) misses the specificity and complexity of women’s lives, and in doing so ignore (s) their realities as they experience them…(and) do not take account of women’s relevant cultural, spiritual, and ethnic sensitivities” (p.74).

Parallel to the Black feminist movement, Asian American feminists were also critical of White feminists’ essentializing and oppressing of women and for injecting Asian ethnicity into the debate. Asian American feminism emerged in the 1960s as a result of the civil rights and anti-Vietnam War movements to put forward Asian women’s interests and experiences. Similar to Black feminism, Asian feminism also emphasizes the importance of examining specific historic, economic and cultural elements and gendered strategies when responding to social problems rather than acceptance of simple generalizations about ethnicity, class and gender (Finn & Jacobson, 2003). Central to the Asian feminist theory is the intersectionality of gender, race and class that influence the social construction of Asian womanhood and which diversely affect the lives and self-identity of Asian breast cancer survivors. While both Black and Asian feminism are established in the feminist movement, and partially share a similar conceptual framework on the intersectionality of social forces, there exist historic, political, economic and cultural differences between the experiences of African and Asian women. The Asian American feminist paradigm has its own historical, cultural and political reference points and special interests it advocates for, but this paradigm does not necessarily apply to all Asian women, particularly Chinese women who are diasporic to Canada.

There are both similarities and differences in the history and experiences of Chinese women in the US and those in Canada. An important similarity is both the American and Canadian early immigration policy towards Chinese was largely shaped by their need for cheap labour. Chinese male migration to Canada in the 1880s was tolerated in part to fulfill the federal
government’s need for a cheap source of labour to build the Canadian Pacific Railway. However, it generated much racial unrest out of fear that the Chinese would take away jobs from the White males (Early Canadiana Online). Chinese women on the other hand, were largely absent due to the discriminatory and exclusionary head-tax imposed by Canada’s Chinese Immigration Act to deter and restrict the reunification of Chinese families; many Asian women who migrated to the US during that period were disadvantaged Chinese who had been tricked, kidnapped or smuggled into the country to serve the male Chinese community as prostitutes and employed as cheap labour (Shah, 1997). The stereotyping of Chinese women as prostitutes generated exotic images of them with bound feet, slanted eyes and docile demeanor, and being labeled by the US media as concubine, dragon lady, lotus blossom and precious pearl (Lu, 1997). These images “colored the public perception of, attitude toward, and action against all Chinese women for almost a century” (Sucheng, 1991). The exotic portrayal of Chinese and other Asian women in the US was further promulgated through Hollywood movies such as The World of Suzie Wong, and stories of American GIs rescuing and marrying Asian women, as reflected in the Broadway production of Miss Saigon. Regardless of their within-group differences, the worldwide oppression of women and major historical influences such as racism, patriarchy, class, and imperialist ideologies have not only shaped the experiences of Asian women, but also subjugated them to a hierarchical, gendered and racially biased North American society (Lu, 1997; Shah, 1997). To date, the lives of Asian women continue to be affected by occupational health hazards and labour exploitation due to economic globalization and anti-immigrant policies (Sze, 1997).

In conclusion, the feminist theory is a White construct that must be reformulated to encompass social factors such as culture, race and class. The emphasis of White feminism on
personal choice and freedom is individualistic and thus fails to capture the broader social context significant to Asian women whose culture stresses collectivism and ancestral reverence. It is the art of balancing the personal and the communal that distinguishes Asians from other ethnic groups (Tan, 1997). While the Asian feminist perspective reflects the standpoint and interests of Asian women, it is not intended to relegate the experiences of other ethnic women to the status of other. The Asian American feminist perspective encompasses the social forces upon which hierarchy and inequality are built within the US and Canada (Brewer, 1993) and embraces the wider social context of race, class and ethnicity. Gender alone does not explain the breast cancer survivorship experiences of Chinese women. As feminist historian Higginbotham (1992) states,

In societies where racial demarcation is endemic to their socio-cultural fabric and heritage – to their laws and economy, to their institutionalized structures and discourses, and to their epistemologies and everyday customs – gender identity is inextricably linked to and even determined by racial identity. We are talking about the racialization of gender and class. (p.253)

3.4.3 Social Class

The issue of health in Canada exists within a gendered, classed and raced society (Anderson & Reimer Kirkham, 1998). Health care reflects the dominant cultural values and the status of individuals within a society, and is the product of a country’s history and elite culture, the White privilege (Evans, 1992). “Whiteness” determines where people live, with whom they go to school, what kind of jobs they obtain, the amount of money they earn, with whom they start families, and who receives health care services (Shah, 1997). Historically, men have not been interested in women’s health. A major issue that consistently plagues health research and health care policy is the lack of attention to gender and ethnoracial groups. White males control the mechanisms of knowledge production and validation so it is their interests that pervade the
themes, paradigms and epistemologies of scientific enquiries and knowledge, and exclude women’s health experiences and their contribution to knowledge (Collins, 2000). A prime example is the 2002 Romanow Commission on the future of health care in Canada, which failed to identify the inequalities in women’s health and the wider social context that shape women’s lives and health experiences. Patriarchy undermines women’s health and renders it invisible. As Doyal (1996) states,

At the heart of all feminist critiques of medicine is the recognition that women lack power in health care institutions. This limits their ability to determine medical priorities or to influence the allocation of scarce resources. It also has a significant impact on their individual experiences as users of health services. It affects their capacity to play an active part in their own treatment and often leaves them feeling uncared for. (p.55)

Women present unique health and service needs that necessitate the development of not only a gender-based but also a racially and classed-based approach to women’s health. Race, gender and class are interlocking systems of oppression that profoundly influence the lives of marginalized populations (Anderson & Reimer Kirkham, 1998). Like gender, race is also a social construct and creates distinctions between people based on physiological characteristics; it shapes people’s lives and their identity formation (Anderson & Reimer Kirkham, 1998; Johnson et al., 2004). As Higginbotham (1992) states,

Like gender and class...race must be seen as a social construction predicated upon the recognition of difference and signifying the simultaneous distinguishing and positioning of groups vis-à-vis one another. More than this, race is a highly contested representation of relations of power between social categories by which individuals are identified and identify themselves. (p. 253)
Racism is embedded in the health care system in invisible ways (Byrd & Clayton, 2002). The marginalized status of women of color renders their experiences invisible and inaudible (Im, 2000) and results in health disparities among medically underserved ethnic women (Anderson, Dyck, & Lynam, 1997; Anderson & Reimer Kirkham, 1998; Evans et al., 2005; Evans & Stoddart, 1994; Fowler-Brown, Ashkin, Corbie-Smith, Thaker, & Pathman, 2006; Kerner, 1996). Pearcy and Keppel (2002) define health disparity as, “a marked difference or inequality between two or more population groups defined on the basis of race or ethnicity, gender, educational level or other criteria” (p.284). Studies show that persons of racial and ethnic minorities have lower socioeconomic status than Whites (Loerzel & Busby, 2005), and in comparison, ethnic minority women experience poorer health, lower breast cancer survival outcomes and quality of life (Evans & Stoddart, 1994; Eversley et al., 2005; Kerner, 1996). The results of a study on Chinese immigrant women with breast cancer showed that women who left their native homeland and resettled in a new country with a different language and culture often worked in low paying jobs and occupied low socioeconomic status; they were more likely to experience greater health disparities and remain vulnerable to higher mortality rates (Loerzel & Busby, 2005). Further, ethnic differences also influence the type of treatment selected. Ashing-Giwa et al. (2004) reported that Asians and Latinas were more likely to have mastectomies and African American women were least likely to have adjuvant therapies, including radiation and chemotherapy. For Chinese women, mastectomies offer more security and reduce the time away from work and family responsibilities. The loss of a breast is also less threatening to Chinese women’s self-identity in that it may be hidden, whereas other physical changes such as hair loss, weight gain and facial changes are more threatening due to their obvious visibility (Lam et al., 2005).

3.4.4 Health Care Environment: Health Care Ideologies
The breast cancer survivorship experience of Chinese women and their re-integration into the community do not occur in a vacuum, but rather, are situated within social, political and historical contexts. Subjectively, their self-identity is further shaped by socially and culturally constructed health care ideologies, such as the idea of a ‘good’ patient that permeates the health care system and underscores the Chinese values of deference to authority. Health care ideologies influence the lived survivorship experiences of Chinese women and their reconstruction of self-identity: how she interacts with other people, how others respond to her, and how she interprets those interactions and meanings. Given the current consumer-patient movement across North America, the existing expectations and norms of the traditional role of the patient are being re-written and replaced by new expectations and norms (Zebrack, 2000). Patients are encouraged to be empowered and better informed and health care providers to be more responsive to the patient-consumer empowerment. Patient education initiatives and community supportive programs are developed with the goal to empower women by teaching them skills to master and take control of their health and health outcomes, all under the assumption that lived survivorship experiences are universal and the adoption of yielding approach results in helplessness and avoidance (Ching et al., 2009). Chinese cultural emphasis on acceptance of authority, and thus deference to authority figures, further reinforces the importance of being a “good” patient by complying with medical advice.

In summary, the health of women must be addressed within social, economic, cultural and political contexts (Anderson, 2000). “Getting a sense of the whole” is crucial to understand women’s health and illness experience (Im, 2000). The lived experience of Chinese women with breast cancer, in particular the way they reconstruct their self-identity, must be understood within the wider social context of survivorship including health care ideologies.
3.5 An Integration of Theoretical Perspectives

The goal of the biomedical model of treating cancer is to cure; the psychosocial consequences of cancer treatments remain a secondary consideration. Although biomedical theories have led to significant reduction in morbidity of and mortality from diseases, they have also promoted a disease orientation that frequently ignores the influences of social factors including gender, ethnicity, culture and social class on a person’s illness experience. This is particularly significant for women whose self-identity is influenced by social factors as well as interactions with others (e.g. the family, health care providers) and the environment (e.g. health care ideologies).

This study drew on the theoretical perspectives of symbolic interactionism, specifically Charmaz’s theory on the effects of illness on self-identity, Asian feminism and the Chinese cultural model to understand the reconstruction of self-identity of Chinese women with breast cancer, as part of the lived survivorship experience. Symbolic interactionism facilitated examination of the interactions of Chinese women with others and the environment to determine their impact on identity formation. Charmaz’s theory extends symbolic interactionism ideas by offering a theoretical lens to understand the effects of illness on a woman’s life and the recovery process of renegotiating and adapting to an altered body, which results in a new preferred self-identity. Asian feminism challenges the mainstream research practice of excluding ethnic minority women and power differentials that influence Chinese women’s illness experience and identity formation. It injected important social factors, such as culture, to broaden the interpretation of the art of survivorship experience and simultaneously facilitated critical examination of western health care ideologies such as the ‘good’ patient. Culture offers a blueprint to view the world and self; it influences a person’s illness experience, the interpretation
and meaning of the experience, interactions with others and reconstruction of self-identity. In this study, the Chinese culture was found to influence the Chinese women’s perceptions and beliefs about breast cancer (e.g. fatalism), the way they respond to breast cancer (e.g. pragmatic acceptance of illness), the way they cope with the illness (e.g. turning inwardly or repressing of feelings), their interactions with others, such as the family and health care providers (e.g. filial piety and deference to authority), their help-seeking behaviours, and the way they perceive themselves before and after breast cancer (e.g. becoming less uptight and more relaxed). Although the infusion of the Chinese cultural model to broaden the art of survivorship is critical, it is not intended to essentialize the lived experiences of Chinese women. The essence of the lived breast cancer experience of Chinese women is transferable to given situations, but cannot be extended to the general population due to within-group differences.
CHAPTER 4
METHODOLOGY AND METHODS

This study sought to understand the reconstruction of self-identity of Chinese women within the lived breast cancer survivorship experience, which necessitated a qualitative approach and application of the philosophy and principles of hermeneutic phenomenology. This chapter examines the philosophical underpinnings that led to the adoption of hermeneutic phenomenology and the location of the researcher. While a full discussion of the philosophical principles of phenomenology is beyond the scope of this paper, key relevant phenomenological principles are presented and several explanations offered to support the use of hermeneutic phenomenology. A description of the study objective and methods used for recruitment process, sample population and pilot-testing is presented.

4.1 Methodology

4.1.1 Philosophy and Phenomenological Principles

According to van Manen (1997), methodology refers to the philosophical framework, the fundamental assumptions and characteristics of a human science perspective. It is the theory behind the method, including the study of the method one should follow and why. To answer the research question, this study was guided by the hermeneutic principles to illuminate the essence of the lived survivorship experience of Chinese women living with breast cancer, in particular, the way they reconstructed their self-identity.

Phenomenology is a “philosophy, an approach, and a method” to study the lived experiences or the lifeworld (Oiler, 1982; van Manen, 1997). As a research method, it is historically rooted in early twentieth century European philosophy, in particular, the philosophical principles of Husserl, Heidegger, Sartre, Merleau-Ponty and Gadamer (Creswell,
Central to phenomenology is the structures of consciousness or *essences* (i.e. the universal elements and relationships that constitute the experience) in human experience (Creswell, 1998; Polkinghorne, 1989). Edmund Husserl, a German philosopher and the founding father of phenomenology, was credited with introducing the study of “lived experience” or experiences within the “life-world”. He developed transcendental phenomenology in response to his criticism of the science of psychology, which tries to apply positivist methods of natural sciences to understand human experience. He argues that psychology ignored the fact that living subjects not only respond to external stimuli but also respond to their perceptions of what these stimuli mean (Laverty, 2003). Husserl believes that individuals go about their daily living without being critically reflective or conscious of their experiences; therefore, the aim of human science is to illuminate the structures of consciousness, or *essences*, to understand human experiences (Koch, 1995; Laverty, 2003).

Central to Husserl's principles are intentionality, essences and phenomenological reduction as key to the understanding of the lived experience (Koch, 1995). Husserl sees intentionality as a process where the mind is directed toward objects of study and that knowledge of reality stems from conscious awareness (essences). By intentionally directing a person’s focus, the person could then develop a description of a particular reality through the use of phenomenological reduction. In other words, Husserl phenomenology is descriptive, with the intent to raise awareness (McConnell-Henry et al., 2009a). Underscoring these principles is his belief that there are facets to any lived experience which are common to all persons who share the experience. For the descriptions to be considered a science, commonalities in participants’ experience must be identified to allow a generalized description. Therefore, essences are
considered a true representation of the nature of the phenomenon being studied, and reality to be objective and independent of history and context (Lopez & Willis, 2004).

Additionally, Husserl also believes that in order to reveal the true essence of the ‘lived experience’ the researcher must remain neutral throughout the research process by setting aside all prior knowledge from his/her experiences, known as bracketing or *epoche* (Laverty, 2003; Lopez & Willis, 2004). To remain objective, some writers suggest the researcher refrain from conducting a detailed literature review or forming any specific questions, and focus instead on the desire to describe the lived experience of participants (Lopez & Willis, 2004).

Like Husserl, Martin Heidegger shared an interest in lived human experience. Both sought an understanding of the structures of consciousness, however, they differed in their approaches. Central to Heidegger’s principle is the concept of *Dasein*, a way of *Being-in-the-world*. While Husserl’s phenomenology was the culmination of the Cartesian duality, the body-mind split, which viewed experience in isolation of the social context and focused primarily on the description of the human experience, Heidegger concentrated on the hermeneutic, or interpretation, and meaning of such an experience (Koch, 1995; McConnell-Henry et al., 2009a). Heidegger believes that a lived experience is essentially an interpretative process, “The meaning of phenomenological description as a method lies in interpretation…The phenomenology…is a hermeneutic in the primordial signification of this word, where it designates this business of interpreting” (Heidegger, 1962, p.37). For Heidegger, understanding is a basic form of human existence in that it is not the way we know the world, but rather the way we are. He believes that consciousness is not separated from the world, but is a formation of historically lived experience; thus, the goals of phenomenology are to illuminate details often taken for granted, to create meaning and to achieve a sense of understanding within the social context. Interpretation is
therefore critical to the process of achieving this understanding, as people exist hermeneutically and derive meanings from their interactions and experiences (Laverty, 2003; McConnell-Henry et al., 2009a).

Heidegger believes that experience and interpretation cannot exist without one another; experiences are revealed through language via interactions, and interpretation reveals the associated meanings. Meaning is multi-dimensional and multi-layered (van Manen, 1997). Meanings are embedded in every day practices; while they are not always apparent to individuals, they may be gleaned from the narratives produced by individuals (Koch, 1995; Laverty, 2003). Interpretation not only influences everyday situations and interactions, but also our understanding of our lived world and ourselves (Vis, 2005). Interpretation of the interactions with our environment is based on how we see ourselves, how we construct our meanings and how we co-construct our stories (Koch, 1995). As an example, culture shapes existence and provides a person with his/her background from birth, which is passed down and represents the blueprint to understand the world (Koch, 1995). In other words, culture influences both present and future situations and shapes understanding. Hence, time is crucial in Heidegger’s thinking; it is seen as fluid, not static in a linear, chronological manner (McConnell-Henry et al., 2009a).

While Husserlian descriptive phenomenology advocates bracketing to fully understand the experience of the participants and avoid imposing a prior hypothesis on the experience (Creswell, 1998), Heideggerian hermeneutics phenomenology rejects this idea. Heidegger believes that people in general are interpreting beings, and thus, any attempt to bracket oneself from a phenomenon is intrinsically impossible. In fact, he argues that the researcher’s prior understanding augments interpretation and is a legitimate part of research, as Being-in-the-world of the participants (Laverty, 2003; McConnell-Henry et al., 2009a); reality is constructed from
our experiences of Being-in-the-world and therefore the researcher cannot not help but bring her own lived experience, specific understandings and historical background into the research process (Finlay, 2002). The researcher’s biases and assumptions are not bracketed or set-aside, but rather are embedded and essential to the interpretive process. As Heidegger states,

Understanding is never without presuppositions. We do not, and cannot, understand anything from a purely objective position. We always understand from within the context of our disposition and involvement in the world. (Johnson, 2000)

Important to this interpretive process was the researcher’s awareness of theoretical location, assumptions and ideas, and how these factors influenced her interpretation and conclusion (Mauthner & Doucet, 1998); the researcher needed to look within herself and attempt to disentangle her own perceptions and interpretations from the phenomenon being studied (Finlay, 2002). Maintaining a reflective journal was a way to assist the researcher to identify her personal values, judgments, background and assumptions, and aided transparency of these factors to minimize their impact on the phenomenon under investigation. Thus, reflexivity or self-reflection not only pertains to the researcher’s experiences and reactions during fieldwork, but also the researcher’s feelings and emotions that may be engendered (Arber, 2006). The practice of self-reflection is crucial to phenomenological hermeneutical research, which involves the engagement of the researcher and the participant in hermeneutic circle of co-constructing of meanings and many levels of interpretation (Koch, 1995).

Hans-Georg Gadamer, who was influenced by both Husserl and Heidegger, extended Heidegger’s hermeneutic ideas by identifying the conditions within which understanding itself takes place. Like Heidegger, he believes that language and understanding are inseparable
structural aspects of human ‘being-in-the-world’ (Laverty, 2003; McConnell-Henry et al., 2009a), and that interpretation is an ever evolving process (Laverty, 2003). Language is the universal medium in which understanding occurs and it is part of the lived experience (Laverty, 2003). To Gadamer, understanding is attained through structured question-answer dialogues and the openness of the researcher to the opinions of others (Laverty, 2003; van Manen, 1997). Gadamer postulates understanding is obtained when the researcher and the text meet as the ‘fusion of horizons’ (Laverty, 2003; McConnell-Henry et al., 2009a); horizon refers to a person’s background which includes various assumptions, ideas, meanings and experiences s/he has. These backgrounds are fluid and open to change, based on world events in time and history (Laverty, 2003; McConnell-Henry et al., 2009a). Every time a participant’s view is expressed, the researcher may see the interpretation as an answer to the question that is being asked (van Manen, 1997). Thus, the conversation has a hermeneutic orientation “to sense-making and interpreting of the optic that drives the conversation” (van Manen, 1997, p.98).

Gadamer further believes that lived experiences are situated within historical and cultural contexts; a value-oriented approach is thus unavoidable as all research involves prejudices or pre-judgments arising from the researcher’s own historical and cultural background (Laverty, 2003; McConnell-Henry et al., 2009a). Gadamer developed the concept of prejudice to support the belief that people understand or make sense of the world based on history and through conversations with others; the combined past and present create new understandings or meanings (Laverty, 2003; Vis, 2005). All researchers bring a history to the research process, and in doing so, these “…values…make the research meaningful to its consumers” (Koch, 1995, p.833).

In summary, hermeneutic phenomenology generates analysis of data at both the phenomenological and hermeneutic levels. It focuses on descriptive phenomenon through lived
experience as proposed by Husserl and negates bracketing or suspending interpretation of one’s lived experience as suggested by Heidegger. While Heidegger argues that interpretation is unavoidable because the researcher inevitably injects her own background into the interpretative process (Koch, 1995), Gadamer extends Heidegger’s ideas with the inclusion of concepts of language, prejudice and the creation of new meaning as part of the interpretive experience (Vis, 2005).

4.1.2 Rationale for Choosing Hermeneutic Phenomenology

The adoption of hermeneutic phenomenology was based on several factors. Since the objective of the study was to understand the way Chinese women reconstructed their self-identity within the lived survivorship experience, hermeneutic principles facilitated the interpretation and meaning of these women’s experiences and took into account the influences of social factors. It acknowledges that understanding is influenced by both internal and external factors, and is guided by language which leads to the creation of new meanings or understanding through dialogue (Vis, 2005). Furthermore, the researcher’s own interpretative and constructivist paradigm on the understanding of truth and reality as well as training as a social worker made hermeneutic principles the natural choice. As a social worker, the researcher is constantly engaged in interpretive interactions and co-constructing meanings or understanding with breast cancer patients as part of the therapeutic counselling process of coming to terms with the impact of breast cancer and its implications, and to gain insights into their concerns and problems. Of significance, the inclusion of the intersubjective experience of the researcher acknowledged shared membership with the participants. Hermeneutic phenomenology involves the process of interpretation and the interaction between the researcher and the participants, requiring the
researcher (as in the social worker) to be reflective, insightful, sensitive to language and open to new experiences (van Manen, 1997). It afforded the opportunity to explore and gain better appreciation of the researcher’s cultural heritage, which enriched the depth of interpretation and understanding of the phenomenon. Van Manen (1997) suggests that hermeneutic phenomenological research may be seen as a dynamic interplay of six research activities:

1. turning to a phenomenon which seriously interests us and commits us to the world;
2. investigating experience as we live it rather than as we conceptualize it;
3. reflecting on the essential themes which characterize the phenomenon;
4. describing the phenomenon through the art of writing and rewriting;
5. manipulating a strong and oriented pedagogical relation to the phenomenon;
6. balancing the research context by considering parts and whole.

These six activities offered a method to guide the enquiry of this study in understanding the reconstruction of self-identity of Chinese women within the lived breast cancer experience.

4.1.3 Reflexivity: Locating Self

The location of the researcher is an important element in hermeneutic approach. Rather than bracketing or setting aside the researcher’s assumptions and biases, the researcher engages in ongoing self-reflection and her assumptions and biases are embedded and essential to the interpretative process. The researcher is asked to give considerable thought to her own experience and to clearly state the ways in which her position or experience relates to the issues being discussed (Laverty, 2003). Reflexivity is particularly relevant in this study where the researcher assumed the dual-role of an ‘insider’ and an ‘outsider’: female, Chinese and an
immigrant who came to Canada at a very young age, and a social worker and doctoral student/researcher, respectively.

Morse (2006) argues that insider knowledge may either sharpen sensitivity or silence the inquiry. To heighten sensitivity and reflexivity, the social location of the researcher must be acknowledged in the research process as it affects not only the translation of spoken words and meanings assigned to an event, but also the value and the significance of any claims made (Alcoff, 1991). The location of myself within the research process was an important factor in acknowledging the influence of my personal and professional experiences in understanding and interpretation of the Chinese Canadian breast cancer survivorship experience. The impetus for the study came from my years of clinical practice in the social services and health care sector and the added benefit of fluency in a second language. It is a well-accepted fact that lack of English language skills affects an individual’s illness experience; it hinders one’s ability to understand medical information, communicate with health service providers and access appropriate community and psychosocial resources; it further exacerbates a patient’s level of distress that arises from the impact of a breast cancer diagnosis and its implications.

My insider knowledge of the psychosocial issues pertaining to women living with breast cancer was gained from clinical experience in my capacity of social worker at a cancer hospital, as well as the shared characteristics of gender, immigrant status, language and community membership with the participants. From personal experience, I am deeply aware of the struggles and challenges faced by immigrants in adjusting and attempting to succeed in the Canadian society. Their ability to adjust and succeed by and large is contingent upon their command of the English language. As a Mandarin-speaking oncology social worker, I am often called upon by the health care providers to serve as an interpreter and clinical cases are often specifically
referred to me to overcome the language barrier. Clinically, I have repeatedly witnessed the relief in patients’ and families’ faces on meeting a health care provider who speaks their language; patients have often expressed appreciation and a sense of relief knowing they may call and depend upon someone who is able to understand their concerns and facilitate communication with their health care providers. In addition to my professional role, I recognize that my ability to speak Chinese enhances my position of power as well as responsibility in ensuring appropriate medical information is interpreted and patients’ concerns conveyed to the health care providers. Language equates power (Temple & Alys, 2004). Chinese cancer patients who do not speak the dominant language therefore lack the appropriate medical information and resources, and consequently are disadvantaged and at further risk of being marginalized; the inability to give voice to their needs renders them powerless and fosters dependency upon those fluent in their language to speak for them (Temple & Alys, 2004).

As an outsider, I am aware that my social work training and professional values including self-determination, anti-oppression and social justice might be brought into the research process. As a female, Chinese researcher, I recognize that my cultural background and language skills may discourage or influence Chinese women’s participation in this research, particularly those who do not speak English.

Therefore, as an ‘insider’ and an ‘outsider’, I was cognizant of my personal and professional experiences, cultural background, social position, theoretical framework and social work disciplinary principles that could influence the questions I asked (Wolf, 1996) as well as the interview process. Awareness of the structure of my own experience provided me with clues for orienting myself to the phenomenon (van Manen, 1997) and thus to all the other stages of the hermeneutic research. Throughout the research process, I maintained a reflexive journal that
documented the research activities undertaken, such as the handling of transcription issues and translational challenges, analysis and synthesis of data, preliminary codes, merging themes, theoretical perspectives and assumptions, as well as my emotional responses to the interviews (Arber, 2006; Rosedale, 2009), while always keeping in mind the epistemological query, “What I know and how I know it” (Finlay, 2002). An added benefit of such a journal is that it could track potential events, which might later be useful to identify leads in the data analysis process (Lofland, 1971).

Overall, this research project has been a learning, enriching and challenging journey. I have gained a deeper appreciation of my cultural heritage and am deeply honored to have borne witness to these women’s stories; I felt most privileged to be the first and the only person with whom they have shared their story. I am grateful to these Chinese women who openly shared their pain and fears, as well as their dreams and hopes, and trusted me with the task of accurately relaying their stories to help other women and families. I hope I have successfully created a space for Chinese women’s voices and experiences to be heard and valued.

4.2 Methods

4.2.1 Study Objective

The primary objective of this study was to understand the lived experience of Chinese women and particularly their reconstruction of their self-identity post-adjuvant treatment as part of the breast cancer survivorship experience, while living under the threat of premature mortality.

The research question of this study was:
• What is the lived survivorship experience of Chinese women living with breast cancer?

4.2.2 Recruitment Process

The study was conducted at the Princess Margaret Hospital (PMH), University Health Network, a major urban cancer hospital in Toronto. Ambulatory nurses at PMH Breast Centre and psychosocial professionals in the Breast Cancer Survivorship Program identified potential participants who met the eligibility criteria and provided the researcher with their telephone numbers. A recruitment flyer (Appendix F) was provided to the staff to assist with the identification of participants. Telephone numbers were necessary to contact the Chinese women on account of their limited visits to the hospital post-adjuvant treatment which were reduced to 6-month or annual follow-up appointments. The researcher approached identified participants during clinic visits or contacted them by telephone to introduce herself and provide a detailed explanation of the study. Verbal consent was obtained from those willing to participate in the study. Thereafter, an interview was scheduled at a mutually suitable time at the hospital or the participant’s home at which time written consent was obtained following review of the consent form. The consent form, in both English and Chinese (Appendix D and Appendix E), describes the study and its objectives, outlines the potential risks and benefits to participants, as well as the safeguards to maintain confidentiality of data. The consent form also advises participants they may withdraw from the study at any time without compromising their clinical care.

4.2.3 Sample Population

Twenty-four Chinese women were recruited from the PMH Comprehensive Breast Centre and the Breast Cancer Survivorship Program, who met the following inclusion criteria: 1)
had a diagnosis of breast cancer; 2) were at least six months post adjuvant treatment (Lam & Fielding, 2003); 3) received well follow-up outpatient care (i.e. receiving follow up after successful completion of treatment for initial tumours) at PMH; 4) were over the age of 18; and 5) were able to read and speak English or Mandarin. Exclusionary factors were Chinese women who: 1) received active clinical interventions from the researcher during the recruitment period; 2) had recurrence of or metastatic breast disease; 3) were in-patients; 4) had cognitive impairments (as identified by the ambulatory nurses or psychosocial oncology professionals); and 5) were unable/refused to provide consent.

A stratified purposeful sample (Sandelowski, 1995) of Chinese women living with breast cancer was utilized to reach theoretical saturation (Strauss & Corbin, 1998). This sample size was appropriate for a phenomenological study (Morse, 2000; Starks & Trinidad Brown, 2007) and achieved the goal of obtaining a varied, rich and deep understanding, or essence, of their lived experience (Creswell, 1998). To further promote achievement of this goal, the sample population included non-English speaking Chinese women whose illness experience could be influenced by their lack of facility in the English language. Traditionally, non-English speaking subjects are excluded from medical and psychosocial research due to the high costs associated with interpreters, translation and the hiring of bilingual staff (Ashing-Gawa, 2005; Frayne et al., 1996). Participants varied in age, the number of years they have lived in Canada, and years of survival to achieve maximum phenomenal variations (Sandelowski, 1995). Studies show age and years of survival are important variables in influencing women’s breast cancer survivorship experiences (Arndt et al., 2004; Kornblith et al., 2007; Lam et al., 2007; Sammarco, 2001; Schover, 1994; Thewes et al., 2003).
For the purpose of this study, Chinese women were defined as women who self-identified as Chinese through their ancestral lineage and included both Canadian-born Chinese women and Chinese immigrant women.

4.2.4 Pilot Testing

The interview guide and its translated version were pilot tested on 2 English-speaking and 2 Mandarin-speaking Chinese women to clarify the parameters and dimensions of the lived experience, to test the clarity of language, including translated language of the questions, and to locate potential presuppositions and biases of the researcher (Colaizzi, 1978). Feedback was sought from participants regarding their willingness to participate in repeated interviews, the length of the interview, the clarity of the questions, whether the questions captured their experiences and of the need for inclusion or deletion of questions. Phenomenology research typically involves a small sample size (usually less than 10) and multiple interviews with each participant (Benner, 1994). As a reflection of the natural phenomenon of life, 4 of the participants had moved on with their lives, and as such, they consented to one interview only. The researcher respected their decision and increased the sample size to achieve saturation for the full study.

The feedback necessitated minimal changes to the interview guide and consequently the data collected from the pilot testing were included in the final analysis. This interview was the first time these 4 participants spoke in detail about their experiences. They enjoyed the intimacy of sharing their stories and reported the overall experience to be positive and cathartic in that it facilitated an ordering of their experiences in a purposeful and meaningful way. As participant M2 said,
I feel that talking about my illness makes me feel quite happy since it has been repressed inside me for a very long time [smiling].

To capture the significance of the participants’ interview experience and solicit feedback on their experience of being interviewed, the question, “Can you tell me what this has been like for you to talk to me about your breast cancer experience?” was subsequently added; these responses would allow the Chinese women an opportunity to re-order their cancer experience and thus, reconstruct their self-identity. Phenomenological questions are meaning questions (van Manen, 1997); therefore, every question was directed to clarify, extract and deepen meanings.
CHAPTER 5
DATA COLLECTION, MANAGEMENT AND ANALYSIS

This chapter presents a detailed description of data collection, management and analysis, including transcription and translation issues and challenges. Rigor and ethical considerations in the study are also addressed.

5.1 Data Collection

Data collection consisted of patient demographic profiles and audio-taped face-to-face interviews which were subsequently transcribed. A semi-structured interview guide (Appendix B) was constructed to facilitate data collection; the questions were partially derived from existing psychosocial literature on the concept of self-identity (Mathieson & Stam, 1995) and modified for the purpose of this study. These questions were constructed to seek meaning and significance of a phenomenon (van Manen, 1997). The interview guide was professionally translated into Chinese to accommodate non-English speaking Chinese women and those who spoke English as a second language (Appendix C). Demographic information (Appendix A) was collected during the interview. All interviews were conducted by the researcher who is bilingual in English and Mandarin. The interviews were digitally audio-taped and transcribed. Each interview lasted about 1 – 1 ½ hour.

5.1.1 Interview process

In hermeneutic phenomenology, an interview serves as a vehicle to explore, gather and develop a conversation with the participants to gain an understanding of the meaning of the lived survivorship experience (van Manen, 1997). In this study, in-depth conversational interviews with a hermeneutic focus were conducted in English and Mandarin with the Chinese women, and
which reflected the themes of the phenomenon being studied. According to van Manen (1997), the art of the researcher in a hermeneutic interview is to keep open the question of the meaning of the phenomenon and as well to keep the researcher and the participant oriented to the idea of being questioned. As Gadamer (1975) states, “The art of questioning is that of being able to go on asking questions, i.e. the art of thinking” (as cited in van Manen, p.330). In keeping with the hermeneutic inquiry, the interview began with a broad question which asked each participant to describe what it was like around the time of breast cancer diagnosis. Thereafter, the researcher sat back and listened, allowing the participants to tell their story and the process to evolve. Probing questions sought deeper meaning and brought the conversation back to concrete experiences (e.g. “Can you provide me an example of that?” or “Where do you think that came from?”). Following the hermeneutic circle of questioning, the researcher went back and forth, deconstructing and reconstructing meanings, while paying particular attention to not only what was said, but also and more importantly, to what was not said to uncover the true essence of the experience (McConnell-Henry et al., 2009a). Additionally, the researcher introduced ideas and concepts expressed from one interview to the next to validate common or varied themes. Attention was directed to whole or overall meanings, and at the same time, the whole or overall meanings were examined by its parts (van Manen, 1997).

A significant number of Chinese women were puzzled by the question on self-identity, “Can you tell me how has breast cancer shaped the way you see yourself?” Probes were therefore used to clarify responses and deepen conversation until the participants had no further details to offer. The research interview was the first time all participants spoke openly and extensively to a person outside of their family about their experiences. A few were initially apprehensive about sharing their stories, though most of the Chinese women found the conversations beneficial and
cathartic. They welcomed the researcher into their homes or workplace and volunteered to come to the hospital during their lunch hours or on their day off for the interview. A large number of Chinese women viewed the researcher as their friend rather than an interviewer with whom they could share their worries, pain, fears and hopes. Participant E12’s comment expressed this sentiment,

Um, I don’t know how to say it you come here, I just get a new friend.

Mandarin-speaking participant M2 also voiced her feelings poignantly,

[smiling] …in your work I regard you as my friend, but then I do not have any friends like you. I can completely open up my heart to you. Being able to express my emotions makes me feel quite good. The feeling is nice.

Shared language afforded participants the opportunity to share their story and thus, facilitated an ordering of their experiences. The presence of a witness to hear their story allowed mutual reflection and the reassurance necessary to resurrect hope and meaning (Frank, 1995). Not surprisingly, the interviews were conversational, similar to talking to a long lost friend, rather than a formal interview.

Field notes and memos were recorded immediately following each interview, with notations on the location of the interview, the participant’s home environment, as well as participants’ body language, facial expressions and emotional responses, such as tone of voice and affective changes observed during the interview. The researcher’s impressions and feelings during the interview and preliminary thoughts on emerging themes and theoretical assumptions were recorded in a reflexive journal (Appendix G).
Although English-speaking Chinese women were not offered a language preference, a couple of Chinese women specifically requested the interview be conducted in Mandarin as they felt more comfortable expressing themselves in their native language. This request validates the common knowledge that when ill, a person tends to return to his/her cultural practices, including language. It was found that as English was the second language for most participants, several Chinese women were unfamiliar with the word “shaped” in interview questions, for example, “Can you tell me how breast cancer has shaped your life?” As a result, the word “shaped” was replaced with other alternatives such as “affected”, “influenced” or “changed,” words commonly used in everyday conversations. In such instances, the participants were offered both a positive and negative alternate to neutralize the potential influence of the question, for example, “Can you tell me how has breast cancer influenced or not influenced your life?” Historical meanings were sought throughout the hermeneutic interview (van Manen, 1997). The researcher reflected on the use of participants’ wording to further clarify and enhance the meanings of the lived experience, particularly in respect to informants with limited English language skills and those who used Chinese idioms or phrases to express their thoughts and emotional responses.

5.2 Data Management

Nvivo 2.0 qualitative software was used for coding of the data. Descriptive statistics (mean, median, SD) were calculated for all demographic variables. Data analysis was conducted based an inductive iterative approach.

5.2.1 Transcription Issues

In qualitative research, a transcript is necessary to achieve the research goal of capturing participants’ reconstruction of their lived experience in their own words (Sandelowski, 1994) and
to complement the level of analysis involved (Drisko, 1997). Sandelowski (1994) believes that a transcript becomes the researcher’s raw data by preserving the interview event and which could be utilized for member checking and expert peer review. If the focus of an analysis is to provide an in-depth description of the knowledge, attitudes, values, beliefs or experiences of an individual, or a group of individuals, then a lengthier and more extensive text is required for the transcript. The interest of researchers goes beyond identifying patterns and salient themes; they also seek to demonstrate variations in the way a phenomenon is framed, articulated and experienced, as well as the relationships within and between particular elements of such a phenomenon (MacLean, Meyer, & Estable, 2004).

As the aim of this hermeneutic phenomenological research was to gain a deeper understanding of the nature or meaning of the lived survivorship experience of Chinese women living with breast cancer, every effort was made to capture not only spoken words but also the emotional content of the interviews. Transcripts were transcribed verbatim and included mispronunciations, grammatical errors, vernacular expressions, intonations, slang, and emotional sounds; these were denoted in the transcripts as [crying softly], [laughing softly] or [sounds like nervous laughter] (MacLean et al., 2004). Attention to the expression of idioms is particularly important in phenomenology as they are born out of lived experience (van Manen, 1997). In the Chinese culture, an idiom [成語, chéng yǔ] is rooted in history and literature. It is an expression usually composed of four Chinese characters to describe metaphorically and capture a large set of psychologically meaningful social situations or encounters in everyday lives (Yang, Read, & Miller, 2006). For example, participant M7 used an idiom 僧粥少 in the interview to express her concern over contacting the researcher too frequently (due to language issues, the researcher was also providing clinical interventions to her and her husband at the time of her diagnosis),
because she knew the researcher/clinician was busy with other cancer patients; this idiom means “not enough for distribution” (Chinese-Tool) and may be traced back to a historical and poverty stricken period in China. It literally translates as too many monks (living in a temple) with a small supply of rice to eat (S.L. Guo, personal communication, February 20, 2009). In relation to the participant’s situation, it meant too many patients with so few health care providers.

To improve understanding of the content and affect of the interviews, transcripts included contextual information such as silences or pauses in conversation and background noises, as well as inaudible segments, which were documented in the transcripts as [cannot hear] or [inaudible] (MacLean et al., 2004; McLellan, MacQueen, & Neidig, 2003). Interviews conducted in English were transcribed verbatim by an English-speaking transcriber, while those in Mandarin were first transcribed verbatim in Chinese and thereafter translated into English by two transcribers and two translators cognizant with the vernacular, nuances, slang and idioms that could be expressed by Chinese participants who spoke Mandarin as their primary or second language. To expound further, a Cantonese-speaking transcriber was hired to transcribe interviews with Chinese women whose primary language was Cantonese but spoke Mandarin for the interview. The researcher clarified and verified the English transcripts against each interview and made changes as required. A decision was made to employ the traditional version (instead of simplified version) of Chinese characters (words) to transcribe interviews conducted in Chinese due to the researcher’s ability to read this version of writing. To ease translation, back-translation and accuracy verification, the English-translated text was located below each Chinese sentence or paragraph and compared to the original text. For accuracy and quality control purposes, spot-checks were conducted on all transcripts and translated transcripts (McLellan et al., 2003).
5.2.2 Translation Issues

Cross-cultural and cross-language psychosocial and survivorship research is needed more than ever as we continue to face an increasingly diversified population who identify English as their second language. Although conducting cross-cultural and cross-language research is rewarding, it introduces a host of methodology concerns and challenges that could compromise the research process and quality of data. Language translation is not a simple linguistic exercise (Shklarov, 2007). It is a complex process that plays a major role in influencing the quality of the data (Twinn, 1998). According to Shklarov (2007), cultural and contextual interpretation always plays a part, because the meanings of words often carry subtle nuances and cultural connotations that have to be captured in translation. Situations may arise where it is impossible to translate a concept into a different language with precise equivalency, as in the case of certain idioms in the Chinese language. To further complicate the translation process, some common Western conceptual meanings may be foreign to other cultures and vice versa, while others may not be shared or understood within the same ethnic group due to within group differences (e.g. regional and educational level differences). Thus, diversity within ethnic groups is another important influencing factor in translation, but is often neglected because of the stereotypical understanding of cultures as fixed entities; the Chinese culture evolves as do other value systems and cultures (Uba, 1994), where cultural practices are transformed in response to changing contexts and changing needs (Brathwaite & Williams, 2004).

Throughout the data translation process, seeking appropriate words or phrases in the dominant language to accurately reflect the depth and breadth of the Chinese women’s stories was an ongoing challenge, particularly in the translation of colloquial or idiomatic Cantonese or Mandarin phrases. This could raise question about the quality and extent to which the translated
data accurately reflects the feelings and experiences of the participants (Twinn, 1998) as reported in the study by Nelson McDermott and Palchances (1994) and more recently, in Twinn’s study (1998).

Twinn’s (1998) study used focus groups as a method of collecting qualitative data on Hong Kong Chinese women. Based on the findings, an important influence on the quality of data was grammatical style, which has particular insignificance for the Chinese language where tenses and personal pronouns are rarely employed in conversations, thereby contributing to the complexity of translating and making sense of the data. The majority of participants in the present study spoke English as a second language, and generally expressed themselves in the same manner as they would in Chinese, which resulted in mixing of grammatical structures and use of English words not applicable in the English context. Furthermore, the responses in Chinese were often negatively worded or expressed with a double negative, even though the informant was conveying the opposite (Nelson McDermott & Palchnaes, 1994; Twinn, 1998). For instance, a Chinese respondent would reply to a question with the Chinese word 有 [meaning: no] but intended to convey 沒有 [meaning: yes], as evidenced by subsequent comments.

Of significance, Twinn addresses the importance of undertaking data analysis in the same language as the interview, rather than that of the translated data, to avoid compromising the quality of data generated from a non-English speaking population. In the present study, data analysis was conducted in both English and Chinese. Every attempt was made to verify the accuracy of translation by mentally back-translating responses and comparing them to the original Chinese text. The back-translation process proved to be rather difficult and labour intensive due to the length of each interview, the structure of Chinese sentences or phrases, the
use of slang or idiom, and the challenge of finding English words equivalent to the Chinese characters. The researcher made every effort to translate all Chinese idioms into appropriate English language with the aid of Chinese-English dictionaries of idioms (Yang et al., 2006). Therefore, parallel to the translation process, the researcher undertook data analysis and coding in Chinese before translation into English to ensure the codes and meanings reflected as accurately as possible the true import of responses in Chinese. A translator spot-checked three randomly selected English-translated Chinese transcripts to verify translation accuracy.

Throughout the data interrogation, the goal was to present the data in a way that preserved the uniqueness of each participant’s experience, while also acknowledging the similarities and differences within each interview as well as the group as a whole. Translation from Chinese to English entailed word-by-word interpretation; in instances where this did not make sense or equivalent English words could not be found, the meaning of the sentence was instead translated. Both translations were included in the transcript to document the incongruence of the word-by-word approach. To retain the essence and authenticity of these women’s voices, grammatical errors were preserved, rather than corrected, in the translation process. More importantly, the preservation of text in its original form minimizes the risk of universalizing women’s breast cancer survivorship experiences and ignoring social differences. As Shklarov (2007) argues, an underestimation of the broad variations in verbal skills within groups, and treating cultural groups as homogeneous populations, could affect cross-language communication processes.

While the inevitability of discrepancies in translated meanings are challenging, Shklarov (2007) postulates that bilingual researchers have a unique and invaluable capacity to accommodate these differences in research investigations. Applied to the current study, the
bilingual researcher sees two parallel cultural meanings or realities, and hears two or more challenging conceptual understandings which allow in-depth perception of the context and contribute to the ethical sensitivity and quality of research. In summary, the position of a bilingual researcher in cross-language investigations has many advantages, in particular, the capacity to identify and understand the participants’ concerns through knowledge of the target culture and familiarity with cross-language experiences.

5.2.3 Phenomenological Orientation, Language and Text

Preparation for data analysis begins by orienting oneself to the phenomenon (van Manen, 1997). To accomplish this, the researcher emerged herself in the data by listening to each tape purposefully and reflectively, paying attention to each participant’s human existence. While listening, the researcher mentally re-lived the interview process; this mental exercise facilitated a deeper understanding and appreciation of the Chinese women’s stories (Base-Smith, 2006). Attention was paid to the participants’ pauses and silences, tone of voice, inflections, word selection, such as idiom or slang, and conversation fillers, such as “mm’s”, “uh-m’s” and “yeah’s”; these fillers were captured in the transcripts to enhance understanding of the data as well as interpretation of the motivations behind the dyadic interactions observed (MacLean et al., 2004). In the case of Chinese transcripts, however, conversation fillers were kept to a minimum to keep the sentences intact for easier translation.

Multi-layered readings allowed a wholistic feeling of the ‘big picture’ and ensured no aspects of the phenomenon were omitted. For a feel of the big picture and its parts, a “bird’s eye view” (Lecture Notes from the Qualitative Analysis & Interpretation Course, offered by Dr. J. Eakin, October 20, 2005) was taken by zooming-in and zooming-out to “open up” the data
(Clarke, 2005) while taking into account the whole facet of the Chinese women’s experience as well as the way they reconstruct their self-identity in relation to one another. A “bird’s eye view” approach avoids the pitfall of being prematurely caught up in a few themes analytically and losing sight of the bigger picture in the early stages of data interrogation (Clarke, 2005). Further, the bigger picture assists the researcher to regard the data as fluid, rather than static and fixed, in relation to other elements of the phenomenon.

Hermeneutic phenomenology involves a specific method of questioning, reflecting and interpreting, with an emphasis on the understanding of the text, thus, creating a phenomenological text that is the object of the research process (van Manen, 1979). Language provides the medium to facilitate understanding by bringing the meanings into a symbolic textual form. Gadamer believes that thinking (rationality) and speaking (language) came from the term *logos*, which means letting what is talked about be seen (van Manen, 1979). In other words, phenomenology is what Heidegger sees as letting “that which shows itself be seen from itself in the very way in which it shows itself from itself” (Heidegger, 1962, p.58). Throughout the writing process, the researcher paid attention to logos by allowing language and thoughtfulness as an aspect of phenomenon to be heard and seen (van Manen, 1979).

The researcher individually coded all the transcripts. During the readings, significant phrases, sentences and statements were highlighted and coded, with particular attention paid to recurrent images, repeated words, metaphors or analogies, and contradictions and transitions in the narratives (Ryan & Bernard, 2003); emerging themes were categorized according to the four structures of the lifeworld. Interpretation and meanings were proposed for each statement employing words as close as possible to those voiced by the participants. Common themes were integrated into the four existential structures that describe the phenomenon, thereby generating a
clear structured cognitive framework of the emergent themes; a distinction was made between incidental themes versus essential themes (van Manen, 1997).

Constant comparison of the text was undertaken to identify negative cases and compare thematic patterns and commonalities that characterized the phenomenon being studied, and to explain individual variations within each interview as well as all interviews as a whole (Thorne, Kirkham, & O'Flynne-Magee, 2004). Phenomenological investigation entails the art of sensitivity to the subtle undertones of language; this requires the researcher to be a true listener to attune to the deep tonalities of language that normally fall out of the range of accustomed hearing (van Manen, 1997). Phenomenological researchers are not primarily interested in the subjective experiences of the participants, but more importantly, seek a deep understanding of the nature of this phenomenon as an essentially human experience. Sensitivity to the undertones of the Chinese language is particularly important as the cultural context in which it is spoken and used to express oneself, such as the use of an idiom, is rooted in historical origin and borne of lived experience.

In adhering to the phenomenological principle on reflexivity, the researcher also focused on her emotional responses to the participants’ experiences throughout the data interrogation process. According to Mauthner and Doucet (1998), attention to the researcher’s emotional responses involves the researcher reading the text and placing herself, her background, history and experiences in relation to her respondents. Central to this “reader-response” element is the importance of reflexivity. I reflected on my assumptions, impressions and cultural values that could influence my interpretation of the respondent’s words, and referred to my field notes/memos and reflexive journal to clarify and elaborate my thinking, as well as to make additional notes as necessary. Of significance, I noted in my reflexive journal my disappointment
around the lack of emotional depth and intensity in the participants’ responses to the question on self-identity, “Can you tell me how breast cancer has affected the way you see yourself?”. Most Chinese women found this question puzzling and difficult to answer, as evidenced by their frowns and slightly nervous laughter. On further reflection and discussion of my disappointment with my thesis supervisor, I realized I had unconsciously brought into the interview process my view of “western” self-concept and therapeutic expectations and had unfairly projected onto the participants my expectation of insightful revelations and meanings about their experiences. Their hesitancy and puzzlement underscores the Chinese collectivist culture and the inappropriateness of applying one culture’s definition of self-identity to another culture, assuming that self-identity is universal and static. Throughout this process, I periodically removed myself from the data to reflect upon my assumptions and responses. An audit trail was created detailing the decisions made about the methodological and practical considerations, such as the challenges associated with transcription and translation to ensure rigor and quality of data.

5.3 Data Analysis

5.3.1 Thematic Analysis

This study employed thematic analysis to describe and interpret the internal meaning structures of lived experience or lifeworld (Figure 1). In qualitative research, thematic analysis is the most common approach for data interrogation (Creswell, 1998). According to Luborsky (1993), the significant benefit of utilizing thematic analysis is its direct representation of an individual’s point of view and descriptions of experiences, beliefs and perceptions. In other words, themes lend more weight to the voices and experiences of the individual than to the expert observer, exemplifying the emic perspective of qualitative research of understanding the
lived experience. Further, themes may be utilized by the speakers to provide structure and coherence, a sense of order, and also express an explicit point or meaning. van Manen (1997) defines a theme and its relation to phenomenological reflection as: 1) the experience of focus, or meaning; 2) at best a simplification; 3) intransitive rather than an object; and 4) an aspect of the structure of the lived experience that one tries to capture. He further identifies three approaches to isolate the thematic aspects of a phenomenon: 1) the wholistic or sententious approach; 2) the selective or highlighting approach; and 3) the detailed or line-by-line approach.

A theme was identified when the researcher was able to answer the question, “What is this expression an example of?” (Ryan & Bernard, 2003).

A theme could be either essential or incidental. van Manen (1997) argues that not all reflected themes are unique to a phenomenon or an experience; essential themes are often historically and culturally determined or shaped. In determining a theme as essential or incidental, he suggests applying the method of free imaginative variation to verify if the elements make a phenomenon what it is and without which the phenomenon could be what it is; this process of free imaginative variation could also be employed to generate other essential themes. To identify a theme, van Manen suggests we ask ourselves two questions: Is this phenomenon still the same if we imaginatively change or delete this theme from the phenomenon? And, does the phenomenon, without this theme, lose its fundamental meaning? In addition to keeping these two questions in mind throughout data interrogation process, the researcher also utilized other means to identify themes including repetition of words, ideas or phrases, indigenous categories, metaphors or analogies, and similarities and differences (Ryan & Bernard, 2003).

As themes within data may emerge as a recognizable whole and as a singular thought process, other analytic devices including multi-layered reading, constant comparison and
reflexivity were utilized to not only to enhance the extraction of the essences of meaning, but also to enrich understanding of the phenomenon.

5.3.2 Lifeworld Existentials as Guides to Reflection

In phenomenology, themes, or existential themes, are viewed as the *structures of experience* and often described and interpreted within the structures of the four existentials of lifeworld - lived space (spatiality), lived time (temporality), lived body (corporeality), and lived relation (relationality) as the means to ground human experience (van Manen, 1997). In other words, recognizing how and where the data was to be categorized thematically not only helped to integrate the themes into a structured meaning, but also provided a clear structured cognitive framework for the researcher and the reader to understand the textual data (Vis, 2005). By utilizing the four existentials of lifeworld to structure the interpretation, meaning was derived from an iterative process and self-reflexivity by listening to and weaving the participants’ accounts of their lifeworld as experienced in past and present situations, and their relations to others as they strive for normalcy while living under the fear of Damocles’ sword. van Manen argues that these four existentials pervade the lifeworlds of all human beings, regardless of their historical, cultural or social backgrounds; they are differentiated but not separated and form an intricate unity called the *lifeworld*.

Lived space, or spatiality, is felt space. This may include mathematical space (e.g. length, height), geographical distance (e.g. miles/kilometers), or physical space (e.g. a house or an apartment). Lived space is pre-verbal that is not ordinarily reflected upon. It is the space in which we ourselves affect the way we feel. Lived space, in general, is the existential theme that refers us to the world or landscape in which human beings move and find themselves at home. When
we want to understand a person, we inquire about his or her lived space or world, profession, interests, background, and so on. Lived space also has cultural and social elements that lend the experience of space a certain qualitative dimension.

Lived time, or temporality, is subjective time as opposed to clock time or objective time. It is the time that appears to speed up when enjoying ourselves, or slow down when bored or anxious. Lived time is our temporal way of being in the world and includes temporal dimensions of past, present and future that constitute a person’s life. Past encounters are retained in a person’s memory or forgotten, yet affect the way he carries himself, the gestures he adopts, the words he speaks and the language that ties him to his past. As the person makes something of himself, he may reinterpret who he once was or who he is now.

Lived body, or corporeality, refers to the phenomenological fact that we are always bodily in the world and on meeting another person, we meet him first through his body. Through our physical or bodily presence we both always reveal something about ourselves and conceal something, not consciously or deliberately, but rather in spite of ourselves.

Lived relation, or relationality, is the lived relation we maintain with others in the interpersonal space we share with them. As we meet other individuals, we usually approach them in a corporeal way, such as through a handshake. Even if we learn about another individual indirectly, usually we have formed a physical impression of that person, which may be confirmed or negated. As we meet others we develop a conversational relation, which allows us to transcend our selves.

Hermeneutic phenomenology provided the interpretative lens to understand the reconstruction of self-identity of Chinese women with breast cancer within the lived survivorship experience and the structural themes of the lived experience, or lifeworld - lived space, lived
body, lived relation and lived time - while acknowledging the influence of social factors within a historical context. These four lifeworlds guided reflection, conceptualization and writing of the study.

5.4 Rigor

Unlike quantitative research which seeks causal determination, prediction and statistical generalization of findings, the aim of a naturalist, constructive and interpretative inquiry is to solicit rich illumination, understanding and extrapolation from the data generated (Hoepfl, 1997; Polkinghorne, 1989). The issues of validity and reliability are just as important in qualitative studies as in quantitative research to establish truth-value; in qualitative investigations, however, validity and reliability are achieved through the concepts of credibility, transferability, dependability and confirmability (Guba & Lincoln, 1985). For hermeneutical research, the multiple stages of interpretation that allow patterns to emerge, the discussion of how interpretations arise from the data, and the interpretive process itself are critical ways to ensure rigor (Koch, 1995). Rigor was further enhanced by having two English transcripts randomly selected and reviewed by the thesis supervisor (CW) and a committee member (DH). They each read the transcripts to verify coding accuracy, reviewed the extracted statements as well as the formulated meanings and themes, and provided additional interpretation of the coded data as necessary. Further, one English transcript was coded by the researcher and two PMH social work colleagues (MJ, JS) to verify codes and themes and to resolve interpretations issues; codes and themes were agreed upon based on group consensus. English translation of three Chinese transcripts were spot-checked by translators to ensure translation accuracy.
Trustworthiness is an important concept in qualitative research in establishing rigor; it relates to truth-value, applicability, consistency and neutrality (Guba & Lincoln, 1985). In this study, trustworthiness was addressed through reflexivity, prolonged engagement, interdisciplinary triangulation, negative case analysis, peer debriefing/support and audit trail (Padgett, 1998).

Prior to detailed discussion of the techniques employed to establish trustworthiness, I pause to acknowledge the current debate and tension regarding the appropriateness of applying quantitative terminology to establish rigor in qualitative research (Golafshani, 2003). While prolonged engagement, triangulation and negative case analysis are acceptable techniques to establish rigor in qualitative research (Guba & Lincoln, 1985), there is, however, an acknowledged need for qualitative researchers to define the meanings of these techniques within the paradigm (Babour, 1998). Therefore, interpretation of the techniques applied in this hermeneutic phenomenological research is explained.

5.4.1 Prolonged Engagement

Prolonged engagement traditionally refers to the duration and acceptance of the researcher in the field (Padgett, 1998). I have almost 20 years’ social work experience in oncology and provide clinical interventions at PMH to women living with breast cancer and their families. I saw prolonged engagement as my immersion in the interviews, asking questions to seek a deeper meaning of the Chinese women’s lived experience. The interviews were lengthy and extensive, lasting about 1 ½ hour, rather than 20-minute short interviews. Further, my shared gender, language and culture with the study participants lent further depth to the interpretation and understanding of the Chinese women’s lived experience.
5.4.2 Triangulation

Hermeneutic phenomenology recognizes that different factors or sources influence the common meaning and the importance of consulting other sources to gain deeper understanding of the meaning of the lived experience (van Manen, 1997). This study employed Janesick’s (1994) concept of interdisciplinary triangulation that calls for the involvement of more than one discipline in a research study; in this study, it was social work and oncology nursing. The inclusion of oncology nursing was a natural extension of my clinical practice in an interdisciplinary health environment that recognizes and values the perspective each discipline brings to the care of patients and families. Further, the inclusion of the nursing perspective helped gain a broader understanding of the phenomenon in response to the question whether it is a common or varied theme that I am seeing. The establishment of a Multidisciplinary Thesis Committee, comprised of Social Work and Oncology Nursing professionals, also served to debrief and code verifications.
Figure 1 – Creation of the Phenomenological Text

Data Interrogation: Thematic Analysis
Extrapolating and Formulating Themes

Taking the wholistic or sententious approach by attending to the text as a whole to get an overall feel of it.

Taking the selective or highlighting approach by underlining paragraphs, statements or sentences that stand out.

Taking the detailed or line-by-line approach by looking at every single sentence or sentence cluster that reveal the experience.

Multi-layered Reading, Constant Comparison

Interpretation, Conceptualization, Reflexivity

Identification of Phenomenological Themes as the Structure of Experiences

Lived Space (Spatiality)
Incidental Themes
Essential Theme

Lived Time (Temporality)
Incidental Themes
Essential Theme

Lived Body (Corporeality)
Incidental Themes
Essential Theme

Lived Relation (Relationality)
Incidental Themes
Essential Theme
5.4.3 Negative Case Analysis

Negative case analysis or ‘varying the examples’ (van Manen, 1997) is an important consideration in qualitative research to ensure verification. In hermeneutic phenomenology, negative case analysis does not reference outliers or negative case findings; rather, it focuses on the unique aspects or phenomenal variation of the lived experience (i.e. a variation that does not fit with the rest) to ensure the voices of all participants are equally and fully represented, and generalization of the experiences is avoided; in this study it refers to avoiding generalization of the experiences of Mandarin-speaking Chinese women to all Chinese women.

5.4.4 Peer Debriefing/Support

In addition to support from the Multidisciplinary Thesis Committee, the researcher initiated discussions with other doctoral students engaged in qualitative or phenomenological investigations, oncology social workers and other psychosocial professionals at PMH regarding her personal values, theoretical assumptions and cultural background in relation to the research process and emerging findings (Pascal, 2005). Further, the researcher enlisted two oncology social work colleagues with clinical experience and qualitative research skills to double-code a transcript to ensure coding accuracy as well as a translator to spot-check English translated transcripts.

5.4.5 Audit Trail

An audit trail, detailed field notes and memos were maintained to enhance reproducibility and dependability (Padgett, 1998). A reflective journal was kept throughout the research process for reflectivity.
5.5 Ethical Considerations

5.5.1 Ethics Review Approval

Ethics approval was sought and obtained from the University Health Network (UHN) Research Ethics Board to conduct both the pilot testing and the thesis research at PMH. Administrative ethics approval was also sought and obtained from the Office of Research Ethics at the University of Toronto for thesis research.

5.5.2 Participant Consent

Participants who met the inclusion criteria were contacted by the researcher to introduce the study, provide written details of the investigation and obtain their consent to participate in the study. The consent form in both English and Chinese (Appendix D) described the study and its objectives, the potential risks and benefits to participants, and the safeguards to maintain confidentiality of data. The consent form also advised participants that they could withdraw from the study at any time without compromising their clinical care. Chinese women who were receiving active clinical interventions from the researcher during the recruitment period were excluded from the study.

5.5.3 Risks and Benefits to Participants

The risk to the participants in this study was limited to possible psychological or emotional discomfort when sharing their experiences; in such cases, the interview would be suspended and participants offered the option of continuing or terminating the interview, as well as a referral to the PMH Psychosocial Oncology and Palliative Care Program for professional
support. Benefits of the study are its contribution to both the development of culturally sensitive psychosocial/supportive care interventions and the knowledge-building process regarding the survivorship experiences of Chinese women with breast cancer.

5.5.4 Confidentiality

To protect the confidentiality of participants, an identifying number was assigned to digitally recorded interviews. All patient identifying information was deleted before they were forwarded to a secured e-mail account for transcription. To ensure security, digital audio recordings were stored in the researcher’s locked office and transcribed data password protected. Participants were assured that their decision to participate, or not would in no way affect their follow up or future treatment and care at the hospital. Participants were referred to another breast site social worker for psychosocial care as appropriate.
CHAPTER 6
RESEARCH FINDINGS: EMERGING THEMES

This chapter describes the sample population and examines the incidental and essential themes derived from, and interwoven into the four existentials of lifeworld to lend structural meaning to the lived experience of breast cancer of Chinese women, in particular the way they reconstructed their self-identity. Though distinct, the themes are interconnected in shaping the reconstruction of self-identity of these Chinese women.

6.1 Description of Sample

To illuminate the essence of the Chinese women’s lived experience, a brief summary of each participant’s narrative is provided in Table 1 and Table 2. The narratives were modified to protect the participants’ privacy. Table 3 summarizes the demographic profile of the sample population.

Thirty-six Chinese women who met the selection criteria were approached to participate in the study. The final sample size constituted 24 participants. Twelve Chinese women who declined to participate cited reasons such as too busy, not interested, lack of fluency in Mandarin, reluctant to return to the hospital, uncomfortable talking to someone about their illness, or did not return telephone messages. Of the 24 participants, 16 (67%) were interviewed in English and 8 (33%) in Mandarin.

Fourteen Chinese women (59%) were interviewed at Princess Margaret Hospital (PMH); 8 (33%) Chinese women were interviewed at their homes, one of which was conducted in the presence of the participant’s daughter-in-law due to the subject’s concern about her proficiency in English. One participant invited the researcher to her
workplace for the interview. Another interview unexpectedly took place in the chapel of a nearby local hospital as the participant did not want the other Chinese tenants who shared the house to learn of her cancer for fear they would ask her to move out.

The mean age of the sample was 55, ranging from 43 to 70 years. Participants’ years of remission from breast cancer ranged from 6 months to 11 years with the majority (71%, n=17) falling between 1-5 years. All respondents had undergone surgery to remove the breast tumour; 16 (67%) respondents had a lumpectomy and 8 (33%) respondents a mastectomy. Ninety-two percent (n=22) of the Chinese women received radiation therapy treatment, approximately half of whom (54%, n=13) were also treated with adjuvant chemotherapy; 75% (n=18) received hormonal therapy. The majority of participants (71%, n=17) were married. Household annual income ranged from $30,000 to $89,999. Over half (58%, n=14) the participants had completed college/university or post-graduate studies.

All but one of the Chinese women were born outside of Canada, half of whom (46%, n=11) were born in mainland China. The mean length of stay in Canada was 24 years, with participants immigrating to Canada as far back as 1964 and as recently as 2007. The mean age of these participants when they came to Canada was 31, ranging from 18 to 57 years old. The dominant Chinese language spoken at home was Cantonese (67%, n=16). While 46% (n=11) of Chinese women reported no religious practices or affiliations, 54% self-identified as Buddhists (n=6), Protestants (n=4) or Roman Catholics (n=3).
At the time of the interview, of the sample size of 24 participants, 9 (38%) worked full-time, 5 (21%) were retired, 2 (8%) identified themselves as homemakers, 2 (8%) were employed part-time, and 6 (25%) participants were not working. Of the 6 participants who were not working, one was unable to return to work due to treatment late effects (e.g. pain and numbness in fingers); 2 participants were recent immigrants and unable to find suitable employment due to language barriers; one participant stopped working following a car accident; one participant was seeking employment and one participant accepted a severance package due to company closure. Only 9 (37%) Chinese women accessed community cancer supportive services (e.g. volunteer drivers and cancer supportive programs) during treatments.

6.2 Emerging Themes

While there are commonalities between the survivorship experiences of Chinese women and women in general, this paper focused primarily on the emerging themes around the identity reconstruction of Chinese women following breast cancer lived experience. An analysis is presented of the identity reconstruction of Chinese women among the four existentials of lifeworld: spatiality (lived space), corporeality (lived body), relationality (lived relation) and temporality (lived time), which offers a structural cognitive framework to understand the identity reconstruction of Chinese women and their breast cancer lived experience.
<table>
<thead>
<tr>
<th>Participant’s Identification</th>
<th>Age</th>
<th>Years in Remission</th>
<th>Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>M1</td>
<td>50</td>
<td>4</td>
<td>M1 is single with minimal social supports. She described in tears the challenges of having to move between 4 temporary homes during chemotherapy due to landlords’ and sister’s family cultural belief that it is bad luck/omen to have a sick person live in their homes. M1 was proud of her ability to remain self-reliant and not be a burden to her sister. She was unable to return to factory work due to arthralgias in her arms and legs and was surviving on her dwindling savings.</td>
</tr>
<tr>
<td>M2</td>
<td>43</td>
<td>5</td>
<td>M2 is married with a teenage son. She too described in tears the challenges of undergoing chemotherapy while at the same time adjusting to a new life in Canada with minimal English language skills and financial and family support. She made the difficult decision of sending her son back to China as she and her husband were unable to provide parental care during her treatment. Moving on with life was an important post-treatment goal; she returned to school and passed her Canadian dental hygienist exam with the hope and aspiration of opening her own dental office in the future. She was a dentist in China.</td>
</tr>
<tr>
<td>M3</td>
<td>69</td>
<td>4</td>
<td>M3 is married with no dependents. She recently retired after running the couple’s business for over 30 years. She assumed the operation of the business when her husband became ill with multiple health problems, including strokes; his health problems and the philosophical teachings of Lao Zi and Zhuangzi seemed to have shaped her pragmatic perspective on life resulting in a practical, matter-of-fact way of approaching and facing her breast cancer. Although her self-identity did not appear to be influenced by breast cancer, it was profoundly influenced by husband’s health problems.</td>
</tr>
<tr>
<td>M4</td>
<td>55</td>
<td>1</td>
<td>M4 is married and has a teenage son. Although she lived with the fear of recurrence, she nevertheless took pride in her efforts to return to normalcy by finding a part-time job at a local coffee shop, earning minimum wage; symbolically, work meant she is healthy, productive and contributing to and building family financial security in the event of her premature death. By taking practical steps to problem-solve, she minimized the burden on her family and also fulfilled her social role and obligations to her family, thus, maintaining harmony.</td>
</tr>
</tbody>
</table>

5 M represents Mandarin-speaking.
<table>
<thead>
<tr>
<th>Participant’s Identification</th>
<th>Age</th>
<th>Years in Remission</th>
<th>Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>M5</td>
<td>43</td>
<td>1</td>
<td>M5 is married, has a teenage son and came to Canada with her family about two years ago. She shares a small house with two other Chinese families. M5 recalled in tears her high distress level and fears during the wait time for tests and to see specialists. Her distress and loneliness from lack of family support and English-speaking skills prompted her to borrow money to return to China for faster medical treatment. M5 can’t read Chinese as well as can’t read and speak English, which made finding a job very difficult. She came from a large rural family of eight children where females were not encouraged to attend school. Very few people knew of her cancer diagnosis, including her son and other tenants in the house.</td>
</tr>
<tr>
<td>M6</td>
<td>57</td>
<td>11</td>
<td>M6 is married and has 3 grown children. Her two main worries were financial security and language. She recalled in tearful detail the harassment and mistreatment from her employer while undergoing treatment; the negative work environment overshadowed the impact of her breast cancer. Nevertheless, she endured the treatments and was self-reliant and practical, feeling it was her duty to problem-solve on her own. The only consolation from the negative work experience was the severance package she received, which allowed her to be financially independent and not a burden to her family.</td>
</tr>
<tr>
<td>M7</td>
<td>54</td>
<td>2</td>
<td>M7’s husband was diagnosed with terminal lung cancer a few months prior to her diagnosis of breast cancer. M7 was quite literal, methodical and detailed in recounting her despair, loneliness, isolation and hardship in response to husband’s illness. M7’s breast cancer experience was completely overshadowed by the demands of husband’s illness and premature death. She had no time to process her own illness experience, as she had to focus on caring for husband and problem solve their financial difficulties. She has no family in Canada. Faith played an important role in her acceptance of and adjustment to husband’s illness.</td>
</tr>
<tr>
<td>M8</td>
<td>56</td>
<td>8</td>
<td>M8 has been using her cancer experience to help others in husband’s Buddhist temple since retirement. With husband and Temple’s Master Monk, she would visit other worshippers to offer comfort and support. M8 acknowledged the importance of support from family and friends, in particular husband’s support, to help her through treatments. She demonstrated a practical, matter-of-fact approach in dealing with her illness and was happy to be discharged from the hospital on surpassing the 5-year survival mark.</td>
</tr>
</tbody>
</table>
Table 2 – A Summary of English-Speaking Chinese Women’s Narratives

<table>
<thead>
<tr>
<th>Participant’s Identification</th>
<th>Age</th>
<th>Years of Remission</th>
<th>Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>E1</td>
<td>57</td>
<td>6</td>
<td>E1 lives with her husband and elderly father and has no dependents. She declined chemotherapy due to borderline condition and family history of depression. E1 sought individual counseling and attended community cancer supportive programs which she found beneficial because she was able to hear other women’s experiences. Volunteerism was important to E1 as part of her recovery.</td>
</tr>
<tr>
<td>E2</td>
<td>51</td>
<td>2</td>
<td>E2 is divorced and lives with her young adult daughter. She described in detail the hardship and difficulties she experienced while undergoing chemotherapy. Since her diagnosis, and out of fear of recurrence, she has made significant nutritional changes underscoring Chinese beliefs on food. She returned to work in a health care setting. She drew on her father as a role model to affirm and reframe her practical approach in managing her cancer.</td>
</tr>
<tr>
<td>E3</td>
<td>65</td>
<td>2</td>
<td>E3 is married and lives with her husband. Both work in the medical field. E3’s illness experience may be summarized by the Chinese expression “麻煩” [má fan – inconvenience or troublesome but is socially constructed with emotional and/or social meanings]. Work, faith and being “vigilant” were important coping tools she used to shield her from dying.</td>
</tr>
<tr>
<td>E4</td>
<td>43</td>
<td>1</td>
<td>E4 is single and lives with her family. She described the hardship of undergoing chemotherapy; she had breast reconstruction. “Thinking like a surgeon” and “dealing with one step at a time” were the mottos of her narrative. E4 commonly used the pronoun ‘we’ rather ‘I’ to express herself, reflecting cultural collectivism rather than individualism.</td>
</tr>
</tbody>
</table>

6 E represents English-speaking.
<table>
<thead>
<tr>
<th>Participant’s Identification</th>
<th>Age</th>
<th>Years of Remission</th>
<th>Narrative</th>
</tr>
</thead>
<tbody>
<tr>
<td>E5</td>
<td>56</td>
<td>6 months</td>
<td>E5 is married and lives with her husband. She is the primary caretaker of her elderly parents. E5 had a difficult time undergoing chemotherapy; her body image was negatively affected by surgery and treatments. Her use of language to describe her illness experience reflected her exposure to the survivorship culture as well as the Chinese values of suppression of feelings and endurance.</td>
</tr>
<tr>
<td>E6</td>
<td>46</td>
<td>6 months</td>
<td>E6 is married and lives with her husband and 2 teenage children. She comes from a “gentle, intellectual” family and regarded her husband as below her social standing. She described herself as a “winner” who has always worked hard and achieved her goals. She holds a senior position in an academic institution. Having breast cancer has “softened” her strong and ambitious traits and identity. She was rational and pragmatic in her acceptance of the disease.</td>
</tr>
<tr>
<td>E7</td>
<td>56</td>
<td>4</td>
<td>E7 is married and lives with husband and adult son. She stressed the importance of continuing a “normal life” and being a “normal person”. Her earlier life working in a rural farm during the Chinese Cultural Revolution seemed to shape her pragmatic approach to life and breast cancer. She endured and survived the harsh rural life through self-discipline, hard work, education and self-reliance, which she internalized and drew upon to shield her from recurrence.</td>
</tr>
<tr>
<td>E8</td>
<td>53</td>
<td>1</td>
<td>Contrary to the Chinese values, E8 openly disclosed her illness to friends and colleagues. As an immigrant and single parent, she worked hard to strive and build a new life for herself, son and mother. Having breast cancer led to personal growth, defined by continuing paid work and being normal.</td>
</tr>
<tr>
<td>E9</td>
<td>44</td>
<td>9</td>
<td>E9 is a homemaker and single parent of 3 young children. She credited her then-boyfriend for supporting her throughout her illness. Survival was very important to her because of the children. She approached her illness with a pragmatic mindset, which extended to her practical acceptance of breast changes. Breast was viewed as insignificant if it meant she could live.</td>
</tr>
<tr>
<td>Participant’s Identification</td>
<td>Age</td>
<td>Years of Remission</td>
<td>Narrative</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-----</td>
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<td>-----------</td>
</tr>
<tr>
<td>E10</td>
<td>69</td>
<td>2</td>
<td>Participant E10 lives with her husband and adult son. She chose to continue to work after retiring from a successful career in financial management. She works at a technological firm and enjoys the collegial relationships with predominantly young male colleagues. Work is an important part of her identity; it helped her cope with husband’s physical and cognitive disabilities and represented continuity of normalcy. She made significant lifestyle changes (e.g. buying organic food and minimizing plastic usage) in response to cancer diagnosis. Faith is an important element in her life. She is not worried and does not think about her cancer because it was detected early and she trusts her health care providers.</td>
</tr>
<tr>
<td>E11</td>
<td>56</td>
<td>10</td>
<td>E11 is a widow; she lost her husband suddenly at the beginning of 2009 to a brain aneurysm and was grieving at the time of the interview. The recent birth of her grandson has given her a new focus on life. She enjoys her new role as a grandparent and plans to retire early so she can look after him. E11 was recently discharged from the hospital due to long remission period. Her main concern at the time of diagnosis was doing everything to survive for the children. She identifies herself as a survivor who had cancer and is working; “I want to be a normal person”; for her normal means “going back to work,” and not working means she is sick.</td>
</tr>
<tr>
<td>E12</td>
<td>63</td>
<td>3</td>
<td>E12 is single and lives with her brother and his family in a townhouse she owns. E12 worked very hard to save enough money to purchase her house and seemed relatively content with her life, “no worries”. She was quite modest about her independence, endurance and self-reliance at managing her chemotherapy on her own (e.g. helping her brother to deliver newspapers and taking the public transit). She was very sincere in participating in the study and her way of giving back to the hospital and furthering researcher’s education.</td>
</tr>
<tr>
<td>E13</td>
<td>58</td>
<td>3</td>
<td>E13 is single and a successful businesswoman managing her own company. She works long hours and travels extensively. She has been quite active on Chinese community boards. E13’s methodical approach to managing her business operations extended to practical management of her breast cancer experience. She accepted it and reframed it as having the “flu”; thus, taking a practical matter-of-fact approach to dealing with the impact of disease so she could “get back to normal” i.e. working.</td>
</tr>
<tr>
<td>Participant’s Identification</td>
<td>Age</td>
<td>Years of Remission</td>
<td>Narrative</td>
</tr>
<tr>
<td>-----------------------------</td>
<td>-----</td>
<td>--------------------</td>
<td>-----------</td>
</tr>
<tr>
<td>E14</td>
<td>70</td>
<td>4</td>
<td>E14 is married and lives with husband, her son and his family. E14 identified several significant factors that appeared to influence her acceptance of and “smooth” adjustment to breast cancer: her experience with two cancers (breast and thyroid) without chemotherapy; her grandson’s diagnosis of childhood cancer; her strong Catholic faith; supportive family; her trust and confidence in health care providers; her cousin who is a RN at the hospital helped navigate the health care system; and her daughter-in-law who acted as an interpreter. She views her breast cancer as a test from God and is accepting this test well.</td>
</tr>
<tr>
<td>E15</td>
<td>69</td>
<td>2</td>
<td>E15 is married and lives with her husband who has multiple health problems. He is legally blind. E15 saw no change in self-identity because she is still able to carry on her activities (e.g. driving). She has an autistic son who lives in a group home. As a retired nurse, E15 was knowledgeable and experienced with medical issues and practices. As such, she is a firm believer in self-advocacy in her care.</td>
</tr>
<tr>
<td>E16</td>
<td>54</td>
<td>5</td>
<td>E16 is married and lives with her husband. Although work was important to E16, she decided to retire due to late effects of her treatment. The flexibility to choose what she wanted seemed to ease the guilt of not continuing to work. Since retiring, she has been active in church activities and making healthy lifestyle changes (including complementary therapies) to minimize recurrence. She reports no identity change and views cancer like “having a flu”, i.e. she had cancer and does not worry about it; to worry means she is not surviving.</td>
</tr>
</tbody>
</table>
### Table 3 – Participants’ Demographical Profile

| Interview Site | PMH = 59% (14)  
|                | Home = 33% (8)  
|                | Other (i.e. work, another hospital) = 8% (2) |
| Age | 55 (min=43, max=70, SD=8.51) |
| Types of Treatment | Surgery: Lumpectomy =67% (16)  
|                 | Mastectomy =33% (8)  
|                 | Radiation Therapy: Yes = 92% (22)  
|                 | No = 8% (2)  
|                 | Chemotherapy: Yes = 54% (13)  
|                 | No = 46 (11%)  
|                 | Hormonal Therapy: Yes = 75% (18)  
|                 | No = 25% (6)% |
| Years of Remission | < 1 year = 2 (8%)  
|             | 1-5 years = 17 (71%)  
|             | 6-9 years = 3 (13%)  
|             | >10 years = 2 (8%) |
| Education | Some High School = 12% (3)  
|            | Competed High School = 21% (5)  
|            | Some College/University = 4% (1)  
|            | Completed College/University = 42% (10)  
|            | Postgraduate = 17% (4)  
|            | No Education = 4% (1) |
| Marital Status | Single = 17% (4)  
|             | Married = 71% (17)  
|             | Separated/Divorced = 4% (1)  
|             | Widowed = 8% (2) |
| Country of Birth | Hong Kong = 21% (5)  
|                | Mainland China = 46% (11)  
|                | Vietnam = 13% (3)  
|                | Canada = 4% (1)  
|                | Other (Indonesia, Malaysia, Burma, Macao) =16% (4) |
| Employment | Full-time = 38% (9)  
|             | Part-time = 8% (2)  
|             | Not working = 25% (6)  
|             | Retired =21% (5)  
|             | Homemaker = 8% (2) |
| Primary Language | Cantonese= 67% (16)  
|                | Mandarin= 21% (5)  
|                | Fukien = 8% (2)  
|                | Vietnamese = 4% (1) |
| Household Income | No income = 4% (1)  
|                  | Below $29,999 = 17% (4)  
|                  | $30,000-$59,999 = 25% (6)  
|                  | $60,000-$89,999 = 25% (6)  
|                  | Above $90,000 = 21% (5)  
|                  | Did not answer = 8% (2) |
| Number of years of living in Canada | 24 (min.=1, max.=44, SD=12.54) |
| Religious Practice | No Religious Practice = 46% (11)  
|                  | Buddhism = 25% (6)  
|                  | Protestant = 16% (4)  
|                  | Roman Catholic = 13% (3) |
| Use of Community Services | No = 63% (15)  
|                        | Yes = 37% (9) |
6.2.1 Reflexivity: Organizing and Presenting Data

Prior to reporting the findings, I pause to discuss the self-reflexive process to support employing the four existentials of lifeworld to guide the presentation as well as the write-up of the findings. On completion of the coding of the 24 transcripts, I was overwhelmed and at a loss as how to organize and present the high volume of coded data in an integrated and coherent manner that reflected the lived experience of the Chinese women. I repeatedly returned to the data and drew maps which reflected all descriptive and interpretative human elements or themes (e.g. relationship with health care providers) and non-human elements (e.g. cancer treatments and medical progress) of the survivorship lived experience and inter-relations between the two (Clarke, 2005). The drawings elucidated the fluidity rather than static nature of the themes, and possible relations to one another. Upon reflection, I realized that the emerging incidental themes consistently spoke to the structures of lifeworld - lived space, lived body, lived relation and lived time - which each Chinese woman experienced. That is, within the context of breast cancer survivorship, the disease affected all the domains of the Chinese women’s life, which forced them to reconstruct a new self-identity while living in constant fear of dying. This reconstruction process was influenced by their culture and interactions with others.

The issues of credibility, transferability, dependability and confirmability, which equate to validity and reliability in quantitative research, were addressed through a constant search for negative cases to ensure varied experiences were captured. For example, the age of each participant and the age when she came to Canada were
compared with the number of years of having lived in Canada to determine if these three variables accounted for any variations of the lived experiences. As well, I searched for the factors that attributed to those Chinese women who did not return to work post-treatment. I continued to document in my journal my assumptions and prejudices, and sought collegial feedback in situations of doubt if the code(s) were reflective of a particular theme. Multi-layered readings verified coding accuracy. Once identified, incidental themes were categorized into the structure of the four existentials of lifeworld and served as guides for further reflection to determine the essential themes that spoke to the lived survivorship experience of Chinese women living with breast cancer. Figure 2 summarizes the identification, categorization and weaving of the inter-related themes.

6.2.2 Lived Space

The concept of breast cancer survivorship within the context of lived space, or spatiality, is the felt, invisible and existential space in which most Chinese women deconstructed and reconstructed their self-identity and derived existential meanings of their lived experience, while living under the constant threat of Damocles’ sword. Spatiality of survivorship influenced all domains of each participant’s life and encompassed the social factors that provide historical, social and cultural dimensions. As reflected in their actions and behaviours, the Chinese women consciously or unconsciously anchored themselves to their cultural values and virtues in their
Figure 2 – Conceptualization of Themes

Lived Space (Spatiality)
- Breast Cancer Survivorship
- Chinese Cultural Context

Lived Body (Corporeality)
1. Normal life as a normal person.
- Normal life as doing paid work.
- Chinese virtues of endurance and self-reliance.
- Valued attributes of being positive and strong.
2. Body image.

Lived Time (Temporality)
- Significant survival milestones.
- Shield from premature death.

Lived Relation (Relationality)
- Lessons of past/current lived experiences.
- Parents as role models.
- Faith.
- Trust in health care providers.

Activation and Anchorage

Normalization
approach to life. Based on her extensive study on the Chinese Americans, Uba (1994) reported that individuals adhere to many of the Chinese values not being aware that these values serve interpersonal harmony. When asked why they behave or think the way they do, they typically responded, “Because that’s what is expected of me,” rather than, “For the sake of interpersonal harmony” (p.15).

The majority of the Chinese women found the question on self-identity difficult to answer (Can you tell me how breast cancer has shaped the way you see yourself?); this finding may be attributed to the influence of the Chinese collectivist culture whereby individuals are unaccustomed to talking about themselves as well as the inappropriateness of applying a western view of self-concept to studying the Chinese culture, assuming this view is the same across all cultures. Most Chinese women spoke from a situation-oriented perspective rather than speaking from the ‘I’ person-oriented perspective; the difference in the speech pattern may be related to the different features of the language and writing systems (Yang et al., 2006). The narratives of these Chinese women, however, were consistently saturated with their individual attempts and efforts at assessing, problem-solving, enduring and overcoming life adversities and illness challenges. Rather than reaching out for external support, these women turned into themselves and engaged in self-supportive behaviours to manage breast cancer impact and its demands.

The Chinese women reported a wide range of emotional responses to breast cancer diagnosis such as shock, anger, sadness, fear, upset, unhappiness, worry,
helplessness, panic, anxiety, overwhelming, “why me”, “má fan”\(^7\), “I’m okay”, “a tiny thing” and calmness. On recovering from their initial emotional responses, the Chinese women adopted a pragmatic approach to accommodate the impact of the breast cancer; it enabled them to understand and accept their illness and take practical action to allow continued normal life, functioning and productivity in the spatiality of survivorship:

You know, Chinese culture, when we’re brought up, is just to be quiet, I don’t know why, but I - that's how I feel, and, for me to, you know, I think we just accept it because we're used to that type of thing. (participant E4)

I just keep thinking, okay, this is life, and, yeah, life has to go on no matter what you have, what you've got, you know...Yeah, I know it’s bad. I always think, that's life. (participant E2)

This illness, I can still accept....I said to other people, “...sometimes (you can get) sick and you have to go to the hospital..” I thought, aiya, I got sick, and then I need to treat it. I was thinking liking this. (participant M1)

I just face it. I have to face whatever is coming to me in the future....I always now keeping busy, working....you're affecting your husband, and your son, you know, your parents, right? They will be changed too. (participant E8)

I just need to deal with it and, and the doctors say that you need to do such and such and I just follow the procedure for what I need to do. (participant E13)

I’m not (in) denial but, I just accept it, you know, like, it’s part of life [with emphasis; laughing], you know. Because, my sister has, you know, breast cancer, so I thought sometime in my life I’m going to have it. Like, people die.. people get other sickness and I have cancer and, you know, that’s it. (participant E15)

\(^7\) For definition see Table 2, participant E3’s narrative.
The Chinese women were in this way able to reframe their illness as a normative life event and adopt a matter-of-fact approach to manage their breast cancer demands. They did what was expected of them to facilitate return to normalcy and ensure economical benefits for others, thereby maintaining interpersonal harmony.

Reject ‘Survivor’ Identity

The Chinese women rarely employed the term ‘survivor’ to describe their identity and lived experience. In fact, the term was unknown to most of them; they were quite puzzled and questioned its meaning. As a witness to disease recurrence in a few of her friends, participant E5 questioned the 5-year survival mark as used to define a ‘survivor’:

This is one thing I don't understand. When you are categorized as a survivor, what is the time frame, though? Because, in the past, if you past five years then, you can call yourself, “I am a survivor.” But a few of my friends, like there was just one happened this year, she had a mastectomy and then after five years, she has cancer to the other breast, so, what is survivor, though, like, how long? Like, I have a big question mark on the survivor thing. Yeah, I'm not sure how do you classify as a survivor.

Participant E15, who has four close friends living with breast cancer and lost another to this illness, also expressed similar confusion and rejected its application to her situation:

I heard that word used a lot of times and, I’m not sure why they choose that word. Okay, I don’t use that word on myself. I don’t know, I think you can use, you always have breast cancer, you know, like, it will probably be in remission, like, you know. It’s never cure...
I never think of that (survivor word). Never.

Participants E13 and E16 extended their pragmatic orientation to the practical ways they accepted and reframed their breast cancer experience. Reframing their breast cancer as the “flu” provided them with practical steps to manage their illness and focus on regaining normalcy, thus rejecting the survivor identity:

I don’t see as a survivor.... I don’t know why. I never thought about it until you mentioned it. Um, it was like a flu and then after, just like, you know, after you had a flu, you go back to work and, you know, life’s the same. I think it was that for me. (participant E13)

It’s just like a flu is gone, that’s it. Don’t have to worry. Or maybe, it’s just a big appendix surgery is gone. I just treat it like that. Yeah, something like that. (participant E16)

Similarly, participant E6 discarded the survivor identity as she did not see herself fitting into her own definition of a survivor, which she described as a heroic figure who has endured pain and suffering such as that associated with giving birth to her daughter. Comparison of her breast cancer to other major issues in her life helped her accept and reframe her illness as a normative event and thus allowed her to focus on what she had to do. Participant E6’s breast cancer was detected early with favourable prognosis. She was treated with a lumpectomy and radiation therapy with minimal debilitating side-effects, except fatigue, which nonetheless allowed her to continue to work throughout her treatment:

I don't relate to (survivor) too much at all, because, my was in early stage, very, very curable. So, I don't want to label
myself as a survivor, because my situation is not as serious as some other situations. So, it's predictable outcome. That's why I don't label myself as a survivor......Because, survivor is sometimes heroic, right? ...And, I don't think I'm heroic in that respect......No, no, I don't think so. Like, it's just normal you have to follow, right? Maybe I been going through so much, like, this is not really a major battle for me, right? Compared with other battles I have gone through.

Ah, there was actually one reason I feel much more heroic than this, which was when I gave birth to my daughter, I hurt myself during the birth. I actually, seven days and nights I couldn't sleep, because of the pain. Muscle pulling. Strong muscle pulling due to misguidance during the, the final stage, like the push - labour. They pushed and they stretched my legs or whatever. But, I was on walker. I couldn't walk. I returned and teach in a class two weeks after, two days after my hospital discharge. So, I feel that was heroic. Like, I used a walker to get to the classroom. No, actually, my husband help me to move to the classroom then I sit and talk. Yeah, I feel that was, like, more heroic.

Participant M8 rejected the survivor identity because in her view it applies to one who has been rescued from near death, a situation that does not apply to her; she did not see herself nearing death and requiring rescue. She reported experiencing personal growth as a result of the breast cancer and felt she had been given a second chance, a person with a new life, but juxtaposed between living and not dying, just existing:

To me survivor has nothing, has no meaning, has no meaning. To become a survivor who has been saved. I say it is not necessary to die, not necessary to die....That is, I will be like a person with a new life. Not like dying or living survivor.

Participant E11 also associated survivor identity with death:
After so many years, I forgotten. Most of the time, I forgotten, I am a survivor. I forgotten. And, I thinking about why I keep worry about it. Yeah, anyone can die (from it).

Although participant E7 identified herself as a survivor, her definition of survivor identity encompassed a person who has returned to and continues a normal life:

(As a survivor) this means you're back to normal life and you just continue, you know, think positively, you know, enjoy your life. Yeah, enjoy your life, do whatever you like, right? I like the garden, you know. Keep yourself busy, very important. Otherwise, you have nothing to do, right?

In summary, the majority of the Chinese women did not embrace the term survivor identity, primarily in deference to their own definition attuned to their pragmatic orientation to life; in fact, a few of the Chinese women rejected this identity on account of its negative association with death.

‘Survivor’ Identity as a Stigma

Susan Sontag’s (1978) book, Illness as Metaphor, poignantly illustrates the historical stigma, secrecy and shame attached to breast cancer. Although breast cancer has become a publicly acknowledged and highly visible disease, the associated stigma still persists, as evident in participant M5 worrying about being interviewed in the house because she feared that other tenants would ask her to leave and the difficulty of women with this illness to secure adequate health insurance. Breast cancer, as a stigmatizing illness, prevents women from securing
insurance, such as life insurance, extended health insurance and private disability insurance (Stewart et al., 2001). Two Chinese women specifically addressed stigma in relation to their breast cancer. Identifying herself as a survivor has been a bittersweet experience for participant E1. Although she openly and proudly identified herself as a breast cancer survivor, she also cited the identity as a liability in terms of insurance:

*Once have cancer then you are always a survivor and the feeling that you have gone through that..... I guess, you have deal with one thing and you feel that you can deal with your, ah, because you have this life threatening illness and you can deal with other things when it comes maybe made person stronger, I hope. I'm not sure [laughing softly], but I hope....Yeah, I think that is, it's bitter sweet, I guess, it's not something you don't want to be, but then now that you're already part of the cancer club, that you have to, ah, I'm glad I'm surviving it. It does have a difference, well even [pause] will be that people outside will look at you a bit different too so, I guess, um, just, like the insurance that I did try to deal with that I cannot buy extra or more insurance.*

Participant E3 elected not to disclose her illness to friends and colleagues and kept her cancer a secret for three years. She finally told her adult daughter in light of the potential for genetic risk and health behaviours. Participant E3 worried that once people learned of her illness they would stigmatize her as a “tainted person” and facing near death, and thus jeopardize her professional credibility as an orthodontist and her financial security:

*I don't want them to know, in the sense, they will think I'm a bit like tainted person. Because, I really feel people have that type of thinking. So, I don't feel any different, so, I don't want*
them to think I'm not as good an orthodontist, or that I'm going to die in two years and, therefore, I can't do my work. So, there's a stigma to most people's thinking. Basically, just because of that. I have no, no qualms about talking, with talking about it, but because of the consequences of people's misguided thinking, there's no point telling people.

Reject ‘Patient’ or ‘Sick’ Identity

Important and essential to the recovery of some women was not only rejection of the survivor identity, but also the overall ‘patient’ or ‘sick’ identity. For participant E7, continuation of normalcy meant rejecting the patient identity:

You know, you can back to normal life. Don’t think about, ‘I'm patient, I'm patient’, always that. You should, you know, back to normal life, right?

Participant E8 also rejected the patient and sick identity based on her need to continue a normal life and be a normal person, and to protect her family. She felt that embracing the sick identity would be reinforced by people who would treat her differently and not as normal:

Yeah, I was thinking I was very lucky. I was so lucky that I discovered it earlier. And, then I thought, now I'm like a normal person. I don't think I am, is a sick person. I always thinking, I'm normal person now. So, if I care all this, what I supposed to do, that's all I can do. Um, I think that's, that's all. Because, mostly important thing is that forget what you had experienced, right, that bad experience, and then face the new life. Otherwise, you know, you will make other people miserable and yourself problem too, right? Don’t think “I'm a patient, I'm a cancer patient.” Everybody has to be nice to me, I am a patient, I am a cancer patient, I am - everybody, you know, have to treat me differently”....No, I'm not a patient
now. I am normal person as other people.....For me, just carry on like before [laughing softly].

Participant E9 rejected the ‘sick’ identity to protect her family; in doing so and by suppressing her feelings, she fulfilled her role obligation of maintaining interpersonal harmony and avoided being a burden to the family:

My father said many times, that you don’t look like a cancer patient at all. To me, I just forget about it, because I never show that part in front of them. Like, I’m a patient, a cancer patient. When I, like, now, every day I do something, I do something, I never think about that I’m a sick person.

Rejecting the patient or sick identity was an important aspect of the self-identity reconstruction process and survivorship experience. Several of the Chinese women rejected the sick identity as it did not fit their approach to life, that of continuing a normal life as a normal person.

No Identity Change

Recent evidence on survivorship and identity among older adults living with long-term cancer suggests that this population is more likely to endorse the survivor identity, which represents an important aspect of who they are (Deimling, Bowman, & Wagner Louis, 2007). It is unclear, however, whether this is on account of the normative aging process or the influence of significant life events. Six Chinese participants over the age of 60 reported no impact of their breast cancer on their self-identity and lifestyles; of these 6 Chinese women, however, 4 reported significant past life events that may have already
shaped their self-identity. These major past life events included: participants’ multiple health problems (e.g. second cancer); husbands’ multiple chronic health issues (e.g. strokes, heart-pass, brain aneurism) and consequent permanent physical and cognitive impairments; a child’s autism and a young grandson’s cancer, occurrences that profoundly disrupted their lives and influenced their attitude towards life.

Participant E10’s husband was a lawyer who suffered a brain aneurysm in the late 1980’s. He required surgery for the removal of his frontal lobe which left him with permanent cognitive and physical impairments. Participant E10 had retired from a successful career in the financial management industry but elected to continue to work; she secured a job as an accountant at an information technology firm. Although she made some tangible lifestyle changes in response to her breast cancer, she discarded the survivor identity as she was able to continue her “normal” work life and activities:

*To me, you know, it doesn't make much changes. I don't know why. I'm not like some people who, you know, but I'm just live the same way, except I told you, we changed our eating habit….. I work, right, and ah, it's normal and then I go to church….. For me, just carry on like before [laughing softly].*

Participant E15’s identity and lifestyle was profoundly affected by her son’s autism. She quit her nursing position to care for him for 10 years. From this caretaking experience, participant E15 learned that “life is not easy” and developed a pragmatic and realistic attitude to life, which enabled her to handle life stressors. She accepted her breast cancer

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8 In this paper, work is defined as paid work.
cancer as well as other health problems (e.g. thyroid cancer, knee surgeries, macular degeneration) as part of the normative aging process, “If I don’t have breast cancer, I might have diabetes, or I might have heart disease or I might have something (else).”

She expressed her response to breast cancer:

Like I have my son and my autistic son, every since he was young, eh, I quit work for ten years, look after him. Like, every day in my life is, it’s not easy. So, you know, like, don’t take things for granted. So...maybe that keeps me going. Even now, he comes home maybe every second weekend...let me see, you don’t expect life to be, smooth sailing all the time. I guess I was prepared for a life that is not smooth, you know.

Because, I’ve gone through so much myself. I had two knee surgeries, okay? And, I was diagnosed with macular degeneration and, you know, to my eyes. So, “Okay, this is just another illness.” I’m not beside myself, the disease hasn’t gone worse....You know my life hasn’t changed.....It hasn’t really affected me that much... because I seen my friends, you know, like, for the past how many years now, five years, I lost a lot of friends to cancer. And, I gone through, you know, not breast cancer, but other cancer. And, I’ve seen them suffer and I say, “Okay.” So, you know, people have cancer, people die and that’s it. Yeah.

Additionally, breast cancer did not significantly alter participant M3’s self-identity and life; she continued her normal life with independence and self-reliance. The researcher was struck by the loneliness in participant M3’s narrative. Her self-identity was by and large shaped by her husband’s multiple chronic health problems. She has been married over 30 years, has no children and spent a considerable part of her married life functioning as a single businesswoman overseeing the couple’s real estate business. Her husband has been unwell following a stroke in his 40’s and subsequently heart
problems. As a result of her husband’s chronic illnesses, participant M3 missed out on the joys and privileges associated with couplehood. Her sadness and loneliness were reflected poignantly in the following comment:

Not very much affected...We been together for over thirty years, so uh...we were doing business together. But he got sick really early, uh...around, his forties that he had the first stroke. So I took over his business, and still had to take care hims. So (I’ve) always been very busy, very busy. Because I was doing it alone, by myself. [laughing sadly] ...[pause] was a bit scared...at that time: ai [sighing], sometimes I felt like, dreaming, why am I alone? To go, to go wherever all by myself, even in my dreams that I went everywhere by myself. To shopping, whatever it is all by myself. All other people were in pairs. Only busy by myself, busy in busy out. But there’s nothing you can do. Because...it is not what he wanted either. Right? There’s nothing (we) can do [voice softening].

Participant E3 was more concerned about the identity changes brought upon by normative aging rather than the breast cancer, as growing old would signify the end of her professional career:

I think we have to live day by day and year by year, make the decisions as we go along. That’s sort of my philosophy. I haven’t changed anything much, really. I try to go on trips whenever there is a chance, you know, like, so that I won’t be caught saying, “Oh, I haven't done my travels.” That’s maybe one thing that I've done a bit more, not that I don’t travel before. I do travel a lot anyway.....Basically we're reaching an age that we should, you know, do as much as we can while we can still walk around and climb the hills and the stairs. I think that's probably more of a motivation than this breast cancer thing hasn’t really affected me too much...I am afraid I can't walk later on, rather than the breast cancer.
Although participant E12 reported no significant life event, her narrative nevertheless revealed endurance, self-reliance and persistence. This is reflected in the achievement of her goal of owning a house as well as managing on her own the harsh chemotherapy demands to avoid being a burden to her family. She did not tell her friends about her cancer because she did not want them to feel sorry for her or “talk behind your back”, preferring to handle her illness on her own. Despite having a “hard time” with chemotherapy, she continued to work by helping her brother with newspaper delivery in the mornings. She was rather modest regarding her individual efforts at managing treatment demands:

_Not much change at all....able to live my life as, you know, as it is. Nothing now; I have, ah, I have my own, own house, right? So I want to, I don’t need to, to try, ah, to try working, get more money, I don’t need. No, before, I have working, right? I want to make more money, I want to buy a house. Before? Yeah. That’s why I make more money, I try working. Now, everything I have, I didn’t worry.....That time? So, I have my brother um, I walking how do you - delivering newspapers in the morning [smiling in a modest way]._

Though breast cancer is life altering, most participants were humble about their singular efforts at managing treatment demands. Their pragmatic acceptance of the cancer diagnosis and the practical, matter-of-fact approach of doing what was necessary to allow continued normal life negated the survivor identity. In fact, a few women viewed the survivor identity negatively and associated it with death, which further alienated them from endorsing this identity. Older women (over the age of 60), reported no identity change and viewed breast cancer as part of a normative life event. Their lives and
identities, however, seemed to have been pre-defined by the impact of significant past life events. As evident in this study, most Chinese women reconstructed an identity reflective of their cultural virtues and valued attributes.

6.2.3 Lived Body

Lived body, or corporeality, refers to the fact that people are always bodily in the world and develop social relationships through their bodily form. There are two elements to the lifeworld of corporeality within the survivorship context. One element is based on the visible, tangible and physical functioning of the body; the other element involves the intangible, the sense of who we are. According to Base-Smith (2006), “Though constitutionally representative of our separateness from others in the world, the body is not who we are” (p.85). As an example, Base-Smith cites the illustration of a patient on life support, identified as the embodied individual, but where the person is unconscious.

Often referred to as the “bible” within breast literature, Dr. Susan Love’s Breast Book (1991) coined the phrase “slash, burn and poison” to describe the traditional medical treatment for breast cancer; slash refers to surgery, burn to radiation, and poison is the often dreaded and feared chemotherapy. The harsh and grueling side effects of cancer treatments (e.g. fatigue, pain, alopecia, nausea) and possible late-effects (e.g. fatigue, ‘chemo-brain’, pain) affect women physically, emotionally, psychologically, cognitively and spiritually, and further, not knowing if and when these late-effects will improve. The physiological element of corporeality is related to a woman’s bodily changes, such as the loss of a breast that could affect her femininity, sexuality and relationships with others. A woman’s bodily function, in terms of her ability to work and
fulfill social responsibilities, generates feelings of productivity as she actively contributes to the economic benefit of others (e.g. the family), or maintains her independence. Function refers to the normal and specific contribution of a bodily part to the economy of a living being and implies a purpose for the particular kind of work it is intended to perform (Merriam-Webster). Being productive was an essential component of the Chinese women’s pragmatic mindset and adjustment to breast cancer. For most of the participants, productiveness was defined by their ability to work and economically contribute to the benefit of the family. This finding corresponds with the Chinese values of duty, obligation and responsibility. An unproductive woman is viewed as not fulfilling her role expectations, which in turn could lead to potential disruption of interpersonal harmony and the woman being a burden to the family.

Though a person’s identity is often derived from her occupation, the sense of who she is, however, is socially constructed through interactions with others. Meanings are constructed through interactions and internalized to provide an orientation to life that guides an individual’s actions and behaviours. The Chinese women in the study adopted a pragmatic orientation to life that guided their practical, realistic and matter-of-fact approach in the acceptance of and coping with their breast cancer. In rejecting the survivor identity, they reconstructed an enduring, self-reliant, positive, strong, normal and modest self-identity, which underscores the Chinese virtues and values of endurance, self-reliance, obligation and responsibility.
Normal life as a Normal Person

The Chinese women repeatedly and consistently emphasized the importance of returning to a normal life and being a normal person as part of their survivorship experience and self-identity:

You know, you can (go) back to normal life. Don't think about, “I'm patient, I'm patient”, always that. You should, you know, back to normal life, right? I am normal people. I am normal person as other people. (participant E7)

I thought, now I'm like a normal person. I don't think I am, a sick person. I always thinking, I'm normal person now. (participant E8)

I'm not the type of person changing things so much around in myself, so, yeah, I know I was sick and but, I try to be myself too, yeah. (participant E2)

I just think about, I'm normal person. (participant E11)

...Just regular normal family life (participant E15)

Life sounds pretty much normal, you carry on. (participant E3)

For me, just carry on like before [laughing in a modest way]. (participant E10)

I did not speak with anyone. Not even friends. Because I felt very normal [laughing softly], very normal. (participant M3)

The desire to be a normal person underscores the pragmatic nature of the Chinese collectivist culture and its values of conforming to the societal norms of being modest and productive. These women quietly returned to their normal lives with the aim of fulfilling their role obligations and working hard for the economic benefit of others and thus maintain harmonious interpersonal relationships.
Normal Life as in Doing Paid Work

The majority of Chinese women defined normalcy in terms of their ability to do paid work, or if they were not working, carry on with their daily social activities. Work facilitated their re-integration into the community so they could continue with their normal lives. Work affirmed who these women were and who they are: positive, strong, confident, self-sufficient and productive, all of which translate into economic benefits for the family and thus the preservation of interpersonal harmony. Most of the women who were employed at the time of the cancer diagnosis returned to work, and their ability to do so appeared to normalize their illness experience:

*I'm happy I get treated enough. So far I don't have all the like, the x-ray, everything is fine and then I still can work. And, I compare to some people, they cannot work, and I still (can), yeah. There's nothing much change really.* (participant E2)

*I love working. I really enjoy working. And, I think whenever I do something, I give 150% into it... I just kind of, I used to think, “Okay, this is work and let’s do it.” And, after all this, everybody, everybody has told me, “[Participant’s Name], you’re working too hard. You shouldn’t be da da da.” And, I kind of say, “Yeah, yeah, yeah.” (participant E13)*

*This (working) means you're back to normal life and you just continue..Yeah, the one thing I’m still proud of myself, I make myself go back to work. A lot of people said, “You, you shouldn’t go back to work because you don’t, you never know how long you’re going to live so you should just, go all, everywhere you want, spend all your money and then die.” [Laughing quietly] Yeah, yeah. So, I myself go back to work, I want to be a normal person.* (participant E7)
Because I can go back to my former professional career...taking care of the family is still quite important right now.... Moreover, I felt that there is still some value in my life. I could create some value in my life for this family and for this society. (participant M2)

I became unemployed. I didn’t work. I have an illness, but I still need to work. Work, work well, then the money can be given to my son. I now go to work, to go to work to earn money...Five dollars, six dollars, seven dollars are all good work. I would use a bit of money and be a bit happier. After buying some clothes, I would then go for dim sum, with my husband. (participant M4)

I thought that (breast cancer) would completely alter my career path. Of course, as time moves on, my hope gets higher, back, a little bit more. But, I at that time, I feel forget it, everything was gone. Ah, but then, as I passed the radiation and in the summer, when I had finished my radiation and then the surgery, I was debating whether I should go ahead (referring to promotion) because, I feel maybe too much stress for me, to pursue. Ah, but now as I’m getting healthier, that concern is getting smaller. It’s not, not a concern. (participant E6)

At this point, I’m pretty good. I go back to work, at least, and try to be productive and, see how long, like, I try to work, as long as I could but then, yeah, when I cannot, then I just have to accept it. (participant E1)

Ever since I went back to work and I feel I am a normal person again. I know a lot of people saying, “Why you go back? Why you going back to work? You don’t have to.” And then, if I don’t have to, it means I’m a sick person. I stay home and waiting for dying, the day comes. And then, I think, yeah, I went back to work and make myself to rebuild. And then I don’t feel like I’m walking in hell again. (participant E11)

Of all the reasons I can stay home but, I still, I go back to work and I want to rebuild my life. And then, that’s, yeah, ever since then I go back to work. (participant E10)
As reflected in the description of the study sample, a few women did not return to work for reasons unrelated to their breast cancer. A couple of the Chinese women were distressed about losing their ability to work. For example, participant, M2 expressed her distress about losing her job and her inability to financially support her family:

I was very stressed....This stress originated from the fact that I had lost my job and I had lost the ability to support my family. Before, my family was very well-off because I was able to earn money to support my family. Later, I lost that ability. Therefore, I was very stressed.

Not only participant M5 felt frustrated about not being able to work, she was also distraught about having to depend on her husband for financial support:

I used to work every day, right now I cannot do any work. Initially, I could support myself, right now my husband is supporting me and it is unbearable to me.

Another participant E6 expressed her distress about not being able to return to work and thus, not being normal:

I have never been bothered emotionally, since I changed from the initial shock. But, there were points, ah, during the process that I feel frustrated, because I feel weak, I feel fatigued, for a while, for a long time without recovering back to normal stage, I lost my hope that I ever become health, like back to my original stage. I, once in a while, like, loss hope... even after now, I can't have, because I'm still not that normal yet...it bothers me. I need perfect physical condition to be able to be very efficient. So, I, right now, I still don't feel good.......from this operation that I had for the ovary, the doctor told me that it would take two weeks to recover, but it's taking six weeks..and the radiation, the radiation doctor say it will take two month to
Participant M1 returned to her factory job on completion of her treatments. She worked for only one year before being let go by her employer because she was still weak from the cancer treatments and unable to fully function. While she sought alternative employment, her options were limited due to inadequacy of English language skills and her physical condition which restricted her ability to work full-time. She was worried about the dwindling of her savings and did not want to become a burden to her sister:

Since last summer I searched, but up until now I still haven’t found any job. In my heart I was thinking, when I get better then (I could) work, my body...uh..it’s ability is still not able to do it. Still.. uh..when the body gets better, then I can find work. Like that. [pause] I think it.. [silent]...the working hours cannot be too long, because my body cannot handle it for the long duration...I’m a little bit worried about my financial situation...I know what my situation is and I cannot give my sister more pressures. I do not dare to tell her, do not dare to tell her. I still have not told her.

Participant E1 was forced into a part-time position due to fatigue:

I think it was my illness. It's much better if I work part-time than full-time so I have a day in between to rest, because I got a bit tired after.

Participant M7 felt pressured about returning to China to work so she could continue to support her son and mother-in-law. She could not find employment in
Toronto due to her inability to speak and read English and lack of stamina for manual work in a Chinese factory:

*I cannot find work here, my energy is also not adequate to do manual labour. [sniffing] If I go back to China, I will look for all kinds of jobs, to do some small things, to get some money. Why do I need this money in China? Because my mother-in-law needs me to take care of her. My mother-in-law does not have a lot of money herself, the retirement funds, when she goes to the senior homes. And I have to take care of my son’s everyday living expenses.*

For those Chinese women who were retired, normalcy was defined by their ability to carry out the activities of daily living or social activities such as volunteering at church. As expressed by participant E16:

*I, go to church. And I was taking two ladies to church, one was, one hundred and one (101), and the other one was eighty six (86)…..But, everything’s the same. And, I was working as the Treasurer for the church, and I just did it until I left that church and went to the other church, yeah. Everything’s the same.*

Participant E15 decided against accepting hormonal therapy out of fear that a possible side-effect, the loss of vision, would compromise her independence, in particular, her ability to drive. She viewed the potential loss of vision as a threat to her quality of life as well as her identity as an enduring, self-reliant and independent person. She defined normalcy in terms of her ability to drive as well as continued involvement in various social activities:
Like, the reason that I don’t, didn’t want to continue with my Arimidex regimen (hormonal therapy), you know, I’m very sensitive a lot of medications. And, the sides, I’m really worried about side effects and I think the side effects really, that is, what is going to interfere in my quality of life. So, that is why I made up my mind and not taking that. I’m not taking the medications, I seem to be, you know, free from the side effect and, you know, able to live my life as, you know, as it is… I want to be able to go when I want to… I go line dancing four times a week… I like cooking and I like to do all this crafts and, you know, like, so right now it hasn’t affected that. So, that’s why I’m, you know, still enjoying… my husband has low vision, he’s legally blind, so I’m the one whose driving. So, I can’t afford to side effects affect my eye sight.

The need for normalcy was an important component of the pragmatic orientation of the Chinese women’s breast cancer survivorship lived experience. They quietly returned to fulfilling their role obligations and were modest about their self-supporting behaviors to cope with treatment demands and minimize disruptions in family routines. In line with their pragmatic orientation to life, the Chinese women adopted a practical approach to defining normalcy, that as a person’s ability to work and thus, being productive and normal. Work symbolized not only a positive step towards continuation of a normal life, but more importantly, economic benefits for the family.

*Chinese Virtues of Endurance and Self-Reliance*

Consciously or unconsciously, the Chinese women drew on the internalized Chinese cultural virtues of endurance and self-reliance to withstand and overcome the adversities and hardships associated with their breast cancer. They clearly held and
demonstrated these values throughout their breast cancer lived experience as reflected in comments such as:

I can depend on myself….I feel that it’s better to keep these things to myself. (participant E12)

I can deal with cancer…and I can accept it. (participant M1)

I do everything, although I am not capable to do it, I make myself to do everything. (participant E11)

I have a strong mind, I have to fight for it. ((participant E8)

I don’t like, “I can’t do anything, you help me.” I don’t like it. No, don’t like that in my life. So, I want to do myself. I want to do the best thing, right? I think it’s made me stronger. (participant E2)

The Chinese women viewed their self-reliance and endurance of breast cancer as a natural response to the associated challenges and difficulties, and they did what was expected of them. Endurance and self-reliance in Chinese women are historically and culturally rooted (Ching et al., 2009; Mok, 2001). The underlying assumption is that these characteristics can overcome adversity and shield one from dying, and also maintain harmony when one continues to be a normal person, leading a normal life.

Participant M7 and her family immigrated to Canada in 2006. They were financially self-supported while her husband worked towards completing the requirements for a trucking license. He became ill just on completion and soon thereafter was diagnosed with advanced lung cancer. A few months later, participant M7 was found to have breast cancer. As she spoke no English, she was dependent on her husband
and son for interpretation. Her husband’s lung cancer completely overshadowed her breast cancer experience; she had to “repress” her emotions and endure what she saw as 地狱 (meaning: hell), not knowing whether the both of them would survive. Due to husband’s illness and cancer treatments, she assumed all the household responsibilities from managing the activities of daily living (e.g. meals preparing, cleaning, laundry, etc.), to worrying about their son’s future, to problem-solving their financial difficulties with the loss of husband’s income and exhausted savings. Their financial hardship was exacerbated by their ineligibility for government financial assistance programs. Within one year, they were forced to sell their house and move to low income-gearied housing at a time when both were undergoing their respective cancer treatments (chemotherapy and radiation therapy). Participant M7 was literal, articulate and expressive; her use of metaphors poignantly conveyed the despair, sadness, anxiety and loneliness she experienced, and the need for her to endure and be self-reliant:

_Just then the weather became cooler, [crying softly] I was standing outside the window of my house, watching the autumn wind blowing the leaves. I thought of a Chinese saying, it’s called 人生悲秋 (meaning: life is sad in autumn) [crying softly]. This saying came from a poem – that is in life, autumn is the end for people and winter is the end of life...A very sad time in autumn. Sad, in the autumn it is very sad. My husband was lying upstairs, he was already immobile on the bed. I was operated on. I was very tired, but I had to do everything at home. In the afternoon around two to three ‘o clock, the place I lived became very isolated. There was no one, the grass outside was dried in the middle of the autumn. Every day the leaves were blowing in circles, I was thinking about our two lives...[continuing to cry_

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9 A Chinese idiom.
softly] they shouldn’t be like this. So I was very sure, since that time, that my depression suddenly began.

All my new hopes were gone. I felt like...I didn’t want to die, but everyday it felt that living was meaningless. That’s because I was living through difficulties everyday. [crying] I don’t know [sniffling] what would happen to my husband. [sniffling] And I don’t know what would happen to my own illness. The pressures on my body, the pain they have brought me, these weren’t too heavy. But the mental suffering affected my entire body. As if I lived in a very deep deep sea and no matter what I could not come back up. [pause] I did not, did not have too much time to be scared [pause] of my illness. Because every day I have too many things to worry about. [sniffling] ... I was very tired of the situation, but I had to hold up this home. You see that I must deal with the moving arrangements; these were all done by one person (participant herself).

Participant M4 came to Canada about 20 years ago “with $20.00 in my pocket” and worked in clothing factories. Endurance and self-reliance permeated her narrative and instinctively extended to the way she coped with breast cancer. Although she initially feared her breast cancer, she became more accepting of possible mortality from her illness after seeing a friend in her 40’s die from an aggressive form of breast cancer. With the help of a friend she found a job at a coffee shop at minimum wage but with which she was quite satisfied given her limited English and skills. This income helped her and her husband to purchase a condominium. Participant M4 positively reframed employment not only as a means of supporting her family, but more importantly, ensuring her son’s financial future:

This life is like this. My life was been destined for me to be like this. I needed to resolve it myself, need to endure people. To work in the society where one needs to endure
anything. You first think that the person is good, even if you talk back, you are risking to get fired? You go back home. So you need to think like this. Because you are not a smart person, you come here with nothing...Need to rely on myself. Need to rely on anything...like you, you people are smart, then you can work at a better job. Like us we are worse (due to the lack of English and education), we need to work at a more stressful job. You need to think like this to understand. You say that the job is stressful then you get yelled at to go home, it will be the same if you go to other work places. Because you are working (for someone else). The boss yells, however it happens, for myself, I need to endure!

Absolutely no, being dead, not a problem... Scared, in the beginning, beginning. I was very scared, very scared. Very scared that after I die, being dead. Now that I have an illness, whatever I do, I give money to my husband, my son, being happy is good enough. I don’t need anything else...this is good for all, so I go do work.

Participant M6 believed she had to rely on herself to face life challenges. This self-reliance was reflected in her strong work ethics and extended to the practical way she managed her illness experience. Participant M6 worked throughout her treatments, taking time off only to go the hospital for her treatments. The following statements exemplify the importance of endurance and self-reliance as part of her self-identity:

*I think I just do what I can normally do. No need for, ai ya, other people come help me. Yes. I need to rely on myself. All must be relied on myself. My attitude, I don’t ask other people (for help). My job needs to be done while standing up. Whatever time it takes I must finish it while standing up. But, there were sometimes when it is too tiring, I sit on the high chair. Huh, then the chief manager comes, “ai ya, why are you sitting down not working?” Just like this, just at that time. Like this, he took off a few point....only ten points. However hardworking you work for them, I let them see that I am very hardworking, there can be no mistakes.*
Participant M8 also believed she had to depend on herself to deal with her cancer. Although she rejected the survivor identity, participant M8’s narrative was combative and militaristic. With support from her family and health care providers, she was not only self-reliant but also confident she would fight her disease:

Allowed me to fight against the enemy as cancer, just like fighting in war, like in war, but it was done by myself. My family and the doctors and nurses were behind me and gave me support. I know that I will not lose. So after doing the second time (surgery) I knew that I can win. I will not lose.

The narratives of participants E5 and E12 reflect not only the virtues of endurance and self-reliance but also the significance of self-responsibility and filial piety:

Not only I had to deal with the treatment, I had to deal with my parents’ health and absolute my dad is, my dad would be 88 this year, so he has a lot of health problem or issue, and mom worry about dad and she herself have a lot of problems, so absolutely they couldn't' help you, like they are in their 80s. So, I just dealt with it myself.”(participant E5)

Only one. I help by myself. Yeah. I take the bus. I going to hospital and I, after chemo, I just take a rest for 10 minute and I get my bus then come back. Oh, I don’t, because, my sister, she has been working. She has been working, so I didn’t want to bother everybody, right? So, my brother is working in night time, right? And, day time he has to sleep. So, I don’t need, I want to try by myself. I going to by myself and down (hospital) by myself. Yeah, I want to know, right? That’s why I try. Every time I going to chemo time is the winter time, right? So cold. So cold and snowing. So, in the morning sometime chemo, they make an appointment, sometime in the morning, sometime in ten o’clock or something, so I want to know how I stand by myself after
chemo, right? I want to know, that’s right. So I don’t need everybody’s help. (participant E12)

Rather than reaching out, the Chinese virtues of endurance and self-reliance led participants to turn inward for self-support; they regarded it as their responsibility to assess, manage and problem-solve. When they did seek external support, it was typically for tangible community services such as requesting a volunteer to drive them to the hospital for treatments, “I tell that volunteer, the volunteer who drives me...at which location to pick me up” (participant M1), or to concrete relaxation classes such as yoga, “I joined yoga for a few sessions. I felt yoga was very good and it made me feel quite good afterwards...there was basically no language problem and everybody around you was ill in someway” (participant M2). Participant E1 attended a support group for cancer patients. Although she did not actively participate in the group discussions, she nevertheless found it beneficial to listen to other people’s experiences, “I mostly listened to other people say and I learned some of the what they have gone through.” Three participants were aware of community resources but did not resort to them because they had adequate support from their family or friends, “I feel the support I have got so far is enough. I do not need to, I don't feel the need of it” (participant E6), or did not need it at the time, “I felt that at that time I did not, did not need those kinds of help.” (participant M8). Participants who sought support from friends or colleagues attributed the help-seeking behaviour to having lived in Canada for a lengthy period or their personality:

Because I've been in Canada for that long, I think that when you really want to talk about your feelings, then I talk
to my friends and we always talk in Cantonese.”
(participant E1)

Chinese people who live Canada, longer, they seem to think like me, they like share with you... Because, you're adapting a culture.... Chinese people, if they still come from mainland China, they're not very open, no. I hope I say right, you know. If you stay here longer, you learn a lot from others. (participant E7)

For Chinese, they don't want to tell people, right? To, saying that I have something, whether it's a cancer or something. But, for me, I don't mind, I'm telling everybody, like a working place (participant E8)

I don't think so. I still think it probably personality, you know. It's not (Chinese). (participant E15)

As evidenced in the narratives of the study participants, endurance and self-reliance are important characteristics of the Chinese women’s self-identity, which are derived from Chinese virtues and their pragmatic orientation to life. The Chinese women drew on these internalized virtues to guide their actions and behaviours in the face of breast cancer; they were modest and practical, doing what was expected of them so they could return to normalcy move on with life and not be a burden to the family. For a few Chinese women, in particular those who have been living in Canada for a lengthy period of time, returning to normalcy included the openness to share their experiences with others.

Valued Attributes of Being Positive and Strong

Two other significant attributes to the Chinese women’s identity were the incidental themes of being strong and positive and were associated with the self-identity
of endurance and self-reliance. Most Chinese women perceived themselves as enduring and self-reliant, as well as positive and strong. While participant E14 was quite modest about her inner strength and positive attitude, her daughter-in-law was forthright in pointing them out, as demonstrated in her matter-of-fact approach in dealing with treatments:

Daughter-in-law:

And yeah...she takes responsibility, you know. After a few weeks, she will just get down to the kitchen to cook again and. I mean, this is... how we live. That's how strong she is.

Participant [laughing softly in a modest way]:

You know one thing, when I was having the radiation. I took the TTC train, TTC bus. I mean I took the bus everyday...I come back..stopped at the bus stop and then dropped by this grocery store, get a fish and then come home. Walk home, you know? And that's winter time. After radiation I can walk to...from [hospital's name] hospital to Eaton Centre, shopping, and take a walk. And then I have some lunch...and then I come back and ask (daughter-in-law) to pick me at the bus stop. Sometimes I can walk back home.

Other Chinese women expressed similar views on the importance of being positive and strong:

Because, first of all, afterwards the first time you lose your hair, then you have problem for eat. You lose your energy, and ah, special for me because my husband's business, most times I have to stay home by myself. And, so, I just think positive that time, think positive, I said, “I will be fine.” I'm very strong....before I always very proud of myself, everything is very good for me, as strong, you know, I never blame anybody just that you shouldn't live by
yourself, how take care of yourself…. And ah, back then, they (family) needed me, right? So, I needed strong. I needed strong and survive, right? (participant E7)

[Smiling gently] I feel my diagnosis with cancer, my childhood education and living environment has a greater impact/influence on me…. Anyways, I feel that it’s better to keep these things to myself. There’s no need to tell other people. Moreover, if I tell others, they would only pity me. I don’t need their sympathy. I feel that I can depend on myself. For example, if I were to tell my boss at the interview that I had cancer before, he probably would hire me. However, would it be because of my ability or my illness? I don’t want sympathy or pity to exist between my employer and me. I have the ability. I want him to hire me because of my ability. (participant M2)

...if you have something happen to you, and your mind know that you cannot die because, many people still waiting for me… my mind is strong, then you have to fight for the cancer. (participant E9)

Just seeing myself, I’m a strong woman. I, I accomplish something, yeah. I think I really did try something to make this go away. I didn’t give up. (Participant E11)

So I said, “What can I do? I lost face every day and miserable to give to everybody? No. I still has to face it. It help yourself to, and plus people see surrounding, they will support you and they see you happy, they happy too. The environment will be changed. The whole environment, if you happy, you’re at home like this and you’re affecting your husband, and your son, you know, your parents, right? They will be changed too.” …Yeah. Have to be strong. I’m facing it, I’m strong. But, whatever I’m now, I have to be strong, to face it. (participant E8)
For participant E6, being positive and strong was important as it set an example for her children in their adaptation to her cancer; it also adhered to the Chinese value of suppression of feelings to maintain harmony in the family:

Yeah, so, anyway, I calm down, not only from that, but also time will calm you down anyways. Initially there was a shock and gradually you have to accept, right? And plus, I'm such a person who never put myself in a negative emotional territory for long [laughing in a modest way]. It is just my nature, I have to get out to become positive again. So, afterwards, I feel that I've maintained very positive, ah, attitude, that helped my children adapt very well. So, you don't seem to have cancer at all, like, everything is just as normal. I never show any sadness or nothing afterwards. So, everything remain normal in terms of emotion and everything, so that helped them to adapt.

Participant E6 also underwent a deconstructing and reconstructing process, arriving at a “softer” and “less perfect” self-identity:

I'm perfectionist. I pursue perfection, so this is imperfect, right? I see myself softened. In many years, like since I was young, I always feel that I wasn't a woman, to be honest. I wasn't confident being a woman at all...I was in engineering environment, and I was also physically tall, so I always feel that I wasn't attractive enough as a woman, right? Ah, but, gradually, I would say this breast cancer also made me more aware of me being a woman, for sure. Not bad thing, for sure not bad thing. It's just, personally, I wasn't confident enough that I was a woman I don't know how to say it, I wasn't', yeah, now I feel that I, everything that a woman has experienced. My husband kept, has been saying a few times that you are softened a lot. You are softened.
The deconstructing and reconstructing process resulted in a positive change in participant M8’s self-identity, from seeing herself as stubborn (negatively defined) to being “calm” and “relaxed” as a result of the breast cancer:

I (was) a very, very self-centered person. Because of that situation I am…I will persist until the end. That is stubbornness. But now I have experienced, that illness. I will relax myself, not to argue with other people about what’s right or wrong. I will use, uh, how to say it, treat matters with a more relaxed manner Because everyone will, in her own perspective, she will always thinks that she is right. I used to be very stubborn. That is, when my daughter doesn’t follow my way of doing things, I would get very angry [laughing in an apologetic manner]. That is a lot better now. My husband also says that when I talk, I am a bit more relaxed.

The incidental theme of valued attributes, being positive and strong, is interrelated to the incidental themes of endurance and self-reliance. These themes affirmed the Chinese women’s reconstructed perception of themselves as being modest, enduring, self-reliant, productive, positive and strong as they strive to function as a normal person and for a life of normalcy. For a few Chinese women, the breast cancer experience clearly resulted in a positive reconstructed self-identity described as gentle, relaxed and being less of perfectionists.

**Normalization**

In summary, the incidental themes of corporality are endurance and self-reliance, the valued attributes of being positive and strong, and continuation of normalcy, defined
as being a normal person and doing paid work. Together, the Chinese women spoke to the essential theme of normalization. The concept of normalization is grounded in the pragmatic orientation of the Chinese collectivist culture, which emphasizes modesty, obligations, conformity, social order and harmony. The desire to return to a normal life and be a normal person is motivated by the obligation and responsibility to meet the basic economic needs of the family. For the Chinese women, normal refers to a person who is functional, and functional equates productivity, as in paid work. Work is historically, culturally and socially constructed. As participant E4 says, “Like, I know from Chinese families, a lot of us, we work hard at everything, and, work, work, work, work, work and we're running ourselves into the ground.” Underlying this construct is the Chinese belief that work is tantamount to happiness; that is, people are happy when their material existence is satisfied and consequently social order and harmony are maintained.

Congruent with their pragmatic orientation to life, work provided the Chinese women with practical means to continue a normal life. More importantly, however, it ensured present and future economic security for their family and thus interpersonal harmony. As part of the breast cancer survivorship lived experience and to achieve normalcy, the Chinese women reconstructed their self-identity as modest, enduring, self-reliant, practical, productive, positive and strong. They drew on their internalized cultural values to understand, problem-solve and support themselves through the treatment demands and to reframe and accept their illness experience.

*Body Image*
The lifeworld of corporeality also includes a woman’s body image. Breast cancer treatment can alter the way a woman feels about herself and body image. Several Chinese women varying in ages and disease-free over 5 years reported that the changes in their physical appearance did not affect their self-identity; the loss of the breast was insignificant if it meant they could live:

*Your life is the most important.* (participant M1)

*But, if you, thinking you don’t have it, it’s not a big deal when you survive, that a better thing.* (participant E9)

*My children, or my husband, and they all think that, your life is more important than your breast. If you have a breast, you don’t have the life, what you need a breast for? I want my life more than my breast…. right now, I can live without breasts.* (participant E11)

*I feel there’s some impact but it’s not that great. I feel that if you are alive, then you cannot ask for too much [smiling]. You cannot request to be perfect.* (participant M2)

On the other hand, three Chinese women age 56 and under and disease-free less than a year reported their body image was negatively affected by their cancer treatments. Participant E5 underwent a mastectomy, which she felt left her with an “amputated” and “unbalanced” appearance:

*Physically, I don’t like myself. I don’t like the way, the amputated look [with emphasis]...No, it's not attractiveness. It's missing, it's imbalance...Yeah, imbalance. It’s as if I feel amputated. Maybe that's my
personality, you know, um, I'm not a perfectionist but, you know, I would expect balance [laughing softly].

Though the female breast is less sexualized in the Chinese culture, one participant E9 tried to conserve her breast out of concern for her new relationship at the time:

_The second time, (doctor) told me, “So now you can decide.” Because if you have the cancer tissue inside, so he said. If I am single I don't worry about that...that we don't have one. But because I didn’t know him (boyfriend) long enough, so I don't want him feel bad. That I will try a second time to take out the lump again. If this time he takes it and, it still happens again, then you have to do a third surgery, third time for surgery. But if this time I take it all, then you don’t have third surgery, then you have to decide. I said I will try to made it out (second surgery). If it happens again I will do the third surgery again. So the second time I made the surgery, its okay._

Participant E4 underwent breast reconstruction so she could feel balanced and more like a woman:

_You know, like when I used to hear about people doing reconstruction, I was like, “Oh, why would they want to do that? Unless it's necessary, right?” But, I'm like, “Why would you want to do that?” And then, now I can relate because I have to do it. You see? Not like you have to, because even if they took it off, you don’t have to do it, but I'm just thinking, at least you feel better about yourself. You feel better about yourself, at least you feel like a woman, you know, because if they don't sort of put you back together, you feel like, how would you explain it? You just feel, like [pause-thinking], you're not fully quite there, you know? I don't know you just don't feel - It just doesn't feel quite right. Until you feel evened out, you just don't feel, um, like a woman._
Participant E7, age 56, declined reconstruction due to her cousin’s painful experience:

*I did not (have reconstruction) because my one cousin, she did in United States, more than ten years now, she said very suffer, very painful, because she younger age, she only forty. She said “Very painful, very painful.” She got two, right? “Painful, painful”, she said. They go inside or something. My husband said, “No.” I said, “No.”*

Participant M3, age 69, rejected reconstruction due to her age and concern about post-surgical pain:

*I have never thought of doing this…doing plastic surgery, I have not... I don’t do this. Never considered. I am afraid of pain. [laughing loudly]. Age is old so it is rather, the impact is rather insignificant.*

Two Chinese women felt unattractive from the chemotherapy-induced weight gain:

*Every time I went to the hospital and they said, “Oh, you’ve gained a bit of weight.” [laughing]. Yeah, and then I feel like, oh, some of the people that I know, used to know, that they don't recognize me because, yeah, I have changed…I really don't know maybe more than 20 lbs. I used to be only 90 something and now, actually it’s more, now I am 125 so, that’s a big difference. (participant E1)*

*Doing the chemo, I've sort of gained weight, I'm still trying to get rid of the weight. (participant E5)*
Some Chinese women accepted the altered body and reframed it as less significant if it meant they could live. Their self-identity did not crumble or spoil; they held fast to their pragmatic outlook and viewed their actions as necessary in order to live. Two participants actually declined reconstruction due to age and concerned about postsurgical pain. Though the body image of some of the Chinese women was negatively affected, their overall self-identity as enduring, self-reliant, positive and strong remained intact. The altered body did not negatively influence their perceptions of themselves. They demonstrated unwavering endurance, self-reliance, perseverance and strengths as they strived to return to their normal lives as normal people, fulfilling familial obligations and expectations.

6.2.4 Lived Relation

Lived relation to the other, or relationality, is the interactions that people share with others in interpersonal space (van Manen, 1997). People meet each other and form relationships through corporeality; interpretation and meanings are derived from these interactions. Relationality may be positive or negative (Base-Smith, 2006). Positive relationality can offer hope, encouragement and fulfillment in facilitating adaptation to breast cancer. The Chinese women with breast cancer drew on positive lessons learned from their past, other current lived experiences and observations learned from their parents as role models to guide and affirm their self-supporting coping behaviours and reframe their breast cancer experience. Conversely, negative relationality may lead to poor quality of life and psychosocial distress.
People may also form relationality with a non-physical higher being (e.g. the “creator”) through felt spatiality. In times of distress, people often turn to and rely on their faith or philosophical beliefs for comfort and hope. In this study, several Chinese women reframed their breast cancer experience as a moral test from the “creator”; they relinquished their fear of death and dying in the belief the creator is capable of deciding what a person is able or unable to handle.

Another important element of lived relation is that of the patient-physician relationship. Base-Smith (2006) argues that maintaining an appropriate social space by following tacit rules of conduct allows people to derive a sense of personal privacy and security. In the sample population, this is reflected in the trust they placed in their oncologists, which translated into the belief, and sense of security, that their oncologists would utilize best medical practices to treat them. The Chinese cultural emphasis on deference to authority figures places the Chinese women in the position of a ‘good’ patient, defined as compliant with treatments and accepting of the hierarchical patient-physician relationship. This does not, however, indicate passiveness or powerlessness (Ching et al., 2009); rather, the Chinese women expected professional competency, timely medical care and appropriate medical information.

*Lessons of Past and Current Lived Experiences*

According to Corbin and Strauss (1987), not all aspects of the self are completely lost when facing a life-threatening illness. They argue that most people are able to retain some aspects of self and emphasize connection with the past for reconstructing self-identity. To support reconstruction of their self-identity as enduring, self-reliant, positive
and strong, the Chinese women drew on past lessons learned and current lived experiences, which affirmed their self-supporting behaviours and facilitated the continuity of normalcy. In addition to the previously described past lived experiences of participants E16 (autistic child) and M3 (husband’s cardiac problems), other Chinese women in the study also reported significant past or current lived experiences that shaped the reconstruction of their self-identity: surviving political oppression, premature loss of parents, multiple losses of family members and friends to cancer, witnessing a grandchild’s treatment for childhood leukemia, diagnosis of a second cancer, living with own as well as family member’s depression and schizophrenia, lack of steady housing and employer’s mistreatment of the participant. These life experiences bestowed on the Chinese women a pragmatic mindset which influenced the way they reframed and derived meanings from their lived experiences, in particular the reconstruction of their self-identity throughout the breast cancer survivorship continuum.

As previously mentioned, the importance of remaining positive and strong and being a hard worker were important internalized attributes of participant E7’s. These attributes were learned and based on her past lived experience of growing up on an impoverished rural farm during the Chinese Cultural Revolution. She drew on positive attitudes, self-supporting behaviours and belief in hard work to help her endure and survive, and anchored herself to them to cope with the impact of breast cancer. In other words, as long as she continued to endure, remain self-reliant, work hard and be positive and strong, she would likely survive breast cancer just as she survived living on the farm:
I'm very strong, I work countryside when I very young age, never sick. That's why, I'm in my family, number three. But only one countryside. Nobody want to go, I go. I always like that way, you know, always do something, you know, I think about, I never think about myself, always think about other people. When I was sixteen years old, that time, I work at the countryside for five years, hard work... little bit of food, and at night time, we don't have electricity. I used oil light. I learned high school lesson by myself, because I did not finish high school, only grade eight (when) we go to countryside. So, I finish by myself. I studied hard, work hard, then I progress good, I get good mark. So, I went to university, the first year they open university. So, that's why I think... because I learn from my very young age, I know how hard will be your life.....(and) you will appreciate what you have.....I'm very strong.

Participant E1 was profoundly affected by the premature loss of her mother and extended family members to cancer. She also lost friends and colleagues to cancer. These multiple losses affirmed her pragmatic orientation to life and the acceptance of her own mortality as part of life. Though she was initially “shocked” at the cancer diagnosis, she emphasized it was “not the end of the world and we'll deal with it”. She stated:

I didn't experience that many deaths except until my mother died and it really affected me a lot that it was almost like 11, 12 years ago, and then after that, all the people from relatives, they started, yeah, and I have two, three cousins that are younger than me that they passed away. One had throat cancer, and then one, the youngest cousin, she died just last year. Yeah, so they have - my uncles, ah, lots have lung cancer, two uncles have lung cancer and only when I diagnosed with cancer that my father told me that my mother also had cancer when she was young...At this point, I'm pretty good. I go back to work, at least, and try to be productive and, see how long, like, I try to work, as long as I could but then, yeah, when I cannot, then I just have to accept it...because of my belief,
maybe I have come to a term with there is always death because but that’s part of it.

Participant E13 recalled an early childhood experience of finding her way home after she became lost as an example of her ability to problem-solve:

I don’t know if I learned it over the years or, I don’t know....I remember, I was very young, I was about three years old, I think or less than three. They took me to - it was in Hong Kong they took me to a, ah something like CNE kind of stuff? And I got lost. Like, I look around and no grownup was there. But, I was able to walk home by myself. So, they were all surprised. I mean, I don’t remember it. Somebody remind me and was like, you walk home by yourself, you were three, two-and-a-half, three years old something like that. So, I may have that. Solve a problem, because I have to go home. So, I am, maybe I have it with me and I learned more as I go along.

Not surprisingly, participant E13 adopted the same practical matter-of-fact approach to reframe and cope with her breast cancer, believing that what worked in the past would help her in the present and future.

Within a year, participant E14 was diagnosed with both breast and thyroid cancer, the latter requiring surgery only. She calmly described her cancer experiences, stating, “I just take it easy”. She saw her cancers as “nothing” in comparison to the experiences of her grandson who was diagnosed and treated for leukemia when only 21 months-old. Her pragmatic approach to accepting and reframing her breast cancer experience seemed to be influenced by her grandson’s illness experience:
... [pause-thinking] keep on easy life. I don’t think 個天唔會、唔係話跌落來 [in Cantonese; meaning: it is not the end of the world]. And then on that day...on that day, on that period, when we went to, to...Sick Kids hospital...for three and a half year. [pause] That time is...really, really hard [voice softening]. Yes. He is twelve years old now.... It doesn’t matter at all. Uh-huh. That’s why when I heard, I was told I was diagnosed with breast cancer is...nothing at all, for me. Just really, really, honestly, it’s nothing.

In addition to the impact of past life events, a small number of Chinese women recalled the despair and distress associated with other major life events that occurred around the same time they were diagnosed with breast cancer, which overshadowed their breast cancer experience. For example, in addition to participant M7’s breast cancer and the stress of dealing with her husband’s terminal lung cancer, other significant lived experiences included loss of husband’s employment and its negative financial impact on the family, employer mistreatment of the participant, loss of job promotion and adjustment to a new life in Canada. The fact that few Chinese women reported clinical depression suggests they endured the emotional and psychological pain at the expense of their own well-being.

The experience of participant M6 illustrates well the impact of additional psychological and emotional stress from major life events. Participant M6 had worked very hard for a Chinese newspaper company for almost 27 years, rising from the printing floor to the position of supervisor and overseeing its operation, though she only had a high school education. Work was very important to participant M6’s identity and approach to life. She was very dedicated to her work and loyal to her employer, taking tremendous pride in her achievements, often at the expense of her family, “work came
first before the family.” She took only four months off from work following the breast
cancer diagnosis, and worked throughout her chemotherapy and radiation treatments,
returning due to organizational changes. She felt betrayed when the company brought in
new managers with minimum work-related experience to oversee the operation of the
printing floor, and in doing so rejected her dedication, work history and loyalty to the
company. These work related events left participant M6 demoralized and angry, and
overshadowed the impact of her breast cancer experience:

When I wanted to go back to work, he, my supervisor at
that time hired several people. (Boss) said, “No matter how
hard you try, you can get sick anytime.” I was very
hardworking. I had been working late at night [starting to
cry]...Then I, just everyday, he was wrong, he said I was
wrong [appearing distressed and angry].... At that time
[the name of a Chinese newspaper company] also went on
strike. Huh, after the strike, he said I stole something, and
wanted to take me to court. So I was at that time I wanted
to quit, but then, if I were to quit then there would be no
retirement fund...

I went back to work, I was very tired very tired, I could no
longer continue. Just then boss added more shifts, at that
time, there was no way to work there. I was also sick,
always crying non-stop... Couldn’t sleep, because of
pressure, heavy pressure from the company, heavy pressure
from the finances as well... I could not eat, could not eat
even if I tried. Could not sleep even if I tried....I did not
dare to yell at (boss). Once I see him, I would cry. I did not,
“ai ya, you said that I am not right?” I don’t say it. I
respect them....When I just cried now it still hurts up until
now..... To them, I say I give you service, what, I did my
best I gave it to you and, you still say that I am no good... it
doesn’t matter, I’ll listen, I only listen to what my
psychiatrist has to say.
Participant M6’s endurance and self-reliance in managing her breast cancer helped her cope, but the unsupportive and negative work environment was a primary contributor to her ultimate clinical depression.

Three of the Chinese women had to deal with the impact of their breast cancer while also meeting the challenges of being new immigrants with minimum family support, lack of English proficiency and financial worries. These women were forced to manage the treatment demands without consideration for the emotional and psychological impact of their breast cancer. In the absence of family support and to meet treatment demands, participant M2 and her husband sent their only child, an 8 year-old son, back to China to be cared for by his grandparents. Participant M2 vividly described her feelings:

*I came here in 2001 and I was diagnosed with cancer in 2003… At that time, I felt very painful because I had just arrived here. Our family situation was still unstable and my English was not good. My son was only eight years old. I felt like it was the end of the world. Also, my husband was to start school soon.*

*Why did I come in the first place? I regret coming here. After we saw so many people immigrating here, we felt we were capable of immigrating too! Therefore, we came. After immigrating here, we realized it was not as good as we had imagined. Therefore, there were many challenges and lots of pressure. This language, it’s a very big barrier… I think there’s a big connection between my breast cancer and my depression for the last two years. I have actually been very depressed… This stress originated from the fact that I had lost my job and I had lost the ability to support my family… There was no one to help me. My son was still young, he was only six. Someone must be home to look after him, to send and pick him up from school. Back in China, his grandparents used to look after*
him. We can only depend on ourselves now….however, I persevered. We, my husband and I, stood by each other and lived through the most difficult period of our lives.

Drawing on the Chinese cultural attributes of perseverance, hard work, and endurance, participant M2 completed her cancer treatments and accomplished two of her vocational goals; she pursued the qualifications for, and secured a job as a dental hygienist.

In summary, a significant number of Chinese women drew upon past lived experiences to facilitate their acceptance and adjustment to breast cancer, with the underlying belief that what had worked in the past could now help them cope with the impact of breast cancer. More importantly, drawing on these past lived experiences reinforced their self-supporting behaviours and perceptions of themselves as enduring, self-reliant, positive and strong. In some cases, other major life events overshadowed the impact of breast cancer in these Chinese women, which generated additional stress that further affected their psychosocial well-being.

Parents as Role Models

A few of the Chinese women clearly identified the positive influence of their parents on their approach to life and acceptance of their breast cancer. As role models, their parents encouraged endurance, self-reliance and positive attitudes, which allowed them to reframe and accept the breast cancer. For example, participant E2 drew inspiration from her father for the strength and courage to face her breast cancer:

*I always think, that’s life (referring to cancer), I don’t know, maybe it’s from my father. My father take, took everything so easily. My brother has schizophrenia….I left*
home early, but my father been looking after my brother for so long and he's still can enjoy his life and took everything easily. Because, my mom passed away so early in '86, so my father been looking after my brother, yeah. My father went through a lot because when my brother, like, at one time I was in Hong Kong, my brother, one time he has episode, all of a sudden he just yelling and everything, and my father was so calm and, “Why don't you –“, I tell my father, my brother, “stop it” and, I don't know, my brother don't want to listen to him, he's throw chair at my father, and my father sometimes, he told me, like, he bit him too. And, so my father still can carry on for so long, for twenty years, I say, my sickness it nothing. Maybe he face more stressful than anything because of my brother, you know, yeah. I guess maybe it's not. He went through a lot. So, I say, okay, my father can do that, I can do that! [Laughing softly].

And, I think I take it up from him, yeah. He always does that. We always have to do the best, and even when he got retired, and he still go back to work part-time and even if he's sick, he still get up and go out and I remember even when I was not in Hong Kong, I know he has surgery, like, minor surgery and stuff like that, he, the next day he just get up and go, and walk around and go out in the morning, and go have tea with his friend. He still does the same, even my brother is around, like, not helping him....Yeah he went a lot of travelling with my brother too. He took him with him and whenever they go away, yeah. And, I guess, every time I think of something, I would think of him. (He was) about 84. I used him as my image too.

Participant E7 credits her mother for her positive attitude:

She (my mom) is positive thinking, and the reason why I'm very positive person...(She) is a very positive person. When I get cancer....my mother come here immediately - then my brother told my mom, she say, “ You told mom, mom has expressed, because she take care of daddy, she know how to deal with patient, right?” So, she support me, right? She even go to hospital surgery, that morning, very early
morning, six o'clock, she want to go, so she go with my husband. She positive thinking, and the reason why I'm very positive person.

Participant E8 also viewed her mother as a role model:

She (mother) now survive, okay. She can eat, she normal now. So, everybody saying, “You should sue the doctor.” But, she say, “No, doctor has a career. I don't do that, no matter. I don’t want to let him ruin his life. But he's young, that's it.” But, you see, after ten years now, she's more strong and strong, healthy and healthy. She has no sickness, nothing. She can walk to my house, subway by herself, eighty seven age. She does all the house work, she doesn’t want a (homemaker) to come to help to do housework. No. She shopping, everything goes, she does by herself, she's so healthy. That's why, we always thinking, I told my mom, “I should learn from you....Because, she set a good example for me. How strong she is with these two bad experiences, before her at that time, because if I never get sick, I never can experience her fears, her situation. She's so strong... So, this help me a lot. We always, I'm always thinking, “I should set a good example for my mother.”

As role models, the parents of a few of the Chinese women provided the encouragement, hope, inspiration and strength to face their breast cancer. Their parents’ own endurance, self-reliance, perseverance as well as their inner strengths and positive attitudes in dealing with adversities in life were internalized by these women and drawn upon to cope with their own illness experience.
Faith

Faith may be defined as a set of religious beliefs or particular Chinese philosophical teachings. In times of crisis, several Chinese women drew on their faith for comfort and meaning, spirituality being an important part of who they are.

The premature death of her mother had a profound impact on participant E3, which led her to search for existential meanings of death. She converted to Roman Catholicism at a young age and sought answers to address her fear of death. Faith helped her reframe and derive meanings from her breast cancer experience, in particular, to manage fears of the unknown and uncertainty of living with this illness:

*There is hope beyond rather than the darkness.... I accepted the faith when I was very young, when my mother was not diagnosed with Gallbladder stones. And so, she was suffering from severe pain but there was no diagnosis even though she went to the best doctors in town. And, I was keeping her company in the hospital and, um, you know, I was really scared, I was probably 10 or 12, I can't remember now. But, that has a big impact in my mind because I was so scared about her dying (that) I would have probably converted so young, if I had not had that experience of the fear of death. Soon after my friends in the class were going to this church and I somehow got to go with them and I hear the message of the Bible and, at that time, it helped me because, “Oh, here's an answer to death. Here's an answer to beyond.” So, I converted without my parents knowing, because I was afraid of the future, afraid of the unknown. So, I sort of had this comfort since a very young age....There's that hope beyond, sort of being so black. I think that (referring to faith) helps me a lot [pause]. Yeah, basically, when there is hope [pause], it's not so impossible to handle.*
Participant E5 also emphasized the importance of faith which offered her comfort and eased her anxiety:

\[\text{I am a Roman Catholic. And, I am a very devout Catholic. And, I never share this information with other before but, I am the type of person, me and my husband, we go to church very, very often. And, in fact, during the week day, I attended the daily mass as well... we have this holy hour. However, on the other hand, um, when you think about, okay, people would say, “What kind of lesson do you receive?” You know, why rushing to the church every night, whereas on the other hand, you have this serious illness? And, ah people would think that what’s the point, you know? And, on some occasion, you would feel helpless... what I did was, if I attended a mass, I will offer my worry, try to offer my worry, my anxiety. I said, “Hey God, take over. (What) I can't handle, you take over.” So, at least I try to do that. But, um, this lady that I know, she didn't have that faith, so she is worrying so much that, I think cancer might not kill her, but other thing might kill her.}\]

Participant E1’s acceptance and reframing of her breast cancer experience was based on Buddhist teachings:

\[\text{Thing is, with the Buddhist belief that, you go if you know where you're going, if you know death, then you will live better. So, I guess that's, if you know death well, you see all this death throughout my life, so I have death experience, so it will be...If I don't have any concerns, then it will be a good death. Something like that...I see some people cannot live well is because they have, um, certain things that they still regret not having done or things in their life. So, I guess that's how I deal with it each day.}\]

Participant M3 studied Chinese history in university and as such, her orientation to life and acceptance of her breast cancer was greatly influenced by
the philosophical teachings of Zhuangzi, a famous Chinese philosopher in 4th century BCE:

*I studied Chinese history. Because I specialized at that...and was researching on Lao Zhuang (a nickname for Zhuangzi)... [laughing softly]. So I was more open-minded. Sooner or later, whether one has wealth, or whether one is poor. Uh, uh, whether one is the president, or whether one is not the president, [laughing softly], one still needs to follow this path (referring to death and dying). In addition, birth, life, old age, getting sick, then death, all are stages that the human life experiences... (For me) I just need to be at ease.*

**Trust in Health Care Providers**

The majority of participants were satisfied with their medical care, progress and relationship with their health care providers. The Chinese women trusted their oncologists, which is reflective of one of the fundamental values of the Chinese culture, that of deference to authority figures. Their acceptance of the hierarchical patient-physician relationship and respect for their oncologist translated into a sense of security and comfort. They viewed oncologists as paternal figures who would utilize all available options to treat them. The Chinese women complied with treatment and thus conformed to the socially constructed image of a good patient. Their trust in the oncologists and other health care providers reflected positive relationality:

*(Nurse) cares about me very much. Because she also knows the situation at my sister’s home....At the time when I was sick, the doctor said whatever it was good for me, I did it... Curing, I completely trusted my doctors. (participant M1)*
I should say that I will win over (cancer). Because there were many people to help me, including my surgeon, the cancer specialist doctor, the radiation therapy doctor... Allowed me to fight against the enemy as cancer, just like fighting in war, like in war, but it was done by myself. They gave me support behind me. (participant M8)

This is the way how I motivated myself. So, I would go and talk to people and, you know, “Don't worry, just follow what doctor said, do the treatment...you have to, also you have to trust your doctor”... And I trust, you know, trust what they told me and so I wasn't worried, you know. (participant E5)

...Put it to the doctors, and just leave it to the doctor... Leave it, leave it to the doctor. (participant E14)

I just have the faith in myself and that, you know, the doctors, they told me, I believe in them that they told me... And I trust, you know, trust what they told me and so I wasn't worried, you know. (participant E10)

In addition to trusting her oncologists, participant E10 also placed her trust in medical progress:

I trust in the medical progress that, doing the research on the, you know, all this medical and, it's not like before that you died of cancer usually. But now, you at least you got the cure and (it) helps you to get rid of it.

Trust in the Researcher

The trust placed in the health care providers by the Chinese women extended to the researcher. As previously mentioned, a few of the Chinese women viewed the researcher as a “friend”, but unlike the other friends they have. Their trust in the
researcher may be attributed to her staff position at the hospital and her professional relationship with the participants’ health care providers; furthermore, the researcher shared culture, language and gender with the participants, all of which enhanced the interviews:

*First, I think that you are very pleasant person and then, when I see you, I want to tell you everything that I feel. That's very important. Some people, if you don't like it, you won't tell. It's very important, because you're very pleasant, and you, the way you're talking, approaching, it's very, very good. And, I want to tell you what I'm thinking. I never hided anything, right? Even my family thinks I don't tell anybody. I even didn't tell my parents what's going on with my husband. I even didn't tell my colleagues, but I told you. I don't tell my friends, but I told you. (participant E8)*

*I met you, you helped me with so many things...It is very comfortable, I feel that - I haven't been this relaxed for so long [laughing softly]. Huh, there are people who [pause - thinking], people who are willing to [pause - thinking] to listen from a very high perspective - my experience of getting sick and suffering. Also to treat it as, a kind of [pause - thinking] experience, belonging, or as an organization, then to experience it. This brings help to people. This is not a typical conversation. I don’t think that this is a typical conversation. (participant M7)*

*If you are not got radiation, and not in hospital, like normal people, they want to ask me to do like this I don’t, I don’t answer you, I don’t want. No, no way, right? ...Yeah, you from hospital and you ask this is what is good for you in the future, you be a doctor, right? Yeah. I answer everything is good for you, good for your education, so I really, really happy to help you. (participant E12)*
Coupled with the willingness to help the researcher complete her thesis, these Chinese women also hoped the study would benefit other women living with breast cancer:

*I'm glad I'm of help. Hope you can help somebody else.*
*(participant E3)*

*I still feel that, “Oh, I feel the sickness. Oh, she die”. I don’t feel that I still in that area, the cancer area. Now, I treat like I don’t have nothing. I just survive, someone who don’t have cancer, then I don’t think that I’m depressed. The depressed person would think that...nobody talk to me about that thing (cancer) happen, right? So, the fact that you are concerned and you can ask me some question, I want to tell you and you can help somebody.* *(participant E9)*

The Chinese women’s acceptance of the hierarchical patient-physician relationship, the trust placed in the health care providers, conformance to prescribed treatments and self-reliance were also part of their quest to return to normalcy.

*Activation and Anchorage*

The reconstruction of self-identity of Chinese women living with breast cancer is influenced not only by social factors such as gender, culture and class, but also by other life events in the women’s lives. The incidental themes of relationality with past or current lived experiences, parents as role models, faith, and trust in health care providers point to the essential themes of activation and anchorage. In times of crisis, such as the diagnosis of breast cancer, the Chinese women activated the internal lessons learned from
their past lived experiences, observations of the way their parents dealt with life challenges, and drew on their faith or Chinese philosophical teachings to affirm perceptions of themselves as enduring, self-reliant, strong and positive, and to reinforce their self-supporting behaviours. Positive relationality with health care providers offered hope and encouragement as they strived to return to normalcy. Once the internal frame was activated, the Chinese women anchored themselves to it to reframe their breast cancer experiences and shield them from premature death.

6.2.5 Lived Time

Lived time, or temporality, refers to a person’s temporal way of being in the world. Temporality is defined by objective and subjective time. Objective time is reflected in calendar time (Baase-Smith, 2006) as measured by weeks, months and years of remission; subjective time refers to the passage of time as felt by the Chinese women in reaching significant survival milestones. Temporality is also comprised of temporal dimensions of past, present and future in relation to a person’s life, such as the breast cancer experience. Connection to the past is important for the Chinese women to facilitate reconstruction of their self-identity in response to the breast cancer and as they re-integrate into the community and resume normalcy.

Significance of Survival Milestones

Historically, the medical profession has used the 5-year survival mark to estimate the impact of cancer on life expectancy or cancer burden (Canadian Cancer Society, 2009). Over the years, reaching this mark has come to symbolize a cure for most women
living with breast cancer. While aware of the possibility that the cancer could recur any time, the significance of reaching the 5-year survival milestone was not lost on most Chinese women, as reflected in following comments:

*Almost four, five years now, until four months it will be five years, right, right? 2004, February I had surgery, right? Almost five years, right? Yeah, I think still survive, you know. But, you know, after five years, you feel better. Yeah, you feel better. Always somebody says that during five years it’s not come back and then the chance come back very low. But, still somebody come back seven years. But, if still after five years you didn’t have a bad thing to start, you can free to do something. (participant E7)*

*I [pause - thinking] now that it’s more than ten years have passed, I feel a little bit better. Huh (in agreement), and then [pause] I don’t know typically how long it would take this disease to recur. I don’t know, five years, ten years, fifteen years. Yes. I’m still scared. We hope that, everyday hope that...ai.. I have several decades of life. (participant M6)*

*But, you know, after five years, you feel better. Yeah, you feel better. Always somebody says that during you five years it not come back and then the chance come back very low. But, I still (know) somebody come back seven years. But, if still after five years you didn’t have a bad thing to start, you can free to do something. (participant E9)*

*....this last October, I think the third year, somehow was a key, I don’t know what it is, is a key time for me that I go, “My God, this is three years.” And, I was, I was quite emotional about it....And I know that my, somewhat psychologically, I feel, um, third year is - a benchmark. I don’t know why that is. But, I guess I set it for myself that, you know, year three is a benchmark. I going to celebrate after a year, celebrate after three, third year. I go, like, “Yes!” I start telling people, I said, “Three years, three*
years.” So, maybe that was a relief or something like that. I see myself as I had it. Yeah. But, it doesn’t take away the fear that it might come back. (participant E13)

Yeah, yeah. It’s five years already. Now I look back, “Oh, it’s five year already.”... I have, I have those, ah, bamboo plant on my desk. “Oh, look at that. So tall now. Five years!” Because I remember at the beginning, I bought them. Small one, tiny one? It’s a tiny one, miniature one, right? But, now it’s so tall. [laughing softly]. Means good. I’m still here. So, I’m still here. And, I’m healthy. So many friends are gone now [voice softening]. (participant E16)

Because, after ten years I, I gain every day. I have already, I really have to be thankful. Yeah, I should die, like, ten years ago. I already got ten years back. I was still thinking, although I am not religion, I’ve been thinking about, I am a, a good person. I should deserve [laughing]....I deserve to live. I do not deserve to die that soon, yeah, yeah. But, right now I’m reach, like, fifty-six, and, of course, you’re thinking - a normal person would die at eighty anyway. Yeah, so, I’m (half) passed that. (participant E11)

All cancer patients live with the fear and uncertainty of recurrence. While reaching the survival milestone was significant for many Chinese women, they were keenly aware of the precariousness of their life knowing that the cancer could return at any time. For some Chinese women, reaching the 5-year survival milestone particularly affirmed their perception of themselves as enduring and “good,” and the belief that continued focus on being “good” would likely shield them from recurrence.
Shield From Premature Death

The Chinese women adopted a range of attitudes and behaviors to shield them against premature death, such as being positive and strong, staying calm and relaxed, accepting, letting go, remaining vigilant, not thinking about cancer, exercising, altering eating habits, living day-to-day and complying with treatment recommendations. Some participants not only activated the virtues of endurance and self-reliance and the valued attributes of being positive and strong to support themselves through the cancer treatments, but also anchored themselves to these virtues and attributes to shield them from dying. As previously noted, the underlying assumption is that if focusing on the positive and being strong helped in the past to overcome and survive adversities, the application of the same approach would help to manage their breast cancer experience and avoid recurrence.

The importance of being positive and self-reliant was a salient theme throughout participant E7’s narrative, which also helped her cope with the fear of recurrence and shielded her from dying:

*Don't see the die. You know, I say that, “Yesterday is history, today is gift, tomorrow is mystery. Why think about die, right?” Think positive. I not think about depress or think about, I think about positive, I think still have long life you know if you, you know, do exercise ever day, you know, you still, that you should back to normal life. The positive thinking, you can do by yourself, so you can protect, you can delete cancer.*
You need to prevent cancer. How can you prevent cancer? Your family history, genetics, you cannot prevent, right? But, you can do something positive, is exercises, and the food. And, the positive thinking, you can do by yourself, so you can protect, you can delete cancer... Just seeing myself, I’m a strong woman. I accomplish something, yeah.

Participant E8 also expressed the importance of being positive to shield her from recurrence:

Sometimes you worry for nothing, I know that. But still, it's because it's in your body, right? You feared. So, after that, you, all of a sudden, oh, bright future. The sky is bright now, not dark. Yeah. So, it's you have to be happy in a positive way of thinking. That's very, very important. Very important. I think I have to be positive thinking, right, do whatever I supposed to do....so make sure I have time to do exercise, make sure that I eating proper food, make sure that I'm happy....Otherwise, you will thinking that you're down, you're coming back, coming back, (cancer) will really coming back.

In addition to being positive and happy, both participants E7 and E8 emphasized self-responsibility and self-supporting behaviours such as exercise and healthy eating to minimize disease recurrence.

Having lived with breast cancer for 11 years, participant M6 stressed the importance of being happy and self-reliant to prevent cancer recurrence:

Have to be happy...Yes. I must rely on myself, must rely on myself so I am not scared. Right now, I have to keep it going, need to relax, don`t be upset then I will be okay. Huh (in agreement), If you are not comfortable, you cannot eat, your body's energy will then be low. Right? It’s not okay because then all the sickness will come out.
To shield against recurrence, participant E8 identified the need to search for a religion:

_One thing I have to (do), I have to have a religious. That's what I'm looking for, the right church, and go to, the community, the right person. I'm searching for that. So, if I do all this and correctly, if it (cancer) comes back, I have no choice. [Laughing softly]._

On the other hand, a few of the Chinese women reported feeling depressed, scared, uncertain and worried, and had difficulty letting go of the fear of recurrence, even though they endured and were self-reliant in managing treatment demands. As explained by participant E1, “Yeah, I think, um, once you have cancer, you always worry.”

Participant E5 poignantly described the feelings of living with fear and uncertainty:

_Sometime I feel, um, depressed. And, sometime I feel [pause] I know I shouldn't do that, sometime I was saying, when you look at people, they are so blessed. And then I say, “Why is this one person can be so blessed whereas some one person have a lot of not only health problem, like you know, looking after parents, and there's a lot of, a lot of things on the plate, right?” Yeah, um [pause] I think at one time somebody asked me, “Do you have, like, any goal? Ah, doesn't necessarily mean long term goal, right?” I said, “I don't have any long term goal.” And, and then, ah, like, people would say, “When you're 65, looking forward to retirement.” The way I look at it, I was, like, I'm not sure that I'll reach 65. So, retirement is, you know, to me sometime is a goal that I might not achieve....after I've been diagnosed with cancer....it's the uncertainty, because you don't know how long you will live._
Participant E9 also expressed similar feelings that held her back from pursuing her business aspirations:

Yes, I know that (cancer) will come back, but I don’t know when…. You know, I want to do some business and start…then I think it will come back but, I don’t know when, right? So, I don’t want to do something until then, you know? That’s why I don’t happy for that.

For a few Chinese women, however, the acceptance of their disease made them less fearful of dying:

Sometimes things do come. I have to accept it, to face it, that is, don’t think about the past, those unhappy matters. Think about some happy things now. ((participant M8)

I feel the key is to accept. If you accept the disease, it's easy, that you will get out. .. it's true that you put yourself in that situation, that it's real, that you actually could die soon, you know what I mean, maybe a few years rather young, right? What I found was I wasn’t really scared and I wasn’t, like I was fine, I accept it. I found that helped a lot. ((participant E6)

Absolutely no, being dead is not a concern. Not a concern. I am already fifty-five years old, being dead is not a concern…. (but )very I’m afraid of having no money. I’m very afraid that my family has no money, my son is already fifteen years old. He needs to study and needs the money…. I just want my family to be happy and that is enough. I have no problem with me dying. ((participant M4)

In summary, some Chinese women initiated tangible action within their control to prevent recurrence, such as adopting a healthy lifestyle, while others focused on their positive attitudes to shield them from dying. The attributes of being positive and strong
not only provided the Chinese women with the inner strength to withstand and overcome challenges and hardships, they also internalized these attributes to shield them from recurrence and premature death.

*Self-Protection*

The incidental themes of temporality are two-fold: reaching significant survival milestones and shielding against premature death. Collectively, they speak to the essential theme of self-protection. Past lived experiences are retained in the memory of the Chinese women and activated to address the current crisis of their cancer diagnosis; they anchored themselves to the virtues and attributes to guide them towards normalcy and at the same time, but more importantly, protect them from premature death.

### 6.3 Conclusions

The three essential themes of this study are: normalization, activation and anchorage, and self-protection. As part of their survivorship lived experience, most of the Chinese women underwent a quiet deconstruction and reconstruction process to arrive at a restored sense of who they are. In the process, they rejected the dominant North American discourse on survivorship and survivor identity, as well as the patient or sick identity. Two Chinese women experienced the stigma associated with breast cancer and its negative implications; one was unable to purchase additional life insurance and the other feared her cancer diagnosis would threaten her professional practice. Notably, a few Chinese women over the age of 60 experienced no identity change; past major life events had already significantly influenced and shaped their self-identity. As a result of the life-
changing event, most of the Chinese women reconstructed their self-identity that underscored the Chinese virtues of endurance and self-reliance, and the valued attributes of being positive and strong, as they strived for continuity of normalcy as defined by the ability to work or continuing previous social activities. Work facilitated reintegration into the community. Underlying their strong desire to return to work were the Chinese cultural imperatives of ensuring economic survival of the family and maintaining harmonious interpersonal relationships.

To manage the impact of breast cancer and its harsh treatments, these Chinese women activated their internalized orientation to life as a means to understand, accept and take action. Their culture provided them with the blueprint to view the world and themselves, and enabled them to assume a practical approach to endure and remain self-reliant while facing a life-threatening illness. They coped with the illness by drawing on the lessons learned from the past as well as current lived experiences, observations of their parents as role models and their faith. They anchored themselves to this frame to affirm their self-identity and self-supporting behaviours, rather than seeking external psychosocial supports. The pressures of face saving and upholding Chinese virtues of self-reliance and self-sacrifice, coupled with the lack of family support and language barrier for new immigrants, may discourage Chinese women from getting the help they need. Some Chinese women did seek external support from their friends or colleagues which they attributed to having lived in Canada for a lengthy period of time. This suggests that they modified the Chinese value of repressing feelings by adopting the attitudes and behaviours of mainstream society. The internalized frame and perception of
themselves also extended to the way the Chinese women coped with the fear of recurrence. As long as they focused on the positive and remained happy and strong, they were likely to be shielded from dying.
CHAPTER 7
INTERPRETATION OF FINDINGS

This chapter discusses the findings and implications for social work education, clinical practice and policy/program development, limitations of the study and direction for future research. The interpretation of findings is presented within each of the four existentials of lifeworld in keeping with the hermeneutic guides for reflection.

This study argues that the social context of survivorship, which encompasses gender, ethnicity, culture, race and social class, shapes the reconstruction of self-identity of Chinese women as part of their breast cancer survivorship lived experience. Interpretation of the data relied on the theoretical perspectives of symbolic interactionism, in particular Charmaz’s theory on the effects of illness on self-identity, Asian Feminism and the Chinese cultural model. These perspectives were interwoven with the four existentials of lifeworld: spatiality, corporeality, relationality and temporality to provide historical, social and cultural dimensions. Symbolic interactionism facilitated examination of the impact of the survivorship experience and interactions with others on the self-perception of the Chinese women living with breast cancer. Charmaz’s theory extends the principles of symbolic interactionism to understand the effects of a chronic illness on a person’s self-identity. To address the exclusion of social factors in Charmaz’s theory, Asian Feminism was adopted to infuse these factors, in particular, the influence of Chinese culture, to broaden the interpretation of the lived survivorship experience as well as to create and legitimize a space and place for this experience to be accepted within mainstream literature. A hermeneutic phenomenological study was
undertaken to answer the research question, “What is the lived survivorship experience of Chinese women living with breast cancer?” While the data generated from this study parallels findings from other studies on Chinese women, it also yielded new insights about the way the Chinese women reconstruct their self-identity within the breast cancer survivorship experience.

7.1 Reflections on Four Existentials of Lifeworld

7.1.1 Lived Space

In this study, “lived” in the context of survivorship is the felt or existential space in which the Chinese women living with breast cancer find themselves forever connected to and profoundly influenced by their attitudes towards life, relationships, aspirations and self-identity. It is the space in which a Chinese woman’s self and identity are socially constructed and derived from interactions with others (e.g. parents, health care providers) and the environment (e.g. the Chinese culture) in an ongoing and constantly evolving process. Similar to other studies on Chinese women with breast cancer, this investigation also found the Chinese culture influenced the lived survivorship of Chinese women, in particular the reconstruction of their self-identity. The Chinese culture seemed to offer these women a blueprint to frame their illness experience as well as an internal mindset to problem-solve, accept, reframe, and cope with the demands of cancer treatments and the after life of survivorship. In response to the threat of mortality, the Chinese women, consciously or unconsciously, drew upon and anchored themselves to Chinese culturally viewed virtues and attributes to derive meanings and facilitate adaptation to the altered body.
Breast cancer affects women from all walks of life. The dominant focus on the breast cancer experiences of American Caucasian women, however, tends to assume their experiences are universal, while those of women of color, including Chinese women, are viewed as the other. Furthermore, with the increasing shift in societal attitudes away from viewing cancer within a web of secrecy and shame and as a death sentence to a survivable chronic life-threatening illness, there arises concern over a similar assumption that all women living with this illness universally embrace a new way of viewing themselves, that is, as survivors (Deimling et al., 2007). Current breast cancer “pink” culture assumes that women readily embrace the identity of a survivor as represented by middle-class Caucasian women and their heroic military metaphoric narratives (e.g. to fight and conquer), while ignoring social differences. Contrary to popular belief, each woman’s breast cancer lived experience is dynamic and unique, and of significance, not all women embrace the survivor identity as part of the lived survivorship experience. The survivorship experience of the Chinese women living with breast cancer in this study was characterized by a quiet, modest, less combative and practical narrative that involved fulfilling life demands, accepting what life offers, and continuing a normal life as a normal person. These women rarely perceived themselves as cancer survivors. On the contrary, some rejected the survivor identity due to its negative association with death and the stigma associated with this disease. In rejecting the dominant survivor identity, these Chinese women reconstructed a self-identity that reflected the Chinese virtues and valued attributes of a normal, productive, enduring, self-reliant, positive and strong person.
The Chinese women’s rejection of the survivor identity is supported by recent findings that not all women living with breast cancer embrace this identity. Kaiser’s (2008) study of women living with breast cancer showed that White and middle-class women rejected the survivor identity. In fact, it alienated some women who were struggling with the fear of recurrence, who felt that their cancer experience was not severe enough to merit such an identity, or who desired a private disease experience. The varied response to survivorship among a relatively homogenous group of women suggests the dominant North American representation of breast cancer poses challenges for women who are attempting to make sense of their illness experience as well as the failure of the breast cancer culture to acknowledge diverse survivorship experiences. Similar results were also reported in a study by Bellizzi and Blank (2007) on post-treatment quality of life of men living with prostate cancer. The majority of respondents identified themselves as “someone who has had prostate cancer,” suggesting minimal identity change among this group.

While the adoption of the survivor identity may be an important step in the identity transformation process and adaptation for others (Deimling et al., 2007), it is clearly evident that not all people who live with cancer embrace the identity of survivor as part of their survivorship experience.

7.1.2. Lived body

Normalization is the essential theme in the lifeworld of corporeality. We live in a world of norms; each person endeavors to be normal or else deliberately tries to avoid that state (Davis, 1995). ‘Normal’ may be defined as “constituting, conforming to, not
deviating or differing from, the common type or standard, regular, usual” (as cited in Davis, p.24). An illness disrupts normalcy; it threatens self-sufficiency and survival (Anderson, Elfert, & Lai, 1989). Current knowledge on the effects of an illness on self-identity suggests that a chronic illness can disrupt a person’s biography and have profound consequences for his/her self-identity, particularly in relation to work and social life (Asbring, 2001). The person’s daily life becomes disjointed and activities previously engaged in can now become more difficult or totally impossible (Bury, 1982). Of significance, there is the disruption of sense of self with regard to the past, the present and the anticipated future, which leads to a fundamental re-thinking of the person’s biography and self that results in a person reconstructing a preferred identity (Bury, 1982; Charmaz, 1983, 1987).

Charmaz (1987) prioritizes four types of preferred identities - supernormal identity, restored self, contingent personal identity and salvaged self - that reflect people’s hopes, desires, aspirations and dreams as they reconstruct their lives apart from their illness. The emergent reconstructed self-identity is dependent upon the type and degree of illness, the meaning of the illness experience, the timing and sequence of the illness, and the individual’s expectation of and for the self. In other words, the emerging self is not static; it may shift between the four types of preferred identities, depending on interactions with the environment as well as changes in medical condition, in an effort to lead a normal life. Although significant, Charmaz’s work is limited in its applicability to understanding the effects of a life-threatening illness, such as breast cancer, on a person’s self-identity which precipitates facing death as a potential outcome of illness rather than
chronicity of illness. More importantly, the exclusion of culture as a social factor ignores its significant influence on a person’s illness experience. Studies demonstrate that the Chinese culture shapes a Chinese woman’s lived breast cancer survivorship experience. Thus, a person’s preferred identity is derived from interactions with others and others’ evaluation, negotiation, confirmation or disconfirmation of the person’s preferred identity within the Chinese culture (Morse, 1997).

The biographies of the Chinese women in this study were disrupted by the onset of breast cancer which had profound consequences for their self-identity. Upon learning of their diagnosis of breast cancer, their self-identity was shaken and threatened. They were immediately thrust into the health care system and forced to assume the role of a patient. They underwent grueling cancer treatments that affected all aspects of their daily life functioning - physical, emotional, psychological, social and spiritual – while facing an unknown future. The disabling effects of breast cancer affected their ability to fulfill roles central to their identity (Deimling et al., 2007). Their lives were disrupted by frequent medical appointments and the demands and length of treatments. For most of the women, the entire breast cancer treatment lasted up to a year. Although the reconstruction of self-identity could occur throughout the illness trajectory, existential questions about the meanings of their illness experience and their self-identities usually arise when women are close to or have completed treatment, around the time when more attention is directed towards getting on with normal life.

Though their former self-identity could have crumbled, in anticipation of the future, most of the Chinese women seemed to activate the Chinese cultural blueprint by
looking to the past to affirm some aspects of the previous self and drawing upon positive past relations for the courage and confidence to deal with their disrupted lives and fears and to reconstruct a ‘new’ self. The cultural blueprint seemed to provide the Chinese women with the internal frame within which to assess the situation, accept the physical changes, initiate practical steps to problem-solve and manage the disruptions while conforming to cultural norms. In the collectivist Chinese culture, individuals are pressured to conform to cultural norms; these norms are internalized as part of their pragmatic orientation to life. Sacrifice, as one of the norms, is central to a Chinese woman’s life (Cheung & Liu, 2004). The Chinese women placed the welfare of their family ahead of themselves and quietly and modestly endured the cancer treatments while remaining self-reliant, strong and productive in fulfilling their roles and maintaining harmonious interpersonal relationships. Failure to conform could result in the family losing face and bringing shame to the family and ancestors. Success was defined by the ability to return to normalcy, which most Chinese women viewed as engagement in paid work and fulfilling the cultural expectations of social roles and familial duty. Conversely, unproductiveness and being a burden to the family was regarded as failure.

In rejecting the survivor identity due to the negative cultural association with death, the Chinese women in the study demonstrated a strong desire to return to normalcy and minimize dependency. They reconstructed a restored self as the preferred identity, a self that is normal, self-reliant, enduring, positive and strong, and capable of doing paid work, all of which underscore Chinese virtues, values and work ethic. Return to normal life, following completion of cancer treatments, signaled preservation of integrity of the
restored self and quality of life, and more importantly, the fulfilling of role obligations and maintenance of harmonious relationships. For older Chinese women (over the age of 60 years) in the study, their self-identity remained intact as their lives seemed to be previously affected by major life events which shaped their pragmatic view of life and equipped them with the skills to cope with breast cancer.

Contrary to the assumption that cancer threatens the continuity of a person’s self-identity and result in a ‘spoiled’ or de-valued identity, the Chinese women focused their efforts on continuing their previous self, of being a “normal person again” – the same sense of self prior to the breast cancer – by either working or participating in social activities. Of significance, though a few of the Chinese women seemed to undergo deconstruction and reconstruction in arriving at a new sense of self (e.g. participant E6), most of the Chinese women in the study focused their efforts on continuing or restoring their previous self; this raises the questions whether the lived survivorship experience of the Chinese women was about reconstruction of self-identity and if the locution ‘reconstruction’ was appropriate in its application to the Chinese culture. The Chinese women seemed to have integrated the breast cancer experience, but they did not appear to have altered drastically in the way they saw themselves. Rather than initiating a new life path and a 'new' identity, these Chinese women sought to continue or restore their previous self, that of a normal person. Though the results suggest there was a process that took place which resulted in the Chinese women continuing their previous self with no identity change, most of the Chinese women did not appear to undergo the reconstruction process that is more evident in the chronically ill populations; this
suggests that the lived experience of Chinese women was not about reconstruction but rather about accepting, responding and managing a life-threatening crisis consistent with their cultural mindset and values, and that reconstruction appears largely to be a phenomenon in the western culture. Furthermore, a more suitable locution would need to be considered in future research. Self is not a separate entity; rather, it is embedded in a culture. In the collectivist Chinese culture, the self is socially constructed reflecting cultural values and social roles. The Chinese women internalized their role as a wife and mother by putting the needs of others ahead of their own and turning inward for self-support; such response is consistent with the cultural values of self-responsibility, self-sufficiency and familial piety to preserve harmony.

The occurrence of breast cancer in the Chinese women in this study did not result in social exclusion or rejection expected within the Chinese collectivist culture. This may be attributed to some Chinese women choosing not to disclose their illness due to fears of stigma or rejection. Further, the lack of social exclusion observed in the sample may also be related to the Chinese women putting the welfare of their family ahead of their own by enduring and being self-reliant, and minimizing financial burden and disruptions to the family, to the extent of continuing to work throughout the treatments (e.g. participant E12 helped her brother deliver newspapers while on treatment). Most Chinese women were able to return to work and thus preserve the family’s material existence. For the few Chinese women who chose not to work the reasons were unrelated to their cancer and their perceptions of themselves remained positive. In light of their financial independence, not working did not significantly impact the family’s economic existence.
Some of these Chinese women were supported by their spouse or had received severance packages, which mitigated the financial burden on the family.

The Chinese women’s reconstructed restored self as a normal person was largely defined by their ability to engage in paid employment. An individual’s self-identity is partly derived from work; individuals who are able to fulfill social and occupational roles tend to view themselves as healthy with improvement in quality of life (Spelten et al., 2002). Continuation of work for women living with breast cancer underscored the Chinese beliefs in self-sufficiency and not being a burden to the family, and thus preserving harmony. Paid work meant a woman was healthy, functional and productive, and also provided economic benefits to others. The significance of work is historically and culturally rooted and an important internalized part of the Chinese women’s pragmatic mindset. Their survival in a new country was based on their ability to secure employment and financially support their families. Working hard to obtain an outcome for self and others is one of the most influential Confucian ethical ideologies in the Chinese culture (Lai, 2006). Thus, continuing to work or returning to work symbolized a continuation of normalcy, which translated into ensuring economic benefits for self and others. In other words, normalization is about material existence and survival (Anderson et al., 1989).

While the cancer treatments negatively affected a few of the Chinese women’s body image, their overall self-identity as enduring, self-reliant, positive and strong remained intact. The adaptation to the altered body may be attributed to the fact that a woman’s physical appearance is less sexualized in the Chinese culture. In a pragmatic
collectivist culture which emphasizes fulfillment of role responsibility, losing a breast is less significant if she can live and work to maintain the economic well-being of her family. Distress towards the altered body for a few Chinese women could be attributed to the fact that they were within the first year of post-treatment, a time when most women are dealing with the existential questions about the meanings of the experience and the sense of who they are while still recovering from the effects of the cancer treatments and returning to their community.

In reconstructing their ‘new’ restored self-identity, the Chinese women activated and anchored themselves to a culturally rooted internalized pragmatic mindset to understand, problem-solve, accept and reframe their illness as a normative life event and strived for the continuation of normalcy, living as a normal person. The reframing and acceptance of reality in Chinese women have been noted as key coping mechanisms in the psychological adjustment necessitated by the impact of breast cancer (Ching et al., 2009; Li & Lambert, 2007; Mok, 2001). Consciously or unconsciously, they drew on the Chinese virtues and valued attributes and past relations (e.g. lived experiences, observations and beliefs) in reconstructing a self-identity as enduring, self-reliant, normal, positive and strong. These virtues and values instilled in them the self-confidence in their ability to endure adversity and suffering. Endurance is highly valued in the Chinese culture where people are accustomed to sustaining themselves during adversity (Ching et al., 2009). Endurance and self-reliance serve as coping strategies to overcome distress and adversities (Fu et al., 2008; Mok, 2001).
The Chinese women internalized their cultural emphasis on repression of feelings, shame, endurance and self-reliance by engaging in self-supporting behaviours, rather than seeking external support. In facing a life-threatening illness, the Chinese women turned to and relied on themselves to reframe a subjective positive interpretation of themselves and their illness experience. The use of reframing as a key factor in the adjustment process has been reported in other studies (Ching et al., 2009; Li & Lambert, 2007; Mok, 2001). In Li and Lambert’s (2007) study, they noted that the role of self is important in creating a subjective positive interpretation in enhancing the acceptance of the cancer experience. The Chinese women coped by engaging in productive or helpful activities for themselves or others. The few Chinese women in this study who sought external support did so mostly for practical assistance (e.g. a volunteer driver), which facilitated adaptation and minimized disruptions, as opposed to emotional and psychological support. Most of the Chinese women turned inward for self-support, conforming to the Chinese virtues of self-reliance and endurance as well as the norms of internalizing and saving face. The pressures to conform can be a “heavy, silent burden” (American Cancer Society, 2010d). Whether new or seasoned immigrants, they fear bringing shame to the family or being rejected for publicly airing the “family laundry”.

Some Chinese women in the study, however, had overcome the heavy, silent burden and openly shared their illness experience with others. While they were aware of the cultural emphasis on repression of feelings, these Chinese women attributed sharing their illness experience with others to either their personality or having lived in Canada for a long period of time, which suggests they may have modified their cultural values
due to the influence of acculturation. These women did not report feelings of shame or disgrace; rather, they felt positively supported by others and in turn, wanted to share their cancer experience to help other women. They saw themselves as positively transformed and experienced gains in relation to their new identity. These findings support the importance of social support and the potentially transforming effects of surviving a life-threatening illness and other hardships shown in other studies (Ashing et al., 2003; Bussell & Naus, 2010; Chiu, 2001; Ho et al., 2004; Kagawa-Singer et al., 1997; Mok, 2001).

The breast cancer lived survivorship experience of the Chinese women in this study seemed to be characterized by a quiet and modest narrative of restoring the same prior sense of self as normal, productive, enduring, self-reliant, positive and strong person with consequent conforming to cultural norms including repression of feelings and avoiding bringing shame to self and family. In addition, the return to normal life did not necessarily entail the embracing of a survivor identity, or a de-valued or fractured self, as promulgated by the literature on survivorship and the effects of a chronic illness on self-identity. Rather, the return to normalcy entailed restoration of previous self shaped by the virtues, norms and imperatives of the Chinese culture. Thus, the biographical disruption and illness experiences comprised both losses and gains that had consequences for identity reconstruction.

7.1.3 Lived Relation

People do not live “in a vacuum”. They define and redefine themselves through social interactions within their environment, and through these interactions, reconstruct
their self-identity. Relations are derived from interactions with others as well as connections to the past and present. Positive relationality seemed to shape the reconstruction of the Chinese women’s self-identity. They drew upon not only the Chinese virtues and valued attributes to reconstruct their self-identity, but also the positive lessons of past or current lived experiences, their parents as role models, faith and trust in health care providers to instill confidence and belief in themselves to endure life challenges and adversities. Activation and anchorage are two essential themes in the lifeworld of relationality. The Chinese women activated and anchored themselves to past memories which carried them forward and helped them cope and accept their illness experience. Though other current major life events may have overshadowed the breast cancer experience of some of the Chinese women, these events, along with their faith, strengthened their resolve and enduring spirits. The Chinese women did what was expected of them. They accepted the hierarchical patient-physician relationship, placed their trust in the health care providers and complied with treatment recommendations, and in doing so, conformed to the ideology of a ‘good’ patient. This trust was also extended to the researcher, which allowed the depth and richness of data to emerge.

Similar to other studies (Ashing-Giwa et al., 2004; Chiu, 2001; Simpson, 2005), this study also found that faith was an important factor in helping some Chinese women to adjust and manage their fears of death. Chiu (2001) reported that religious beliefs and Chinese philosophical teachings, as spiritual resources, positively influenced the healing of Chinese women living with breast cancer.
Health care ideologies are part of the social context of survivorship and may potentially influence the reconstruction of a woman’s self-identity as a result of the breast cancer experience. During the intense period of treatment and ongoing interactions between the patient and health care providers, health care ideologies are communicated both directly and indirectly, including the ideology that a good patient is one who is compliant and adherent to treatment protocols and empowered and proactive in self-care activities (e.g. what symptoms are important to monitor and report and act on). Ching et al. (2009) found that Chinese women trusted and depended on their health care providers for decision making and advice, which could be explained by the Chinese people’s acceptance of and convictions regarding authority. These researchers argue, however, that the acceptance of and deference to the authority of health care providers does not necessarily suggest that the Chinese women were helpless, hopeless and avoidant. Rather, they adopted a positive yielding approach (acceptance) to cope by conforming to the changes brought about by the breast cancer and its treatment. Acceptance of illness underscores the Chinese cultural emphasis on harmony (Mok, 2001). The Chinese women were able to relinquish the psychological struggle early on in the cancer experience and focused on what they could do to cope, that is, surrendering control to powerful others and conforming to changes. This renouncing of control, however, does not suggest they were passive in their care.

Similarly, Fu et al. (2008) reported that Chinese women took an active role in their treatment by trusting their health care providers and following their advice, asking questions and learning about cancer treatment. In another study, Mok (2001) found that
health care professionals played an important role in empowering Chinese cancer patients. These patients perceived health care providers as experienced, knowledgeable and kind; they felt empowered knowing the health care providers were there to help them and by their genuine interest in patients’ well-being.

Unlike the western culture’s emphasis on control of events and outcomes (Lazarus & Folkman, 1984), Ching et al. (2009) posited that for these Chinese women a sense of control did not equate with mastery of the situation; their objective for coping was simply to have the problems under control, either through their own efforts or the efforts of their social support system, rather than relying solely on individual control to master the situation. Chinese women in this study accepted external support from their health care providers, reached inwardly for strengths, and anchored themselves in the past relations or faith for guidance as well as to reduce fears and maintain hope.

7.1.4 Lived Time

People always live through time. Corporality exists in a space and that space is located in time (Munhall, 2007). Lived time for the Chinese women living with breast cancer may be defined both in terms of subjective time, a sense of one’s mortality, and objective time measured by reaching the survival milestones. Restoration of normalcy occurred under the constant threat of premature death. Self-protection is an important element in temporality. Like all women with breast cancer, the Chinese women experienced fear of recurrence. They responded by initiating positive changes to self-protect against recurrence, including positive lifestyle changes (e.g. diet, exercise) and the reduction of potential environmental threats (e.g. eliminating the use of plastics).
Success was marked by reaching survival milestones. Of significance, Chinese women anchored themselves to the valued attributes (positive and strong) that had helped them cope in the past to shield them now against dying. They internalized the lessons learned from the past lived experiences, observations of their parents, or faith to support their internalized psychological mindset. As long as long they remained positive and strong, they would more likely be shielded against premature death. This finding reflects the “constant striving spirit” (Li & Lambert, 2007) and the importance of the role of self in creating a positive subjective interpretation of the threat.

7.2 Implications of the Findings

The purpose of this study was to explore in-depth a relatively new area and to broaden the interpretation of the lived breast cancer survivorship experience. The art of survivorship encompasses all women regardless of race, culture, ethnicity and social class. The findings of this study identify important implications for social work education, clinical practice and policy/program development.

7.2.1 Implications for Social Work Education

Cancer incidence is on the rise primarily due to a growing and aging population (Canadian Cancer Society, 2009). With increasing cancer diagnosis and longevity, social work education needs to respond to this health trend by further developing specialized oncology social work. Oncology social work would contribute to the growth of the social work profession through evidence-based practice, particularly in an academic health care environment that has traditionally been dominated by the oncology medical and nursing...
professions. Such specialization would offer social workers the knowledge, values and skills to understand how an unpredictable life-threatening event, such as the diagnosis of breast cancer, can disrupt multiple levels of systems in an individual’s environment as well as her biography which in turn, influences her illness experience and identity reconstruction. Social workers would bring to oncology settings the ability to intervene effectively to facilitate optimal adaptation and recovery while acknowledging barriers such as social factors, systemic and structural barriers that prevent individuals from obtaining the help they need, and privilege and power that oppress individuals which influence the illness experience (Bogo, 2006). This specialization would also promote the social work profession by utilizing empirical research to inform theory and practice.

The theoretical premise underlying social work education and practice is based on ecological concepts or systems theory. It recognizes the inter-relatedness or interconnection of people and their environment as part of a unitary system in which each continually shapes the other (Maluccio, Washitz, & Libassi, 1992) and a competency model of practice (Bogo, 2006) that encompasses diversity, social exclusion and marginalization. The findings of this study suggest that the humanistic and culturally competent ‘client-centered’ approach is crucial to understand the impact of breast cancer on the multi-levels of the Chinese women’s lives and their responses to life-threatening illness. In this study, the Chinese cultural values, beliefs and norms shaped the lived survivorship experience of the Chinese women. Many of the participants consciously or unconsciously drew on the Chinese culture virtues and values to manage and respond to the threat of dying, as well as in the reconstruction of their self-identity. Therefore,
awareness of and sensitivity to the influence of culture is particularly important to avoid the premature assumptions that the lived breast cancer survivorship experience is universal to all women, that all women embrace the survivor identity and seek mastery over the situation, or that their help-seeking behaviours and coping strategy of turning inward are not indicators of lack of motivation and interest. The Chinese women’s trust and yielding approach to health care providers is a not sign of passivity, but rather cultural acceptance of the hierarchy and deference to authority. Understanding the Chinese culture can help social workers and other psychosocial providers to support the Chinese women’s inner frame to self-protect and their coping strategies. In summary, this study supports the holistic person-in-the-environment approach and recommends ongoing training and awareness of the environment and its social factors to all psychosocial providers.

7.2.2 Implications for Clinical Practice

The multitude of complex health care needs of Chinese women living with breast cancer and their ongoing involvement with the health care system in an economically constrained environment necessitates reconsideration of the way existing services are utilized and delivered. Of greater importance is the need to understand how Chinese women interpret their illness experience and perceive themselves post-treatment, a crucial component for oncology social workers committed to assisting women in their recovery. The findings from this study provided invaluable insights to aid oncology social workers and other psychosocial providers to assess these women’s needs, anticipate potential problems, facilitate their internal ‘positive and strong’ frame of
coping as well as support the development of culturally appropriate psychosocial and supportive care services to maximize adaptation and recovery. Significant to all women, these findings also challenge the universal definition and application of survivor identity as part of the lived survivorship experience. While this identity may be an important element in some women’s adaptation, it may also alienate and silence others.

From an Asian feminist perspective, the survivor identity, viewed as a label, was created in the interests of the dominant groups and diffused in ways that produce a set of labels that further subjugate women. Women who do not embrace this identity are viewed as being unhappy, pessimistic and maladjusted. The assumption that all women subscribe to this universal survivor identity without taking into account the social context and their individual unique lived experiences may inadvertently alienate them or contribute additional psychological distress among women who subscribe to a different illness experience. Most of the Chinese women in this study sought a quiet, modest and private experience in conformance to the Chinese cultural values and norms. The application of the survivor identity to these women, without further exploration, can contribute to psychological distress generated from this identity negative association with death, thus hindering the goal of returning to a normal life. Further, applying a western concept of self-identity to the Chinese collectivist culture also highlights the importance for clinicians and researchers to engage in self-reflection in order to be aware of biases, judgments, ideas and assumptions that the substance of self-concept is universal across all groups.
While Charmaz’s theory on the effects of an illness on self-identity provided the initial conceptual framework to understand the impact of a chronic illness, the findings of this study yielded new insights on the effects of a life-threatening illness on identity formation. The findings of this study confirmed previous investigations where the Chinese culture was found to influence the lived breast cancer survivorship experience of Chinese women. They also added new understanding on the way culture as a social factor seemed to shape the reconstruction of the normal, productive, enduring, self-reliant, positive and strong self-identity of the Chinese women. Though breast cancer disrupted the Chinese women’s biographies, contrary to the literature, it did not result in a spoiled or fractured self-identity. These women held onto some elements of their previous self and drew on the Chinese cultural blueprint to help them assess, problem-solve, reframe and cope. The findings suggest that health care and psychosocial providers need to be aware of their role in promulgating the dominant survivorship discourse, including the survivor identity, and critically ask the questions: who created it, what purpose does it serve, who benefits and when does it apply or not apply in clinical settings.

Training in the culturally competence models (Dyche & Zayas, 1995, 2001; Tsang & George, 1998; Williams, 2006) offer the cultural lens to assess the impact of the Chinese culture on how Chinese women respond, access external help and cope with breast cancer. A few Chinese women in the study were distressed in response to their altered body and felt uncomfortable in expressing their distress and worries. The cultural competency perspective offers social workers and other psychosocial providers the knowledge of the Chinese cultural emphasis on modesty and shyness that can hinder
these women from speaking openly about their concerns about their body image and sexuality and the appropriate counselling skills to facilitate discussion and expression of feelings. Since the role of self and the use of reframing were two important coping strategies Chinese women used to facilitate the acceptance of breast cancer, specific psychosocial interventions could be developed to support and strengthen these strategies.

Health care and psychosocial providers are in a unique position to instill confidence in cancer patients (Deimling et al., 2007), in particular those from a collectivist culture that emphasizes the acceptance of hierarchy and deference to authority. The Chinese women trusted their health care providers; thus, these providers are in a position to encourage and promote a diverse survivorship orientation that acknowledges the interplay of social factors. When developing psychosocial programs or offering professional advice to Chinese women with breast cancer, more salutary would be the adoption of a flexible approach that allows for differing degrees of control, guidance and empowerment responsive to their needs. Recognizing and acknowledging the influence of the Chinese collectivist culture would be of significantly greater benefit than individual-level perceptions of control or mastery of situations (Ching et al., 2009; Thompson, 2002). Furthermore, awareness of the meanings Chinese women attribute to their illness is important as they likely influence subsequent actions (Kaiser, 2008; Swidler, 1986), particularly their efforts towards self-protection and restoring normalcy. The development of culturally sensitive language-based services and programs are essential to minimize marginalization of non-English speaking patients and to enhance their access to health care and psychosocial services.
7.2.3 Implications for Policy/Program Development

While the Chinese cultural model offers explanations to understand the reluctance of Chinese women to seek external support, Asian feminists argue that the lack of comprehensive policy to address the cultural and language-needs of Chinese women discourages the non-English speaking Chinese women from receiving the help they need. Most services and programs are developed to reflect the dominant group’s interests and values. Breast cancer support groups are most often offered in English, which ignores the fact that non-English speaking Chinese women, or those whose speak English as a second language, may prefer speaking in their own language. Although a couple of participants in the study benefited from attending the yoga classes and hearing other women’s experiences in a support group, policy is needed to further develop and make programs more accessible for people who are coming from diverse cultural and linguistic backgrounds.

Further, Chinese women with breast cancer are surrounded by a plethora of Western constructed self-care knowledge and expert advice which encourages taking responsibility for themselves, monitoring their bodies for recurrence, maintaining optimal health and seeking self-improvement resources (e.g. support groups) to improve their psychological adaptation and well-being. However, the false underlying assumptions are that all patients have equal access to information and resources, that they seek equal power with the medical profession and mastery to control the situation, and that the adoption of a yielding approach results in helplessness and avoidance (Ching et al., 2009). Chinese women do want medical information and resources, but these are often
denied to them due to language and resource barriers (Liang, Yuan, Mandelblatt, & Pasick, 2004; Moy, Park, Feibelmann, Chiang, & Weissman, 2006). The goals of patient education initiatives are to empower women by teaching them the skills to master and take control of their health and health outcomes, but they fail to recognize that the concepts of empowerment, mastery and control have different meanings for Chinese women. Thus, this heavy silent burden, as well as language and structural barriers, discourage Chinese women from receiving the help they need.

Based on the data from this study that returning to work was essential in the recovery and adaptation process for the Chinese women, policy directed towards program development to address the after-care and rehabilitative as well as vocational needs of cancer patients would highly benefit this client population. Such programs can include a post-treatment after-care or well follow-up clinic to address the long-term effects (e.g. arm functioning, fatigue or pain issues) from cancer treatments, vocational workshops to address return to work concerns, and cultural services to support the internal frame, self-support coping strategies and self-protecting behaviours of the Chinese women.

7.3 Limitations of the Study

This study entailed several limitations. Although the sample size was appropriate for a qualitative inquiry and generated valuable insights into the experiences of Chinese women living with breast cancer, the findings cannot be generalized to all afflicted Chinese women due to each individual’s diverse and unique political, economic and social experiences. In qualitative research, generalization of findings is negated on account of close ties to a specific time, place and person (Pelusi, 1997). The
understanding of the findings, however, may be transferable to similar settings, depending on the degree of similarity between the actual setting and the study population (Pelusi, 1997). While the study identified commonalities in the Chinese women with breast cancer, there were also distinct differences based on social factors that influenced the reconstruction of their self-identity.

Another limitation was the application of a western concept of self-identity to a Chinese collectivist culture where individuals are defined in relations to others, rather than to individuals. To mitigate this limitation, I maintained a reflexive journal as well as sought collegial/peer consultations throughout the research study to reflect upon and document the researcher’s biases, judgments and assumptions and avoid oversimplification and generalization. The restriction of the study to English and Mandarin, and the exclusion of Cantonese-speaking Chinese women, the second dominant language of the Chinese population, may have limited the depth and richness of the data.

The lack of opportunity to conduct repeated interviews and member checking were additional limitations. As a researcher, I recognized and respected the Chinese women had moved on with their lives and were discharged from the hospital which influenced their decision to participate in one interview only. However, the interviews were long and extensive, and yielded rich information on the meaning of participants' lived experience.

Another limitation was the years of remission may have affected participants' identity reconstruction. Since years of survival is an important variable in influencing
women's breast cancer experiences, temporality may account for the lack of absorption of new identity in those Chinese women who reported no identity change.

Translation challenges posed another limitation. As previously noted, the lack of equivalent English words or terms to capture particular cultural nuances, expressions and meanings in the Chinese transcripts of interviews could diminish the richness and depth of data in the translation process.

Lastly, there exists the potential for bias in the coding of interviews due to the researcher’s duo-role. To mitigate such bias, the researcher engaged in constant reflexivity and enlisted others to double-code for accuracy.

7.4 Direction for Future Research

The current knowledge base on quality of life outcomes and breast cancer survivorship experiences has evolved from studies conducted primarily on Caucasian American women, unmasking a glaring absence of the psychosocial impact of breast cancer on ethnic minority women in the psychosocial oncology literature. With the increasing longevity of women with breast cancer, it is imperative that the voices, perspectives, concerns and survivorship experiences of ethnic minority women be heard and documented to promote their visibility in the literature, influence policy development and promote culturally appropriate cancer screening and treatment practices (Evans et al., 2005). Researchers, therefore, should be encouraged to conduct cross-cultural research and recruit diverse participants in order to broaden the interpretation of the lived survivorship experience. These investigations would require additional funding to offset the added expenses associated with cross-cultural and cross-language research.
Understanding the way Chinese women manage the impact of breast cancer and their survivorship experience significantly contributes to the knowledge-base of this minority population within the Canadian context, in particular, what constitutes a ‘survivor’ identity, while also recognizing the uniqueness of the women’s individual survivorship experiences. Importantly, the Chinese women in this investigation rejected the survivor identity due to its negative association with death. Instead, they relied on their culturally rooted values of self-reliance and endurance to help them manage and cope within the new environment of breast cancer, its treatments and recovery. Building on the results of this study, culturally-sensitive psychoeducation interventions can be directed at helping Chinese women to adapt to this new environment by teaching them how to use coping skills, such as reframing, that respect their cultural values while at the same time meet the demands of the new environment; for example, learning how to use reframing to understand that developing healthy reliance on others or seeking external social support to manage breast cancer experience is a means to endure and maintain self-reliance within this new environment. For women who prefer a more private illness experience, interventions can be developed to provide culturally appropriate problem-solving skills that support the pragmatic inner frame and self-supporting behaviours.

It is clearly evident from the result of this study that not all women who live with breast cancer embrace the identity of survivor as part of their survivorship experience. Given this, cross-cultural and cross-language psychosocial and survivorship research requires greater attention to challenge the tendency within the mainstream culture to universalize women’s breast cancer lived experiences and its application to survivor
identity. Further research is needed to continue broadening the interpretation of lived breast cancer survivorship experience and the representation of the survivor identity by including women from many ethnic groups to fully understand how social factors influence the reconstruction of self-identity and the range of identities that result from the configuration of these factors in women’s lived experience, and to identify those most likely to adopt or reject the survivor identity as part of their recovery. This understanding of women’s lived survivorship experience and identity formation is important to ethnic women with breast cancer who are living in Canada and even more crucial given that more ethnic groups are immigrating to Canada (Statistics Canada, 2006). Broadening research activities in this area will also lay the foundation to develop psychosocial interventions that harness strength-based aspects of the ethno-cultural mindset to support and strengthen coping strategies of all women.

7.5 Conclusion: Final Reflection

This study has been a journey of self-discovery. On a personal note, I gained a new perspective of my culture and appreciation of its strengths, raising questions of my dual-role within the Chinese culture and medical setting. As an insider, I am aware of the Chinese cultural values and pressures to conform. I recognize my values and beliefs may differ from those of the participants, as I grew up in Canada and was educated in the western culture. Through reflexivity, I became aware of my biases, beliefs and stereotypical views of the Chinese culture; one of the biases I brought to the research process was my perception of the Chinese as passive. To work through my misconceptions, I reflected on what I had learned as a child growing up in Canada from
observing the actions of my parents, family members and friends, family and cultural rituals and celebrations, and watching eastern and western movies. I remembered watching Chinese movies that depicted the Chinese people as passive and being taken advantage of because of it. I recalled my first exposure to the portrayal of the Chinese in western movies such as *The World of Suzie Wong* and *Seven Faces of Dr. Lao*, which depicted Chinese females in submissive and passive roles as well as the philosophical and wise orientation that permeated the Chinese culture.

I remembered hearing from others how important it was to remain quiet and silent, to not stir up trouble and from reading English materials that reinforced the Chinese as passive. On hearing the participants’ narratives, however, I realized that though the Chinese women were quiet and modest, their actions did not in any way reflect passivity in managing their illness. I gleaned the strengths and resilience in these participants as they endured and remained self-reliant in managing the treatment demands while also fulfilling their social roles and meeting family obligations. They accepted the hierarchical physician-patient relationship, acquiesced tacitly and placed their trust in their health care providers. This led me to question the discourse on the Chinese culture and people and those who promoted such discourse. I am still learning about the Chinese culture and trying to locate myself within it through an evolving process.

As an outsider, I became aware of my need to appease both the quantitative and qualitative worlds and struggled at times to exclude quantitative language from entering into the hermeneutic writing. I realize this struggle is unlikely to abate due to my work environment, necessitating constant reflexivity as I develop as a researcher.
While there are commonalities in the lived breast cancer survivorship experience that unite all women, it is important that we do not lose sight of the individual uniqueness and dynamic lived experience of each woman. Just as there are different interpretations on a piece of artwork or a music score, there are mosaic interpretations and meanings that women attribute to their breast cancer experience. The development of a culturally sensitive educational, clinical and research environment is essential in promoting social inclusion and justice.
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Appendix A
Patient Demographics Information Sheet

Please check (v) appropriate box.

1. When were you diagnosed as having breast cancer:____________________

2. What type of treatment have you received (check as many as apply):
   - Surgery: ___Lumpectomy or ___Mastectomy
   - Radiation
   - Chemotherapy
   - Hormonal therapy

3. Age (please specify): ___________________

4. Relationship Status
   - Single
   - Married/Common Law
   - Separated/ Divorced
   - Widowed
   - Other

5. Living arrangement:
   - Lives alone
   - Lives with others (check as many as apply): ___Spouse/partner/roommate
     ___Child (ren). Ages:
     ___Parents/in-laws
     ___Siblings (brothers/sisters/in-laws)
     ___Others

6. Highest education level:
   - Some high school
   - High school graduate
   - Some college/university
   - College/university graduate
   - Postgraduate degree/studies

7. Employment status:
   - Working full-time
   - Working part-time
   - Self-employed
   - On contract
   - On sick leave
   - Unemployed
Homemaker/Full time caregiver at home
Other: please specify:________________________

8. Household income:
- Below $29,999
- $30,000 - 44,999
- $45,000 - 59,999
- $60,000 - 74,999
- $75,000 – 89,999
- Above $90,000

9a. Country of Birth:
- Canada (go to question #10)
- Hong Kong (answer b)
- Mainland China (answer b)
- Taiwan (answer b)
- Vietnam (answer b)
- Other: please specify:__________________ (answer b)

  b. If you were not borne in Canada, please indicate when you immigrated to Canada? ______

10. Primary language spoken at home:
- Cantonese
- Mandarin/Putonghua
- Hakka
- Taiwanese
- English
- Other: please specify:________________________

11. Faith practice:
- Buddhism
- Taoism
- Islam
- Christianity/Protestant
- Roman Catholicism
- No faith practice identified
- Other: please specify:________________________

12. Health care providers who are involved in your care (check as many as apply):
- Family Physician
- Oncologist(s)
- Other specialist(s): please specify:________________________
13. Have you used any services in the community?
   □ Yes (check as many as apply)  
   ___ Chinese Cancer Support Groups
   ___ Guilda’s Club
   ___ Wellspring
   ___ Willow
   ___ Canadian Cancer Society (e.g. volunteer driver)
   ___ Other: please specify____________________

   □ No
Appendix B
Interview Guide (English version)

1. I want to begin at the time of your breast cancer diagnosis. Can you tell me what was it like for you?
   Probes:
   - Who discovered it?
   - How was it discovered?
   - Can you tell me more about that?
   - What kinds of treatment did you have?
   - During your treatment, have you thought about trying or tried complementary therapies such as Chinese herbal medicine?

2. Can you tell me what meanings did you give to the diagnosis?
   Probes:
   - What went through your mind when you heard the word ‘cancer’?
   - Was anyone (family member? friend?) with you when you were told this information?
   - How did you understand the medical information provided to you?
   - How did you feel about yourself having this illness?
   - How did you respond to these feelings at the time?
   - What is your understanding of your breast cancer?

Sometimes having a diagnosis of breast cancer shapes people’s lives significantly; alternately sometimes a person’s life may return to a ‘more or less’ normal state after treatment is completed.

3. Can you tell me how has breast cancer shaped your life?
   Probes:
   - How would you describe your life now than before you had breast cancer?
   - If yes, in what ways? / Can you tell me more about that?
   - Have you experienced difficult things (i.e. negative factors) while living with breast cancer?
   - Has your experience of living with breast cancer resulted in any positive things for you (e.g. personal growth)?
   - How has being Chinese effect how you coped with this illness?
   - If yes, in what ways? / Can you tell me more about that?

4. Can you tell me how has breast cancer shaped the way you see yourself?
   Probes:
   - If yes, in what ways? / Can you tell me more about that?
   - How would you describe yourself now than before you had breast cancer?
• How would you describe the changes to your body as a result of the treatment you had for breast cancer?
• How do you feel about these changes?
• How has being Chinese influenced the way you see yourself?
• If yes, in what ways? / Can you tell me more about that?
• Would you say this is a positive or negative influence?
• How do you see having breast cancer affecting your ability to obtain future life goals?

5. Can you tell me what has the relationship been like between you and your family since your diagnosis?
   Probes:
   • What do you think it has been like for your family facing your diagnosis?
   • Would you say they are for the better or worse?
   • Can you tell me more about that?
   • What did your family do that was helpful or not helpful?
   • Can you tell me more about that?
   • How would you describe your family?
   • How did this shape your role in the family?

6. Can you tell me what has the relationship been like between you and your friends since your diagnosis?
   Probes:
   • Would you say they are for the better or worse?
   • In what ways? / Can you tell me more about that?
   • What did your friends do that was helpful or not helpful?
   • In what ways? / Can you tell me more about that?

7. Can you tell me what has it been like in your work situation and in your relationships with co-workers since your diagnosis?
   Probes:
   • Would you say they are for the better or worse?
   • Can you tell me more about that?
   • Were your co-workers helpful or not helpful?
   • In what ways? / Can you tell me more about that?
   • How did having treatment for breast cancer affect your work life?
   • Did you have any financial worries during this time? Can you tell me more about that?
   • How do you see having breast cancer affect your ability to obtain your future career goals?
Being diagnosed with and treated for breast cancer has brought you into contact with a number of health and community care professionals and resources.

8. What were your experiences with your health care professionals like?
   Probes:
   - How did this influence your experience with breast cancer?
   - Were your health care professionals helpful or not helpful?
   - In what ways? / Can you tell me more about that?

9. As you were going through your cancer experience, who provided support outside your immediate family (such as speaking to other women with breast cancer, speaking to a counsellor, attending a cancer support group, etc.)?
   Probes:
   - How did it help or not help?
   - How did you find or become connected?
   - Where did you turn for help? (e.g. physician, nurse, social worker, friend, another patient, cancer support groups, etc.)?
   - How has being Chinese influenced your decision about asking or not asking for help?
   - What was it like for you to ask for help?
   - What kind of help have you received?

10. Looking back on your experience, can you tell me about the most significant event in your life that has taken place since living with breast cancer?
    - How do you feel about this event?
    - How have you responded to this event?
    - How are you doing now?

11. Is there anything else you would like to talk about that we have not covered or you think it is important for me to know?

12. Can you tell me what this has been like for you to talk to me about your breast cancer experience?
1. 我想從您被診斷出乳癌開始。能跟我談談您當時的感覺嗎？
   進一步問：
   ● 是誰發現的？
   ● 如何發現的？
   ● 能再講得詳細些嗎？
   ● 您接受了什麼治療？
   ● 治療過程中，您是否想過要嘗試、或有嘗試過輔助療法，例如中草藥？

2. 能否告訴我您賦予這個診斷什麼樣的意義？
   進一步問：
   ● 您聽到「癌症」這個字的時候，心中想到什麼？
   ● 您得知這個消息時，身邊有其他人（家人？朋友？）嗎？
   ● 您如何了解當時提供給您的醫療資訊？
   ● 對於自己患這樣的疾病，有什麼感覺？
   ● 當時您對這些感覺的反應是怎麼樣？
   ● 您對自己的乳癌了解多少？

   有時候，診斷出乳癌會大大地影響一個人的生活；然而在治療結束後，生活可能會「或多或少地」回復正常。

3. 能否告訴我乳癌如何影響了您的生活？
   進一步問：
   ● 相較於得乳癌之前的生活，您會如何形容您現在的生活？
   ● 如果有，在哪些方面？/ 能再講得詳細些嗎？
   ● 罹患乳癌期間，您是否經歷了困難（例如一些負面的事情）？
   ● 罹患乳癌的經驗是否有導致任何正面的事情？（例如個人成長）？
   ● 身為華人，是否有影響您如何處理這個疾病？
   ● 如果有，在哪些方面？/ 能再講得詳細些嗎？

4. 能否告訴我乳癌如何塑造了您對自己的看法？
   進一步問：
   ● 如果有，在哪些方面？/ 能再講得詳細些嗎？
   ● 相較於罹患乳癌之前，您會如何形容現在的自己？
   ● 您會如何形容乳癌治療導致的身體變化？
   ● 您對這些變化的感覺如何？
   ● 身為華人有影響您對自己的看法嗎？
   ● 如果有，在哪些方面？/ 能再講得詳細些嗎？
5. 能否告訴我自從得知診斷以來，您跟您家人之間的關係如何？
進一步問：
- 您認為您的家人是如何面對您的疾病診斷？
- 您覺得他們與您同甘共苦嗎？
- 能再講得詳細些嗎？
- 您的家人做了哪些有或沒有幫助的事？
- 能再講得詳細些嗎？
- 您會如何形容您的家人？
- 這如何塑造了你在家庭中的角色？

6. 能否告訴我自從得知診斷以來，您跟您朋友之間的關係如何？
進一步問：
- 您覺得他們與您同甘共苦嗎？
- 在哪些方面？能再講得詳細些嗎？
- 您的朋友做了哪些有或沒有幫助的事？
- 在哪些方面？能再講得詳細些嗎？

7. 能否告訴我自從得知診斷以來，您的工作狀況和您跟同事之間的關係如何？
進一步問：
- 您覺得他們與您同甘共苦嗎？
- 能再講得詳細些嗎？
- 您的同事對您有沒有幫助？
- 在哪些方面？能再講得詳細些嗎？
- 接受乳癌治療如何影響您的工作生活？
- 在那期間您有任何財務上的擔憂嗎？
- 您認為罹患乳癌如何影響您追求未來事業目標的能力？

診斷出乳癌並接受治療，您接觸到了許多健康和社區照護的專家和資源。

8. 您和您的醫護人員之間的經驗是怎樣的？
進一步問：
- 這如何影響了您罹患乳癌的經驗？
- 您的醫護人員對您有幫助嗎？
- 在哪些方面？能再講得詳細些嗎？

9. 在您罹患乳癌期間，除了最親近的家人以外，還有誰提供過支援（例如和其他患有乳癌的婦女交流、和輔導師談天、參加癌症支持小組等等）？
進一步問：

● 您認為這是個正面還是負面的影響？
● 您認為罹患乳癌如何影響您追求未來生活目標的能力？
● 有用嗎？
● 您如何尋得這些管道？
● 您向誰尋求幫助？（例如：醫生、護士、社工、朋友、另一位病患、癌症支持小組等等）
● 身為華人，如何影響了您決定是否尋求幫助？
● 您尋求幫助的感覺是怎樣？
● 您獲得了什麼樣的幫助？
Appendix D
Consent Form (English version)

Title: A Phenomenological Study on the Reconstruction of Self Identity of Chinese Canadian Women in the Social Context of Breast Cancer Survivorship

Principal Investigator: Terry Cheng, PhD Candidate, MSW, Psychosocial Oncology and Palliative Care Program (416) 946-2197, Princess Margaret Hospital, University Health Network

Thesis Supervisor: Dr. Charmaine Williams, Faculty of Social Work, University of Toronto (416) 946-8225

You are being asked to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study procedures. The following information describes the purpose, procedure, benefits/risks and safety measures associated with this study. It also describes your right to not to participate or to leave the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the study investigator to explain any words you do not understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

Purpose
The aim of this study is to develop an understanding of the survivorship experience of Chinese women living with breast cancer. This information will help us to better understand their concerns and plan future resources suitable to meet their needs.

Procedure
If you agree to participate in this research study, you will be asked to participate in a one time 1 - 1 ½ hours face-to-face interview at the Princess Margaret Hospital (PMH) or in your home. The focus of the interview will be your experience and the meaning you attribute to your breast cancer. The interview will be digital audiotaped and the tape will be professionally transcribed.

Risks
While there are no known risks for taking part in this research study, some women may feel uncomfortable from discussing some topics. If you feel uncomfortable, you may stop the interview at any time.

If you experience high levels of emotional distress during the interview, the interviewer can refer you to professional health care providers who specialize in emotional and psychological support if you wish.
Benefits
It is important to know that the knowledge that we gain from completing this research study may not directly benefit you. However, it may benefit other patients who attend PMH in the future.

Confidentiality
All information gathered in this study will be kept strictly confidential and will not be discussed with your health care providers or family members. All digital interviews will be assigned an identification number and all patient identifying information will be stripped before they are sent electronically to a secured email account for transcription.

If you refuse to participate or choose to withdraw from the study at any time, this will in no way affect your care at PMH.

In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities

Participation
Your participation in this study is voluntary. You can choose not to participate or you may withdraw at any time without affecting your ongoing medical care.

If you have any questions about the study, please call Terry Cheng, MSW (PhD Candidate and Principal Investigator) at (416) 946-2197, or Dr. Charmaine Williams (Thesis Supervisor), Faculty of Social Work, University of Toronto at (416) 946-8225.

If you have any questions about your rights as a research participant, please call Dr. R. Heslegrave, Chair of the University Health Network Research Ethics Board at (416) 946-4438. This person is not involved with the research project in any way and calling him will not affect your participation in the study.

Consent
I give permission to be enrolled in this study. I have had this study and the consent form explained to me and I have been given the opportunity to ask questions. I have been assured that all information gathered would remain confidential, and that my name will not appear on any forms. I further understand that if the study is not undertaken, or if it is discontinued at any time, the quality of my medical care will not be affected. I understand that if any knowledge gained from this study becomes available that could influence my decision to continue in this study, I will be promptly informed.

_________________________  ____________
Study Subject’s Name (Please Print)          Study Subject’s Signature   Date
I confirm that I have explained the nature and purpose of the study to the subject named above. I have answered all questions.

_________________________  ______________________  ___________
Name of Person              Signature                Date
Appendix E
Consent Form (Chinese version)
參與研究之知情同意書

題目：自我認知的重建：華裔加拿大婦女罹患乳癌之倖存經驗

主要研究員：Terry Cheng, PhD Candidate（博士候選人）, MSW, Psychosocial Oncology and Palliative Care Program（心理社會腫瘤學及安寧療護計畫）(416) 946-2197, Princess Margaret Hospital（瑪嘉烈公主醫院），University Health Network（大學健康網絡）

論文指導教授：Dr. Charmaine Williams, Faculty of Social Work（社會工作學院）, University of Toronto（多倫多大學）(416) 946-8225

我們邀請您參與一項研究。在您同意參與這項研究之前，請務必閱讀並了解下列關於這項擬行研究程序的說明。下列資訊闡述了與此研究相關的目的、程序、受益/風險和安全措施，並且描述了您不參與或於任何時間退出此研究的權利。為了決定是否參與此項研究，您應該充分了解研究的風險和受益，以作出知情下的決定，即所謂的知情同意手續。在簽署這份同意書之前，請要求此研究的研究員說明任何您不了解的字句。確定您所有的問題都得到了滿意的答案後，再簽署此文件。

■ 目的
此研究的目的，在於瞭解罹患乳癌的華裔婦女的倖存經驗。這份資訊有助於我們更了解她們的擔憂，並規劃未來適合她們需求的資源。

■ 程序
若您同意參與這項研究，我們會邀請您出席一次約 1-1½小時的面對面訪談，可在瑪嘉烈公主醫院（PMH）或您家中。訪談將著重在您的經驗，和您對您的乳癌所賦予的意義。訪談將會錄音，錄音帶將會由專業人員譯寫。

■ 風險
參與此項研究沒有任何已知的風險，但有些婦女可能對於談論某些主題感到不舒服。如果您感到不舒服，您可以於任何時候中止訪談。

如果訪談中您情緒上感到極為痛苦，訪問者可轉介您至情緒和心理方面的專業健康照護提供者，若您願意的話。

■ 受益
您務必要了解，完成此項研究所獲得的知識可能不會讓您直接受益，但可能會有助於以後來PMH的其他病患。
保密
此研究所收集的资料都将严格保密，亦不会与您的健康照护提供者或家人讨论。

如果您拒绝参与或选择在研究中任何时间退出，皆不会影响您在PMH接受的照护。

签署此同意书绝不会免除您的法律权利，亦不会免除研究员、赞助者、或参与机构的法律和专业责任。

参与
您的参与此项研究纯属自愿。您可选择不参与或在任何时间退出，都不受影响您正在接受的医疗照护。

如果您对此研究有任何疑问，请电Terry Cheng, MSW（博士候选人和主要研究员），电话是(416) 946-2197，或Dr. Charmaine Williams（论文指导教授），电话是(416) 946-8225，多伦多大学社会工作学院。

如果您对自己身为研究参与者的权利有任何疑问，请电University Health Network Research Ethics Board（大学健康网络研究操行委员会）的主席Dr. R. Heslegrave，电话是(416) 946-4438。此人没有在任何方面参与我们的研究计划，联络他不会影响您参与此研究。

同意
我同意参加这项研究。我已得知此项研究和同意书的说明，也被赋予了提问的机会。我已获得保证，所收集的所有资料都会保密，而且我的名字不会出现在任何表格上。我也进一步了解到，如果此研究并未进行，或于任何时间中断，我接受的医疗照护品质不会有所影响。我亦明瞭，如果从此研究获得的任何知识可能影响我继续此项研究的决定，我会被即时告知。

研究受试者姓名（请写正楷）研究受试者签名日期

我确认，我已经向以上签名的受试者说明了本研究的本质和目的。我已经回答了所有问题。

姓名签名日期
Study Title: Reconstruction of Self-Identity: The Survivorship Experience of Chinese Women living with Breast Cancer

Principal Investigator: Terry Cheng, PhD Candidate, Social Work

Dear Medical/Nursing Colleagues,

I am writing to request your support in identifying potential Chinese female patients for my qualitative thesis study.

I am looking for 20 Chinese women who meet the following selection criteria:
• Have a diagnosis of breast cancer (no metastatic/recurrence disease).
• Are at least six-month post completion of adjuvant treatment.
• Receiving well follow-up outpatient care at PMH.
• Adults over the age of 18.
• Able to read and speak English or Mandarin (Chinese).

To refer a potential participant, you can reach me by:
• pager 416.790.4526
• email terry.cheng@uhn.on.ca or
• telephone ext.2197.

Please provide the identified participants’ MRN, name and telephone number. I will contact them to introduce, explain and obtain consent for the study.

Thank you for your support and consideration of my request.

Regard
Appendix G
Reflection Journal Sheet

ID# ______

Date:
Site of Interview:
Interview time:
Language Spoken:

Impressions/Observations:

Reflection: