PUNJABI IMMIGRANT WOMEN’S EXPERIENCES OF BREAST CANCER

by

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ABSTRACT

There is a notable absence of women from specific ethnocultural groups, including South Asians, in the published breast cancer research. The breast cancer experiences of Punjabi immigrant women, who represent the most populace group of South Asians in British Columbia, need to be understood in order to provide culturally appropriate cancer care. The purpose of this qualitative study was to explore the ways Punjabi immigrant women told stories of having breast cancer in order to uncover how they made sense of their experiences. The cultural and social world reflected in women’s stories was also considered. This investigation was a secondary analysis of interview data collected for a larger study investigating South Asian women’s experiences of self-discovered breast changes. In-depth, open-ended interviews with twelve Punjabi immigrant women who had breast cancer within the last eight years were available for this study. A combination of narrative analysis strategies were used to guide this secondary analysis, focussing on stories the Punjabi women constructed. Four storylines emerged from the analysis reflecting different constructions of experiences of breast cancer. The storylines were: dealing with just another health problem, surviving a family tragedy, living with never-ending fear and suffering, and learning a lesson from God. The minor theme, “being part of a close-knit family,” illustrated the collective experience of breast cancer within the family and highlighted the family context as the most pronounced influence on the women’s experiences. The detailed storylines suggest that Punjabi women’s constructions of breast cancer are influenced by traditional family roles and expectations, spiritual beliefs, perceptions of breast cancer as treatable/untreatable, fears of speaking about breast cancer, and difficulties with translation and communication. These findings provide valuable insights for health care professionals into how culturally appropriate cancer care might address the needs of Punjabi women with breast cancer and their families.
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CHAPTER ONE: INTRODUCTION

Breast cancer is an important community, family, and woman's health issue. This is a disease that afflicts women of all ages, races, and ethnicities, and in all socioeconomic strata and geographic areas (Hoskins & Haber, 2000). Breast cancer is the most frequently diagnosed cancer among Canadian women and it is currently expected that one in nine women will develop breast cancer sometime in their lifetimes (Canadian Cancer Society, 2004). In addition, an estimated 21,200 women will be diagnosed with breast cancer in 2004, and 5,200 will die of this disease (Canadian Cancer Society, 2004). Although breast cancer incidence rates have risen in Canada, the United States, and most Northern European countries, the mortality rates have been decreasing, as a result of more women living with and surviving this disease (Mettlin, 1999). The impact of breast cancer on women's lives is immense and far reaching. Researchers, health professionals, women, and communities are demanding research that promotes understanding of this disease and the development of quality health care supporting the health and wellness of all women affected by breast cancer.

Research Problem

Having breast cancer has been documented in the research literature as a significant life event for women and their families, with the breadth and depth of experiences varying widely. The marked physical, emotional, and psychological challenges of breast cancer have been described as traumatic (Langellier & Sullivan, 1998) and life altering (Landmark & Wahl, 2002). Breast cancer has also been documented as a disease defined by uncertainty, pain, and suffering (Arman, Rehnsfeldt, Lindholm, & Hamrin, 2002; Hilton, 1988; Nelson, 1996). In addition, because it is a cancer of the breast, distinctive challenges to a woman's self concept, identity, body image, and feminity have also been described by women and documented in the research
literature (Im, Lee & Park, 2002; Kagawa-Singer, Wellisch, & Durvasula, 1997; Lackey, Gates, & Brown, 2001). The meaning and purpose of the breast has varied throughout time, cultures, societies, and religions (Yalom, 1997) and these contexts most likely influence how cancer of the breast is considered, treated, and experienced. Although the majority of research describing the experiences of breast cancer has been conducted with Caucasian women, it is not unreasonable to predict that breast cancer is also a significant life event for women of various ethnocultural groups. Recognizing a lack of understanding and documented research literature on women in ethnocultural groups, researchers have begun to describe these women’s breast cancer experiences. A synthesis of the small but growing qualitative breast cancer research with Asian American, African American, and Native American women in the United States demonstrated that breast cancer is significant and experienced in varying ways, with particular challenges and issues that are unique and shared among the women of these ethnocultural groups (Howard, Bottorff, & Balneaves, 2004). Findings of this synthesis also indicated that certain ethnocultural groups remain absent in this body of literature.

A growing number of South Asian women, the majority of whom are Punjabi, have immigrated to and currently reside in British Columbia’s (B.C.) Lower Mainland. Punjabi women have predominantly emigrated from the Punjab state of north western India since the 1970s through the family sponsorship program (Nayar, 2004). Considering the growing number of Punjabi immigrants to B.C., it is imperative to consider the various health needs of this population. Although no published research is available focussing on immigrant South Asian

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1 The term Caucasian is used throughout this thesis to refer to individuals of European ancestry, and is not meant to imply a racial category based on an imaginary biological genetic basis. Although the term Caucasian is often used synonymously with fair skin color (Adams, 1999), in this thesis it goes beyond this racial definition and may also include some of the following cultural characteristics: English speaking, residents of the North versus the South [as used by Anderson (2000) to refer to capital wealth not geographical location where North = rich and South = poor], and followers of Western religions (e.g., Christianity and Catholicism).
women’s experiences of breast cancer in Canada, it is reasonable to assume that breast cancer is indeed significant and life altering for these women and their families.

There is emerging evidence that immigrant South Asian women, including women who are Punjabi, face challenges in seeking health care in Canada and elsewhere (Browne et al., 2002; Choudhry et al., 1998, 2002; Johnson et al., 2004; Neufeld et al., 2002). Being a member of an ethnocultural group in a North American country predisposes Punjabi immigrant women to particular experiences when confronted with issues of health and illness. Challenges in navigating the health care system may arise as a result of being a person of color, being an immigrant, speaking a language other than English, and holding cultural beliefs that are not aligned with the western medical health system. For example, language and communication have been identified as barriers to accessing breast screening information, as well as receiving the services and assistance that ethnocultural Canadian women, including South Asians, need in situations of illness (Anderson et al., 2003; Sodhi, 1995). Furthermore, Anderson et al., (2003) reported that without a common language, the potential for women and health care professionals to develop meaningful relationships with each other is minimized and the development of shared understandings and negotiated meanings of health and illness is difficult. If a woman and the health care professional are unable to communicate effectively, the potential for misunderstandings and inappropriate care increases, which may adversely affect a woman’s ability to cope with breast cancer.

Marginalization and exclusion from appropriate health care services have also been linked with racism and discriminatory practices. “Othering” practices among health care providers refers to the process that identifies those that are thought to be different from oneself or the mainstream, and reinforces and reproduces positions of domination and subordination (Johnson et al., 2004). Ralston (1991) reported that being a South Asian immigrant woman is
experienced as being ‘different’ from other Canadians – not only in visible and audible characteristics like skin color and accent, respectively, but also in such social characteristics as educational and work experience prior to migration. In one ethnographic Canadian study, health care professionals made broad generalizations about the culture, race, social background, and health practices of South Asian women, and these women’s health behaviours were subject to over-simplified, culturalist and racialized explanations (Johnson et al., 2004). South Asian women described their Canadian health care experiences with frequent reference to ‘us and them’, ‘white and brown’, and ‘our women and their women’, reflecting participants’ acute awareness of being identified as different (Browne et al., 2002). How experiences of othering influence Punjabi immigrant women’s experiences of accessing health services and receiving treatment for breast cancer is unknown.

Cancer has been documented in the research literature as being a disease that invokes feelings of fear and suffering in some South Asians. In most developing countries, including those in South Asia, any form of cancer is associated with death and many people have never seen a cancer survivor (Sodhi, 1995). Although people do survive cancer in Canada, the fear associated with cancer among South Asians, including Punjabi people, seems to have prevailed. Shame, and the fear of bringing shame to the family by having cancer, has been cited as reasons for not seeking health care, avoiding screening, not disclosing a cancer diagnosis to others, and also refusing cancer treatment (Bottorff et al., 1998; Johnson et al., 1999). South Asian women are committed to maintaining the appearance of their families as healthy and strong, even if a member of the family has an illness such as cancer (Bottorff et al., 1998; Johnson et al., 1999). The stigma attached to cancer in the South Asian community has been linked to beliefs that it is contagious, that it could be passed down in the family, that it may be punishment for bad deeds in present or past lives, and that it may have been intentionally brought on by a curse.
Furthermore, Kleinman (1988) points out that breast cancer carries an ancient stigma for women: it is “a culturally marked illness, a dominant societal identity that, once applied to a person, spoils radically the individual’s identity and is not easily removed” (p.22). This stigma may also cause considerable distress to women with breast cancer.

The majority of the mainstream health programs available to South Asian and Punjabi women are designed from the perspective of health care professionals, rather than the people and communities they are expected to serve (Choudhry et al., 2002). The importance of women-centred health care services is receiving increasing attention (Bottorff et al., 2001). Obtaining an understanding and appreciation of the experiences that may be unique to Punjabi and other South Asian women with breast cancer is crucial in supporting nurses and other health care professionals in providing appropriate, relevant, and culturally sensitive and safe health services. In order to be culturally sensitive, health care professionals require an understanding of the various beliefs, values, and meanings that breast cancer may hold for their patients. This may inform and promote positive interactions and participation, empower women and their communities, support care that is not offensive or degrading, but rather, is culturally acceptable and appropriate to these women’s needs and experiences. Knowledge of Punjabi immigrant women’s unique experiences of breast cancer is foundational to developing specific interventions that will support Punjabi women who are diagnosed with breast cancer, as well as their families. Such understanding is also needed for program and policy development and implementation of health services.

Considering the magnitude and impact of breast cancer in Canada, the demand by Canadian women for breast cancer research, and the significance and life altering effect of this disease, it is crucial that research explore how women incorporate breast cancer into their lives and the meanings they ascribe to these experiences. Punjabi women’s voices must become part
of the discourse on breast cancer if we are to understand the diverse ways this illness touches all women’s lives. In addition, it is important to understand how various factors, including culture, ethnicity, acculturation and structural factors (such as gender, politics, history, and class) influence women’s lives, perceptions and experiences of illness, and their ability to access quality health care. An understanding of these factors with respect to Punjabi women’s experiences of breast cancer is necessary to inform the provision of sensitive and culturally appropriate health care.

**Purpose**

The aim of this study was to gain an understanding of the meanings of breast cancer ascribed by Punjabi immigrant women who have been diagnosed and treated for this disease. The meanings associated with breast cancer reflect what a woman considers significant, the emotions attached to particular events, and how breast cancer is incorporated or accommodated into a woman’s life and her identity. The aim was also to comprehend women’s personal values and beliefs, as well as the diverse social, cultural, and life contexts in which breast cancer may occur for Punjabi immigrant women. Considering these aims, the purpose of this investigation was to explore Punjabi immigrant women’s stories of their breast cancer experiences and to analyze these stories to uncover the meanings of these experiences of breast cancer from their perspective.

**Research Questions**

The following questions guided this study:

1. What are some of the diverse ways Punjabi immigrant women construct stories of their breast cancer experiences?

2. What meanings of breast cancer are revealed by Punjabi immigrant women in their narratives of breast cancer?
3. What identities or roles do these meanings and experiences reveal about Punjabi immigrant women who have breast cancer, and how do these women rework their personal biographies to incorporate breast cancer?

4. How are personal values and beliefs, and cultural, social, and life context factors reflected in Punjabi immigrant women's narratives of their breast cancer experiences?

Assumptions

The following assumptions were recognized as being integral to this research project.

1. Punjabi immigrant women represent their culture and are able to relate their life experiences in verbal "story" form. Culture is represented and becomes apparent in an individual's story (Reissman, 1993).

2. Conceptualization of the interaction of class, racialization, gender relations, and other social relations will be considered because women experience their lives not solely as gendered persons, but also as classed and racialized persons (Anderson, 2000). This research is an attempt at understanding "cultural meanings" not as "neutral scripts" for people's lives tied to their ethnic roots, but as "dynamic, socially constructed, and produced within historical, gendered, 'raced', and political context" (Anderson, 2000, p. 225).

3. There is no ultimate truth to be found in these women's accounts. Informants' stories do not mirror a world "out there," rather they are "constructed, creatively authored, rhetorical, replete with assumptions, and interpretive" (Riessman, 1993, p. 5). Stories are also co-created through interactions between women and the interviewer.

4. The researcher influences the results because she is interpreting the interpretations of these women's breast cancer experiences.
5. The researcher, as a 29 year old Caucasian female nurse who has lived in Canada her entire life, represents a historical position of power and domination, and is an outsider to Punjabi culture, as well as to the experience of having breast cancer.

**Summary**

Punjabi immigrant women’s experiences of breast cancer are poorly understood or documented in the breast cancer literature. In order to provide culturally appropriate care to these women and their families, research focussing on their breast cancer experiences is required. The purpose of this study was to examine the ways Punjabi immigrant women story their experiences of breast cancer and to analyze these stories to uncover the diverse ways in which these women created meaning from their experiences.
CHAPTER TWO: LITERATURE REVIEW

Introduction

This literature review consists of four main foci. Firstly, an overview of the need for breast cancer research with Punjabi immigrant women in British Columbia is provided. Secondly, descriptions of the qualitative research literature on women’s experiences of breast cancer are reviewed, with an overview concentrating on women’s responses to diagnosis and treatments, support and adjustment, interactions with health care professionals, and self-transformation. The research reviewed focussed primarily on Caucasian women, however, findings of studies conducted with women in ethnocultural groups also provides comparisons and diversity in the breast cancer literature. The third section is a discussion of ethnocultural women and breast cancer research, and more specifically, of preliminary work completed in preparation for this master’s thesis investigation. This preliminary work was a synthesis of the qualitative research on the breast cancer experiences of women from diverse ethnocultural groups. The fourth main focus of this literature review concerns South Asian immigrant women’s health experiences in relation to cultural influences, current participation in cancer screening programs, and beliefs about cancer in South Asian culture. Selected research literature focussing on South Asian immigrant women will be reviewed because Punjabi women are considered part of this larger community and are often included in these studies.

Breast Cancer and the Punjabi Population in British Columbia

South Asia includes the countries of Bangladesh, Bhutan, India, Maldives, Nepal, Pakistan, and Sri Lanka (Statistics Canada, 2003), with the majority of immigrants to Canada
emigrating from India. Of the individuals emigrating from India, the majority are Sikh Punjabi\(^2\) people from the north western state of Punjab. Punjabi people were among the first immigrants to Canada from South Asia, beginning in the early 1900s. They were drawn to Canada because of possibilities for economic advancement, and by 1903 there were approximately 300 Punjabi individuals in Canada (Tatla, 1999). Until 1951, however, Punjabi immigration to Canada was minimal due to marked discrimination and racism (Singh, 1999). Only after 1951, following changes in Canada’s immigration law, and in wake of Indian independence in 1947, was there a real change in immigration patterns (Nayar, 2004). The majority of Punjabi immigrants in the 1950s and 1960s came under the family sponsorship program and helped meet Canada’s demand for white-collar professionals (Nayar, 2004). From 1951 through to today, family members arrived through family sponsorship or arranged marriages. The largest influx of Punjabi immigrants to Canada occurred in the 1970s after the multiculturalism policy was initiated in 1971, bringing many blue-collar labourers (Nayar, 2004). Following 1984, when Indian government troupes stormed a Punjabi Sikh temple in India, a number of Punjabi’s arrived to Canada as political refugees, however, as the political climate cooled down in the Punjabi area of India, immigrants mostly migrated to Canada through the family sponsorship program (Nayar, 2004).

British Columbia (B.C.) is one of the Canadian provinces that receives the largest number of total immigrants, with the immigrant population continually rising and representing 26.1% of the total population in 2001 (Statistics Canada, 2003). Other statistics indicate that within Vancouver, the number of immigrants increased to 37.5% of the population in 2001, and of these

\(^2\) Punjabis are of various religious backgrounds but are predominantly Sikh. In the 15th century Guru Nanak founded Sikhism in the Punjab region of northern India. In the religious sense, a Sikh, which literally means learner, is someone who believes in one God, Sat Guru, and follows the teachings of Gurus who reveal his teachings. The Gurus are the ten leaders of the Sikh faith, from the founder, Guru Nanak (1469-1539), to Guru Gobind Singh (1666-1708); and the Guru Granth Sahib, the Sikh scripture that became the final Guru after the death of Guru Gobind Singh (Punjab Online, 2004).
immigrants, 23% were South Asian, which composed the second largest group of immigrants in the city (Statistics Canada, 2003). Of the South Asian immigrants in B.C. the overwhelming majority are Punjabi. Considering the growing number of Punjabi immigrants to BC, it is imperative to consider the various health needs of this population, including support for the prevention and treatment of breast cancer.

Breast cancer is a global women’s health issue that affects more women around the world than any other cancer and has significant effects on women, their families, and communities (Kaur, 2000). Breast cancer incidence and mortality have differential trends throughout the world, yet, the factors contributing to these differential trends remain poorly understood. Although the incidence rates of breast cancer have risen in Canada, the United States (U.S.) and most Northern European countries, the mortality rates have been decreasing with more women living with and surviving this disease (Mettlin, 1999). In other European nations such as Spain, Portugal, and Greece, however, breast cancer incidence and mortality are on the rise (Mettlin, 1999). Compared to European and North American countries, the breast cancer rates in Asian countries are considered relatively low. Korean women, for example, have the lowest incidence rates in the world (Haynes, 2000).

Differential incidence and mortality rates among varying ethnocultural groups within countries have also been documented. This data indicates that women who immigrate to a country develop incidence and mortality rates similar to those in the country to which they immigrate (Kaur, 2000; Kliewer & Smith, 1995). Despite recent advances in cancer diagnosis, treatment, and survival, many ethnocultural populations suffer disproportionately from cancer. For example, breast cancer incidence in the U.S. is highest for Caucasian women, and lowest among Korean American, Native American, and Vietnamese American women. Yet, Native American women have one of the highest mortality rates from breast cancer (Baquet &
Commassky, 2000). Although breast cancer incidence for African American women is 12.5% lower than for Caucasian American women, the mortality rate for African American women with breast cancer is 44% higher than for their white counterparts (Shinagawa, 1999).

In Canada and B.C., it is impossible to obtain data regarding the incidence of breast cancer in various ethnocultural groups because provincial breast cancer registries do not collect information regarding ethnicity. There is evidence in India, however, that the incidence of cancer is rising steadily, with 1 in every 12 women expected to develop cancer in their lifetimes (Women's Environment and Development Organization, 1997). As well, breast cancer is the second leading cancer in India, making up 19.3% of all cancers for women (Rao & Ganesh, 1998). Breast cancer has been recognized as a major concern for many immigrant South Asian women in Canada as they witness family members, friends, and acquaintances in their community being diagnosed with and sometimes dying from breast cancer (Bottorff et al., 1998). Community nurse clinicians working in the Lower Mainland have reported that their case loads included Punjabi women initially presenting with advanced breast cancer (S. Grewal, personal communication, July, 2003). Presenting with advanced stage breast cancer raises concerns that Punjabi immigrant women are delaying seeking appropriate medical care for symptoms indicative of breast cancer, thereby reducing their chances of survival.

In order to begin to understand the experiences of Punjabi immigrant women with breast cancer, it is crucial to consider how other women, Caucasian or in other ethnocultural groups, experience this disease. This literature review will now focus on the experiences of women with breast cancer and the major themes reflected in the scientific research literature.

Major Themes Reflected in the Experiential Breast Cancer Research

An overview of both the qualitative and quantitative research of women's experiences of breast cancer is presented in this section, which briefly outlines the experience of breast cancer
related to the following themes: responses to a diagnosis of breast cancer, responses to breast cancer treatments, support and adjustment to breast cancer, interactions with health care professionals and health care systems, and self-transformation and transcendence. Both quantitative and qualitative research methods have been utilized to investigate women’s experiences of breast cancer. This research literature is diverse and encompasses such factors as psychosocial issues, quality of life, coping and adaptation, survivorship, suffering, uncertainty, body image, transcendence, spirituality, family involvement, and social support. As well, having breast cancer has been documented in the research literature as a significant life event for women and their families, marked by various physical, emotional, and psychological challenges. The majority of the qualitative research, however, has predominantly been conducted with Caucasian women.

Social constructs of breast cancer as a disease that can be fought and beaten, and that ultimately a strong woman can rise above, have emerged and been reinforced by the media. The published research literature on women’s experiences of breast cancer reflects dominant Western values, beliefs, and ideals related to personal independence, resiliency, and the effectiveness of conventional cancer treatment. This research fails to represent the perspectives of women from ethnocultural groups, thereby limiting the diversity inherent in the reported experiences of having breast cancer. The limited literature describing ethnocultural women’s experiences of breast cancer will also be briefly reviewed in this section of the literature review, highlighting some of the similarities and differences when compared to Caucasian women’s experiences. A more in-depth review of the breast cancer literature with women in ethnocultural groups is discussed following this section.
Responses to a Diagnosis of Breast Cancer

The time of diagnosis has been described as a time of shock, disbelief, and upheaval as breast cancer confronts women with the fact that life is no longer a matter of course (Landmark & Wahl, 2002; Lyons, Jacobson, Prescott, & Oswalt, 2002). Researchers report that this existential awareness is often accompanied by immense denial, depression, fear, anxiety, uncertainty, and feelings of vulnerability (Arman et al., 2002; Halldorsdottir & Hamrin, 1996; Landmark, Strandmark, Wahl, & Polit, 2001; Landmark & Wahl, 2002; Lyons et al., 2002). The uncertainty that many women with breast cancer face is particularly marked at diagnosis when important decisions about treatments are being made, the outcome of their breast cancer treatment is unknown, and their mortality is threatened. For example, some of the nine Caucasian women in one phenomenological study reported consciously suppressing thoughts related to their uncertain futures in order to control the overwhelming spectrum of emotions they continually experienced (Nelson, 1996).

A persistent theme in the qualitative research, with various groups of women with breast cancer, is the emergence and recognition of women’s personal strength in response to their diagnosis, which has been described and includes references to a fighting spirit, the will to live, being ready to face the challenges ahead, and “not giving in” (Fallowfield & Clark, 1991; Jensen, Back-Paterson, & Segesten, 2000; Landmark & Wahl, 2002; Luker, Beaver, Leinster, & Owens, 1996; Lyons et al., 2002). Researchers report that these responses to a diagnosis of breast cancer have often been accompanied by a positive attitude and a desire to put the cancer behind oneself, which may assist in coping, adjustment, and coming to terms with the disease.

A range of other emotional reactions associated with breast cancer have been described. Kiser-Larson (2002) reported that each of the ten Native American women in her study, without exception, described having breast cancer as a life of disorder, chaos, and uncertainty. South
Asian and African American women have been found to view breast cancer as a death sentence and a disease without a cure because they were unaware that women of their ethnocultural group survive this disease (Bottorff et al., 1998; Lackey et al., 2001; Mathews, Lannin, & Mitchell, 1994). In contrast, some ethnocultural women do not consider their breast cancer as a serious threat to their health or as taking precedence over existing life circumstances. For example, a Nepalese woman in a case study refused surgery and further treatment because of her responsibilities at home, which included cooking meals, cleaning, shopping, domestic farming, and taking care of children, in-laws, and additional extended family members (Braun & Itano, 2001). This woman did not feel her illness was serious enough to interfere with her daily responsibilities. Although this was a case study involving a single woman in rural Nepal, these findings draw attention to the possibility of diverse reactions to breast cancer inherent in various cultures and ways of life.

**Responses to Breast Cancer Treatments**

Researchers have focussed attention on women’s experiences of the side effects and symptoms associated with breast cancer treatments such as radiation, chemotherapy, lumpectomy, and mastectomy. Outcomes and side effects of treatments often include breast deformity, loss of breast(s), hair loss, fatigue, physical pain, nausea, and skin and membrane reactions. Discrepancies are apparent in the literature about how these side effects are framed by women. Phenomenological and grounded theory descriptions of predominantly Caucasian women’s experiences of breast cancer suggest that treatment made their cancer feel “real”, and offered women a sense of security and a feeling that they were actively doing something to fight the cancer (Pelusi, 1997; Richer & Ezner, 2002). In a study of Native American women with breast cancer, however, treatments were experienced as “enduring the suffering” accompanied
by physical and emotional loss, and included feelings of a loss of control over their lives and their bodies (Kiser-Larson, 2002).

The loss of hair and breast(s) and its effect on body image, womanhood and femininity has been a theme in the qualitative research focusing on women’s breast cancer experiences. Research with Caucasian women has indicated that breast cancer treatment caused a distressing disturbance of body image, partly because of the breast’s symbolic and physical association with being a woman (Bredin, 1999). Qualitative researchers studying Caucasian women treated for breast cancer have reported that women’s physical experiences of their bodies also extend beyond concerns about body image (Zichi Cohen, Kahn, & Steeves, 1998). Phenomenological analysis of 17 Caucasian women’s breast cancer narratives did not support a narrow or primary preoccupation with femininity, sexuality, or “cosmetics and beauty culture” (Langellier & Sullivan, 1998). Rather, these women constructed their “breasted experience” in ways that “embraced issues of feeling whole and healthy, of feeling able to engage in physical activities, of sensation and touch, of sexuality and spirit, as well as the look of the breast” (Langellier & Sullivan, 1998, p. 90). Furthermore, in a grounded theory study with 18 Caucasian women with breast cancer, researchers described women’s experiences of loss associated with loss of body parts, bleeding, sexual sensations, and womanhood (Chamberlain Wilmoth, 2001).

Significant physical and emotional changes were related to an inability to return to ‘normal’ among 13 Euro-American, 18 Chinese American, and 15 Japanese American women interviewed in a mixed qualitative quantitative study (Kagawa-Singer & Wellisch, 2003). For the Euro-American women in this study, substantial focus and anxiety regarding femininity post-breast cancer treatment was a source of marital distress. Yet, for the Asian American women, such concerns were notable only in their absence. These findings, however, may not indicate a
lack of distress, but rather the need to ask Asian American women questions about their experiences differently (Kagawa-Singer & Wellisch, 2003).

Body changes following breast cancer treatment have been reported as traumatic for African American and Native American women. For Native American women in an ethnographic medical ecology study, these physical changes and losses represented a confirmation of having breast cancer, and invoked the possibility of further loss of life, family and identity (Colomeda, 1996). All of the 13 African American women with breast cancer in Lackey, Gates, and Brown’s (2001) phenomenological study reported questioning if they were still women following breast cancer treatment. Seven of these women had undergone mastectomy, five had lumpectomy, and one woman did not receive surgical treatment. These women reported that their body changes significantly altered their sexuality, threatened their femininity, and influenced their sexual relations and feelings of attractiveness (Lackey et al., 2001). Interviews with single African American women reported fears of being unable to attract and sexually satisfy potential partners and concerns about myths that potential partners may have about the sexuality of breast cancer survivors (Ahing-Giwa & Ganz, 1997).

Chinese women in Lam and Fielding’s (2003) phenomenological study, indicated that the hair loss and weight gain were more troublesome than the loss of their breast(s). This was because the loss of a breast could be hidden, whereas hair loss and weight gain could not. For Chinese women, hiding the signs of cancer was considered important because this illness carried a stigma that undermined personal and familial integrity and could lead to social exclusion. In a descriptive longitudinal study that explored cultural meanings of breast cancer among newly diagnosed women in South Korea, researchers found that in Korean culture, breasts are associated with generosity, good luck, and good things from God (Im, Lee, & Park, 2002). The loss of a breast, therefore, was equated with bad luck and punishment among Korean women and
their families. These two studies of Asian breast cancer survivors were conducted in Hong Kong and South Korea, respectively, and it is unknown the degree to which women who immigrate to North America retain the values and beliefs acquired in their homelands.

**Support and Adjustment to Breast Cancer**

Social support has long been regarded as a powerful influence on emotional and interpersonal adaptation to breast cancer diagnosis and treatment, helping prevent and alleviate pain, depression, and anxiety in cancer patients (Bloom, 1982; Koopman, Hermanson, Diamond, Angell, & Spiegel, 1998; Ord-Lawson & Fitch, 1997). Yet, the specific strategies and programs required to meet these needs vary, as do the documented effectiveness and usefulness of these strategies. Important types of support described by researchers include social support by friends, family, support groups, and breast cancer survivors (Ashing, Padilla, Tejero, & Kagawa-Singer, 2003; Kagawa-Singer & Wellisch, 2003; Kiser-Larson, 2002; Marlow, Cartmill, Cieplucha, & Lowrie, 2003), assistance with decision making and emotional coping (Palsson & Norberg, 1995), and practical help such as financial support and help with housework (Ashing et al., 2003; Gates, Lackey, & Brown, 2001; Thorne, Balneaves, & Reimer, 1999).

The benefits of social support may be influenced by the type (e.g., affective or instrumental) and source of the support received (e.g., formal or informal) (McArdle et al., 1996). A qualitative research study of Australian women with breast cancer suggested that positive social support assisted women in regaining a sense of control over treatment decisions, provided reassurance and information about what to expect, helped women to organize their care, and validated their experiences (Marlow et al., 2003). Yet, researchers have also documented that breast cancer challenges women’s personal social support networks, and may lead to negative relationships and difficulty maintaining the quality of relationships (Samarel, Tulman, & Fawcett, 2002). The strain on interpersonal relationships caused by a woman’s
diagnosis and treatment has resulted in women feeling alienated, lonely, and unsupported (Bolger, Foster, Vinoker, & Ng, 1996; Lugton, 1997).

Researchers have also shown that group therapy improved Caucasian women’s psychological adjustment, and decreased distress and pain during breast cancer treatments (Cunningham et al., 1998; Edelman, Lemon, Bell, & Kidman, 1999; Goodwin et al., 2001). There is inconclusive evidence, however, regarding the effectiveness of social support in the form of psycho-educational group therapy in prolonging survival (Cunningham et al., 1998; Edelman et al., 1999; Goodwin et al., 2001; Spiegel, Bloom, Kraemer, & Gottheil, 1989; Waxler-Morrison, Hislop, Mears, & Kan, 1991). Volunteer peer support provided by breast cancer survivors has also commonly been delivered in the U.S. and Canada. Evaluation of such a peer support program, the Reach to Recovery program in Canada, indicated that women with breast cancer who received peer support were satisfied with this support and reported incremental benefits to their quality of life (Ashbury, Cameron, Mercer, Fitch, & Nielson, 1998). Results of a study in the U.S. with 312 predominantly Caucasian women, however, showed mixed results. Researchers found that a subgroup of women who previously lacked emotional support from their partners, or reported negative interactions with their partners, benefited from peer discussion groups (Helgeson, Cohen, Schulz & Yasko, 2000). Yet, they also found that women who were previously satisfied with the level of emotional support received from their partners deteriorated in their level of functioning following peer-discussion groups. These studies suggest that the effectiveness of peer support on women’s quality of life may depend on women’s needs and the type of peer support provided.

Researchers who have reviewed descriptive and correlational studies on social support and adjustment to breast cancer concluded that the type of support most desired by women and most strongly linked to positive adjustment was emotional support (Helgeson & Cohen, 1996).
Specifically, emotional support was defined as the availability of someone with whom women could discuss illness-related concerns and worries. These authors did not make reference to including studies with ethnocultural women. In a narrative qualitative study of women in metropolitan Japan, researchers concluded that the sources and forms of social support valued by Japanese women differed from those valued by Western women (Makabe & Hull, 2000). Japanese women preferred the supportive physical presence of others and assistance with practical duties rather than opportunities to verbalize personal feelings and emotions with others. Some researchers have focussed on the need for practical support among Caucasian Canadian women. Many of the women who responded to a questionnaire in Thorne, Balneaves and Reimer’s study (1999), identified practical support as a specific cancer-related need, yet women also identified significant unmet needs despite increasing attention to some elements of support within the health care system. These researchers suggested that practical support is an issue that transcends the family and may require formal intervention specifically tailored to the unique social circumstances of each woman (Thorne et al., 1999). Further research of appropriate social and practical support with women in diverse social settings and ethnocultural groups is needed to comprehend the complexity of providing effective and useful support.

**Interactions with Health Care Professionals**

Responses to health care professionals’ approach to women with breast cancer may be influenced by cultural values, beliefs, and norms, as well as social, economic, and life contexts. The desire for active involvement in decision making and the high value placed on discussions about breast cancer with health care professionals is evident in a survey study conducted with Canadian Caucasian women (Degner et al., 1997). A review of the literature on information needs of women with breast cancer revealed that Caucasian, middle-class, well educated women with breast cancer were often dissatisfied with the information they received from their health
care professionals, and family members often perceived their information needs to be ignored (Rees & Bath, 2000). Similarly, highly acculturated Chinese American and Korean American women in the U.S. have also been reported to be dissatisfied and concerned about their lack of inclusion in the treatment decision-making process (Ashing et al., 2003). In an ethnographic study with Native First Nations women in northern Alaska and Canada, Colomeda (1996) found that women felt rushed to make decisions and left out of the process of decision making because they were unable to understand the medical terminology and the procedures that their doctors expected them to undergo. Conversely, women in a narrative study in Japan indicated that immediate action (i.e., surgery) and little discussion, rather than an invitation for them to share their feelings, was considered supportive because it was seen as a way that others were trying to help them move forward with appropriate treatment (Makabe & Hull, 2000). These findings reflect typical communication patterns in Japan where talking about cancer openly and encouraging women to share their emotional concerns does not frequently occur (Makabe & Hull, 2000). Clearly, there is not one approach to providing care that is appropriate for all women with breast cancer.

**Self-Transformation and Transcendence**

The breast cancer experience has been reported to propel some ethnocultural and Caucasian women into new spheres of self-discovery because life takes on new meaning when a person is faced with a life-threatening illness (Kiser-Larson, 2002; Utley, 1999). In the research literature, this has been referred to as self-transcendence or transformation, and has been considered a positive sequelae associated with adjustment to disease for both Asian and Caucasian women (Chui, 2000; Coward, 1989; Luker et al., 1996). For example, in Coward’s (1989) phenomenological research with five women with stage IV breast cancer, transcendence involved experiences from which they derived an increased sense of self-worth, purpose in life,
and interconnectedness with others. Self-transcendence involved an effort to reach out beyond themselves to help other women, to permit others to help them, or to “just accept” unchangeable situations. For these women, transcendence encompassed an integration of illness-related changes in the self. Narrative analysis of interviews with Caucasian women, however, suggested that transcendence occurs in varying degrees, and may be influenced by women’s self-esteem and feelings of well-being (Carpenter, Brockopp, & Andrykowski, 1999). In a grounded theory study of 10 African American and 14 Caucasian women who experienced transcendence following a breast cancer diagnosis, the experience was reported to include: re-evaluation and reprioritization of personal values, reconsideration of life direction and mission, urgency and immediacy about life, profound appreciation and joy for life, intensified spiritual awareness, increased self-knowledge and self-respect, and a healthy perspective about self in relation to others and the world (Taylor, 2000).

Although transformation and transcendence may occur for women who survive breast cancer, findings from a phenomenological study of eight women in the south western U.S. who had completed breast cancer treatment suggested that some women also experience marked uncertainty about the future, fear of recurrence, feelings of abandonment by health care professionals, and an ongoing inability to return to normal, or to the life they had prior to breast cancer (Pelusi, 1997). Similarly, in Nelson’s (1996) phenomenological study of mostly Caucasian women who had completed breast cancer treatment, uncertainty was a common experience. The women felt uncertain about the future and the possibility of cancer recurrence, the transitions in self-identity (from being in treatment to being a “survivor”), and the reflections of themselves they saw in other survivors.

There are inconsistent reports about the fear of recurrence among survivors. Thibodeau and MacRae (1997) found that most of the 45 Caucasian women in their phenomenological study
did not worry about the return of cancer. In contrast, studies by Fallowfield and colleagues
(Fallowfield, Baum, & Maguire, 1987; Fallowfield, Hall, Maguire, & Baum, 1990) revealed that
some women experienced crippling anxiety, exhibited by hyper-vigilant monitoring of their
bodies for signs of cancer recurrence. Qualitative researchers have described the difficulties
Native American, African American, and Caucasian American women encountered
incorporating breast cancer into their identities, their families, and their outlook and attitude
about life (Colomeda, 1996; Lackey et al., 2001; Pelusi, 1997). These findings provide important
insights about the changes women experienced following breast cancer diagnosis and treatment.
However, the research on transformation and transcendence has focussed primarily on Caucasian
middle-upper class women and there has been limited research on the reactions, adjustment, and
possible changes that women in ethnocultural groups with breast cancer may experience.

Breast Cancer Research with Women in Ethnocultural Groups

This section of the literature review focuses on the current state of breast cancer research
with women in ethnocultural groups, including a discussion of the need for enhanced cultural
competence in nursing research and practice. The impact of immigration on women’s health is
also briefly discussed, followed by a summary of preliminary work completed in preparation for
this investigation.

Despite attempts by researchers to obtain study samples that include a variety of women
from varying ethnocultural groups, these women have remained underrepresented in the breast
cancer literature. Consequently, over the last decade in the Western world, researchers have
increasingly focussed on the experience of breast cancer in ethnocultural groups. In nursing, an
interest in the cancer experiences of ethnocultural groups has been prompted by an increased
recognition of the need for cultural competence. This development has been influenced by (a)
projected demographic changes resulting from globalization, (b) continuing disparities in cancer
incidence and mortality among women in ethnocultural groups, (c) commitment to diversity and quality cancer care, and (d) the increased emphasis to include racial and ethnic populations in research (Phillips & Weekes, 2002). The breast cancer experiences of women in ethnocultural groups may be unique in many ways and researchers have attempted to demonstrate the influence of various cultural norms, values, and beliefs on women’s experiences throughout the breast cancer trajectory.

Much of the breast cancer literature with women in ethnocultural groups has been based on race. This focus on racialized groups, however, may unintentionally fail to acknowledge the dynamic nature of culture and the intersection of gender, class, history, politics, and social and life contexts in the creation of experiences. Simple cultural definitions have been used to account for differences and to construct groups or individuals as “other.” This also reinforces positions of domination and subordination, thereby marginalizing those that are “othered” (Reimer Kirkham & Anderson, 2002). Anderson (2000) argues that researchers, “should make a space to understand cultural meanings not as neutral scripts for people’s lives tied to their ‘ethnic roots’, but as dynamic, socially constructed, and produced within historical, gendered, ‘raced’ and political contexts” (p. 225). Stereotypical descriptions of the health care practices of different ethnocultural groups illustrate the tendency to essentialize or stereotype behaviours, values and beliefs in a way that ignores individuality and diversity (Anderson & Reimer Kirkham, 1998). Researchers focussing on othering practices within a South Asian immigrant community in British Columbia found that some health care professionals drew upon culturalist explanations to explain observations that South Asian women were not receiving optimal health care, rather than looking at structural barriers present in accessing health care services (Browne et al., 2002).

Being an immigrant woman in Canada may also have particular effects on the overall health of Punjabi immigrant women, particularly if they develop breast cancer. Research
suggests that when immigrants migrate to Canada, they are often healthier than the Canadian-born population when they first arrive, but lose this health advantage over time (Hyman, 2001). The health of immigrant women is largely shaped by social, environmental, and living conditions, and may change in response to pressures associated with poverty, marginalization, and class inequity (Hyman, 2001). Immigrant women have been identified as a sub-group with specific unmet needs that influence their health (Hyman, 2001). For example, despite higher education levels, immigrant women tend to earn less, are more likely to be unemployed or underemployed, and are more likely to live in low-income situations than their Canadian-born counterparts (Almey et al., 2000). Poor health status related to stress, lack of preventative behaviours, and lower health care user rates have also been reported for immigrant women in Canada and the U.S. (Hyman, 2001; Kinnon, 1999; Meyer, Torres, Cermeno, MacLean, & Monzon, 2003). Moreover, the effects of immigration on health status are compounded by major cultural adjustments involving language, economic stability, and family relationships and roles (Patterson, 2004). Social determinants of health and the additional individual and family stresses associated with immigration most likely have an amplified effect in the context of illness, thereby influencing or shaping women’s experiences of breast cancer.

**Preliminary Work: A Synthesis of Ethnocultural Breast Cancer Literature**

In preparation for this master’s thesis investigation, a synthesis of the qualitative research focussing on the breast cancer experiences of women from diverse ethnocultural groups was completed by Howard, Bottorff, and Balneaves (2004). For this synthesis project, a qualitative meta-study approach (Paterson, Thorne, Canam, & Jillings, 2001) was used to systematically analyze and synthesize this research, and included analysis of the theoretical orientations and methodological approaches underlying the research, and an interpretive synthesis of the research findings. A comprehensive search of electronic databases resulted in retrieval of 12 research
studies that met the inclusion criteria. Ethnocultural groups represented in the studies included Asian American, Native American, and African American women. The synthesis revealed diverse experiences within and among these ethnocultural groups. Themes that emerged included receiving care as a woman who feels ‘different’ from others, spirituality as a source of strength, family as supportive and stressful, a sense of loss and suffering, and coming to terms with a ‘white woman’s disease’. The synthesis also highlighted the need for further experiential breast cancer research with other ethnocultural groups. There was a notable absence of women from specific ethnocultural groups, such as Hispanic and South Asian women, in the published research. As well, despite the growing number of ethnocultural and immigrant women in Canada who are diagnosed with breast cancer, there have been no Canadian studies published that focus on experiences of women in these ethnocultural groups. The findings of this synthesis project that have the most relevance to this master’s thesis investigation have been selected and will be discussed in the following sections of this literature review.

**Receiving Care as a Woman who Feels ‘Different’ from Others**

The first theme, “receiving care as a woman who feels ‘different’ from others,” reflected findings that highlighted women’s experiences of feeling different from mainstream women with breast cancer despite having the same disease. Disarmed by the emotional impact of breast cancer, feelings of being different created additional difficulties for women as they interacted with health care providers. Feeling disempowered, they often perceived an inability to be involved and had limited participation in medical decisions despite their desire to partake in the treatment decision making process. Some African American women perceived that they had “no control” over their illness and medical treatments, and viewed their physicians as “authoritarians” who did not encourage them to participate in decisions (Ashing-Giwa & Ganz, 1997). Some Asian American women were hesitant to “finally ask” about their treatment,
believing that asking their physician too many questions may show disrespect and negatively affect the relationship (Ashing et al., 2003). In the two studies with Native American (First Nation) women, the language used to describe health care providers was strikingly negative and a clear sense of powerlessness was evident. As Kiser-Larson (2002) stated, “Some felt victimized not only by the cancer but also by the medical treatment they endured” (p. 65). These Native American women often felt degraded by paternalistic doctors, disrespected, afraid to ask questions, and rushed because physicians were “always in a hurry” (Colomeda, 1996; Kiser-Larson, 2002). Although most women tried to fit in and follow recommended treatments, there were occasional examples where women’s strongly held beliefs led to their rejection of their physician’s advice. Despite these findings, most researchers acknowledged that some women were very satisfied with the care they received, as well as their involvement in their medical treatment. Differences in women’s experiences were not, however, explored.

**Spirituality as a Source of Strength**

The second theme, “spirituality as a source of strength,” highlighted spirituality as a source of emotional and inner strength common to many Asian American, Native American, and African American women, despite varying religious beliefs (Ashing et al., 2003; Chui, 2001; Henderson et al., 2003; Kiser-Larson, 1996). The women included in the studies suggested that their spirituality increased when cancer entered their lives, lessening their fears of dying, helping them maintain a positive attitude, and supporting their adjustment to having breast cancer. Similar findings have been documented by researchers investigating breast cancer experiences of American Hispanic and Canadian Caucasian women (Gall & Cornblat, 2002; Mickley & Soeken, 1993). African American and Asian American women have been reported to rely on God throughout the breast cancer trajectory to cure them of the disease (Ashing et al., 2003; Lackey et al., 2001). Some women believed that their physician was only a vehicle by which God
administered healing, and thus, these women thought that praying to God was more efficacious than discussing treatment options with their physician (Ashing & Ganz, 2003). Common among the Native American, Asian American and African American women and their families who were studied was a dependence on spirituality, spiritual leaders, and traditional cultural practices to cope with the challenges of breast cancer diagnosis and treatment. These spiritual resources may have been utilized because of a lack of available health care professionals providing culturally appropriate or readily accessible support. (Howard et al., 2004).

**Family as Supportive and Stressful**

The third theme that emerged from the synthesis of research findings was, "family as supportive and stressful." Family members and friends were viewed by women across the ethnocultural groups studied as central to accepting, coping, and recovering from breast cancer. Women identified their social network as important, with support being demonstrated in culturally specific ways through the provision of encouragement, comfort, presence, and understanding. Children were consistently cited as providing women “the will to live” and “something to fight for.” In addition to emotional support, family and friends also provided practical support in the form of financial assistance, language translation, and physical care.

The findings of the qualitative studies revealed that family and friends were also sources of stress and disappointment. Women were frequently reported to have mentioned feeling abandoned, isolated, and neglected. Both emotional support and practical support from family members were reported by Asian American women. Yet, some Asian American women felt pressured to continue to fulfill their family roles as self-sacrificer and nurturer of their families, even though they were dealing with a diagnosis of breast cancer. Some Asian American women themselves rejected the role changes brought about by breast cancer, believing they should be able to fulfill their responsibilities at home and in the family (Ashing et al., 2003). Among the
African American women participants in one study, support from their families was attributed to their physical presence and expressions of love and reassurance (Gates et al., 2001). For some African American women, however, this support was lacking and women revealed that their partners left, their families neglected to visit when they were ill, or they received little assistance with practical tasks. Breast cancer seemed to challenge African American women’s self-identity as strong, independent women who were the caregivers in their families, by limiting their ability to care for their families. For Native American women, their self-identities as leaders of family units as well as nurturers were reflected in the studies reviewed. The support the women received and valued was related to physical presence, and acceptance from family members, particularly husbands (Kiser-Larson, 2002). In Colomeda’s (1996) study, however, Native women received treatment far from their home villages and were physically and emotionally isolated from their families. As well, when women returned home, some husbands found it difficult to talk to and about the woman’s loss of her breast (Colomeda, 1996).

The influence of breast cancer on intimate relationships was a consistent finding across ethnocultural groups. For many women, the adverse effects of breast cancer included increased pain with intercourse and decreased desire for sexual activity. Asian American women referred to feelings of obligation and guilt when talking about breast cancer and intimacy. African American and Native American women expressed their fear and concern about sexual attractiveness and the ability to physically satisfy their partners. Some women feared that their partners would leave or their marriages would end as a result of their partners no longer finding them sexually attractive (Lackey et al., 2001). Some African American women also questioned whether they were “still women.”
A Sense of Loss and Suffering

The fourth theme, "a sense of loss and suffering," reflects the predominant sense of physical and emotional loss expressed by the Native American, Asian American, and African American women who had breast cancer. The physical changes, such as mastectomies, hair loss, and fatigue, appeared to confirm to women the reality of their breast cancer and invoked the possibility of further losses. The initial shock of breastlessness and baldness seemed particularly traumatizing for Native American, Asian American, and African American women. Some women did not look at their bald heads or mastectomy scars and hid their bodies from their families. Some Asian American and African American women described themselves as disfigured and deformed. Beyond the sense of loss associated with physical changes, women expressed negative feelings about themselves and their sense of worth. Some Native American women were reported to have felt suicidal. Other women described feeling "not whole" or being "lost" to themselves and to those closest to them. Across ethnocultural groups, breast cancer interrupted women's roles as wives, mothers, sisters, coworkers, and community members, which further contributed to their sense of loss.

Coming to Terms with a 'White Woman's Disease'

"Coming to term with a 'white woman's disease'" was the fifth theme that emerged in the preliminary synthesis project. Across the studies included in the meta-study, breast cancer appeared to be framed as a white woman's disease because of a commonly held belief that only Caucasian women developed and survived breast cancer. For instance, an African American woman stated that because she had never seen a black woman with breast cancer on TV who lived, she believed that only white women survived (Moore, 2001). Furthermore, the inability of women to obtain prostheses of the appropriate skin color raised concerns that their survival was not expected. Native American women felt abandoned, isolated, and situated on the margins with
regards to the care they received for breast cancer. In keeping with this sense of marginalization, Asian American women reported a lack of culturally appropriate resources, such as educational pamphlets in their language and community support groups. The absence of such resources was perceived by the women to be an indication of society’s indifference to ethnocultural women with breast cancer.

Women in the three ethnocultural groups believed that support groups were instrumental in coping with, accepting, and coming to terms with breast cancer. Support groups provided women with information, a forum to talk and share experiences with other women, and the courage to fight breast cancer. Attending support groups that predominantly included Caucasian women could be uncomfortable. Both Asian American and African American women described wanting support groups with other women of the same ethnicity because they believed their experiences were unique. This inspired some women to develop community support groups for other ethnocultural women.

Some of the women who participated in the studies reviewed came to terms with their breast cancer by transcending the loss and suffering associated with their breast cancer and re-examining their lives and life priorities. Across all ethnocultural groups some women reported becoming increasingly spiritual, reinvested themselves into their cultural community and families, embarked on new careers and hobbies, and developed a renewed sense of meaning.

The results of the meta-study synthesis project provided insight into the diversity of breast cancer experiences of ethnocultural women. Although many similarities and differences were documented among the Asian American, African American and Native American women included in this synthesis, it is also apparent that further research with women in these ethnocultural groups is needed to understand the complexity of women’s experiences. This research needs to focus upon the diversity of women’s experiences, with consideration of such
factors as gender, personal history, class, and social relations. As well, research with women in other ethnocultural groups is essential, because their voices must become part of the breast cancer discourse in order to provide a foundation for appropriate support, health care, and services.

South Asian Immigrant Women's Health Experiences

Although the focus of this study was on Punjabi women, the majority of researchers have referred to their participants as South Asian women, including Punjabi women as well as women from other South Asian countries. Cultural influences on immigrant South Asian women's perceptions of health and illness, reactions to alterations in health, health-seeking behaviour, and the meanings associated with various illnesses have begun to be described (Bottorff et al., 1998; Choudhry, Srivastava, & Fitch, 1998; Grewal, Bottorff, & Balneaves, in press; Hilton et al., 2001; Shankar, 1997). It should also be noted, however, that South Asian women in Canada are far from being a homogenous group and represent great social and cultural diversity (Assanand, Dias, Richardson, & Waxler-Morrison, 1990). In addition, although generally accepted beliefs and practices become associated with particular cultures, culture is dynamic rather than static and unchanging. There is no published research investigating the experiences of Punjabi or South Asian women with breast cancer, but there is a small, growing body of literature on health promotion, beliefs about breast health practices, and breast and cervical cancer screening among South Asian women (Bottorff et al., 1998; Bottorff et al., 2001; Choudhry, 1998; Choudhry et al., 1998; Choudhry et al., 2002; Grewal et al., in press; Gupta, Kumar, & Stewart, 2002; Johnson et al., 1999; Sodhi, 1995). This literature provides important background information for understanding Punjabi women's health behaviours and the ways Punjabi women experience breast cancer. The subsequent section is a discussion of the common cultural themes that influence Punjabi women's lives, including interconnectedness and the importance of family,
and gender roles for women. This is followed by a review of the research literature on the participation of South Asian women in cancer screening, as well as beliefs about cancer that are thought to be common in South Asian communities.

**Interconnectedness and the Importance of Family**

The concept of interconnectedness is pinnacle in South Asian culture, with individualism and collectivism being considered complimentary (Shankar, 1997). The family is generally considered to be at the centre of South Asian life and is the most important social unit (Assanand et al., 1990). Extended family relationships are often very strong among South Asians, affecting interpersonal relationships within the family and with outsiders, such as health care professionals (Ahmed & Lemkau, 2000). The community is often viewed as an extended family and community involvement is highly valued and considered an important responsibility (Ibrahim, Ohnishi, & Sandhu, 1997). For South Asians, family and kinship traditionally provided the basis of an individual’s identity as well as facilitating continuity of culture and religion (Choudhry, 2001). At the core of family life is respect for elders and filial piety, with parents being honoured and revered and elders valued for their wisdom and consulted on all important issues. Family needs are often given priority over individual needs, and emotional restraint is encouraged to promote family harmony and izzat (family honour) (Ahmed & Lemkau, 2000).

Health is valued at the individual, family, and community level. Ethnographic research conducted with immigrant South Asian women in Canada revealed the high value placed on health (Choudhry, 1998). The reasons for staying healthy were more altruistic than personal and health was seen to be important for the sake of the women’s children, family, and community. This study’s findings indicated that following immigration to Canada, the South Asian women modified their lifestyle behaviour, such as diet, activity, and weight control, in an attempt to stay healthy. The women relied upon and consulted family and community members about health
information and concerns. Likewise, in an ethnographic study focussed on breast health practices of healthy South Asian women, women believed they should first consult close family members and confidantes about breast problems and, only with the sanctions of family members, would they seek medical advice (Bottorff et al., 1999).

**Gender Roles for Women**

Traditional South Asian roles of a good woman, wife, mother, and daughter are influenced by cultural norms and standards, yet vary with generational, socioeconomic, and educational levels. When South Asian women marry, they tend to live with the husband’s family, with the mother-in-law being the head of the household (Assanand et al., 1990). South Asian families have been described as patriarchal or egalitarian, with women often assuming domestic responsibilities, bearing and nurturing children, tending to the sick, and generally deferring to the authority of their husbands (Ahmed & Lemkau, 2000; Choudhry, 2001). Women’s conduct is commonly guided by *dharam*, a divinely ordained norm of good conduct and righteous living, by which much of a woman’s personal and social behaviours are judged (Shankar, 1997). *Dharam*, therefore, can influence how a woman presents herself in society and how she acts (Bottorff et al., 1999). An ethnographic study focussing on South Asian immigrant women in western Canada revealed that *dharam* continues to influence many aspects of women’s lives following immigration and, ultimately, provided a lens through which women viewed breast health and illness, including breast cancer (Bottorff et al., 1998). The study participants talked about the importance of upholding family honour, protecting their modesty, and putting others first. Women protected their modesty by not doing breast self exams to check for breast cancer, as well as not discussing breast health activities, concerns, or cancer. Women in Bottorff et al.’s (1998) study indicated that potential future marriages of their children depended on maintaining the appearance of a healthy family with strong lineage. Their family’s standing in the community
was of utmost importance to these women. Fear of the repercussions of ill health and specifically cancer, may therefore have a dramatic impact on Punjabi women who do develop breast cancer.

Many South Asian women are particularly modest about their physical body and believe they should remain covered, especially in the company of men (Assanand, et al., 1990). This modesty was evident in two Canadian studies where South Asian women reported being reluctant to ask their male physicians to examine their breasts or perform cervical cancer screening, and were hesitant to remove clothing for examination in front of others (Bottorff et al., 1998, 2001). Women who attended a cervical cancer screening clinic for South Asian women reported in interviews that they wanted female physicians and nurses whom they could trust and feel comfortable with to perform the screening (Bottorff et al., 2001). These women also reported feeling uncomfortable and shy discussing screening with their male physicians, and these physicians, out of respect for these women, did not broach the topic.

Traditional gender roles for women also involve sevah (service to others). In this context, household and community needs are considered paramount to the extent that personal health concerns are placed behind family well being (Choudhry, 2001). For example, in Choudhry et al.'s (2002) participatory action research program, South Asian immigrants to Canada consistently described how they placed their families’ needs and societal expectations before their own. These women believed that putting others before themselves, self-sacrifice, and erasing one’s ego were attributes of a good woman. In addition, the numerous demands and busy lives at home and work left little time for these women to engage in health-promoting activities. Although these South Asian women valued health and were capable of engaging in health-promoting activities, making time for themselves at the cost of family needs was not an option, nor did they see it as a priority (Bottorff et al., 1998; Choudhry et al., 2002). Many South Asian women take pride in their strength and commitment to their families, and women are admired for
suffering in silence and enduring great physical and emotional pain to protect the family (Shankar, 1997).

Clearly, cultural beliefs and values influence many Punjabi women’s health care practices in different ways. Concepts of health and illness are derived culturally, as are the perception and evaluation of symptoms and ways of coping with illness (Choudhry et al., 1998). Yet, the dynamic nature of culture must also be recognized, especially for immigrant women who no longer live in their country of birth, as well as the influence of social factors and life contexts. These factors may have a profound effect on women’s experiences of breast cancer.

**Participation in Breast and Cervical Cancer Screening**

Researchers investigating South Asian women’s participation in screening programs have revealed both barriers to cancer screening as well as factors that promote these health practices. South Asian women’s participation in breast and cervical screening have been reported to be lower than mainstream groups in studies conducted in the United Kingdom (Sutton, Storer, & Rowe, 2001) and Canada (Gupta et al., 2002). Researchers have suggested that programs have not met the unique and culturally specific needs of these women (Choudhry, 1998). On the other hand, the most common reason South Asian immigrant women provided for not participating in cancer screening in Canada was that they perceived it as unnecessary (Gupta et al., 2002). Underutilization of cancer screening has also been related to lower levels of acculturation, education, and length of time in Canada (Choudhry et al., 1998; Gupta et al., 2002).

In an evaluation of cervical cancer screening centres established for South Asian, Asian, and First Nations women in British Columbia, some South Asian women were unsure of the benefits of early detection and were reported to believe that diagnosis would lead to fear, anxiety, and painful or unsuccessful treatment (Bottorff et al., 2001). Other women, however, viewed screening as a way to keep healthy, and protect families from the suffering caused by a
disease that could affect any woman (Bottorff et al., 2001). South Asian women’s access to Pap testing was not only influenced by health beliefs, but also by a complex interplay between cultural values and structures within the health care system that limited women’s perceived access to care (Bottorff et al., 2001). In one unpublished pilot study conducted in Canada, 18 recently immigrated South Asian women, both with and without breast cancer, encountered cultural and structural barriers when accessing information and services related to breast cancer and breast health (Sodhi, 1995). These barriers included not speaking the same language as health care professionals, lack of transportation, and the loss of family support in the form of social networks to call on for advice and assistance. A lack of knowledge of Canada’s social and health care infrastructure as well as cultural insensitivity were also found to be barriers to breast care (Sodhi, 1995).

**Beliefs about Cancer in South Asian Culture**

A variety of beliefs about breast cancer and preventive behaviours have been described by researchers studying ethnocultural groups. Ethnographic studies with healthy South Asian women indicated that some women believed that cancer is contagious, caused by damage to the breast, brought upon oneself (*karma*) and others (curses), and passed down through the family (Bottorff et al., 1998; Johnson et al., 1999). Beliefs about cancer have largely been investigated by interviewing healthy South Asian women rather than South Asian women who have breast cancer. In these studies, South Asian beliefs about the causes of breast cancer seemed to contribute to a sense of stigma, fear, and secrecy surrounding cancer. The fears associated with cancer may be related to the lack of effective quality care and treatment for cancer in developing countries, and the fatal outcome associated with this disease. Canadian South Asian immigrant women in Sodhi’s (1995) pilot study indicated that cancer was associated with death. Similar views have also been reported in other studies where healthy South Asian women described
cancer as a hidden killer, an illness that is incurable, and a “death sentence” (Bottorff et al., 1998; Johnson et al., 1999). It is possible that the fear associated with cancer may cause women to delay seeking medical treatment or refuse treatment once a diagnosis has been made. Some of the healthy women in Bottorff et al.'s (1998) study also believed there was no cure for breast cancer and because of this preferred not to know whether they had cancer. They reasoned this knowledge would create unnecessary worry and depression, thereby removing any hope of recovery from illness.

The secrecy about cancer in some South Asian communities may be related to beliefs about developing or catching cancer. Open discussions about cancer have been discouraged by healthy members in South Asian communities out of fear of fating cancer on oneself or others (Choudhry et al., 1998). Similarly, healthy women in Johnson et al.'s (1999) study thought cancer could be caused by a poor lifestyle, speaking about cancer, or by divine power. Curses, through the practice of black magic (jadhu) or harmful words (suraph), were thought to cause cancer, as was one’s fate (kismet) or deeds in present or past lives (karma) (Bottorff et al., 1998; Choudhry et al., 1998; Johnson et al., 1999). To be diagnosed with cancer could be interpreted by these women as a reflection of poor character, having performed bad deeds, or neglected family or community responsibilities. These beliefs imply that avoiding cancer is, to some extent, within a woman’s control. South Asian women may fear bringing shame to themselves and their family with a diagnosis of breast cancer, therefore women may withhold a diagnosis of cancer from friends and community members limiting the social support that is available to her. Further investigation into how South Asian women’s beliefs influence their breast cancer experiences will be important to understand how health care services may be provided in culturally sensitive and appropriate ways.
Summary

Although researchers in the Western world have begun to focus on the breast cancer experiences of women in ethnocultural groups, these women have remained underrepresented in the breast cancer literature. There is limited understanding about Punjabi immigrant women’s experiences of having breast cancer because there have been no Canadian studies published that focus on these women’s experiences. Research with Punjabi women with breast cancer is needed. The scientific literature to date has demonstrated that breast cancer is a significant life event for many women and research with Caucasian and selected groups of ethnocultural women have shown marked diversity in women’s experiences. The ways that Punjabi women conceptualize breast cancer, including their cultural and social values and beliefs, may influence their experiences of diagnosis, treatment, and recovery from this disease. Research on breast health practices and breast and cervical screening has demonstrated that cultural values and beliefs, structural barriers in the health care system, and racism by health care professionals influences health-seeking behaviour and, ultimately, the health of South Asian women. As well, the fear and secrecy associated with cancer in South Asian communities may have profound effects on those Punjabi women who develop breast cancer.

The aim of this thesis project was to understand Punjabi immigrant women’s various experiences of breast cancer, those aspects of the disease considered significant, the emotions attached to particular events, and how breast cancer is incorporated into a woman’s life and personal identity. By analyzing Punjabi women’s stories of having breast cancer, the aim was also to comprehend the dynamic social, cultural, and life contexts in which breast cancer may occur. Knowledge of Punjabi women’s unique experiences may inform health care professionals’ practice, as well as health service development and implementation that addresses the unique needs of these women.
CHAPTER THREE: RESEARCH METHODS

Study Design

In order to gain an understanding of the breast cancer experiences of Punjabi immigrant women, an ethnographic narrative analysis approach was used to guide this qualitative study. This study was a secondary analysis of interview data collected during a research project that investigated Punjabi women’s experiences of self-discovered breast symptoms. The primary study also utilized an ethnographic narrative approach and, through interviews about self-discovered breast changes indicative of breast cancer, Punjabi women concurrently told stories of having had breast cancer. The transcribed interviews with Punjabi women with breast cancer were collected and their stories analyzed for this secondary analysis.

Secondary analysis is a form of research in which the data collected by one researcher is reanalyzed by another investigator to answer new research questions (Polit & Hungler, 1999). This approach to qualitative research is a credible method for generating knowledge that will contribute to nursing (Szabo & Strang, 1997). Secondary analysis is also considered efficient and economical because data collection is typically the most time consuming and expensive part of a research project (Polit & Hungler, 1999). In addition, secondary analysis is a good fit with a master’s thesis and a viable option when the research purpose and question fits the available data. According to Thorne (1994), this fit must be on two levels: first, the research question posed on the secondary analysis must be sufficiently close to that of the original research so that the data set will represent uniformly the topic of secondary inquiry. Secondly, there must be a close fit between the formal methods by which the original data was derived and those used in the secondary analysis (Thorne, 1994). The research questions for the primary study investigated Punjabi immigrant women’s experiences of the discovery of breast changes indicative of breast
cancer. In the process of sharing these stories, participants also told stories about their experiences of breast cancer. For this secondary analysis, the research questions were similar to the primary study because they attempted to elicit women's stories and experiences and the meanings women attached to their breast cancer experiences. The research methods for the primary study and this secondary analysis both were guided by ethnographic narrative methods.

Ethnography is a means of gaining access to the health beliefs and practices of a culture and allows the observer to view phenomena in the context in which they occur (Morse & Field, 1995). Historically, ethnography has been utilized as a qualitative research method to examine various health and illness experiences of ethnocultural groups (Bloor, 2001). It is the emic perspective and the way members of a culture envision the world, including language, concepts, and means of expression, that is sought in ethnography (Polit & Hungler, 1999). In addition, Polit and Hungler (1999) pointed out that tacit knowledge is also accessed through ethnography, which is information about the culture that is so deeply embedded in cultural experiences that members do not talk about or may not be consciously aware of this knowledge. In this study, this knowledge and perspective was gained through the Punjabi immigrant women who storied their experiences of breast cancer.

Narrative research is a qualitative approach based on the foundation that human beings are able to narrate or “story” experiences in their lives (Mishler, 1986). Narrative research takes as its object of investigation the story itself (Riessman, 1993). The underlying assumption of narrative research is that the construction of a story by an individual serves a purpose and is the primary way human beings make sense of their experiences (Mishler, 1986). Furthermore, these stories provide a way for individuals to construct new perceptions of their relationships to the world, to relive the experience being storied, and to assist in the ongoing understanding of how their experiences shape who they are (Frank, 1995; Garro & Mattingly, 2000; Riessman, 1993).
In the narrative approach researchers examine stories that are concrete, personal, temporal accounts in which the narrator sets the scene and describes the main events and their resolution (Mishler, 1986). These stories can provide a powerful medium for learning and gaining understanding about others by affording a context for insights into what one has not personally experienced (Garro & Mattingly, 2000). The usefulness of incorporating narrative analysis in ethnographic research has received increasing recognition because narration is viewed as an important way that individuals make sense of past experience and share it with others (Cortazzi, 2001). Narrative research has been used to investigate a wide range of health related topics, including nicotine addiction among teenage girls (Moffat & Johnson, 2001), critical and chronic illness (Frank, 1995, 1998), smoking relapse during postpartum (Bottorff, Johnson, Irwin, & Ratner, 2000), infertility in South Indian women (Riessman, 2000), and blindness (Wikan, 2000).

This study took direction from the four different narrative approaches described by Cortazzi (2001), Frank (1995), Mishler (1986), and Riessman (1993, 2000). These approaches directed the investigator to examine the way each woman’s story was told, including how it was put together, the linguistic and cultural resources narrators drew on, and how narrators "performance persuaded the listener to authenticity" (Riessman, 2000). As Cortazzi (2001) explains, careful analysis of the topics, content, style, context, and telling of stories and narratives told by individuals under ethnographic study should, in principle, give researchers access to storytellers’ understanding of the meanings of key events in their lives in cultural context. Therefore, this ethnographic narrative approach fit with the purpose of exploring various ways in which Punjabi immigrant women provided stories of their breast cancer. As well, it facilitated the analysis of these stories to uncover the various ways that meaning was created about the experiences of breast cancer. The narrative approach is also a method that may be well suited to the familiar use of storytelling by women to share significant and sensitive experiences.
and knowledge (Bottorff et al., 1998), and to the oral traditions common in Punjabi culture (Nayar, 2004). Oral storytelling pertains to, “A traditional mentality in which speech consists of the telling and retelling of ideas and stories that have been passed from one generation to the next” (Nayar, 2004, p. 26). Furthermore, the importance of narratives in studies of women’s lives is articulated by Langellier (as cited in Riessman, 2000), who stated that women have always opposed their oppression in myriad ways and narratives open up a discursive space in which individual women can resist dominant expectations by articulating contradictory meanings in their experience.

**Definitions**

For this ethnographic narrative secondary analysis, the terms story, narrative and storyline were used, taking direction from Frank (1995). Story was used when referring to actual tales women told and storyline to the general plot of women’s stories. The term narrative referred to the general structures that were comprised of the various stories and storylines and included three narrative types described by Frank (1995): restitution, chaos and quest. Frank (1995) further explains that a narrative type is the “most general storyline that can be recognized underlying the plot and tensions of particular stories” (p. 188). Although these definitions were used for this study, it is important to point out that narratives, storylines and stories tend to transform into one another. As Frank (1995, p. 188) states, “Since narratives only exist in particular stories, and all stories are narratives, the distinction is hard to sustain.” To remain clear in this thesis, the term *narrative* will refer to the type of *storylines* revealed in women’s *stories*. Narratives and storylines will infer the themes present in this study.
Sample

The women included in this secondary analysis were Punjabi immigrant women who participated in a primary study exploring South Asian women’s experiences of breast changes and signs and symptoms of breast cancer. For the primary study, a Punjabi population was selected on the basis that this ethnocultural group comprises the majority of South Asians residing in the Lower Mainland of B.C. As these individuals originate from the same geographic region in India, Punjabi immigrants share many cultural practices surrounding food, dress, ceremonies, and cultural norms, values, and beliefs. Women included in the primary study were required to meet the eligibility criteria of being an immigrant Punjabi woman who had self-discovered breast changes or breast cancer symptoms, which resulted in the diagnosis of breast cancer, benign breast disease, or no clinical diagnosis. As well, Punjabi women were selected from a variety of backgrounds with regards to their education and immigration history.

For this secondary analysis, a convenience sample of 12 Punjabi immigrant women, who had previously been interviewed for the primary study, were selected. The transcribed interview data was collected and analyzed, and because it was data from previously conducted interviews, the eligibility criteria were the same as in the original study. The only additional eligibility criterion for the women in this secondary analysis study was a personal diagnosis of breast cancer. The number of women included in this secondary analysis was determined by the number of women with breast cancer interviewed in the primary study investigating South Asian women’s experiences of self-discovered breast changes. It was assumed that variation in women’s demographic characteristics, such as acculturation level and socioeconomic status, facilitated obtaining diverse stories and accounts of having breast cancer. The gathering of some interviews occurred simultaneously with the data analysis.
**Data Collection**

The data collected for this secondary analysis was in the form of transcribed interviews with Punjabi immigrant women, obtained for the primary study investigating South Asian women's experiences of breast symptoms indicative of breast cancer. All of the 12 interviews took place in the Lower Mainland of B.C., Canada. These interviews were conducted at a time and place convenient and comfortable for them, in the participants' language of choice (i.e., English or Punjabi), and tape-recorded. Ten women were interviewed in their homes, while one woman chose to be interviewed at her place of work, and another woman chose to be interviewed at her mother's home. Eleven of the twelve interviews were conducted in Punjabi, translated to English and transcribed, with the accuracy of translation and transcription double checked by Punjabi-speaking research staff. Some Punjabi words were not translated and remained in Punjabi because they would lose some of their meaning in translation (see Appendix for a glossary of Punjabi terms). One interview was conducted in English and transcribed verbatim. The details of speech, such as pauses and changes in tone and volume, were also included in the transcriptions using standard conventions identified by Psathas (1995).

One of the interviewers was a trusted and highly regarded nurse in the Punjabi community and another interviewer was a Punjabi breast cancer survivor who volunteers and works with the local cancer society. The other two interviewers were Punjabi research assistants with knowledge and training in interviewing and research methods. Interviewers were familiar with the culture and customs common in Punjabi communities and were also trained in qualitative research methods and received in-depth training from the investigative team of the primary study to ensure they had the requisite interview skills to obtain detailed stories of women's experiences. The majority of women were agreeable to being interviewed because they knew the interviewer or someone else in the community who had been interviewed for the study,
and trust had been established. Yet, some women were still reluctant to be interviewed. For example, one woman told the interviewer that she almost backed-out of the interview and another woman, a recent immigrant, was initially reluctant to sign the consent because she thought the interviewer may be a government employee checking up on her.

The interviewers of the primary study encouraged the respondents to tell their accounts in their own way, by posing broad open-ended questions and using prompts to encourage informants to enrich their accounts with explanations or detail. Although interview guides were developed and used during the interviews with women, interviewers were instructed to remain flexible and open to exploring variations in participants’ experiences. In the primary study, interviewers encouraged women to share stories related to the discovery of breast changes and their responses to the breast changes, however, they also asked women to elaborate on the experiences that the discovery precipitated. For women with breast cancer, this included their experiences of being diagnosed with and having breast cancer.

Interviews were in-depth and open-ended for the purpose of obtaining rich, comprehensive, detailed stories of participants’ experiences. These interviews ranged in length from 40 minutes to 2 hours and 15 minutes, with the quality of the interviews varying. In four of the interviews, grandchildren interrupted the conversation by coming into the room and asking questions, turning on the television, or wanting the woman to play with them. These women were often responsible for the childcare because there was no one else home to look after the grandchildren. In one interview, the woman’s husband was in the room when the interview was conducted but he said very little during the interview.

The field notes recorded by research assistants following interviews, as well as the demographic data collected, were also included in this secondary analysis. The field notes in the primary study described how each informant was recruited into the study, the participant’s
response to the interview and interview questions, as well as any other pertinent observations about factors influencing information shared during the interview. The field notes helped inform the context of the ascertained stories, which is crucial in narrative analysis (Cortazzi, 2001; Mishler, 1986; Riessman, 2000).

The stories told by the women in this study were co-constructed by the women and the interviewers. The stories that were told and the meanings that were conveyed were shaped by the relationship the interviewer and the woman interviewed had established, as well as the atmosphere and setting that had been created. Some women seemed to be aiming to please and wanted to tell “good” stories. For example, during their interviews the women asked whether they had answered questions correctly or if they had said “something wrong.” The interviewers reassured women that they were interested in their personal experiences, and the women who were interviewed presented themselves as forthcoming with their stories, with only one exception. In the field notes, the interviewer identified one woman as expecting a traditional question-answer interview and seeming reluctant to share her feelings and emotions. This interview, however, still provided a valuable story about having breast cancer and was used in this analysis.

Data Analysis

The interview data was analyzed using a combination of narrative analysis strategies identified by Frank (1995), Mishler (1986), Riessman (1993, 2000), and Cortazzi (2001). Following close reading of the interviews, summaries were prepared to highlight impressions of each woman’s story. Women’s stories were then compared to identify storylines and subjected to analysis focussing on the structure and function of the storyline. Finally, consideration was given to the larger social context in which the stories were told. Narrative analysis can be used for systematic interpretations of other’s understandings of events, and can be an especially powerful
research tool if the stories are accounts of significant incidents in people’s lives (Cortazzi, 2001). Previous research has indicated that breast cancer is indeed a significant event for many women (Arman et al., 2002; Kaur, 2000; Utley, 1999).

A full narrative involves an event or series of events (what happened or what is presumed to have happened in the past), experiences (the images, reactions, feelings and meanings ascribed to recounted events), and the story (the linguistic form of telling the events) (Cortazzi, 2001). In accordance with ethnographic research, these were considered when analyzing the stories provided by the Punjabi women with breast cancer. Along with the structures and content of the stories, this analysis took into account the functions of particular stories, the cultural conventions and the context they occurred in, which, together with the speaker’s motives and intentions, constructed the meaning for the storyteller (Cortazzi, 2001). This secondary analysis included analysis of the content and the social and cultural context surrounding and revealed within the women’s stories.

The data analysis began with close reading and re-reading of the women’s interviews to identify parts of the interview that made up each woman’s story and these sections were highlighted on the transcripts. According to Riessman (1993), the task of identifying narrative segments and their representation is not a technical operation but the stuff of analysis itself; the “unpacking” of structure that is essential to interpretation. Initial and global impressions and unusual features of the story were also written on the transcripts. Because the interviews were translated, the structural analysis did not concentrate on specific words as heavily as on the meanings of what women were saying. As well, some English words have no Punjabi translation (see Appendix for a glossary of Punjabi words). For example, there is no Punjabi word for ‘breast’, and in these interviews women used the Punjabi word “chati” for ‘chest’ to refer to their
breast, or they said ‘breast’ in English. Similarly, there is no Punjabi word for ‘cancer’ and when the women referred to their breast cancer, they used the English word ‘cancer.’

Following this step, a one page summary of each woman’s story was prepared, referred to as a constructed summary, to obtain a global sense of the types of stories and possible storylines about breast cancer that were being revealed. These constructed summaries included the type of story revealed, meanings of breast cancer shared, self-identities portrayed, the influence of structural factors, and the general storyline that women used to explain their experiences of breast cancer. Demographic data was also included at this stage to help inform and provide context to the women’s stories. The individual summaries were then analyzed for similarities and differences and possible storylines were reviewed with the faculty members who were part of the thesis committee and co-investigators on the primary study. The interviews were then coded according to the content of stories and storylines identified, using the electronic transcripts and the electronic data management program NVivo. This type of analysis provided a systematic way to compare and contrast the stories and storylines women presented about their breast cancer experiences. Following this coding, some storylines were rejected and other storylines were refined.

To further extend the analysis completed, Franks’ (1995) narrative framework was use to understand how women’s stories were created and presented following specific plot sequences. Franks narrative analysis methods have been used by other researchers investigating women’s breast cancer stories (Thomas-Maclean, 2004). According to Frank (1995), people tell their own unique stories, but they compose these stories by adapting and combining the narrative types that an individual’s culture makes available. Storytellers learn and make use of “formal structures of narrative, conventional metaphors and imagery, and standards of what is and is not appropriate to tell, from their families and friends, from the popular culture that surrounds them, and from the
stories that other ill people tell” (Frank, 1995, p. 3). The three narrative types identified by Frank include restitution, chaos, and quest. Restitution narratives are ultimately about health and move through three phases; beginning with health, followed by sickness, and looking to a return to health in the future. Chaos narratives are the opposite of restitution narratives, conveying “wreckage” and depicting people “sucked into the undertow of illness” (pp. 110, 115). These stories “reveal vulnerability, futility, and impotence,” and may be considered “anti-narrative” (Frank, 1995, pp. 97, 98). The third type, quest narratives, “accept illness and seek to use it” (p. 115). This narrative shows how illness is a challenge, the impetus for change, and is ultimately beneficial for the narrator.

In this next step, interviews were re-read and brief abstracts of each woman’s story were prepared, compared and contrasted, to determine the narrative type of stories (restitution, chaos, or quest) revealed by these women. The interviews were again re-read and sections of the transcripts were color coded with markers according to the narratives presented, to obtain a general impression of how each woman used the three narratives and to confirm the dominant narrative revealed in each woman’s story. The abstracts were then grouped by the three narratives, chaos, restitution, and quest, and compared and contrasted within and between narrative types. This facilitated the identification of five storylines as they were situated in the three narratives. One paragraph abstracts for each storyline were then prepared and refined with the author’s supervisory thesis committee members. The analysis of the storylines, by narrative type, included examination of the plot, the structure of how the story was told, and the women’s constructions and positioning of themselves within their stories (Frank, 1995).

This analysis was complemented by further functional analysis guided by Labov’s model (Cortazzi, 2001; Mishler, 1986; Riessman, 1993, 2000). In the structural analysis of each story, an attempt was made to identify the following structural components: the abstract, orientation,
complication, evaluation, resolution, and coda of the story. These structures are defined by Cortazzi (2001) as follows: the abstract summarizes the point of the story; the orientation gives details of time, place, persons, and situation; the complication shows the crisis, problem, or turning point; the evaluation indicates the importance to the narrator; the resolution shows the result or solution; and the coda finishes the story. Close attention was given to the orientation, or context, revealed within the story because this helped reveal social and cultural beliefs and values. Women's evaluations of their stories were also important because it reflected the cultural meanings and experiences that they considered important. These elements of the storylines occurred in various sequences and combinations. This analysis of each storyline, in combination with the structural analysis, included examination of how the elements of each storyline fit together, each storyline's sequence of events, the favouring of particular stories in each storyline, the linguistic tools women used, the repetition of certain words, phrases and events, and how women transitioned from one story to another within each storylines. Following this structural analysis, two of the storylines were found to be quite similar and were combined, resulting in the findings consisting of four storylines situated in three narratives.

Riessman (2000) contends that stories reveal the biographical work that women do to position themselves in the social world. Furthermore, stories have an individual role in the formation and maintenance of identity because through stories individuals make sense of themselves. According to Cortazzi (2001), people “tell what they are or wish to be, as they tell so they become, they are their stories” (p. 388). Given these functions of women's stories, analysis of the Punjabi women's stories in this study focussed on identifying the language and storytelling devices that women used to construct and support explanations of their decisions, actions, and emotions with respect to their breast cancer. This helped to reveal women's constructions and portrayal of self-identity, which are discussed in each of the four storylines, and are explored in
the findings according to the narratives of chaos, restitution and quest. In the final step, the
analysis of each interview was synthesized as the findings were compiled and written as a
coherent whole.

**Scientific Rigor**

Scientific rigor is concerned with the reliability and validity of research, however, the
criteria for evaluating rigor must be appropriate to the research and the type of research methods
used (Davies & Dodd, 2002). The quality of qualitative research, including narrative research,
can not be evaluated using traditional notions of reliability and validity that are central in
quantitative research (Mishler, 1986; Riessman, 1993). It is important for qualitative research to
be reliable but not in the sense of replicability over time and across contexts. Rather, the aim is
for reliability in the data based on consistency and care in practices, and reliability on the
analysis and conclusions, reflected in open accounts that remain mindful of the partiality and
limits of the research findings (Davies & Dodd, 2002).

Validation, the process through which claims about the trustworthiness of interpretations
was made, is the critical issue in evaluating the scientific rigor of narrative research (Mishler,
1986; Riessman, 1993). The emphasis in narrative research is not on ‘truth’ which assumes an
objective reality, but is on ‘trustworthiness’, which moves the process into the social world and
assumes a point of view where facts are an interpretive process (Riessman, 1993). Punjabi
immigrant women’s storylines of breast cancer may be described in many different ways. Their
stories may change with time, be presented in alternative ways under different political and
social climates, and be altered depending on to whom they are offered (Riessman, 1993).
Therefore, as Mishler (1986) states, “It has become clear that the critical issue is not the
determination of one singular and absolute ‘truth’ but the assessment of the relative plausibility
of an interpretation when compared with other specific and potentially plausible alternative
interpretations” (p. 112). The trustworthiness of narrative research can be evaluated using the criteria of persuasiveness, correspondence, and coherence (Riessman, 1993), which were considered and addressed in this thesis project.

Persuasiveness is the degree to which the interpretations are reasonable and convincing, which was addressed in this thesis by providing supporting claims with evidence from informants’ accounts. This was in the form of quotes and detailed interpretations. Alternative interpretations of the data were also explored and included in the research findings. Correspondence refers to taking results back to those studied to determine if the investigators reconstructions are recognizable as adequate representations (Riessman, 1993). In this thesis project, interpretations of Punjabi women’s storylines and narratives of breast cancer were shared with the Punjabi consultant of this project, as well as the supervisory thesis committee members. The third criterion of trustworthiness is coherence which is concerned with the relation of findings to the narrator’s overall goals (global coherence), the tools the narrator uses to structure the storyline (local coherence), and how chunks of interview text about themes are important and repeated (thematic coherence) (Riessman, 1993). In the analysis of Punjabi immigrant women’s stories, storylines and narratives, attention was paid to all three levels of coherence and detailed explanations of the way interpretations were produced was made apparent. A clear paper trail was kept that described how interpretations were produced. As well, the involvement of the research committee and consultant in the analytical process helped ensure that multiple interpretations were considered and were true to the data.

Summary

Narrative inquiry was used in this study to investigate the meanings of breast cancer among Punjabi immigrant women in the Lower Mainland of British Columbia. This was a secondary analysis of interview data gathered for a primary study, in which researchers
investigated South Asian immigrants' experiences of self-discovered breast symptoms indicative of breast cancer. Interviews were transcribed into English and analyzed for content, structure, context, and meaning. This analysis resulted in detailed descriptions of four storylines, situated within three narratives, as well as one minor theme. It must be recognized that the findings presented in this study do not encompass all Punjabi immigrant women’s stories of breast cancer, rather, these findings provide a "window to understand" how meaning is created from the experiences of breast cancer for these women.
CHAPTER FOUR: NARRATIVES, STORYLINES AND MINOR THEMES

The primary findings of the analysis of interview data provided by the 12 Punjabi immigrant women with breast cancer in this study resulted in four storylines. These storylines are: “dealing with just another health problem,” “surviving a family tragedy,” “never-ending fear and suffering,” and “a lesson from God.” Although not present in all interviews, three of the four storylines were present as minor storylines in at least ten of the twelve interviews. “A lesson from God” is an exception because it was only revealed as the main storyline in one woman’s interview, yet this was a compelling storyline. Analyses also lead to the categorization of these four storylines into the three narratives of restitution, chaos, and quest, as outlined by Frank (1995).

The four storylines represented in the breast cancer stories shared by the Punjabi women in this study were not mutually exclusive, but each woman often had one predominant storyline evident throughout much of her interview. Some women presented a more pure form of the storyline, while others told stories interjected with other storylines. All of the women interviewed also interrupted their own stories with asides and explanations, which were not always consistent with the storyline or narrative. For example, when telling their breast cancer stories, women in this study shared stories of other women with breast cancer. These stories were not always consistent with their storylines, but rather, had four main functions; to explain how the stories of pain and suffering experienced by other women scared them, to demonstrate how stories of breast cancer survivors provided women with hope, to reinforce ideas of appropriate breast cancer management, and to explain how they had provided advice or hope to others. This interruption of stories with other stories, and consequently of narratives with other narratives, is what made each woman’s breast cancer story original. No actual telling of a story conformed
exclusively to one narrative or storyline; rather they were combined and perpetually interrupted each other as observed among other storytellers (Frank, 1995; Thomas-MacLean, 2004).

It must also be noted that the Punjabi women in this investigation avoided saying the word ‘cancer’ in their interviews. Rather, the women referred to their cancer as “it,” “that thing,” “that problem,” “that disease,” “an ugly disease,” and “a death sentence.” This hesitancy to mention the word ‘cancer’ seemed to reflect women’s fear of the disease and their discomfort in talking about cancer.

This chapter begins with a brief overview of the demographic characteristics of the sample. The three narratives are then outlined, and the four general storylines discussed, as they are situated within each narrative. This chapter ends with a discussion of a minor theme, “being part of a close-knit family,” and a summary of the findings of this investigation.

**Demographic Characteristics**

The demographic information pertaining to the 12 participants in this study was obtained by the interviewers following each tape-recorded interview. The Punjabi women in this study ranged in age from 34 to 63 years old. The length of time since breast cancer diagnosis ranged from ten months to six years, and the various cancer treatments women underwent included lumpectomy, mastectomy, radiation, and chemotherapy. Only one woman had reconstructive breast surgery. Eleven of the twelve participants in this study had immigrated to Canada from Punjab, India, with years since immigration ranging from one year to twenty-nine years. The majority self-identified as being Sikh, with one woman being Hindu. The participants’ educational preparation was quite varied, with some women having elementary schooling and other’s finishing trade/vocational/college preparation. Only one woman had attended university. Seven of the twelve women in this study worked for pay outside the home and all were married and either lived with their husband or were widowed. The majority of the women in this study
also resided in a household composed of extended family, including parents, in-laws, siblings, children, and grandchildren. To maintain confidentiality, all participants were assigned pseudonyms, and these pseudonyms will be used throughout the discussion of the findings. The following section contains the four breast cancer storylines identified in the interviews with the women in this study, as they are situated in the three narratives: restitution, chaos and quest.

**Narratives of Restitution**

The Punjabi women in this study told two storylines that can be considered restitution narratives. These were, “dealing with just another health problem” and “surviving a family tragedy.” These two storylines are restitution narratives because of their structure and underlying plot of a return to health. Further details concerning the fit between each storyline and the restitution narrative are discussed within each storyline. More women told restitution narratives (seven women) than chaos narratives (four women), or quest narratives (one woman).

**Dealing with Just Another Health Problem**

One of the storylines reflected in the breast cancer stories shared by Punjabi women was “dealing with just another health problem.” This storyline was the main storyline in three women’s interviews. Three other women included this storyline in their breast cancer stories, however, it was not their central storyline. Although the specific details of women’s stories varied, this storyline can briefly be summarized. The following summary was constructed from a number of different stories provided by the Punjabi women in this study:

> When I was diagnosed with breast cancer I was very frightened, but my family helped me realize that breast cancer was just like any other disease that could be treated. Now that my treatments are over and I am as healthy as I can be, I try not to think about breast cancer. It was just another health problem among other health problems that I deal with.
"Dealing with just another health problem" was a storyline woven throughout the women’s interviews, yet was most pronounced at the very beginning or toward the end of a woman’s interview. Aman, a 60 year old woman who had a lumpectomy and radiation, provided the abstract, or point of her story, as she started her interview, “I had it and I had treatment. I’m okay now.” Other Punjabi women implied this storyline throughout their interview, and then overtly expressed the abstract and evaluation of the storyline at the end of their interview. Nearing the end of her story Harjop, a 36 year old woman who lived with her husband, children, brother and sister-in-law, and their child, summarized her current situation in relation to her role in the family as a mother.

When my first surgery happened I had felt that I couldn’t do housework, my body had become in that condition. Now I can do all housework, I have none of those feelings. I drop the kids and pick them up from school, walking there. [R: so you can jog] Yes, I can jog as well.

In the story of “dealing with just another health problem” the women portrayed themselves as part of caring and concerned families who took an active role in the women’s health matters. Yet, they also portrayed themselves as brave, independent, stoic women, who accepted their fate and strengthened their resolve when faced with the difficulties of breast cancer. The women presented themselves as strong because they had dealt with other health problems and, therefore, were capable of dealing with breast cancer. One woman proudly stated: “When someone hears of this [having had breast cancer] they always say I was brave…” Another woman described in detail her independence following surgery to emphasize the extraordinary nature of her strength:

I was quite strong. I didn’t let any of the nurses get me out of bed. I did everything myself. I would get out of bed and go to the washroom myself. I think there was only one day that the nurses had to help me because I was still under the medication from the surgery and they had to help me. So I would do everything myself and when my
daughters used to come to see me the nurses used to say to them, “You know, your mom’s very brave. She does everything herself.”

The Punjabi women also presented themselves as spiritual Sikh women. They demonstrated this by accepting breast cancer as part of their *karma* (reflection of one’s deeds in present or past lies) and *kismet* (fate) and reaffirming their commitment to *paath* (prayer) and reading from the *Guru Granth Sahib* (Sikh holy scripture) in response to breast cancer.

The plot of the storyline, “dealing with just another health problem,” began with revelations of the shock of their unexpected diagnosis of breast cancer, though the women tended not to elaborate on their emotions. The women regarded their families as essential in reframing their situations so that they altered their conceptualization of cancer as being a “death sentence” to breast cancer being a treatable disease, like many other health problems. This reframing of breast cancer was not challenged by the women, and appeared to help them reduce their worries and to focus on their cancer treatments and recovery. One woman resisted commonly held assumptions about breast cancer being fatal. At the beginning of the interview, Aman began to speak prior to being asked any questions:

> I had the surgery the day of the fundraising dinner and dance. It started when we were going from home to home-selling tickets and my daughter told this family we’d gone to that I have breast cancer, and their faces just dropped. They were shocked. But to me, I didn’t really feel that breast cancer was bad. There are people who upon hearing that they have cancer they start feeling bad. But for me it, I just thought, “Yes, I’ve got it,” and I didn’t think it was bad to have it.

Family members were presented as playing an integral role in women’s experiences of breast cancer. They accompanied the women to appointments and treatments and often communicated with health care workers. Some women were “shy,” or they did not speak or understand English, and did not take an active part in the consultations. For example, Parveer, a 60 year old woman who had lived in Canada for four years and understood little English, explained that her family had not told her about her diagnosis of breast cancer initially.
And he [physician] told her [Parveer’s daughter-in-law] that she [Parveer] did not know [about her diagnosis of breast cancer]. She said no we have not told her, and the doctor started to get angry, and asked, “Why haven’t you told her. She does not understand English and you have not told her.” I said no I have found [out]. See here English, you know how they say Punjabi language, we can’t give an answer in English, but we can understand, but we can’t answer. [R: Okay] I said I have understood when he said breast cancer. [R: Okay] I found out then that they have said this. Then I understood properly.

Consequently, these women’s breast cancer stories were not medical stories. On the contrary, medical descriptions were absent from this storyline. The women entrusted the medical stories to their family members, telling the interviewer that their family member could provide information concerning the specifics of their diagnosis and treatments if the interviewer required such information. These Punjabi women also explained that they relied on the advice of physicians, fully trusting them to advise the best treatment, as they had with other health problems. Harjop, who had initially attributed her breast cancer to being kicked in the breast by one of her children, explained how she came to have a mastectomy.

My doctor, the specialist, who was going to do this surgery, she told me that it depended on me. That they could also remove it all or just a little but if it came back there was no guarantee. Right? [R: right] We told the doctor that it was up to her. That whatever she wanted, it was dependent on her. Then she removed my breast.

The women accepted their family and physician’s opinions that these treatments were necessary to be cured, and the women emphasized carrying on with their lives, without elaborating on the difficulties associated with breast cancer or the treatments they received.

Many of the Punjabi women’s stories of breast cancer where situated within stories of other health problems, which at times seemed more significant than being diagnosed and treated for breast cancer. For example, Aman consistently described her other health issues including diabetes, coronary artery disease, menopausal symptoms and previous surgeries, while talking about her breast cancer. Although she did not depict herself as free from disease, she portrayed herself as a woman who was as healthy as she expects to be. Breast cancer was just another
health problem among other health problems, dealt with no differently than another health problem would be.

Although some women described residual side effects from surgery, chemotherapy, or radiation, they downplayed these problems promoting a story that conveyed a return to their previous state of health. Women shared stories of their breast cancer as though it was in the past, using the past tense, conveying a sense of distance from the time when they had breast cancer. Women referred to themselves as “healthy,” “fine,” “okay,” and “happy.” The Punjabi women provided evidence that not worrying about cancer recurrence was appropriate by drawing on reassuring messages from family members, as well as their health care team, that there was no reason to worry. Some women demonstrated their return to health by describing their ability to perform household tasks and fulfill their family roles, their return to work, and travelling to India to provide evidence of their health to relatives. “So whatever’s there is fine with me. I just try to stay happy. I go out, I go to India every now and then. And, you know, whatever’s going to happen is going to happen.” Some of the Punjabi women also described having “no fear” about the future and believing their fate was in God’s hands. Satpal stated: “[I have] No fear and I just thank God. And one should thank God, that he’s given me good health; I’m healthy now.”

In summary, the Punjabi women that shared this storyline minimized their breast cancer by situating their breast cancer as just another health problem, by downplaying the side effects of breast cancer, and referring to breast cancer as an event in the past. Minimizing and distancing themselves from their breast cancer helped the women who told this storyline to distance them and their families from the stigma associated with breast cancer, and also assisted their family to return to ‘normal.’
Dealing with Just Another Health Problem: A Restitution Narrative

Frank (1995) stated that the plot of the restitution narrative is, “Yesterday I was healthy, today I’m sick, but tomorrow I’ll be healthy again” (p. 77). Women who conveyed the storyline “dealing with just another health problem” shared this restitution narrative retrospectively, looking back on events that were in the past. Women described briefly the life disruption of being diagnosed with breast cancer. They quickly moved into telling about their physician’s and family’s recommendations to remedy their breast cancer. One woman introduced the subplot of her family’s initial rejection of her physician, turning to her naturopaath instead, but quickly returned to accept her physicians’ treatments. The restitution narrative usually demands medical compliance achievable through being disciplined in seeking a cure (Frank, 1995). The Punjabi women who shared the storyline “dealing with just another health problem” followed their prescribed medical treatments without question but were also self-disciplined in religious and spiritual practices, such as paath (praying), reciting the Guru Granth Sahib (Sikh holy scripture), and visiting the gurdwara (Sikh temple). Although the women explained what their treatments were like, their emphasis was on life after treatment and their stories ended with examples of their return to health or previous state of health. Some women suggested that their family members also encouraged them to forget about breast cancer and to concentrate on staying healthy, thereby favouring this storyline and reinforcing the restitution narrative. According to Frank (1995), one purpose of the restitution narrative is that, “The ending is a return to just before the beginning: ‘good as new’.” In the storyline, “dealing with just another health problem,” the women ended their stories by describing breast cancer as a small glitch that was dealt with, like any other health problem would be dealt with, and now they have continued on with their ‘normal’ lives.
Dealing with Just Another Health Problem: Exemplar Summary Story

Aman was a 60 year old Punjabi woman who had resided in Canada for 29 years prior to being diagnosed with breast cancer. She lived with her husband and had four grown children living in B.C.'s Lower Mainland. She did not work outside the home and had received some elementary schooling in India. Aman explained that she discovered a “little hard guthee (lump),” which lead her to wonder if she could have breast cancer. She stated, “At that time what one thinks is, at that time, I wonder what’s in my fate? What has God written for me? What is in my kismet.” After waiting a week, she visited her female physician who referred her to an oncologist. Accompanied by her husband, Aman received her breast cancer diagnosis. She recalled feeling “really bad for two or three days,” until her family insisted she stop worrying and be “thankful” she had cancer of the breast because it could be removed and treated by Western medicine.

And my daughter, the eldest one, said, “What’s wrong with you? There’s nothing wrong. You know, you should be thankful that it’s only in the breast, it can be removed. And so you’re very lucky there’s nothing wrong with you. You’re going to be fine.”

Aman believed God was in ultimate control and accepted her breast cancer because it was in her kismet (fate). “Whatever is written in our kismet, whatever God has written, it’s going to happen regardless of what you do.” Aman also attributed her breast cancer to the hormone replacement injections she was having for unbearable menopausal symptoms. She blamed herself for not discontinuing these injections, remembering that a doctor instructed her to do so to avoid getting cancer. Aman emphasized the suffering she endured from her menopausal symptoms to justify not heeding the doctors’ advice, suggesting feelings of guilt and responsibility for developing breast cancer. Yet, attributing her breast cancer to her kismet helped counter the self-blame and guilt.
Aman emphasized that her family was, “Very, very supportive.” Her husband and daughters consistently reassured her, refusing to allow her to think negatively, feel sorry for herself, or talk about her concerns. They repeatedly encouraged her to think positively. Aman described how her daughters, one of whom was a nurse, accompanied her to all medical appointments, spoke to the doctors on her behalf, and found her a new physician when they thought this was necessary. Not able to understand or speak English, Aman entrusted them with understanding the medical explanations of breast cancer and the necessary treatments she needed, just like she would have done for any other health problem. There was no mention of needing to know the details of these consultations. It was more important to follow the advice and directions of her doctors and family. Even with important treatment decisions, her own preferences appeared to take a back stage to the decisions of others. Regretful, but uncomplaining, Aman recalled:

And in fact I said that rather than having surgery time and time again I’d rather have it whole, all of it removed. But then they only removed just the lump. So you know, instead of having to suffer many times going through surgery time and time again, like my neighbour, I would have preferred to have it taken off.

Aman had treatments for breast cancer which she rarely mentioned. At times, it was unclear whether she new the names of the treatments she received because she did not refer to having radiation or chemotherapy, rather, she mentioned having “the shot.” Aman only described her treatments once during her interview.

And you know I had whatever that is, the shot, I had the shot for 16 times and when I first started having the shots, first week I didn’t feel anything and they used to ask me every time if I felt anything... but for the first week, ten days, I didn’t feel anything. After that I started feeling nauseated. I would feel kind of sickly. I felt weak; I couldn’t walk around very well. So that’s the only time I felt anything bad.

Aman presented herself as a “strong” Punjabi woman who was not a burden to others during her illness. She explained that post-operatively she did everything herself in the hospital. Although once home, she admitted to “feeling down” for four or five days because she could not do any of
her housework. “For about a little while it was difficult and you can’t ask your children to sit at home and look after you, they have to go to work and stuff, and you have to feed yourself.”

For Aman breast cancer was behind her now and just one of the other illnesses in her list of health problems. Even so, she claimed that her family still insists that she think positively, minimize her breast cancer and other health problems, and carry on with trying to be healthy.

If I’m lying down for a little while, my daughters will come and start asking me questions and start saying, “What is it? Why are you lying down? Come on, get up. Let’s get you moving around.” So it’s very very important. They don’t like me getting down or they don’t like me lying down and not, because they might think I’m thinking about things. So they, you know, they’ll come and say, “Why are you lying down? Why are you feeling sorry for yourself? Shall we take you to the hospital? Show you people who are far worse off than you are? So you know that’s kind of good because I get up and start doing things and stop feeling sorry for myself.

As she summed up her current health status, almost as if she was parroting her family’s words, there are hints that important worries about breast cancer remain a part of her experience. “I have the sugar problem, I have the heart problem, I have the cancer problem and which one should I think about?’ So [laughs] I just don’t worry too much.” She goes on to repeat, “So I just don’t. I try not to worry at all.”

**Surviving a Family Tragedy**

A second restitution storyline, “surviving a family tragedy,” was shared by all of the Punjabi immigrant women in this study. This was the main storyline for four women and also appeared in the remaining eight women’s stories, but not as the main storyline. The storyline, constructed from different women’s stories, is briefly summarized as follows:

*My entire family was shocked when I was diagnosed with breast cancer. We were all extremely worried and in complete disbelief because we never considered that this would happen to our family. We had difficulty getting the health care we needed from some doctors, but the family made sure I received the treatments necessary to beat cancer. My*
treatments were never-ending and caused a great deal of pain and suffering for the entire family. Although we survived, I still feel down at times.

Surviving a Family Tragedy: Thematic Overview

The storyline “surviving a family tragedy” was woven throughout women’s interviews, as women recounted their experiences of breast cancer in chronological order, beginning with breast symptoms and ending with their current situation. The women were skilled storytellers who often established the orientation, complication, evaluation, resolution, and coda of their stories. Compared to the previous storyline, “dealing with just another health problem,” the Punjabi women who told this storyline provided extremely detailed, vivid, and, sometimes, exaggerated accounts throughout their interviews. These vivid descriptions convinced the researcher of the pain and suffering that embodied the breast cancer experience, reinforcing the tragic nature of the experience for the woman and her family, and emphasizing the valiant efforts of women and their families as they rose above and survived this disease. The exaggerated explanations added to the drama of women’s stories, further supporting the tragic nature of their suffering. Descriptions of family suffering were also more prevalent and detailed in this storyline than in any other storyline. These women presented themselves as “strong” Punjabi women who survived against all odds. One woman laughed throughout her interview while telling about the pain and suffering she had endured, thereby making light of her situation, drawing attention to the absurdity of all that happened, and convincing the listener of her status as a survivor.

Punjabi women who shared the storyline “surviving a family tragedy” described the shock and complete disruption to their families’ lives when they received the unexpected diagnosis of breast cancer. Renu, whose husband and sister had passed away the year prior, described how her 15 year old daughter would not talk or eat after finding out Renu had breast cancer. The women’s breast cancer diagnosis marked the beginning of the family tragedy, with
one woman invoking the metaphor that, “Cancer is like a bomb dropping.” Breast cancer was tragic and unexpected because the women and their families reasoned that the women were too young to get this disease, breast cancer had not previously been in their family, and they had always been healthy. The women recounted exactly what their physicians had said to them during the disclosure of their diagnosis, and the context in which this occurred. For example, Baljit described being sent to a specialist by her family physician, who was a family friend, unaware that she had breast cancer.

So I just went into the surgeon’s room laughingly. The surgeon was totally...he was Chinese...he has 33 years of experience. He just turned around his chair like they do in the movies [laughs] and asked me, “So, you are ready?” I said, “For what?” He said, “What did your doctor say?” I said, “He sent me to you.” He asked, “Did he say what problem you have?” I said, “He told me to talk to the surgeon.” He said, “Did he say that you have cancer?” That was the moment, literally, I felt that my feet just came up. I started to cry loudly.

In this storyline, the breast cancer experience seemed unrelenting and consisted of going from one horrific experience to the next with little reprieve, especially during treatments. Treatments, particularly chemotherapy, were constructed as emotionally and physically arduous for the women and their family. Although women’s descriptions of their treatments seemed all consuming, the voice in this storyline was also confident and able to story painful events with reflection, coherence, and sequence. This suggested emotional and temporal distance from those events, as if to emphasize that the tragedy was in the past. The women provided numerous details of bodily changes including hair loss, weight gain, skin changes, gastrointestinal upset, and fatigue. One woman recalled her first chemotherapy session: “My tongue was hard as iron. My eyes were pale yellow. My face became swollen. I had six more treatments to go.” Another woman described her last two chemotherapy treatments:

Then, during my 5th and 6th chemo, I was very down; thus, I used to lie down. I could not sit down. They also could not find my veins. My body had turned all blue with the poking. So, I had requested them that I could not sit down. Yeah, I used to vomit a lot. Every time, the tray was right in front of me. Then, I used to go back to sleep, then wake
up, again I would go back to sleep...like now I am talking about it I can see the whole picture from A to Z.

The women described how difficult their breast cancer was on their families, thereby providing further evidence of breast cancer as a family tragedy. Baljit explained that her husband took her illness "hard." She stated, "He did not show it. Now he tells me about it. He said that he used to check my pulse at night to see if I was still alive." Another woman described changes in her husband: "His hair also got grey then [during her chemotherapy treatments]. He started to look very aged since then." Having breast cancer was also difficult for the women's children and grandchildren as highlighted by one woman's story:

My son stopped going to... kindergarten because he used to bring infections from school. We also thought why should we send him. He was upset. He knew that my hair had fallen off. He had seen me once. He used to cling to my chest. He would ask...then everyday, his grandma would ask him to pray to God that mom would get better. He would say that every night before going to sleep.

Accounts of family members attempting to hide their suffering were also shared by the women in their interviews. One woman recalled:

They [her in-laws] used to cry behind my back. Now, I hear about it from other people how my mother-in-law used to call our relatives and cry. But she always used to say to me, "Nothing is going to happen to you. Nothing." She would say just these words. Very plain. After every chemotherapy, she would hug me and say, "Nothing will happen, dear. Nothing is going to happen. You will see."

Despite the difficulties family members experienced coping with the woman's breast cancer, the stories of "surviving a family tragedy" included descriptions of how family members became advocates and were essential sources of emotional and practical support. The women recounted heroic stories of family members accompanying them to appointments and treatments, taking care of their children, providing physical care, quitting their jobs, and providing encouragement when they felt down. Priya, a 62 year old woman who lived with her husband, two sons, daughters-in-law, and grandchildren, described how her family cared for her:
My daughter when I was having my chemo would sit with me and after she used to give me medication [every] four, four hours at night. She would sleep with me. Until the medications were finished she would stay with me, then she would go home after three days. After that my daughter-in-law's mother used to come to me, she stayed with me the first week when I was very sick. I have a lot of family support.

Participants in this study rarely criticized health care workers directly, as if it might convey ungratefulness, which may be looked down upon by others. Rather, the women demonstrated dissatisfaction with their care indirectly by sharing dramatic tales, which were possibly a more acceptable form of revealing concerns. The women told stories of treatments going wrong, inappropriate health care, and mistakes made by doctors and nurses. Their family members were portrayed as vital in making sure they received the care they needed because at times the women felt uninformed, unable to understand medical terminology, and unable to make physicians listen to them or consider their wishes. Despite these communication challenges, the women presented themselves as medically informed and their stories often contained medical explanations. Renu, a 52 year old woman who had a lumpectomy and radiation, told a story about being discharged home too early and having a post-operative wound infection.

When they sent me home I said doctor I am not well please do not send me home. He said no. My doctor, the specialist, was on holiday. There was another doctor and he pushed me to go home. When I got home I told them that I had a lot of pain here, the area was red. I woke up in the morning on the second day, I was only drinking tea. The nurse would come to the house to change the dressing. She changed the dressing and left and when I took a look at the breast there was so much blood and pus. It must have been more than two pounds, more than a kilo and I went to the kitchen and stood up and the kitchen floor was full of blood and pus and my clothes were soaked.

Baljit told a story of a near death experience during her first chemotherapy session when she was given her medication too fast.

So, suddenly, taxol went on my brain. I could feel death at that time. I felt that my lungs were collapsing and in my brain, I felt something was going to blast. So I rang the bell but they did not answer. Nurses were on the other side [of the ward]. Then, another patient ran to get them and said, "She has a problem." I turned blue...But they went to get some medicine. They did not know she gave me [a drug] by mistake. I felt that I was going to die. So, at once, they called Dr. for an emergency. Right away they took the
medicine out. They asked if I could breathe. But I could not breathe. I [thought I] was going to die that day.

In the stories of "surviving a family tragedy" the women focussed on portraying themselves and their families as survivors because they endured such a difficult time. The women now proudly considered themselves survivors, despite the ongoing effects of their breast cancer experiences and treatments. Baljit described her current situation:

Sometimes I am fine and other times, I am very down... Otherwise, I am feeling normal now. My hair has come back. [R: looks nice] Yeah, whenever I go outside or to parties, everybody appreciates me that I am a big survivor.

Priya saw herself as a survivor despite feeling weak, her legs hurting, having arm numbness and leg cramps: "Now when we go to the doctor it is true that people get better, like me thus far I have beaten cancer." The women portrayed their family members as survivors by providing examples of their families returning to their "normal" lives. This included resuming their roles around the house and within the family as husbands, children, parents, and in-laws. Two women described their family members returning to work after having quit their jobs to care for them while they underwent breast cancer treatments. Other women mentioned their children and grandchildren returning to school, as well as family members concerns dissipating: "Like my dad prior to my surgery, he just would not eat, he was very worried about me and then when I finally had my surgery and everything went well, then he started to come around."

Although the women described continued effects from treatments such as depression, arm troubles, pain or skin irritations, they convinced the interviewer that the worst was in the past and they made concerted efforts to focus on the future. Renu outlined her method of fighting depression, which included helping other Punjabi women with breast cancer by driving and accompanying them to appointments and treatments. Although these women described "surviving" and "beating" breast cancer, it seemed that breast cancer left a mark in their lives. By
describing some of the ongoing troubles they had, these women also presented the possibility
that they were continuing to suffer in silence. They were thankful to be alive and wanted to
appear as grateful women who do not complain.

Surviving a Family Tragedy: A Restitution Narrative

Similar to the storyline “dealing with just another health problem,” the storyline
“surviving a family tragedy” was also a restitution narrative (Frank, 1995). Although the
diagnosis and treatment experiences related to breast cancer were told retrospectively, these
women presented themselves as survivors, albeit not completely healthy. They told their stories
as though they were on the path to health. Unlike the women who shared the previous restitution
narrative, “dealing with just another health problem,” these women told long and detailed stories
of family disruption and suffering with control, sequence, and context, thereby convincing the
researcher of distance from the tragic experience of those events. Their diagnosis of breast
cancer served as the initial interruption to the family and treatments where depicted as the
journey away from health, amplified by medical complications. Frank (1995) points out that the
restitution story displays the heroism of the ill person, which is invariably tied to the more active
heroism of the healer, the physician. In this storyline, the women conveyed their families rather
than themselves as heroic, because their families ensured they received the care they needed,
advocated on their behalf, and provided emotional support. In the previous storyline, “dealing
with just another health problem,” women’s families advocated on their behalf but the women
did not share as detailed descriptions of family suffering as in this storyline.

Although these women described complications and times when nothing was “going
right” with some physicians, this was contrasted with other physician healers that provided
“good care,” whom women romanticized. Renu compared her physicians to God:
The doctors gave me more than enough care than needed to make me comfortable… and the Cancer Agency. People say there is nothing higher than God… but I feel that those doctors that took care of me were like God. They made me very comfortable and gave me a lot of care.

Women shared medical stories, in which treatments eventually cured their “broken-down bodies” (Frank, 1995). Yet, lasting physical and emotional effects of breast cancer were also described by the women. The women did not explore the impact of these lasting effects, however, nor did they minimize their breast cancer as in the previous storyline. Rather, the women who shared the storyline, “surviving a family tragedy,” chose to share the methods they were using to ensure their return to health. This return to health is the hallmark of a restitution narrative.

**Surviving a Family Tragedy: Exemplar Summary Story**

Baljit was a 32 year old married Punjabi woman with two young children, who had immigrated to Canada seven years prior to developing breast cancer. She held a bachelors degree, and was working outside the home full-time prior to having breast cancer. Baljit described her story of breast cancer with vivid detail and as a “tragedy,” yet she survived against all odds. When Baljit was diagnosed with breast cancer, she recalled that, “everyone was shocked” because she was only 32 years old. Much to her surprise, she then discovered she was ten weeks pregnant. Baljit recalled her surgeon refusing to allow her to have an abortion, despite her and her husband’s pleas, because it was counter to the surgeon’s personal Christian beliefs. While waiting for her lumpectomy, Baljit’s breast grew noticeably larger very quickly. She recalled:

> My breast was growing bigger day by day. It was so big it started to fall down… I could feel the tumour under my arm. It was like an egg… I remember that my mother used to give me bath because I could not lift up my arm. [The] tumour was so heavy.

Baljit explained that her family became increasingly worried and her brother-in-law, a veterinarian, was consulted. He checked her breast. She stated, “When he put his hand under my
shirt to check it, he started crying. Then he went to another room and said to his wife, “I do not think that she will survive.” Diagnosed with inflammatory breast cancer, Baljit explained:

Then, I went for an abortion. After two days, we went there in Vancouver. It was awful. Again, it was different thing, right? It was a difficult thing. After that, I came back home. I had flu for two, three days. I was shocked because everything was happening all at once. Then, doctor… I remember my God… That one month my husband and I used to go to the hospital in the morning and come back at night. I had bone scans, brain scans, and all other scans [laughs].

Baljit described how her breast cancer consumed the entire family. Her husband quit his job to care for her and accompanied her to all her treatments.

My husband had just started his real estate business. His work suffered a lot for one year. He did not go to work. How could he go? …He said, “Who cares for the work. First, you are the one. If I am not with you, then who is going to be with you?”

The involvement of other family members was also a focus of her story. A volunteer breast cancer survivor, as well as Baljit’s aunt from India, were crucial in preparing her for chemotherapy. Baljit made various references to the traumatic experience of losing her hair.

Supported by her aunt, she described her experience of having her hair cut prior to chemotherapy.

So, when I went to get bald, it was so difficult. I took my aunt with me. I did not want to go to the barber. I used to think, “How would I look like? Totally bald!” But she [aunt] said to me, “I’ll keep doing the paath [reading from the Sikh holy scripture], you are not going to look at the mirror.” But I took my scarf with me. So I could cover it afterwards. My son was very upset. [R: Did he know about it?] We had told him that his mom was sick. But he did not know much. When my hair started falling off, it really impacted him. I did not want to show him my bald head. Then he [barber] started to shave my head. Afterwards, he said, “You are all done.” When she saw me, my aunt really encouraged me and said, “You look very nice. You look like Percy Combata.” She is a Hollywood heroine. I started crying again when I looked at myself. I used to cry a lot in those days.

Chemotherapy for Baljit was recalled in great detail, with her first treatment being a near death experience and subsequent treatments becoming progressively worse. She described the treatments as ongoing physical and emotional “torture,” filled with sadness, depression, crying, pain, and suffering. “I used to feel that I was a walking ghost. Only my heart was beating but I
had no feelings for my son and husband. I just felt that I was good for nothing.” It was only through the chance meeting of another survivor during one of her last chemotherapy treatments that she began to think she might be able to “walk like her one day.” But it was not until Baljit’s breast was removed that she began to feel relief from the tragic circumstances that consumed her and her family. She explained:

Then, during the day of my surgery, my husband thought that if he went in the room then I might start crying because there was no breast. [R: Did you feel that yourself?] No. I just felt that a big mess has been removed from my body. I was happy that I do not have the breast. I had my lipstick on. That day, I did not cover my head. My head was bald. I was very happy. When my husband came there, he said, “So positive.” I was smiling [laughs]. I said, “Thank God. [laughs] it has gone.” It used to feel like evil to me.

Even following treatment, there were challenges to be faced. Baljit found herself depressed. Slowly, over time, with the help of antidepressants and seeing a psychiatrist regularly, she has recovered. She framed her story as restitution by reassuring the interviewer that she is, “feeling normal now.” Her achievements also take on a heroine tone when she states, “Everyone appreciates me that I am a big survivor.” Yet, Baljit hinted that her family continues to worry about her. She described wanting to return to work:

But my husband said, “You have to relax now all of your life and volunteer.” He said that he will do double-shift. But I just feel that I should try even if I am not fit to work. But my family says, “No. You are not going to work anymore.”

Baljit concluded her interview by revealing how her family continues to care for her:

Now, my mother-in-law went outside and she was thinking that I would be all alone by myself [this afternoon]. I think more when I am home all by myself. Now, you came. So, she was happy that I will be busy for one or two hours. Otherwise, she does not go out normally. I told her that she could go out today [laughs].

Summary

The two storylines “dealing with just another health problem” and “surviving a family tragedy” differed in plot, structure and content, yet they also shared similarities. As restitution narratives, the Punjabi women who revealed these two storylines did so with coherence and
confidence, yet, the storylines differed dramatically in the detail and events shared. The Punjabi women who shared these two restitution storylines owned their breast cancer stories and framed these stories as ultimately concerned with health rather than illness. Breast cancer was portrayed as a survivable disease that they storied to be in the past.

A Chaos Narrative

In the previous section, the two restitution storylines the Punjabi women shared situated breast cancer in the past and the women were healthy, looking to the future to be healthy, or carrying on with their lives. In this section, the storyline “never-ending fear and suffering” is discussed as a chaos narrative, where the women conveyed a sense of being “sucked into the undertow of illness” (Frank, 1995, p. 115). Originally a second chaos storyline, “being consumed by the endless worry of breast cancer” was considered. After exploring both storylines in greater detail, however, it became apparent that endless worry can be considered a subplot to the overarching storyline, “never-ending fear and suffering.” This was the main storyline presented by four Punjabi women who participated in this study. Seven other women shared this storyline but not as a main storyline.

Never-Ending Fear and Suffering

The following is a brief summary of the breast cancer storyline “never-ending fear and suffering,” constructed from a number of different stories:

Having that problem was a time filled with fear and suffering for my family, and we worried about what would happen, and thought I might not survive...and it is very hard to talk about. My family attempted to reassure me but we were all suffering so much because my family had to care for me when we were so naïve about this disease. And we all feel worn down by everything now and we are trying to get back to normal...I am
continually worrying that it will reoccur, and I am suspicious that it has spread. I just want to forget about everything but...

Never-Ending Fear and Suffering: Thematic Overview

The Punjabi women who told stories of "never-ending fear and suffering" did so in a disjointed, confusing and chaotic manner, suggesting that there was no clear purpose to their stories. Clarification by the interviewer was sought throughout because these women's stories were often difficult to follow and lacked sequence. Despite seeking clarification, interviewers were frequently unable to discern the events around the woman's breast cancer because it seemed that some women's knowledge and understanding of the treatments they received was limited. It is possible that some women were not informed by their family members, who protected the women from knowing the full extent of their medical condition or the details of their treatments. The Punjabi women who shared this storyline spoke mostly in the past tense but occasionally used the present tense and told their breast cancer stories in a fragmented manner, which lacked consistent structure. Despite being diagnosed two to four year ago, their experiences of breast cancer seemed fresh and difficult to explain, as though the women were still trying to make sense of their experiences. There was no apparent purpose to this storyline, and the women who shared this storyline portrayed themselves as stoic and brave, but also vulnerable and "wounded" (Frank, 1995).

The storyline "never-ending fear and suffering" was evident from the beginning of the women's stories. At the beginning of their interviews, the Punjabi women briefly described their breast symptom experiences and then quickly shifted to focussing on their emotional reactions, in some cases dramatizing their fear, worry, suspicion, and shock of the possibility or diagnosis of breast cancer. Sandeep, a 48 year old woman who had lived in Canada for less than a year, explained her initial reaction when she was told she had breast cancer: "I sort of froze, I was
paralyzed as if some sort of mountain had just been dropped on me.” Gurminder, a 41 year old woman who was working outside her home when she was diagnosed, also focussed on the emotions that marked the beginning of her never-ending fear and suffering. She described in a wavering voice:

It seems like the whole world just came down... it was really dreadful, it was very emotional, it was very upsetting. It’s really hard to...accept, it was really [raising voice to emphasize word]...to hear the words ‘you have cancer’. It was really, really hard. It was kind of shocking.

Throughout their interviews, the women who told this storyline often avoided saying the word “cancer” when referring to themselves.

The Punjabi women told how they quickly agreed to the treatments suggested by their physicians. They described their lives as filled with a deep sense of worry, suspicion, and fear that their cancer was incurable despite reassurance from family members. Preet, a 50 year old woman who had lived in Canada 27 years, was worried she was going to die from breast cancer because her aunt was dying of cancer at the time of Preet’s diagnosis. She recounted her initial thoughts.

I just thought it is just that thing [cancer]. Feelings were bad, right [R: yes]? Because it had happened in the family...we could see that it was going to happen within a month [her aunt’s death]. We could only see the bad news ahead of us. Similarly, I was feeling that I might have to go through the same thing as my aunt did.

Another woman revealed that when she was previously in India, she had heard that cancer was incurable, therefore, when she was diagnosed with breast cancer, she became fearful that she was going to die. The fear of cancer as a “death sentence” prevented some women from disclosing their breast cancer diagnosis to certain family members because they wanted to protect them from worrying. Some women also kept their breast cancer diagnosis hidden from friends and community members because of the fear and stigma associated with “such an ugly disease.”
In the storyline, “never-ending fear and suffering,” the women portrayed their families and close friends as reassuring, providing them with much needed encouragement and support. Throughout her interview, Sandeep, a recent immigrant with little family close by, repeated how important it was for her to hear stories about breast cancer survivors to convince her that she could also survive.

[They] gave me a lot of support and encouragement. They told me about cases in their families and how the women in their families had beaten the cancer. That was helpful for me. For some women, they had been cancer-free for twelve years, eight years. Hearing about their stories gave me lot of hope.

The women who told stories reflecting this storyline also portrayed breast cancer as a painful time for the family members who cared for them. Women described their family members “crying,” “worrying,” and constantly “checking-up” on them. Post-operatively, Preet’s two sons, whom she lived with, were informed by her sister-in-law that Preet had breast cancer. She explained: “When they [her sons] found out about it, they went to the hospital and cried a lot and got very upset.”

The stories of the pain and suffering caused by their treatments were not as vivid or detailed as the stories told by the women with the storyline “surviving a family tragedy,” rather, they were disjointed and chaotic. They conveyed a sense of being consumed by their suffering, which was difficult for them to discuss because it brought painful emotions to the surface. Gurminder, who underwent a lumpectomy, chemotherapy, mastectomy, and then radiation, described chemotherapy as unrelenting as she recalled being sick and nauseated for six months and crying all the time. She also told the interviewer:

It was so hard. I find ... it’s really as difficult as you think, “Oh, are you gonna make it through the 6 months? Are you gonna make it or not?” It was really hard. Chemo is the hardest thing.

The only time in Sandeep’s interview that she talked about her chemotherapy was when she mentioned that she did not think she would survive having cancer again.
I mean I was able to beat it this time around but I don’t think that I could survive another attack of cancer. The chemotherapy was the most difficult, I don’t know if I could go through that again. I mean even my nails went black. The chemotherapy was very painful, very painful. I just keep hoping that the cancer will not return. That is what worries me the most about my situation now.

Although treatment was now over for all of the women, having breast cancer is still an ongoing and painful process for them and their families. Along with being worried and fearful about recurrence, the women mentioned struggling with financial difficulties because they were unable to work, felt weak, and continued to experience physical pain since having breast cancer. The women conveyed a sense of being worn down by the physical and emotional suffering caused by breast cancer and struggling to move on with their lives. Preet explained that:

For a year, you know, I could not sleep very well...what if that happened to me. Because it [cancer] had started from breast for my aunt. Then I used to think...what if...aunt had breast and then it spread...what if it happened to me.

Since having breast cancer, some of the Punjabi women reported doing frequent breast self exams, a few times every day or week. Sandeep stated that, “I do it [breast self exam] whenever I think about it. Sometimes I feel my breast on a daily basis, sometimes even two or three times a day.” Women conveyed that they were making an effort to cope with having breast cancer by going to social events, going to the gurdwara (Sikh temple), and trying to forget about breast cancer. Only one woman attended a support group, which she continued to do at the time of the interview. Gurminder explained struggling to move on with her life:

It’s scary, yeah. I do get emotional, even now. On and off. It’s very upsetting. I just try to... keep myself busy and happy. Yeah. I just want to live in the pa-, in the... present. [RA: Present. Yeah.] Not in the past.

Never-Ending Fear and Suffering: A Chaos Narrative

The structure, content, and plot of the storyline “never-ending fear and suffering” was consistent with the chaos narrative. This storyline was disjointed and events were recounted out
of order, with limited coherence or chronological sequence, reflecting a lack of structure. The
Women often left sentences unfinished and interrupted their own telling of their story with other
experiences of worry, fear, pain, and anxiety. Even after seeking clarification, the interviewers
often had difficulty fitting together the pieces of women’s stories. Chaos narratives are
considered anti-narratives because of the storyteller’s lack of reflexivity (Frank, 1995). The
Women attempted to portray themselves as strong, but actually conveyed a sense of
vulnerability, and a loss of control over their previously predictable lives. They were unable to
minimize their breast cancer and conveyed passivity in relation to their suffering because of
feeling helpless, unlike the women who accepted illness because of kismet. Although the women
reported having trust in western medicine, they also described having serious doubts of their
physician’s ability to cure them of breast cancer and to prevent recurrences in the future. This is
consistent with the chaos narrative, which presupposes a sense of helplessness where the ill
person’s loss of control is complemented by medicine’s inability to control the disease (Frank,
1995).

According to Frank (1995), the plot of the chaos narrative “imagines life never getting
better,” as opposed to the restitution narrative where illness is transitory. While the women
attempted to tell a restitution narrative by explaining that they tried to forget about breast cancer,
they were unable to do so because they remained consumed with fears of recurrence, still felt
physically and emotionally “wounded,” and had not yet made sense of their breast cancer.

Never-Ending Fear and Suffering: Exemplar Summary Story

Narinder was a 53 year old woman who immigrated to Canada 11 years prior to
developing breast cancer. She lived with her husband and four grown children. Narinder
completed some high school in India, and was working outside the home prior to having breast
cancer. When asked about her breast symptoms at the beginning of the interview Narinder
explained, “I went to see the doctor in June. My arm was aching. The doctor told me that the pain could be due to the lump. Then, the doctor examined me and asked for the operation.” She remembered feeling pain under her arm but attributed this to “heavy lifting or doing some heavy work.” The events that transpired around her diagnosis and treatments were unclear but Narinder underwent two operations. She recalled her first operation: “They [her doctors] are more suspicious that there could be a lump in the underarm. But they could not find about it. They did my operation but my arm kept aching.” The surgeon, she explained, attributed her ongoing arm pain to a “cut nerve” and recommended a second operation. Fearing that the cancer “could have spread in the blood,” she had the surgery on her families’ insistence. The three months wait for chemotherapy was long and difficult. Alone at home, because she was unable to work, worry filled her day. Mostly, she worried about metastasis: “I was scared that it might be something wrong and it may get into my stomach. I was just suspicious.” She stated, as a matter of fact, that the attempts by her family members to reassure her had little effect.

Narinder recalled receiving three or four chemotherapy treatments followed by fifteen or sixteen radiation treatments. Descriptions of her chemotherapy, however, were chaotic and disjointed.

I got fever. I used to vomit and could not eat anything... I could not swallow anything, not even water for three or four months. Then I told my doctor. He said that was due to the side effects of the medicine. I was very weak.

She frequently switched between re-telling her experiences and those of her family. Her descriptions of their response to her breast cancer were analogous to her own. She described her children as “afraid” and “crying all the time,” and her family as “worried.” When asked how her family supported her, Narinder said they helped her a great deal but then went on to talk about her side effects. “I was very irritated. I could not swallow anything. I was just so anxious and worried. I did not have any hair. Whenever I remember this, I just hope that nobody gets this.”
Later, we learn that Narinder’s sons accompanied her to the hospital because she could not drive or communicate in English and that one son quit his job to do this. Narinder emphasized that she did not tell her mother about her breast cancer diagnosis but does not tell us how her mother found out. When asked whether she told others she had breast cancer Narinder gave the impression that the word spread, “Yeah, they found about it. They used to ask my mom on the phone. If one person knows about it then it spreads.” Narinder also admitted to trying to hide herself from others in what appeared to be an unsuccessful attempt to protect herself from the stigma of cancer:

When my brother’s mother-in-law called at our house, I just hid myself in the bathroom. My kids were with me. They were crying. I was also crying... Like you know, this is such an ugly disease. You never know if someone would survive or not.

Narinder recalled being scared of receiving radiation treatments because she was told by a family member that the machine might “hit her in the face.” When this did not happen she decided to try to ignore others’ stories about cancer for her own peace of mind. Yet, peace of mind was difficult to find even as she began to re-engage in regular activities.

Doctor had told me that I might get flu from someone in the gurdwara [Sikh temple]. One day I went to gurdwara, I got sneezes. My family members got scared that I might get sick. It was my kid’s birthday; so I wanted to go there. Even though I came back right away... it was packed there and I had covered my face but... I want to go out but I am scared.

Now, four years after her diagnosis, Narinder has started to go out again. She feels badly because her breast cancer treatments have caused financial difficulty for the family. There has been the cost of expensive medications and both her and her son lost their employment. Narinder explained:

I talked about it [the cost of her medications] to someone in the hospital and he said something about applying somewhere. [My] kids know about it but I do not know how to go there and apply. He [husband] was thinking that I might be able to get back to work... Medicines are expensive but I have to take it. You know, it is so hard... you have to pay the rent, bills and everything... and what can you do with one person’s payment? These days I just get very irritated.
Narinder considers her story by suggesting her breast cancer is not over. She remains frightened about recurrence, weak from the treatments, and uncomfortable because of the persistent pain in her arm.

**Summary**

The chaos narrative with the storyline “never-ending fear and suffering” differed from the two restitution storylines discussed previously in several ways. In this storyline the pain and suffering associated with breast cancer was not in the past. The Punjabi women’s stories were fragmented and chaotic, with the constant interruption of stories with other stories. The women conveyed emotional upheaval evident in their difficulties recounting painful events and their stories of the never-ending fear of a cancer recurrence. These women remained “wounded” in this storyline, unable to make sense of their breast cancer, and their struggle with breast cancer seems never-ending.

**A Quest Narrative**

The Punjabi immigrant women who participated in this study rarely shared quest narratives and only one storyline was a quest narrative. The theme of this storyline was “a lesson from God.” Only one woman revealed this as her main storyline, but it was a powerful and rich story that could not be ignored. Six other women shared elements of this storyline but not as a complete quest narrative. To explain this storyline the thematic outline and exemplar summary story will be combined because the storyline is largely based upon one woman’s story.

**A Lesson from God**

The storyline “a lesson from God” can be summarized as follows:

*When I was diagnosed with breast cancer I knew it was part of my kismet and that whatever was going to happen was in God’s hands. I meditated, prayed, and saw my desi*
doctors but my family insisted I also see a Western doctor and have conventional treatments. These treatments were difficult for the family but I learned to slow down and strengthen my faith to get through these hard times. Looking back on my breast cancer I believe it was an important lesson from God.

A Lesson from God: Thematic Overview

The storyline “a lesson from God” was a spiritual tale from the beginning. Manjit was a 54 year old Punjabi woman who had immigrated to Canada 29 years prior to developing breast cancer. She was married and lived with her husband, son, and in-laws. She received some elementary school education in India and was working part time outside the home prior to being diagnosed with breast cancer. Her story was situated in her past experiences of other illnesses and her use of prayer and meditation to ensure her recovery. She began her story by attributing breast cancer to her kismet and reiterating her unfaltering belief that the outcome was in God’s hands. Manjit explained that she had “shooting pain” in her chest but “wanted to ignore the pain” and she continued working. She later discovered a breast lump: “One day I kind of felt this lump in my breast and I told my husband that night. And he immediately wanted to take me to the doctor.” Following testing, Manjit described being informed of her breast cancer diagnosis from her husband, whom the doctor had phoned. She reassured him: “I told him not to worry so much... Whatever is going to happen, is going to happen. It’s in God’s hands. God does everything; it is not up to us to do anything.”

Manjit portrayed herself as a self-assured woman with unwavering faith, which she suggested provided comfort during difficult times. She believed in the power of prayer and provided examples of how others, as well as herself, were able to control various ailments through meditation and prayer. Manjit had thought she could “cure herself” of breast cancer with her “will-power” and through meditation and prayer, but her family insisted she seek
conventional cancer treatment from Western doctors. “My inner voice told me that if I wanted to
cure myself that I could. But my husband insisted that I go see a doctor. Also my sister-in-law
encouraged me to seek professional help.” Although she followed her family’s advice, her
resolve to do everything she could to heal herself did not weaken. Manjit included her family in
her story of breast cancer, but her spiritual journey was more of an individual journey, which her
family played a lesser role in.

This woman portrayed a strong sense of personal agency throughout her interview and
provided numerous examples of trying to maintain control over medical and personal decisions.
Manjit described being treated throughout her breast cancer by two desi doctors, but did not
disclose this to her Western physicians. She offered praise for all Western and desi doctors but
also questioned the Western medicine and the motivations of Western physicians. Manjit stated,
“No, I don’t think that I ever really believed that I had cancer. No I still don’t believe it.” She
also said that, “Sometimes I think that maybe the doctors just make up these things to make their
business grow. Like I don’t even understand what cancer is.”

In the storyline “a lesson from God,” little attention was paid to the details of breast
cancer treatments, and a spiritual story was relayed rather than a medical story. Manjit’s
explanation of her surgery and post-operative course was matter-of-fact and unembellished.

Then they did the surgery to remove the lump and I stayed at the hospital for some time
after my surgery and then I came home. Then a nurse used to come to my home to check
on me. She would change my dressing and stuff like that.

Yet, this woman described the pain and suffering she encountered with treatments, particularly
chemotherapy, as a call for personal change and spiritual action. Turning to God became her
solution to this crisis and was presented as the turning point in this storyline. As Manjit
recounted her experiences, her increasing reliance upon God became apparent.

The pain became very unbearable for me, and I kept praying to God. I kept asking God to
save me from this pain, I kept saying that I did not want to die in the hospital. I began to
barter with God. I said save me from this pain and I promise to go to the gurdwara everyday. I began to do paath [reading from Sikh scripture]... When you believe in God, and really have faith in him then half of your problems [ills] go away. If you believe in God then you can be cured from your pain.... There is no problem that God cannot cure.

Manjit also worked hard at staying optimistic and surrounding herself with positive people. In reflecting back on her experiences, she had personal advice for others with breast cancer, further emphasizing the responsibility women have for their own health without burdening others.

You should believe that you are going to get better. You will get better.... Moreover, you should stay happy. Have nice interactions with your children. Like sometimes you do get very angry when you are undergoing chemo but try not to get into the anger. Keep a happy face on.

Throughout her interview, Manjit emphasized the importance of meditating, praying, and going to the gurdwara (Sikh temple) as important sources of support. But, she also referred to the hope and encouragement she received from her family. Manjit’s sister-in-law had been cancer free for 11 years and she drew strength from her. Her husband and children also provided practical, emotional, and physical support.

Like my husband gave me a lot of support. He massaged my feet, he massaged my back. He gave me a lot of support. He gave me so much help that I cannot even begin to tell you how helpful he was for me. I think your husband can give you lots of support. If the husband or wife is not supportive towards each other then I think the person can become even more ill.

Manjit also described how her family helped her to prepare for breast cancer treatments.

They [doctors] gave me books on what to expect. But you see, I don’t know how to read English. But my husband and my children read the books and they told me what to expect and they explained to me what could happen.

Manjit’s spiritual journey entailed facing the adversity of breast cancer and using this experience to learn how to be a more devout person. Though breast cancer was constructed in the past, Manjit saw her life as forever changed, with a renewed sense of faith. Manjit shared the abstract of her story toward the end of her interview:
I think that God wanted to teach me something, like he punished me so that I would learn something, maybe I had done something wrong. Maybe I was to learn to meditate more strongly, maybe God wanted me to strengthen my faith in him. I don’t know. Like, God I think that if you don’t listen to God then he has ways to make you listen. Like, God can find a way to control you, like in my case, when I got cancer then I was forced to slow down. You see everything happens for a reason.

**A Lesson from God: A Quest Narrative**

The storyline “a lesson from God” was structured as a quest narrative. Central to the quest narrative is the usefulness of illness. In this storyline, illness was useful in initiating the spiritual journey that resulted in a renewed and enhanced religious faith. The woman who told this story did so with a controlled, distinct voice. She was clear in the story she wanted to tell and could not be convinced to alter the point of their story. During the interview with this woman, the interviewer often attempted to probe for specific details of her breast cancer experience, yet she resisted and continued to story her spiritual journey.

The plot of this storyline was consistent with the three stages of the quest narrative structure: departure, initiation, and return (Frank, 1995). The initial stage of departure from health included the dismissal of breast cancer symptoms as well as the seriousness of the breast cancer diagnosis. This woman accepted her breast cancer as God’s will and her fate. The pain and suffering associated with surgery and chemotherapy marked the beginning of initiation, requiring self-transformation attainable only through the spiritual acts of paath (reading of Sikh holy scripture), meditation, positive thinking, visiting the gurdwara (Sikh temple) and enhancing one’s faith. The end of the journey brought what Frank (1995) called the ‘boon,’ where the storyteller implied that she had been given something by the experience, insight that must be passed on to others. In this story, this woman saw herself as becoming more devout, and she conveyed a renewed and strengthened religious faith. She positioned herself as an advice giver who wanted to pass on her insights about the importance of a strong belief and commitment to
God in overcoming illness. This woman portrayed herself as a survivor who was no longer ill, but also someone who was changed from having had breast cancer. This marked the stage of return in the quest narrative.

Summary

The storyline “a lesson from God” depicted the experience of breast cancer as a spiritual journey. The woman who told this story learned to slow down, listen to God, and strengthen her faith all because of her diagnosis of breast cancer. This woman’s breast cancer story was inseparable from her stories about turning to spirituality and the meaning of her breast cancer was intertwined with her religious Sikh beliefs.

Minor Theme

The following section focuses on the minor theme “being part of a close-knit family.” The role of family was briefly discussed earlier in this chapter, in relation to the four storylines. This minor theme, however, was woven throughout all twelve interviews, irrespective of the storylines revealed by the women. The family context was the most pronounced and frequently mentioned influence on the Punjabi women’s experiences of breast cancer.

Being Part of a Close-Knit Family

The Punjabi women in this study portrayed their families as an integral part of their stories of having breast cancer. This minor theme was introduced at the beginning of the women’s stories of finding breast symptoms and was incorporated throughout their stories of having breast cancer. Some women used the noun “we” when referring to actions or decisions surrounding their breast cancer, highlighting the collective experience of their breast cancer. Repeated praise for family members support and assistance reinforced the women’s positioning as part of a ‘good family’. Only one woman relayed a negative story about her in-laws, and then immediately told a story portraying her family in a positive light. There was a matter-of-fact tone
to the way women constructed their experiences of breast cancer within their close-knit families. They did not question family members’ involvement in discussions about their treatments. The women depended on and accepted their advice and assistance on matters related to breast cancer, just as they would about other matters in their lives. Four women in this study described how another family member, rather than themselves, was the first person to be informed of the woman’s breast cancer diagnosis by the physician. They presented this as common place, with family members fulfilling expected roles in Punjabi culture.

The women also described their family members providing them with much needed advice about the appropriate course of action to treat their breast cancer. For example, Harjop’s family advised her to seek a second opinion and to see a naturopath. Manjit and Renu’s families insisted they accept medical treatments, Sandeep’s son and husband advised her to “have surgery quickly,” and Baljit’s brother-in-law suggested she take part in a clinical trial. Without exception, all women suggested that they heeded the advice of their caring families. Manjit explained, “You have to listen to your partner, right? If you don’t listen to your partner then you have problems.”

The Punjabi immigrant women in this study portrayed themselves as women who protected their close-knit families from worry and suffering, which lead them to consider to who they would disclose their breast cancer diagnosis. The women may also have been maintaining their families’ honour and protecting their family members from the stigma associated with cancer by limiting who was told outside of the family. Decisions about disclosure, however, were often made as a family, or influenced by family members. Aman revealed how her daughter-in-law advised her not to disclose her breast cancer to anyone outside the family.

The only one that was a bit cautious was my daughter-in-law, my son’s wife, she said, “Mom, don’t tell anyone that you have this problem because when people hear this they’re going to say, ‘Haah, you know, poor thing, she’s got cancer. She’s not going to live.’”
Baljit told the interviewer how she was reluctant to tell her parents in India that she had breast cancer, but her husband insisted they be informed. “We had to tell them. I was thinking of not telling them. But he [her husband] said that it is necessary.” Manjit shared her initial reluctance to tell her children that she had breast cancer, but that her husband advised her otherwise.

I told my children, well actually before telling my children, my husband and I talked and we asked each other as to who we should tell, I did not really want to tell my children because I knew that they would really worry about me, but my husband said that, “sooner or later you are going to have to tell the children.” He encouraged me to speak to the children about the cancer. My children do not give me any trouble, they do not want to make my life difficult, they are good children. I listened to my husband, then we called all of the children and we sat down as a family and told them that I had cancer.

The women depended on family members to advocate on their behalf, speak for them at appointments with health care professionals, and assist them in getting the care they needed. Although some women were dependent on their families to communicate with health care professionals because they did not speak or understand English and translators were not always made available, others felt they would not be listened to unless a family member was present.

Family members were described as providing unwavering practical, emotional, and physical support. The women recounted how family members drove them to appointments, provided language translation, helped with housework and looking after their children, and sat with them through treatments. Many women told stories of family members physically caring for them, providing encouragement, and reassuring them when they felt discouraged. Some women attributed their survival to their families. Renu was initially very depressed because of the death of her husband and sister, and she described finding the will to live from her other family members when she was diagnosed with breast cancer.

I thanked God for giving me cancer because I thought good, I will die. I will be with my family now. After, my family advised me not to do this. They told me to go to the doctor if the doctor wanted to see me and that they would have my treatments done. I went to
the doctor at their request. At that time, I made myself emotionally strong... I was not going to die. If I had family, I should live for them.

Part of being a close-knit family also meant that the women’s families experienced distress and upheaval with their diagnosis of breast cancer. Manjit described the effects of her breast cancer on her parents:

My parents love me very much. Especially my dad, my dad is very close to me. Like my dad prior to my surgery, he just would not eat, he was very worried about me and then when I finally had my surgery and everything went well, then he started to come around. He was too worried to even eat. My dad has a very strong mind but even so because he was so worried about me that he began to become weaker and weaker. My father loves me very much [still crying].

Knowing they could count on family support, the majority of women turned down offers of professional support, explaining that this was unnecessary because they had their families. Preet stated:

They [health professionals] offered us, “If you needed any help, rides, or any other help then come and tell us.” I did not need anything because our family is very big. My aunt’s daughters also work in the hospitals; so if I needed any help, they used to help me.

Only two of the twelve women in this study shared stories of receiving support other than from family and friends. Parveer told the interviewer that she accessed the volunteers on a few occasions to drive her to chemotherapy sessions because her family members were ill. Gurminder attended a breast cancer support group she found helpful. Although all women portrayed their families in a positive manner, some women hinted that they were reluctant or discouraged by other family members to access professional support outside the family. Two women mentioned feeling lonely and wanting to return to work so that they could either forget about breast cancer or talk to their co-workers, but their families insisted that they stay home. Other women tried unsuccessfully to obtain needed support. For example, Prem also attended a support group meeting but found she “got depressed from listening to them talk.” Sandeep, who
had immigrated to Canada only a few months prior to being diagnosed with breast cancer, and
did not have many family members close by, was unable to get help when having difficulties.

My first dosage of medicine was approximately $250. Then we wrote a letter to welfare
saying that it was difficult for us to pay that amount of money for the medicine because
we were recent immigrants and consequently were not yet working. They were able to
reimburse the money for that medicine. Then I also told them that I needed some help at
home because I was unable to do any of the housework, and also I was paying close to
$300 a month for taxi to get to and from my appointments but the welfare people told me
that they could not help me with that.

Summary

The minor theme, “being part of a close-knit family” suggested that breast cancer was
experienced collectively, as well as individually for the women in this study. The ideals of what
constitutes a ‘good Punjabi family’ were reflected in the women’s stories of decision making and
support received when they had breast cancer. The context of family was the most frequently
discussed influence on women’s experiences of breast cancer. Therefore, the meanings of breast
cancer reflected in women’s stories were shaped family values, beliefs, and experiences. Despite
the family support provided, some women lacked appropriate support.

Summary of Findings

Four storylines and one minor theme emerged from the narrative analysis of transcribed
interviews for the 12 Punjabi women who had breast cancer. The storylines were categorized by
the narrative type; restitution, chaos, and quest. The first storyline discussed, “dealing with just
another health problem,” was a restitution narrative derived from stories about breast cancer
being in the past and just another health problem among other health problems. In the second
storyline, “surviving a family tragedy,” also a restitution narrative, women described enduring a
great deal of suffering but they storied as though they were in the process of returning to health.
The third storyline was a chaos narrative and “never-ending fear and suffering” was derived from
stories of being consumed by breast cancer, which continues to feel ongoing and painful. Women with the last storyline, “a lesson from God,” depicted having breast cancer as useful for their spiritual journey, consistent with a quest narrative. The minor theme “being part of a close-knit family” was woven throughout women’s stories, highlighting the significance of the family context on women’s breast cancer experiences.
CHAPTER FIVE: DISCUSSION AND IMPLICATIONS

This final chapter begins with a brief summary of the findings from this study that were presented in Chapter Four. A discussion of the most relevant findings are then highlighted and explained in relation to existing breast cancer research literature. Limitations of this study are then described, followed by a discussion of the implications the findings have for nursing practice and research.

Summary of Findings

The purpose of this study was to develop an understanding of the meanings of breast cancer to Punjabi immigrant women. This investigation involved a secondary analysis of interview data that had been collected for a previous study researching South Asian immigrant women's responses to self-discovered breast changes. The Punjabi immigrant women in the primary study whose breast changes resulted in a breast cancer diagnosis concurrently told their stories about, and experiences with, this disease. The storylines, narratives, and themes that emerged from the narrative analysis of the interview transcripts conveyed the various meanings, identities, and contexts shared by the Punjabi immigrant women in this study. It is noted that breast cancer held different meanings for the participants in this study and these meanings also shifted throughout women’s stories.

The storyline “dealing with just another health problem” was derived from stories about breast cancer being treatable, transitive, and just another health problem among other health problems. Experiences of breast cancer were constructed in the past and this storyline, as a restitution narrative, was about carrying on with life as it was before breast cancer. In the second storyline, “surviving a family tragedy,” women vividly described themselves and their families enduring a great deal of pain and suffering because of breast cancer, and ultimately rising above
and surviving. Although these women did not see themselves as completely healthy, they told their stories as though they were in the process of returning to health. This storyline was the second restitution narrative that emerged in this study. The third storyline was a chaos narrative. The theme of this narrative, “never-ending fear and suffering,” was derived from disjointed, emotional stories of being consumed by breast cancer. The women whose stories made up this storyline portrayed themselves as “wounded” and although treatments were completed, breast cancer continued to be an ongoing and painful part of their lives. The fourth storyline, “a lesson from God,” depicted having breast cancer as a spiritual journey. This storyline about breast cancer focused on learning to turn to God during difficult times and renewing one’s religious faith. The positive changes experienced because of breast cancer in this storyline were consistent with a quest narrative. The minor theme “being part of a close-knit family” was woven throughout women’s stories, highlighting the significance of the family context on women’s breast cancer experiences. The cultural and life contexts in which breast cancer occurred for the women in this study were reflected in the findings throughout the three narratives, four storylines, and the one minor theme.

The Meaning of Breast Cancer

This investigation is the first systematic exploration of Punjabi immigrant women’s experiences of breast cancer. The four storylines that emerged from this study reinforce what has been written about the meanings of breast cancer in other breast cancer populations and also contain novel ideas that go beyond the current literature. Some significant issues that emerged from this study are reflected upon and discussed under the following four headings: breast cancer narratives, Punjabi culture and breast cancer, breast cancer in a family context, and health care system issues.
Breast Cancer Narratives

The stories the Punjabi immigrant women in this study constructed were both similar and different to stories told by women in other studies. Although the women in this study told stories that reflected the universal narratives of restitution, chaos, and quest, the four storylines within the narratives represent the unique ways Punjabi women in this study made sense of their breast cancer experiences. This investigation is a good illustration of the overarching relevance of Franks (1995) three narrative types of restitution, chaos, and quest across cultures and illness experiences. Yet, this study also illuminates some of the unique ways that Punjabi women’s stories were constructed using storytelling devices available and learned within the cultural context. The cultural context influences the structures of stories and the metaphors and imagery used in storytelling about breast cancer, as well as the standards of what is and is not appropriate to discuss (Frank, 1995).

In other breast cancer research, the restitution narratives of women move quickly through diagnosis and treatment, and women reintroduce themselves as healthy, with their focus on the acknowledgement of having been ill and now being ‘normal’ (Thomas-MacLean, 2004). The Punjabi women in this study with the storyline “surviving a family tragedy” similarly acknowledged having been ill with breast cancer and returning to their previous state of health, yet, their stories did not move quickly through diagnosis and treatment. Rather, theirs were embellished, vivid, and detailed stories. The Punjabi women who shared the storyline “dealing with just another health problem” moved quickly through telling about diagnosis and treatment, similar to the restitution narratives of the women in Thomas-MacLean’s (2004) study, but were more intent on minimizing rather than acknowledging having been ill because of breast cancer.

Some of the Punjabi women hinted that the development of their restitution stories was influenced by family members favouring stories about health rather than stories about breast
cancer. The favouring of restitution narratives has been documented with others who experience illness (Frank, 1995; Thomas-MacLean, 2004). Yet, family members do not figure as predominantly in some women’s breast cancer stories as they did in the stories told by the Punjabi women in this investigation. Research with other women has also indicated that those who told restitution stories about their breast cancer were concerned about the appearance of their chest as ‘normal’ through the use of a breast prosthesis to reconstruct the look of the chest (Thomas-MacLean, 2004). Conversely, the Punjabi women in this study never mentioned the appearance of their chest or the use of prostheses; their restitution narratives centered on their roles within their family, participation in community and social activities, and other health problems.

The chaos storyline shared by the Punjabi women in this study, “never-ending suffering,” was similar to the chaos narratives seen in studies of other women with breast cancer with regard to structure, the lack of coherence, fragmentation, the mixing of tenses, and the interruption of stories (Frank, 1995; Thomas-MacLean, 2004). The reasons the Punjabi women constructed chaos narratives, however, were different than for other women with breast cancer. Women in Thomas-MacLean’s study were reported to recount their experiences as chaos narratives most often when speaking about bodily difficulties (e.g., reactions to medications, side effects, and surgery) and their family’s difficulties. Some of the Punjabi women’s chaos stories contained similar descriptions, although they may have been constructed as chaos narratives because women lacked a clear understanding of their breast cancer diagnosis and treatments. Most of the women received care through translators because of their lack of fluency in English. When family members act as translators there is increased potential for censorship of information because of norms related to family members assuming responsibility for making health care decisions for women and the importance of maintaining hope for recovery, as well as difficulties
relaying medical explanations or sensitive information (e.g., about women’s breasts) (Anderson et al., 2003; Grewal et al., in press). Language barriers and the nature of their interactions with health care professionals may have contributed to women’s difficulty in telling their stories in a coherent manner. Native American, Asian American, and African American women in other studies have also encountered difficulty understanding their breast cancer diagnosis and treatment options due to a lack of effective communication and language barriers (Ashing et al., 2003; Ashing-Giwa & Ganz, 1997; Colomeda, 1996).

Most published illness stories, including breast cancer stories, are quest stories (Frank, 1995; Thomas-MacLean, 2004). Yet, in this study, there was only one quest narrative constructed by one woman with the storyline “a lesson from God.” The cultural consultant to this investigation, however, expressed surprise that more women had not shared this storyline because a number of the Punjabi women she had cared for expressed related quest stories (S. Grewal, personal communication, July, 2004). Similar to research findings with Native American, African American, and Asian American women (Chui, 2001; Howard et al., 2003; Kiser-Larson, 2002; Matthews et al., 1994), the potential for experiences of breast cancer to contribute to spiritual growth is evident in this study. One type of quest narrative discussed by Frank (1995) is the manifesto that supports a “demand for social change” (p. 120). Other researchers have documented women’s desire and commitment to social change following their breast cancer treatment through actively helping others struggling with the disease (Arman & Rehnsfeldt, 2003; Coward, 1998; Nelson, 1996; Thibodeau & MacRae, 1997). None of the Punjabi women in this study, however, shared manifesto stories. This was not surprising considering the stigma and secrecy associated with breast cancer in some Punjabi communities and that South Asian women’s strong commitment to family needs often overshadows their own health needs (Ahmed & Lemkau, 2000; Choudhry et al., 2001).
**Punjabi Culture and Breast Cancer**

The stories the women in this study constructed were shaped by Punjabi culture and these stories offer “an avenue for linking personal experiences to cultural knowledge, norms, and tenets” (Garro & Mattingly, 2000). Cultural norms, values, and beliefs favoured the telling of breast cancer stories in particular ways, illuminated certain events and experiences, and also restricted certain stories. Throughout the Punjabi women’s interviews, women often avoided saying the word “cancer” and referred to their cancer as “it,” “that thing,” “that problem,” “that disease,” and “an ugly disease.” This hesitancy to mention the word “cancer” seemed to reflect women’s fear of the disease and their discomfort in talking about cancer. In other research with healthy South Asian women, researchers reported that open discussions about cancer are often discouraged because of fear of fating cancer on oneself (Bottorff et al., 1998; Johnson et al., 1999; Choudhry et al., 1998). In this study, some of the Punjabi women were very worried about having a recurrence of their cancer and may have feared fating the recurrence of their breast cancer by talking openly about breast cancer. The reluctance of women to say the word cancer may also reflect the stigma attached to the word, which women resisted and did not want to incorporate into their identities. For example, although some women referred to themselves as survivors, no woman in this study ever referred to herself as a “breast cancer survivor.” This runs contrary to some of the published breast cancer research where Caucasian women are sometimes reported to be proud of having survived the disease (Arman & Rehnsfeldt, 2003; Coward, 1998; Nelson, 1996; Thibodeau & MacRae, 1997).

Researchers have documented women’s concerns about the impact of breast loss on their self-worth, body image, sexuality, and femininity as being paramount in their breast cancer experiences (Ashing-Giwa & Ganz, 1997; Lackey et al., 2001). Concerns about losing a breast, or their husband’s reactions to their breast loss were not included in these Punjabi women’s
stories of breast cancer. In fact, it appeared that the women avoided attaching much significance to their breast(s) and were more concerned with cancer as a life-threatening disease. Only one woman in the study hinted that she was concerned about what her husband’s reaction to her breast surgery would be. The women may not have directly discussed these concerns because such topics are considered private and there may have been discomfort in sharing this information with a stranger. These findings are consistent with research indicating that talking about breast(s) is difficult for healthy South Asian women because of tendencies to be modest and to maintain family honour (izzat) (Bottorff et al., 1998; Bottorff et al., 1999; Choudhry et al., 1998).

Some Punjabi women did share stories of the significance of losing their hair, suggesting hair loss was more acceptable to discuss than breast changes or loss. In other research literature, African American (Chamberlain Wilmoth & Sanders, 2001; Lackey et al., 2001) and Chinese women (Lam & Fielding, 2003) found their hair loss to be extremely upsetting. For Chinese women, hiding this symptom of cancer and cancer treatment was considered important because breast cancer carried a stigma that undermined personal and familial integrity and could lead to social exclusion (Lam & Fielding, 2003). Hair loss for some of the Punjabi women in this study was particularly upsetting and a serious concern because many of the women conformed to the customary Sikh practice of not cutting their hair. Traditionally, cutting one’s hair is considered a violation of Sikh beliefs and is thought to bring bad karma (destiny based on one’s deeds in present and past lives) later in life (Nayar, 2004). For some of the participants in this study, loosing their hair threatened their identity as spiritual Sikh women and may have contributed to feelings of guilt and shame. One woman who was distressed about losing her hair hid when visitors came to her home.
A number of the Punjabi women in this study presented themselves as spiritual women who attributed their breast cancer to their *karma* (destiny based on one’s deeds in present and past lives) or *kismet* (fate), yet many women appeared to use these terms interchangeably. Healthy South Asian women in other studies have identified *karma* and *kismet* as causes of cancer (Bottorff et al., 1998; Johnson et al., 1999). Attributing their breast cancer to their *karma* or *kismet* was a belief that ran parallel to other beliefs about the cause of their cancer, such as hormone replacement injections, trauma to the breast, not having breast fed, or having a poor diet. Holding these contradictory beliefs about the cause of their breast cancer suggested that these women were continuing to make meaning of their breast cancer. Holding contradictory beliefs about the cause of breast cancer has been documented by other researchers with African American women (Matthews et al., 1994). The Punjabi women also believed that the outcome of their breast cancer and the possibility of recurrence were determined by what was “written in their *kismet*.” This belief presupposes that there is little a woman can do that will change what is predetermined by past events and lives, although through prayer and spiritual practices women believed they influenced their future *karma* and *kismet*. This provided some women emotional support and peace of mind. Similar to research with Native American, African American, and Asian American women, these Punjabi women drew strength from spirituality (Ashing et al., 2003; Chui, 2001; Henderson et al., 2003; Howard et al., 2004; Kiser-Larson, 2002; Mathews et al., 1994). In these studies, spiritual beliefs and practices, such as prayer and consultations with spiritual leaders, were a source of emotional and inner strength which lessened their fears of dying, helped them to maintain a positive outlook, and supported adjustment to their breast cancer diagnosis.
Breast Cancer in a Family Context

In South Asian culture, of which Punjabi women fall within, the family is the most important social unit and provides the basis of an individual’s identity (Assanand et al., 1990; Choudhry, 2001). This was evident in the stories constructed by the Punjabi women in this study who portrayed themselves as members of caring families who were greatly affected by their breast cancer. Research with South Asian women has indicated that household needs are considered paramount compared to personal needs, which are placed behind family well-being (Choudhry et al., 2002). The Punjabi women in this study shared stories of family members making sacrifices, advocating on their behalf, and providing emotional, physical, and practical support, even though family members themselves endured much pain and suffering.

Women conveyed appreciation of their family’s support but also an expectation that family members, especially husbands and other women in the family, would fulfill this role. The Punjabi value of fulfilling one’s dharam (duty) is central to the smooth functioning of the traditional family household and is associated with an orientation to the collective (Nayar, 2004; Shankar, 1997). Looking after ill family members has traditionally been considered part of every woman’s dharam and this may have been reflected in the stories of female family members caring for the Punjabi women during their breast cancer treatments. It seemed that the women considered a good Punjabi family to be one in which family members look after each other. The expectation for family members to provide the women with extensive emotional, physical, and practical support also raises questions about how families cope with this added responsibility, especially considering that they may also be struggling to cope with their family member’s breast cancer.

The disclosure of women’s breast cancer diagnosis outside their immediate or close family was an issue for some of the Punjabi women in this study. Some of the women kept their
breast cancer hidden in order to protect family members from the worry and suffering their breast cancer diagnosis would bring. Women may also have been reluctant to disclose their diagnosis to protect their family members from the stigma associated with cancer. The importance of protecting one’s family from suffering has been documented in other studies with healthy South Asian women (Bottorff et al., 2001; Choudhry, 1998; Choudhry et al., 2002). Chinese women with breast cancer have also been documented as keeping their breast cancer diagnosis a secret to protect themselves and their families (Lam & Fielding, 2003). Although the Punjabi women’s decisions about disclosure were often influenced by family members, secrecy about breast cancer appeared to contribute to women’s feelings of isolation, loneliness, and emotional distress when disclosure was restricted.

The women in this study emphasized that their families provided them with all the support they required, and therefore they declined the support offered by the local cancer agency. Although some women hinted that they still felt isolated, they were reluctant to access support outside of their families. Other women described being encouraged by their family members to put the cancer behind them once treatments were completed and discouraged from discussing their concerns about having had breast cancer. Women who were particularly worried about a recurrence, or continued to experience side effects from breast cancer, were sometimes without the emotional support they required to cope. The women did not directly complain about these circumstances. In part, this may reflect commonly held values about women’s roles. Many South Asian women take pride in their strength and commitment to their families, and women are admired for suffering in silence and enduring physical and emotional pain to protect the family (Shankar, 1997). Limited opportunities for continued storying by talking with others may, however, be a barrier to incorporating evolving meanings of breast cancer into one’s life and identity.
Consistent with Punjabi tradition, a number of women in this study lived with their extended family members who provided practical support by helping with child care, income, household work, transportation, translation, accompanying women to appointments and treatments, as well as financial security. A number of the Punjabi women in this study mentioned the importance of this practical support but also shared stories of practical needs being unmet. Women who did not have extensive family available shared stories of encountering difficulties with housework, expenses, childcare, and transportation. Practical support has been identified by other researchers as a specific need for those receiving breast cancer treatments (Thorne et al., 1999). These researchers suggested that practical support is an issue that transcends the family and may require formal intervention specifically tailored to the unique social circumstances of each woman (Thorne et al., 1999). Some of the women in this study may have benefited from culturally appropriate practical support.

**Health Care System Issues**

The majority of Punjabi women in this study talked about their trust in conventional western medicine and the cancer treatments they received. A few women also consulted traditional desi doctors but this was in combination with conventional treatment, a finding consistent with research on South Asian women’s health practices (Hilton et al., 2001). Trust in western medicine was an important focus in the restitution storylines which reinforced descriptions of unquestioning compliance with treatments and strong beliefs that they had survived the disease.

The Punjabi women in this study also described their interactions with doctors, nurses, and other health care professionals. Some women explained that they learned about their diagnosis from their husbands reflecting how important information is the husband’s privilege in Punjabi culture. Other women shared stories of being sent to the surgeon by their family
physicians unaware of their breast cancer diagnosis because their family physician did not want
to deliver the bad news. Although the women were sometimes confused and shocked when they
learned of their diagnosis, they did not criticise others for the way information was
communicated to them. It appeared as if the Punjabi women did not want to be seen as ungrateful
for the treatments they received, rather, they wanted to show respect for their health care
providers.

Researchers have indicated that breast cancer threatens women’s mortality invoking fear,
uncertainty, anxiety, and depression (Arman et al., 2002; Halldorsdottir & Hamrin, 1996;
Landmark et al., 2001; Landmark & Wahl, 2002; Lyons, et al., 2002). The findings of this study
are consistent with this research. The Punjabi women in this study were also faced with their
own mortality although their fears were grounded in beliefs about the futility of cancer
treatments. Some women indicated that these beliefs were common in many communities in
India. Breast cancer as a “death sentence” carried literal meaning for some of these women,
which has also been documented with African American women with breast cancer (Lackey et
al., 2001; Matthews et al., 1994) and healthy South Asian women (Bottorff et al., 1998).

The desire for active involvement in decision making is evident in the breast cancer
research with Canadian Caucasian women (Degner et al., 1997). A number of the Punjabi
women in this study, however, shared stories of being invited to take part in treatment decision
making but deferred decisions to their physician or to family members. The women in this study,
for example, described leaving the decision of whether to have a mastectomy or lumpectomy, or
to participate in a clinical trial or traditional treatment, to their family members and their
physicians. It may be possible that the women did not feel they had the knowledge to make such
decisions and they believed their family and physician were better equipped to decide, yet some
women hinted that they did not receive the treatment they would have preferred. If women
disagreed with their family members or physician about important decisions, they did not say so in the interviews. Rather, they portrayed themselves as women who expected and respected the advice of family members. Listening to family members and deferring decisions to the family is consistent with Punjabi women's traditional roles (Grewal, 1999; Nayar, 2004). One woman initially decided against conventional cancer treatment but then agreed to accept treatments based on her family's wishes. It is also possible that other Punjabi women may have been discouraged by family members from accepting conventional cancer treatment. For example, one woman indicated that her relatives advised her to seek a second opinion from a desi doctor about alternative treatments for breast cancer.

Although one woman attended a support group for women with breast cancer and spoke favourably about her experiences, two other women attended a support group meeting but thought the discussion was discouraging, depressing, and unhelpful. Other women mentioned wanting to talk about their experiences of breast cancer but mainly limited these conversations to immediate family members. The need for emotional support was alluded to, yet the availability of appropriate, useful, or accessible support was sometimes lacking if family members discouraged women from focussing on their breast cancer. Researchers have shown that group therapy improved Caucasian women's psychological adjustment and quality of life, and decreased distress and pain during breast cancer treatments (Ashbury et al., 1998; Cunningham et al., 1998; Edelman et al., 1999; Goodwin et al., 2001). Similar support group therapy may not be culturally appropriate for Punjabi women with breast cancer considering women's concerns about confidentiality, protecting their modesty, and upholding family honour (izzat). Both Asian American and African American women in other studies wanted support groups with other women of the same ethnicity because they believed their experiences were unique (Howard et
This may hold true for Punjabi women who do wish to partake in a breast cancer support group.

Despite the Punjabi women providing praise for their physicians, nurses, and other health care professionals, there were indirect expressions of dissatisfaction, including discriminatory practices. Hints of dissatisfaction with cancer care appeared to be linked to unmet needs and the lack of culturally sensitive or appropriate health care. Research with women in other ethnocultural groups has indicated that Native American, African American, and Asian American women also received culturally inappropriate health care (Howard et al., 2004). Discriminatory practices by health care professionals have been described as a form of “othering,” the process that identifies those that are thought to be different from oneself and reinforces and reproduces positions of domination and subordination (Johnson et al., 2004). Feeling ‘different’ from other Canadians and being subjected to over-simplified, culturalist and racialized explanations by health care professionals has been documented in other Canadian studies with South Asian women (Browne et al., 2002; Johnson et al., 2004; Ralston, 1991).

Study Limitations

The purpose of this investigation was to explore the various ways Punjabi immigrant women provided stories of their breast cancer and to analyze these stories to uncover the diverse ways these women created meaning from their experiences of breast cancer. This investigation was an ethnographic narrative secondary analysis of interview data from a primary study investigating South Asian women’s self-discovered breast changes.

All of the women who had breast cancer in the primary study were included in this secondary analysis. Although the women included in this secondary analysis were a diverse group (e.g., in relation to their age, education, and years since immigration), they were similar in that they had all disclosed their breast cancer to their immediate families and had received
conventional cancer treatment. There were no women who had completely hidden their breast
cancer diagnosis or refused treatment. Stories of breast cancer recurrence were also missing. All
women in this study were from the B.C.'s Lower Mainland and women's experiences may have
been shaped by the health services offered in that area.

Limited data was collected for the primary study on economic status, class, and
immigration history, and women were not probed for this type of information in their interviews.
This information, therefore, was not available to be incorporated into the analysis and was not
reflected upon in the storylines shared by the Punjabi women. The examination of the influence
of these factors on ethnocultural women's experiences of health and illness has been strongly
argued for (Anderson, 2000, 2002).

The interviews for the primary study had been conducted in Punjabi, translated to English
and transcribed. Because the researcher did not speak Punjabi, she was reliant upon the translated
transcripts and field notes during data analysis, which may have led to alternate meanings and
loss of non-verbal cues. Subtle nuances may have been missed by the researcher of this study
because she was unable to listen to the interviews. To counter this limitation, analysis
concentrated on the meanings of what women had said as opposed to using a close discourse
analysis. When ambiguities occurred in the translated data clarification was sought from Punjabi
speaking research assistants and the cultural consultant to this project.

**Implications for Practice**

The findings of this study have important implications for the way health care is provided
to Punjabi women with breast cancer. Knowledge of the storylines identified in this study
enhances health care professional's ability to recognize the ways women are making sense of
their experiences and to tailor their care accordingly. It may also be possible to help women
construct other versions of their experiences with breast cancer to address their psychological
concerns. The reworking of one’s story through narrative therapy (Freedman & Combs, 1996) may assist women to “overcome disempowering discourses and to establish ways of being that favour individual freedom and choice” (Collie, 2003, p. 159). Furthermore, Frank (1998) argues that:

Telling one’s own story can help move a person through a particularly difficult situation by providing some critical distance. When a story is well heard, it becomes something that teller and listener can talk about and reflect on. When experience becomes an object for what is now a mutual involvement, the teller gains some distance between what is being lived and what is being told. Only at this distance can actions – including interpretations – be perceived as possibly having alternatives, thus making change imaginable. This critical distance is the key to any “movement” that may occur (p. 207).

The language used to communicate about breast cancer with Punjabi women should be selected carefully, acknowledging women’s fears of speaking about cancer. Based on the findings of this study it seems particularly important that information about breast cancer be provided in an easy to understand manner with accurate information about the benefits of treatment. Sharing stories of South Asian women surviving breast cancer with treatment may help to change the perceptions of breast cancer as a “death sentence” to a survivable disease. To enhance support and communication Punjabi women need to be encouraged to bring their family members and allowances made for these members to be included in appointments and treatments. Rather than rely on family members as translators, however, formal translators should be used to facilitate communication between health care professionals and Punjabi women. This may also assist Punjabi women and their family members in understanding their breast cancer as well as their treatments.

Sensitivity to women’s traditional values and roles within Punjabi families must be reflected in the provision of health care, and Punjabi women’s need for modesty and privacy respected. It is important that women and family members be reassured that health care professionals and volunteers will respect and protect the confidential nature of their breast cancer
diagnosis. Discussions about breast changes and loss must be approached gently and in a private setting so that women do not feel embarrassed asking questions or voicing their concerns. Health care providers must also recognize the importance of spirituality as a source of support. Respect should be demonstrated for spiritual practices and beliefs and spirituality should be accepted as an important resource for coping with breast cancer.

Health care professionals need to recognize the importance of family in Punjabi women's breast cancer experiences. Orientation to the family, using a family-centered approach, includes assessing women in the context of their families, followed by planning and implementing care that addresses women's individual needs, as well as their family's needs. A family-centered approach will also address the information and education needs of family members. Information about breast cancer, treatments, side effects, and available resources are essential for preparing and supporting women and their families. This information should be accessible to women and their families in a private setting. Video information that women could view in their own homes and in Punjabi could overcome literacy and language barriers. Recognition of the support provided by family members must also be acknowledged and resources for family members, as well as women, be made available. Furthermore, practical support, such as help with child care, transportation, and housework must be made available for women who need this assistance. Family members of women with breast cancer may also be encouraged to accept assistance, rather than requiring women to request such services themselves.

**Directions for Future Research**

The findings of this study raise questions for further research and give direction for the development and systematic evaluation of culturally appropriate support services for Punjabi immigrant women and their families. The women in this study all received conventional cancer treatment, only two women were over the age of 60, and none of the women had experienced a
recurrence of breast cancer. Future research with Punjabi women who rejected conventional cancer treatment, were older, and had a recurrence of breast cancer is needed to understand these women's experiences. As well, the influences of socioeconomic factors were not examined in this study and further research is also needed to understand the influence of these factors on Punjabi immigrant women who have breast cancer. The findings of this study suggest that some Punjabi women face barriers to needed support and quality care, yet these remain poorly understood. Future research identifying what those barriers are and how these barriers can be eliminated or minimized is needed.

Further research focussing on the experiences and needs of family members is also essential considering the significance of the family context in shaping Punjabi women's experiences of breast cancer. This understanding would also be helpful in learning how to provide culturally appropriate support to family members of Punjabi women with breast cancer. Research is also required to develop and investigate the effectiveness of culturally appropriate, family-centered strategies to address the practical, emotional, and physical needs of Punjabi immigrant women with breast cancer. This research should recognize the diversity in the meanings breast cancer holds for Punjabi women. As well, the development and evaluation of services should be conducted in partnership with women in the Punjabi community.

**Conclusion**

The aim of this study was to gain an understanding of the meanings ascribed to breast cancer by Punjabi immigrant women who have been diagnosed and treated for this disease. Transcribed interviews with 12 Punjabi immigrant women provided a window into each of these women's lives and experiences. The findings that emerged from this study provided detailed descriptions and explanations from the perspective of these women. For the women in this study breast cancer was constructed as just another health problem, a survivable family tragedy, an
experience of never-ending worry and suffering, and as a lesson from God. Women’s experiences were shaped by their family members and framed within their cultural and life contexts. These findings provide a beginning understanding of what breast cancer is like for other Punjabi women and advance what is known about the experiences of breast cancer. Consideration of these findings by health care professionals and researchers will enhance current cancer services and promote culturally appropriate care.
REFERENCES


**APPENDIX: GLOSSARY OF PUNJABI WORDS**

<table>
<thead>
<tr>
<th>Word</th>
<th>Meaning</th>
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<tbody>
<tr>
<td>Chati</td>
<td>chest, word used to refer to a woman’s breast.</td>
</tr>
<tr>
<td>Desi</td>
<td>‘indigenous’; refers to Indian or Punjabi; a Punjabi term referring to the health practices in the country of origin.</td>
</tr>
<tr>
<td>Dharam</td>
<td>duty or righteousness; the performance of right action according to the moral and ethical regulations of nature and society.</td>
</tr>
<tr>
<td>Izzat</td>
<td>honour or respect; family honour.</td>
</tr>
<tr>
<td>Gurdwara</td>
<td>name given to a Sikh temple; 'Gateway to the Guru.'</td>
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<tr>
<td>Karma</td>
<td>reflection of one’s deeds in present and past lives; action, merit, and demerit; the reward or punishment of any action of man is given by Gods order according to merit, God may give it or withhold it.</td>
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<tr>
<td>Kismet</td>
<td>fate, what is divinely written for a person.</td>
</tr>
<tr>
<td>Paath</td>
<td>chanting, meditation, austere self-discipline and the reading of the Sikh holy scripture; reading of the Guru Granth Sahib.</td>
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<tr>
<td>Sevah</td>
<td>volunteer service; service to ones fellow beings, a cornerstone of Sikhism.</td>
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<tr>
<td>Waheguru</td>
<td>‘infinite light that dispels darkness’; Sikh mantra used in devotion to God</td>
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