

MOTHERS AND DAUGHTERS'  
EXPERIENCES OF BREAST  
CANCER: FAMILY ROLES,  
RESPONSIBILITIES, AND  
RELATIONSHIPS

A Thesis Submitted to the College of Graduate Studies and  
Research in Partial Fulfillment of the Requirements for the Degree  
of Master of Arts in the Department of Sociology  
University of Saskatchewan

By

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## ABSTRACT

Existing research suggests that illness can have profound implications for the family. The purpose of this thesis is to explore mothers and daughters' experiences of the mothers' breast cancer in order to determine how their lives were affected by the illness. In particular, I focus on shifts that occurred in their family roles, responsibilities, and relationships. Twelve qualitative interviews were performed with four mother-daughter dyads. Each mother and daughter participated in an initial interview together, as well as a separate follow-up interview. Interview data was analyzed thematically using a blended feminist-interpretive approach. The major themes emerging from the analysis pertained to: shifts in family roles and responsibilities, coping with breast cancer, and growth in family relationships. These themes identify specific aspects of mothers and daughters' lives that were affected by breast cancer. Specifically, the findings contribute to the overarching theme that mothers and daughters experienced "biographical disruption" as a result of the mothers' breast cancer, in that the illness required the women to re-assess their everyday lives and expectations for the future. However, the range of experiences described by the mothers and daughters suggest that the degree to which biographical disruption occurred varied depending on the extent to which their lives were altered by breast cancer. Therefore, I conclude that mothers and daughters experienced varying degrees of biographical disruption as a result of the mothers' breast cancer. This conclusion indicates that the breast cancer diagnosis has an array of significant implications for mothers and daughters, some of which continue well beyond the completion of acute care. Recognizing that mothers and daughters' family roles, responsibilities, and relationships were affected to some extent by the breast cancer experience will help to improve the types of support offered to women in the future.

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## **CHAPTER ONE: INTRODUCTION**

### **1.1 Background Information**

While it is commonly accepted that illness can have profound implications for individuals and their families, the sociological consequences are less clear. Research is needed on the social implications of illness in the family setting, in addition to an established focus on psychological effects. Various forms of illness may affect family members differently and some family members may be affected more than others. For instance, women can experience physical, psychological, and social limitations as a result of breast cancer, which may require their families “to accommodate new daily routines, re-distribute roles, develop a new sense of normalcy, offer her emotional support and anticipate future changes in family functioning” (Lewis & Hammond, 1992, cited in Petersen, Kruezek, & Shaffner, 2003, p.101). The degree to which family members are influenced by illness is connected to social variables, such as age and gender, as these variables often have an effect on the roles and responsibilities assumed by individuals. Some illnesses may also cause greater disruption to certain members of the family if there is a hereditary component.

This thesis concentrates on the impact a mother’s breast cancer had on the mothers and daughters’ family roles, responsibilities, and relationships. A blended feminist-interpretive approach informed an analysis of data generated from twelve qualitative interviews with mother-daughter dyads. Based on the analysis, I identify specific aspects of participants’ lives that were affected by the mothers’ breast cancer experiences. I highlight three major themes emerging from the interviews: 1) shifting roles and responsibilities, 2) coping with breast cancer, and 3) growth in family relationships. The findings demonstrate some of the possible sociological and psychological consequences that breast cancer can have for mothers and daughters. A better understanding of illness experiences in the family setting could inform the



practices of health care professionals and shape the support services available to those who are ill and their families.

In the past few decades, there has been a proliferation of literature in the area of health and illness. Much of this literature is part of a shift in sociology that has led to increased interest in research on individual experiences of illness, rather than the potentially limiting accounts from those researching in the biomedical arena (Turner, 1987). Specifically, this shift recognizes that illness is subjective, as each person will make sense of its implications in a unique way. Personal narratives of illness provide “a glimpse of what it means to live informed by [certain] values, meanings, relationships, and commitments” (Frank, 2000, p.361). Subjective accounts of illness contribute to an improved understanding of how individuals are affected by and negotiate various aspects of illness.

In order to build on the focus on individual experiences of illness, it is important to include family members in the study of health and illness. During times of illness, the family emerges as the primary source of social support (Pierret, 2003; Steinglass, 2000) and further research needs to explore specific effects that illness has on family members within different contexts. Research, including my own study, address the following questions. How does illness affect the lives of ill individuals and their families? What are the implications of illness for family roles and responsibilities? Do changes resulting from illness affect family relationships and, if so, in what ways? The inclusion of family members in social research on health and illness will help answer these questions.

Further, increasing incidence rates of cancer in our society indicate the need for continuing research on the various forms of cancer and the corresponding impact for individuals and their families. Specifically, the large number of women diagnosed with breast cancer emphasizes the need to better understand this particular illness. In Canada, it is estimated that 22,200 women will be diagnosed with breast cancer in 2006 (Canadian Cancer Society, 2006). Recent developments in treatment have resulted in an improved prognosis and fewer adverse effects for women who are diagnosed with breast cancer (Compas & Luecken, 2002, p.111). Thus, there is a need to examine the experiences of breast cancer survivors from medical, psychological, and sociological perspectives, because the effects of illness do not end with the completion of treatment.

In particular, the lack of research on the social and familial dimensions of breast cancer is notable.

Research on the effect that breast cancer has on women's families is necessary because of the range of issues involved with a breast cancer diagnosis. One study shows that women with breast cancer face concerns related to limitations in physical, role, social, and emotional functioning (Luoma & Hakamies-Blomqvist, 2004). The findings of that study indicate that family members may be required to provide various forms of care and social support, which has the ability to alter roles and responsibilities within the family during the illness experience. Shifts in roles and responsibilities may lead to lasting changes in family relationships. Therefore, further research is necessary to improve understanding of the impact that a mother's breast cancer has on family roles, responsibilities, and relationships.

While shifts may take place with respect to family roles and responsibilities during the illness experience, breast cancer often has physical and psycho-social consequences that continue after treatment is complete. Breast cancer is conceptualized as a chronic illness because women may experience ongoing physical limitations and other health problems, as well as psychological distress, such as anxiety and depression (Compas & Luecken, 2002; Dukes Holland & Holahan, 2003; Petersen et al., 2003; Remennick, 1998). Research also indicates that women who survive breast cancer experience lasting changes with respect to identity, outlook on life, and relationships (Holmberg, Scott, Alexy, & Fife, 2001; Kayser & Sormanti, 2002; Walsh, Manuel, & Avis, 2005). These findings demonstrate some of the ways that women's lives continue to be altered long after their breast cancer treatment has ended. The ongoing impact of breast cancer on women's lives relates to the concept of "biographical disruption" proposed by Bury (1982), which refers to the need for chronically ill individuals to re-examine their taken-for-granted assumptions and expectations for the future because of their illness. The lasting impressions of breast cancer can also profoundly impact family members, who may be unsure of how to deal with these changes.

Mothers' breast cancer diagnoses have significant consequences for daughters and other female relatives. The discovery of the genetic mechanism responsible for hereditary transmission of breast cancer in the 1990s (Armes & Venter, 2002)

exemplifies one potential impact that a mother's breast cancer can have on her female family members. Although hereditary breast cancer accounts for a minority of all breast cancer cases, daughters commonly feel at greater risk because of their mother's diagnosis; this may have adverse psychological effects (Armes & Venter, 2002; Bouchard et al., 2004; Chalmers, Marles, Tataryn, Scott-Findlay, & Serfas, 2003; Press, Fishman, & Koenig, 2000; Rees, Fry, & Cull, 2001). As a result, daughters of women with breast cancer often perceive themselves to be at an increased risk and experience disruptions to their well-being. Kenen, Ardern-Jones & Eeles (2003) extend Bury's (1982) concept of "biographical disruption" to women with a family history of breast cancer. Specifically, Kenen and her colleagues assert that these women experience "chronic risk", which poses them with "many of the same issues pertaining to biographical disruptions and an uncertain future" as the chronically ill (p.329). Therefore, it appears that a mother's diagnosis of breast cancer has complex implications for daughters, more so than for spouses and sons. Consequently, the inclusion of daughters in social research on breast cancer allows for the exploration of the influence of risk, as well as the provision of care and support, on family relationships.

Daughters' experiences are also relevant to studies of illness in the family context because daughters are often the family members who are responsible for caregiving and social support. As determined by several studies, gender norms depict caregiving tasks as feminine in nature (Aronson, 1994; Kayser & Sormanti, 2002; Raveis & Pretter, 2005; Roberts, Baile, & Bassett, 1999). Accordingly, a daughter may be expected to take on significant responsibility during her mother's illness, whereas a son may not face the same expectations. Providing care and social support during times of illness may require daughters to: take on new roles, balance old responsibilities with new ones, negotiate the provision of care with their ill parent, and adjust their perceptions of their ill parent (Germino & Funk, 1993). Each of these outcomes is likely to alter the relationship that daughters have with their ill parent. Thus, there is a need to investigate the ramifications of care and support provision for the mother-daughter relationship.

Drawing upon the background literature discussed above, as well as sociological domains related to health and illness and the family, I explore mothers and daughters'

experiences of the mother's breast cancer. In particular, I focus on the implications that breast cancer has for roles, responsibilities, and relationships within the family. As mentioned previously, women with breast cancer experience a variety of changes as a result of their illness, many of which last long after breast cancer treatment has ended, indicating that the family may also continue to be affected after treatment is complete. The hereditary component of some breast cancer cases, as well as the depiction of caregiving as a female role, are added complexities in the study of mothers and daughters' illness experiences. Therefore, my research will enhance understanding of the ways that the family roles, responsibilities, and relationships of mothers and daughters are affected by the mother's breast cancer experience.

### **1.2 Statement of Purpose, Objectives, and Thesis**

The purpose of my study is to gain a better understanding of aspects of the breast cancer experience that mothers and daughters feel are significant. Herein, I illuminate some of the implications that illness has for individuals and their families. While a number of studies have investigated women's experiences of breast cancer, further research is needed on how their diagnosis influences their family roles, responsibilities, and relationships. The recognition that family members are also affected by illness may lead to a greater awareness of the changes they experience and the consideration of their support needs. While existing research has focused on the psychological effects that a mother's breast cancer has on her daughter (Wellisch, Schains, Gritz, & Wang, 1996), sociological research is necessary in order to understand the shifts that occur in other aspects of daughters' lives. Existing research has also typically focused on the concerns of daughters who are either young or adolescent children or middle-aged adult children (Forrest, Plumb, Ziebland, & Stein, 2006; Raveis & Pretter, 2005; Spira & Kenemore, 2000). Thus, the perspectives of young adult women have largely gone unexplored. Also, existing research on biographical disruption has focused on individuals with chronic illness (Bury, 1982), healthy women with a family history of breast/ovarian cancer (Kenen et al., 2003), and women with chronic muscular pain (Asbring, 2000). This research identifies the usefulness of the concept of biographical disruption and suggests that it is applicable to mothers and daughters' experiences of breast cancer.

The overall objective of my research is to gain a better understanding of how family roles, responsibilities, and relationships are influenced by illness-related issues, such as care and social support provision, coping, and risk perception. I focus on the impact a mother's experience of breast cancer has on the mother-daughter relationship. I believe that this study will help to improve understanding of women's experiences of breast cancer and how family relationships are affected by illness.

The specific research objectives of this qualitative study of mothers and daughters' experiences of breast cancer are:

- To gain a better understanding of illness-related issues in the family setting, such as care and social support provision, coping strategies, and risk perception from the perspectives of women themselves.
- To explore the impact of mothers' experiences of breast cancer on mothers and daughters' family roles, responsibilities, and relationships using a feminist-interpretive lens.

Based on the exploration of these research objectives through qualitative interviews, I argue that shifts in roles and responsibilities, the ongoing coping process, and growth in family relationships all serve as evidence that mothers and daughters experience some degree of biographical disruption because of the mother's breast cancer.

### **1.3 Rationale**

By suggesting that mothers and daughters experience biographical disruption because of breast cancer, I examine the idea that women are required to re-organize their lives to some extent because of illness. It is important to acknowledge that the degree to which biographical disruption occurs depends on the physical, sociological, and psychological implications of illness, as well as women's support and coping resources. I suggest that improved understanding of these women's experiences could lead to improvements in support resources for women with breast cancer and their daughters. It is important for families and health care professionals to recognize that both mothers and daughters' lives are affected by the breast cancer experience. It is likely that a greater awareness of the needs of women with breast cancer and their daughters will encourage increased sensitivity to their situation. In addition, the acknowledgement that breast

cancer also has a number of implications for family members in general, and daughters in particular, is an important step in addressing the support needs of families.

By highlighting the stories of mothers and daughters, I also endeavour to help other women going through a breast cancer experience. Although it is evident that women experience illness in unique ways, women's stories of breast cancer can help others to give meaning to their illness. For daughters especially, they may be able to relate to the stories of other daughters whose mothers have breast cancer. It may also be beneficial for mothers and daughters to be informed of the issues that other women faced and to increase awareness of their ability to successfully cope with breast cancer. Thus, the findings of this study have a number of implications for breast cancer patients and survivors, their families, and health care professionals.

#### **1.4 Outline of the Thesis**

In this chapter, I introduce the topic of my research. I lay out the purpose and research objectives that guided the study, as well as the thesis statement and rationale for doing the study. In the second chapter, I review the existing literature on my research topic. The literature review is divided into four major sections, which focus on: the psycho-social implications of breast cancer for mothers and daughters, experiential accounts of illness, illness in the family context, and the significance of caregiving. The third chapter describes the methodological approach utilized in this research, as well as the design of the study, selection and recruitment of participants, data analysis process, issues of credibility, and ethical considerations. In the fourth chapter, I introduce the mothers and daughters and present the selected themes that emerged from the interviews. I have organized this chapter into three major themes, each of which is divided into three to five sub-themes. The major sections of the fourth chapter are: shifts in roles and responsibilities, coping with breast cancer, and growth in relationships. The fifth chapter presents a discussion of the selected themes with respect to existing literature. After this discussion, I highlight conclusions and implications drawn from the selected themes. Specifically, I apply the work of Bury (1982), Kenen et al. (2003), and Asbring (2000) to the findings in order to substantiate my claim that mothers and daughters experience some degree of biographical disruption as a result of the breast cancer experience. I also identify the strengths and limitations of the study, recommend

potential for future research, and reflect on the methodological approach. I finish the chapter with a summary and conclusion.

## **CHAPTER TWO: LITERATURE REVIEW**

The importance of breast cancer research is emphasized by current statistics, which indicate that approximately 22,200 women will be affected by the illness this year in Canada (Canadian Cancer Society, 2006). The increasing success of treatment, improvement of prognosis and reduction in adverse effects (Compas & Luecken, 2002, p.111) suggests that there is a need to examine the experiences of survivors from medical, psychological and sociological perspectives. In particular, current research has neglected to explore the impact that breast cancer may have on women's social well-being, as well as their ability to maintain roles and responsibilities. At this time, there is a need for research on the social implications of breast cancer, which will help us to understand the social issues faced by women with breast cancer and help to improve their adjustment to life after breast cancer. In addition, family members, and daughters in particular, should be included in research, as they also experience a variety of implications as a result of their mother's diagnosis.

Studying the social impact of a mother's breast cancer on the mother-daughter relationship involves several domains of knowledge. I drew upon relevant literature from the following areas: sociology, biomedicine, psychology, women's studies, gender studies, family studies, and social work. These domains have all contributed to the existing body of literature related to this subject and provide the background for a sociological analysis of illness and the family. The incorporation of multi-disciplinary literature provides depth to the study of this complex topic. I organized the literature review into four sections, each of which outlines the key contributions of prior research. The sections include background on breast cancer, health and illness, the family, and social support and caregiving. Within each section, I identify specific directions for further research on illness and the family and, in particular, breast cancer and the mother-daughter relationship.



## **2.1 Breast Cancer: Psycho-social Implications**

A review of the existing literature on breast cancer indicates that women face a number of sociological and psychological issues as a result of treatment and illness-imposed limitations. As such, women with breast cancer usually require care and social support. These requirements can affect social relationships both positively and negatively and may lead to disruptions in women's psycho-social well-being. Female relatives of women with breast cancer often face similar disruptions, as they are learning of their own possible diagnoses. The potential threat that breast cancer poses is commonly overestimated by women with a family history of breast cancer and can lead to feelings of uncertainty. Consequently, female relatives may experience distress, changes in health behaviour, and the desire for information and surveillance (Chalmers et al., 2003; Kenen et al., 2003; Rees et al., 2001; Wellisch et al., 1996). These consequences of uncertainty can substantially influence women's psycho-social well-being. While the issues identified in the existing literature suggest that women and their female relatives are affected by a breast cancer diagnosis, further exploration is necessary to ascertain the effects that the illness has on women's social roles and relationships.

For those diagnosed with the illness, breast cancer can have profound implications on several aspects of life. Specific issues highlighted in the research include: negative psychological reactions, such as anxiety and depression, for women diagnosed with breast cancer (Compas & Luecken, 2002; Dukes Holland & Holahan, 2003), diminished ability to maintain social roles for women being treated for breast cancer (Kayser & Sormanti, 2002), limitations in physical, role, social, and emotional functioning for women with advanced breast cancer (Luoma & Hakamies-Blomqvist, 2004), relationship issues for women who have survived breast cancer (Holmberg et al., 2001) and emotional crisis, pain, and ways of coping for cancer survivors (Remennick, 1998, p.116). Relevant issues vary for each individual, but often require the provision of care and social support. The need to rely on others for various forms of support during the breast cancer experience may have a variety of implications for women. An understanding of the ways in which breast cancer survivors negotiate their need for

support and the social implications of their illness will improve the provision of care and social support in the future.

Psychological research indicates that women who have recently been diagnosed with and treated for breast cancer seek support from their network of family and friends (Bloom, Stewart, Johnston, Banks, & Fobair, 2001, p.1513). The provision and receipt of social support is commonly associated with improved adjustment to breast cancer and intensified personal relationships (Dukes Holland & Holahan, 2003; Raveis & Pretter, 2005). Despite the benefits of social support, some women's social relationships can be negatively affected. For instance, when those experiencing a major life crisis are given support that is seen as unhelpful (such as unsolicited advice, forced cheerfulness, and encouragement to recover), relationship difficulties may occur (Wortman & Lehman, 1985, cited in Bloom & Kessler, 1994). Having to rely on others for care and support can also put stress on social relationships (Ferrell, Smith, Ervin, Itano, & Melacon, 2003). These consequences provide evidence that the breast cancer experience can have both positive and negative effects on social relationships.

Research also suggests that the illness-imposed restrictions faced by women with breast cancer can negatively impact social relationships. For example, limitations in physical abilities may emerge post-surgery, such as decreased range of motion or lymphedema (swelling of the arm, shoulder, or hand), which can lead to a reduction in social interaction (Bloom et al. 2001; Holmberg et al., 2001). Diminished social interaction may cause disruptions in women's social and emotional well-being. It has also been proposed that some social interactions further contribute to feelings of stigma and isolation because of the way breast cancer is broached in conversation (Luoma & Hakamies-Blomqvist, 2004, p.734). As a result, women may refrain from divulging their breast cancer diagnosis to others in order to maintain current relationships (Holmberg et al., 2001). Thus, women with breast cancer may experience difficulty in maintaining social relationships due to the various physical and psycho-social issues they encounter.

Breast cancer also has profound consequences for female relatives of women with breast cancer. The discovery of the genetic mechanism responsible for hereditary transmission of certain types of breast cancer in the 1990s (Armes & Venter, 2002, p.309) identifies one potential impact a woman's breast cancer diagnosis can have on

her family members. Research indicates that familial breast cancer represents a minority of all breast cancers, ranging from approximately five to ten percent (Armes & Venter, 2002; Bouchard et al., 2004; Chalmers et al., 2003; Press et al., 2000; Rees et al., 2001). Despite this small proportion, daughters and other female family members commonly feel susceptible to the disease. This is demonstrated by research which found that women perceive a greater vulnerability to breast cancer when a family member has breast cancer (Wellisch et al., 1996, p.271).

Women's perceptions of increased vulnerability to breast cancer because of a family history of breast cancer was also found by other studies which emphasize that feelings of risk can have adverse psychological effects, such as fear, distress and anxiety, (Chalmers et al., 2003; Press et al., 2000; Rees et al., 2001). Overestimated risk can lead to unnecessary stress for women with a relative who has experienced breast cancer. In particular, Rees et al. suggest that women who perceive an increased risk of breast cancer may be uncertain about their actual risk and how to manage it (p.1438). In addition to psychological effects, a greater perception of risk can greatly affect a woman's relationship with the family member who had breast cancer, as well as others (Holmberg et al., 2001; Kenen et al., 2003). Learning of their possible high-risk status may also lead to changes in behaviour and identity (Kenen et al., p.316). Thus, in a variety of ways, women's breast cancer experiences have the potential to drastically affect not only themselves, but their family members as well.

The increasingly widespread awareness of familial breast cancer has generated desire for the availability of genetic testing for breast cancer and access to preventive measures. According to Bouchard et al. (2004), the recent availability of genetic testing to women with a family history of breast cancer has allowed cancer geneticists to give out greater information regarding genetic risk and preventive measures (p.1086). The greater availability of genetic information, coupled with women's amplified perceptions of risk, have led to an increase in genetic testing for women with family histories of breast cancer. Women with a family history of breast cancer may therefore feel anxiety about their risk and seriously consider preventive measures to diminish that risk. This underscores Press et al.'s (2000) claim that the recent emphasis on genetic screening for

breast cancer shows that “the discourse of fear has worked to make many women exceptionally afraid of breast cancer” (p.240).

Although great desire for genetic testing exists, research on the genetic transmission of breast cancer concludes that “only a minority of breast cancers occurring in a familial setting are due to mutations in [the BRCA] genes [and] further, not all people who inherit mutations in these genes will develop breast cancer” (Armes & Venter, 2002, p.309). This demonstrates the inaccuracy of many women’s perceptions of their risk of breast cancer because the presence of a BRCA gene mutation does not necessarily dictate a breast cancer diagnosis. Despite this, research suggests that “women in families having risk factors for carrying a BRCA mutation, but where none is found, face a substantially higher risk for breast/ovarian cancer than do women in the general population” (Armstrong et al., cited in Kenen et al., 2003, p.317). Therefore, a family history of breast cancer does appear to play an important role in women’s risk of breast cancer, but it cannot always be linked to genetic transmission. Many women experience distress because of their “chronic risk” of breast cancer, which may in turn affect their social relationships as well as other facets of their lives (Kenen et al., p.318).

The degree to which daughters perceive themselves to be at risk can vary depending on their experiences of their mothers’ or other family members’ illnesses. Rees et al. (2001) argue that “women with the same objective family history may have had differing levels of exposure to the effects of breast cancer and have witnessed different consequences of the disease” (p.1436). This argument suggests that exposure to and outcome of the illness can influence the extent to which daughters are concerned with their own risk. For instance, a mother’s survival of breast cancer with few long-term side effects may result in her daughter being less concerned than others whose mothers have not been as fortunate. The extent to which daughters are involved in caring for or supporting their mothers can also affect their perceptions of risk. One study found that adult children who perceived their family member’s illness to be stable or non-life threatening chose to focus on other roles and responsibilities and thus diverted attention from anxieties about their own risk (Sanders, Campbell, Sharp, & Donovan, 2003, p.61). This finding proposes that greater involvement in a family members’ illness is associated with increased perceptions of risk. Thus, exposure to and outcome of a

mother's breast cancer may influence the extent to which daughters are concerned about their own risk and experience disruptions to their lives.

The perceived threat of a breast cancer diagnosis also has significant implications for women's health behaviour. Changes may take place with respect to diet, exercise, and other lifestyle choices (Kenen et al., 2003, p.322). Other changes may include surveillance and preventive measures, such as breast self-examination, mammography screening, chemo-prevention and prophylactic surgery (Bouchard et al., 2004, p.1086). According to Rees et al. (2001), "an individual will be most likely to engage in preventive behaviour if they regard themselves as susceptible to a serious illness and consider some preventive behaviour to have more benefits than costs" (p.1437). This demonstrates the possible impact a woman's diagnosis of breast cancer can have on her female relatives. Research shows that a daughter's perception of changes in her mother's life resulting from breast cancer affects her own beliefs regarding risk, as well as her desire for information about the likelihood of being diagnosed with breast cancer (Wellisch et al., 1996, p.280). Thus, women with affected family members may seek access to information on preventive measures and susceptibility.

A nursing study completed in Manitoba focuses on the information and support needs of daughters and sisters of women with breast cancer, identifying that many of these women do not feel their needs are being met (Chalmers et al., 2003, p.88). The women who participated emphasized the need for information regarding the "likelihood of cure, treatment options, [and] risk of breast cancer to family members", which are similar to the needs of those women with breast cancer (Ibid., p.88). This finding identifies the importance of access to accurate information sources for both women diagnosed with breast cancer and those who wish to assess their future risk of breast cancer. In addition to informational needs, it is evident that female relatives of women with breast cancer require other types of social support as well. For instance, increased knowledge and support will improve adjustment to breast cancer for those women experiencing it as well as family members affected by it indirectly. Thus, access to information and support related to breast cancer has the ability to address questions that mothers and daughters may have regarding the mother's illness as well as the daughter's

risk; both of which may ease their feelings of susceptibility and allow mothers and daughters to better support one another.

In summary, there are many issues faced by women who experience breast cancer and their female relatives. These issues have the ability to profoundly affect their lives. Current research has failed to focus on the consequences a breast cancer diagnosis may have on women's social well-being. Specifically, limitations caused by breast cancer may hinder women's ability to fulfill previous social roles and maintain past social relationships. Such limitations require women to negotiate issues related to care and social support which can affect their relationships in various ways. Female relatives are also affected by a woman's breast cancer diagnosis, which in turn may influence their ability to offer social support. Increased perceptions of risk and uncertainty of how to manage this risk may be detrimental to women's psychological well-being, and can lead to changes in their current roles and relationships. These consequences, in addition to unfulfilled information and support needs, may have significant implications for women with a family member with breast cancer. Therefore, it is important to undertake research with women who have experienced breast cancer and their female relatives in order to better understand the sociological and psychological implications of the illness.

## **2.2 Health and Illness: Experiential Accounts**

An important aspect related to the study of health and illness is the shift that has taken place in sociology to focus on the individual's perspective of illness, rather than that of the medical profession (Turner, 1987, p.1). In the past, research focused on health professionals' views of the ill, without taking into account the consequences that being ill had for individuals (Pierret, 2003, p.6). The shift to a focus on lay perspectives has proved to be extremely beneficial in informing the medical profession and the public on the main concerns of the ill. Although this shift has taken place in sociology, there still remains a hierarchy of knowledge in which individual perspectives of the ill are subordinate to the perspectives of those charged with treating them. Therefore, it is necessary to continue to highlight individual experiences of illness in order to give them a more prominent position in the study of health and illness.

The experiential shift can be expanded to include the perspectives of family members, in addition to those who experience the illness directly. Family members'

experiences of illness contribute to our understanding because they highlight the context in which illness occurs. Spira and Kenemore (2002) note that, despite being central to the management of illness, “the significance of relationships is overlooked” in traditional medical treatments (p.175). Spira and Kenemore acknowledge that, because ill individuals require care and support from others, their social networks become involved in and are affected by the illness experience. Thus, calling attention to the experiences of ill individuals and their family members can bring about recognition of the significance of relationships to illness experiences. This recognition may help to improve social support and health care services. Focusing on individual experiences can also advance societal understanding of what it means to be ill, as well as what it is like to live with and support those who are ill.

Recently in the social sciences, a substantial body of work on illness narratives has emerged. Illness narratives are stories of illness that “provide a means of making sense of one’s life and experiences” (Thomas-MacLean, 2004, p.1648). Through the process of telling their stories, the ill are able to move toward a better understanding of the changes that have taken place in their lives. Illness narratives provide an opportunity for storytellers to share their experiences with others and help them to understand what it means to live with illness (Frank, 2000). This idea suggests that illness narratives are an outlet by which stories of illness are shared, understood by self and others, and integrated into one’s self identity.

According to Frank (2000), narratives have a recuperative role for the ill, in that “people use stories as part of their remoralization” (p.355). Frank acknowledges the demoralization which takes place for those who experience illness, as it changes their lives and often makes past roles and responsibilities unattainable. The act of storytelling helps to give meaning to illness experiences for both those who live them first hand and others who live them indirectly. Frank (2002) asserts that, “stories are attempts of a self to find identity in terms outside itself” (p.15). This claim communicates that meaning and identity are found in the act of storytelling because it allows the ill to examine their own experiences from a distance. Illness narratives are also valuable because they “provide clues to the ways in which body, self and society are linked in late modern cultures” (Bury, 2001, p.282). Thus, illness narratives reflect the ways in which physical

illness is connected to personal and social being in our society, which again improves understanding of illness. The dual function of illness narratives described here emphasizes their significance for both ill individuals and the rest of society, and confirms the need to focus on individual experiences.

Applying a narrative approach to women's breast cancer accounts provides valuable insight into the way women's experiences and the meaning given to them are shaped by culture. Thomas-MacLean (2004) analyzed women's breast cancer stories using a narrative approach, which enabled identification of "the ways in which stories are culturally constructed" (p. 1647). A narrative approach explores women's stories with the goal of understanding how they are influenced by "the social context in which they occur" (Ibid., p.1648). Thomas-MacLean's statements suggest the importance of incorporating context into investigations of individual experiences of illness. This belief adds weight to the argument for the inclusion of family members in research about illness experiences.

Acknowledging the subjective nature of disease is crucial to understanding the social implications of health and illness. Turner (1987) proposes that illness "refers to the individual's subjective awareness of the disorder" which draws attention to "the role of choice, meaning and agency in the experience of illness" (p.2-3). This recognizes that individuals have different experiences of being ill as a result of their unique interpretations regarding the illness and its effects. Therefore, it is necessary to study individual experiences of illness in order to draw attention to the perspectives of those who have lived with illness. Specifically, it is necessary to recognize that women's experiences of breast cancer vary in many ways, as do the experiences of their family members. Recognizing that their experiences are unique elevates them to a more prominent position in our society's hierarchy of knowledge and helps to better inform those who are responsible for treating and supporting them.

Related to this need to recognize subjectivity in illness experiences is the necessary inclusion of timing and context into research on illness. Pierret (2003) describes the increasing inclusion of social variables into qualitative studies of health and illness, such as age, gender and social class (p.9). Taking social variables into account is crucial to understanding how individuals give meaning to their experiences of



illness. For example, Williams (2000) discusses the idea of the ‘normality’ of illness, which refers to individuals who feel that illness or health problems are to be expected because of class, age, or another social variables (p.50). Williams’ work suggests that some individuals have less difficulty giving meaning to their illness because of previous expectations of becoming ill, which may also allow them to more quickly adapt to being ill. Therefore, timing and context, along with norms and expectations, must be included in research on illness experiences in order to better understand how individuals give meaning to illness and its consequences (Pierret, 2003; Williams, 2000).

With this in mind, the age at which diagnosis occurs is likely a notable influence on the impact a mother’s breast cancer has on the mother-daughter relationship. Hockey and James (2003) argue that there are “aged identities” which are “inscribed with culturally specific social roles and experiences” (p.82). Hockey and James’ assertion insinuates that ‘aged identities’ include the conventional roles and expectations associated with certain ages or stages of life. Becoming ill can threaten an individual’s ability to fulfill conventional roles and expectations because it involves a disruption to “the structures of everyday life and the forms of knowledge which underpin” (Bury, 1982, pp.169). Thus, the extent to which everyday life is disrupted, in addition to the severity of the illness, is associated with the age of the individual because roles and expectations differ with age or stage of life.

Women’s experiences of breast cancer vary with respect to how they make sense of the illness. This variation is related to the variety of consequences that breast cancer has for social roles and responsibilities depending on a woman’s age at the time of diagnosis (Dunn & Steginga, 2000). Research has indicated that “older cancer patients often experience less distress associated with their diagnosis because they have previously achieved many of the common developmental tasks of our society” (Schnoll & Harlow, 2001, cited in Petersen et al., 2003, p.116). In other words, women who are older, whose children live outside the home, and who have retired from paid work may have less difficulty fulfilling conventional roles and maintaining current responsibilities because these have already become fewer with age. On the other hand, women who are younger, have children at home, and/or engage in paid work may struggle to fulfill the conventional roles and expectations associated with their current age because of having

breast cancer (Ibid, p.111). Thus, for some, a diagnosis of breast cancer might imply “premature ageing”, as their diagnosis “mark[s] a biographical shift from a perceived normal trajectory through relatively predictable chronological steps, to one fundamentally abnormal and inwardly damaging” (Bury, 1982, p.171). The degree to which a mother can resist illness-imposed limitations and successfully maintain the roles and expectations associated with her age and gender may influence her relationship with her daughter and other family members, as their views of her may change if the mother’s past responsibilities are not met. Thus, the stage of life at which diagnosis occurs is likely influential in determining how a woman’s family roles and responsibilities are affected by breast cancer; this may also shape the impact breast cancer has on the mother-daughter relationship.

Another important aspect related to the study of health and illness is the duration of the illness or its effects. Breast cancer is particularly complex because the completion of treatment does not necessarily signify the end of the illness. Therefore, breast cancer is often portrayed as a chronic illness. Reasons for this may be associated with women’s ongoing need for treatment related to their breast cancer (such as reconstructive surgery, hormone therapy or physiotherapy), health problems resulting from breast cancer (such as lymphedema), or psycho-social problems (such as fear of recurrence or other mental health problems) (Dukes Holland & Holahan, 2003). These issues can have vast implications which may hinder a woman’s ability to return to former roles and fulfill expectations.

The physical and psycho-social changes women undergo as a result of having breast cancer can be characterized as what Bury (1982) describes as a “biographical disruption”. According to Bury, illness can cause disruptions to “the structures of everyday life”, which require “the expectations and plans that individuals hold for the future... to be re-examined” (p.169). These disruptions can include changes in the individual’s ability to perform everyday activities, such as household tasks or paid work, or changes in the individual’s conception of her self. Biographical disruptions may or may not involve complete reconfigurations of one’s identity. In a qualitative study of women with chronic fatigue syndrome or fibromyalgia, illnesses which affect women more frequently than men, the author concluded that “biographical disruptions are

partial rather than total, calling for different degrees of identity transformation” (Asbring, 2001, p.312). Relating this finding to women with breast cancer, it is possible that some women feel that the breast cancer diagnosis requires a drastic reconfiguration of their biographies because of changes in physical and social functioning, while others feel the changes are slight because of a relatively small impact on physical and social well-being. As noted previously, social variables may also affect an individual’s perception of whether or not illness causes a biographical disruption, as “what, for some, may be a disruptive experience may, for others, be part and parcel of normal everyday life” (Williams, 2000, p.61). Therefore, the use of the concept “biographical disruption” requires the recognition that the degree to which individuals undergo disruptions to their everyday lives and self concepts is not uniform and varies depending on the severity of the illness as well as the timing and context.

Although many improvements have been made in the treatment and prognosis of breast cancer, especially when diagnosed in its early stages (Compas & Luecken, 2002), it remains an illness whose cause, outcome and long term effects are not completely understood. Consequently, a breast cancer diagnosis may cause women to re-examine their plans and expectations for the future because of the uncertainty it entails. As Bury (1982) recognizes, the uncertainty felt by ill individuals includes “both uncertain knowledge about the impact and course of the condition and of appropriate behaviour in the face of its effects” (p.172). This necessitates that individuals try to make sense of both the physical and psycho-social aspects of their illness in order to create a more certain reality for themselves. According to Bury, individuals must look to their own knowledge and biography in order to reconcile their self-concept with their illness experience because medical knowledge is limited and cannot satisfactorily provide meaning to illness (p. 179). Therefore, the uncertainty associated with illnesses such as breast cancer may cause a biographical disruption that requires the affected individual to reconfigure her/his former self-concept in order to live with the continuing ambiguity of chronic illness.

In addition to the biographical disruption women affected by breast cancer feel as a result of their diagnosis, treatment and ongoing side effects, they also may live in constant worry of a recurrence or diagnosis of another illness. McKenzie and Crouch

(2004) argue that cancer survivors are “persons who are afraid that, in the ‘longer term’, they may *not* be survivors” (emphasis in original, p.140). This idea is illustrated in a study of women who previously had breast or ovarian cancer and had recently undergone BRCA1/2 genetic testing. It was found that all participants were aware of the risk of recurrence and continued to monitor their bodies after treatment was completed (Hallowell, Foster, Eeles, Ardern-Jones, & Watson, 2004, p.557). The participants’ awareness of risk and ongoing surveillance of their bodies demonstrate the uncertainty experienced by women who have survived breast cancer, which may have profound psycho-social implications.

In order to address future risk, some women affected by breast cancer undergo genetic testing to confirm if their illness was genetically linked, which allows them to estimate the likelihood of future illness and inform family members of their potential risk. The majority of women in the aforementioned study who underwent genetic testing did not feel the result added to their perceptions of risk because they already felt susceptible due to their initial diagnosis (Hallowell et al., 2004, p.559). While the majority were able to accommodate their risk of recurrence or future illness over time, some women felt an increased susceptibility because of the results of the genetic testing which negatively affected their view of the future (Ibid., p.560). Thus, recurrence was a concern for all women in this study, despite the outcome of the genetic testing. While the participants shared a mutual concern regarding future risk, it appears that women vary in whether this concern is exaggerated by the presence of the BRCA1/2 gene.

As I described earlier, perceptions of future risk of breast cancer are also commonly experienced by female relatives of those who have had breast cancer. Kenen et al. (2003) found that many women live with a chronic risk that involves many of the same uncertainties faced by those with chronic illness (p.329). Chronic risk is defined as “the increased lifetime risk over the general population of developing breast/ ovarian cancer due to a family history of cancer” (Kenen et al., p.316). A mother’s diagnosis of breast cancer may lead her daughter to acknowledge her own susceptibility to breast cancer, which can have an array of psychological, behavioural and social implications. Living with chronic risk is characterized as a biographical disruption because it causes “changes in [women’s] behaviour, relationships and identity that are analogous, though

not identical to those found in individuals suffering from chronic illness” (Kenen et al., p.318). Therefore, upon their mothers being diagnosed with breast cancer, daughters may also feel that their everyday lives have been disrupted and that they need to re-examine their future plans as they become aware of their own possible breast cancer diagnosis.

In summary, the sociological study of health and illness provides important theoretical insight into the social impact a mother’s breast cancer has on the mother-daughter relationship. First of all, the shift of research to focus on the individual enables the exploration of subjectivity in illness experiences. This includes a focus on both those who experience illness directly and those who experience illness indirectly via family members. Incorporating timing and context into research on illness is also valuable in that it improves understanding of how meaning is given to illness and its consequences. Additionally, the characterization of chronic illness as biographical disruption sufficiently lends itself to the exploration of experiences of breast cancer, as diagnosis and the ensuing effects require individuals to re-assess everyday activities and the future. While women with breast cancer will likely experience some form of disruption as a result of their diagnosis, it is crucial to recognize that the extent of the disruption may vary depending on individual circumstances. Finally, the uncertainty of the future faced by women with breast cancer is commonly felt by their daughters as well, who must accommodate their own chronic risk in addition to their mother’s well-being. Therefore, I propose that both mothers and daughters face biographical disruption to some extent as a result of the mother’s breast cancer, which may have a number of implications for families.

### **2.3 The Family: Putting Illness in Context**

When studying the social implications of health and illness, it is crucial to place illness in context. One way of doing this is by focusing on the ill individual and their support network. In general, the family may play a significant role in illness experiences by providing care and social support. The family is also the site where gender and age-related roles are learned and distributed, which influences how families manage illness. When studying women’s experiences of breast cancer, the mother-daughter relationship emerges as a significant family relationship, because mothers and daughters often have

close relationships based on mutual support and interdependence in adulthood. Therefore, daughters commonly play an important role in their mother's illness experiences. Highlighting the perspectives of daughters adds to an understanding of women's experiences of breast cancer and the role that the family plays in them.

The family is often defined in terms of biological relationships, but is understood by sociologists as a social construct. The organization of individuals into families is reliant on structural, cultural and historical conditions. Consequently, the composition of families varies widely and is far from uniform. In an attempt to provide an adequate definition, Fox and Luxton (2001) define family as "the relationships that bring people together daily to share resources for the sake of caring for children and each other" (p.29). From this definition, it is evident that social relationships are significant to the family and provide a basis for considering the family as a social institution.

Another important factor in conceptualizing the family is that, despite being characterized and referred to as a "social unit", the family is composed of individuals who have both shared and unique characteristics. This characterization of the family as a group of individuals is exemplified by the life course approach, which "enables the family to be seen as a 'lived' experience, enacted by individuals, rather than simply as an institutional structure comprising sets of fixed roles" (Hockey & James, 2003, p.87). This conveys the belief that family identity relies on the group of individuals who negotiate their place and role within the family unit. In addition, this approach emphasizes that the family is dynamic rather than static. Families are constantly changing as individuals come into and leave the family and roles are shifted, gained or lost.

Gender is a central factor in determining how social interaction is carried out within the family. As Marx Ferree (1990) points out, gender provides "a hierarchical structure of opportunity and oppression as well as an affective structure of identity and cohesion, and families are one of many institutional settings in which these structures become lived experience" (p.870). Marx Ferree communicates the influence that gender has in shaping individuals' lives, both inside and outside of the family. Within the family, gender is especially significant, as it is commonly thought that the socialization of children continues to fall along gendered lines (Jacklin, 1989, cited in Petersen et al.,

2003, p.104). This belief indicates that the family is one site where children learn gendered behaviour that is often continued throughout their lives. While families may socialize children to fulfill gender stereotypes, they may also encourage divergence from conventional roles (Huston & Alvarez, 1990, cited in Balter Blume & Blume, 2003, p.786). Therefore, gender socialization that takes place within the family influences future behaviour and the roles that individuals assume within their family of origin and family of marriage. For instance, gender is typically a determining factor in who is responsible for care of elderly family members (Brewer, 2001, p.218).

Comparable to gender, age also has a significant influence on the distribution of social roles and responsibilities within the family. The family is often the location where children learn age-specific identities (Farmer, 2000, cited in Hockey & James, 2003, p.160). Identities based on age rely on the roles and expectations associated with that age range, as well as their position in relation to other age-based social positions. Because family roles vary within an individual's lifetime, "familial social identities... and the expectations, responsibilities and attitudes tied to these social roles, will [also] shift and change throughout his or her life course" (Hockey & James, p.88). Thus, different roles and identities are available depending on one's age and the family form one belongs to, as well as current conditions.

Age is also important to understanding family relations because changes in age-based identities are accompanied by changes in roles and expectations. According to Cowan (1991), transitions, or major life changes, "result in a qualitative reorganization of both inner life and external behaviour, or a reorganization of relationships between individuals and their social networks" (cited in Lowenstein, 2003, p.110). Life course transitions, such as illness, pervade all aspects of being. These transitions or changes require individuals, as well as other family members, to adapt and give meaning to them (Ibid., p.109). Changes in identity that often result from illness, whether age-related or not, have the potential to affect the entire family.

In relation to family experiences of illness, age plays an important role in determining how the family adjusts and copes with illness. In response to illness, family members may assume new roles in order to maintain stability and successful functioning of the family unit (Petersen et al., 2003; Spira & Kenemore, 2000; Northouse, 1995).

Because age-based identities are relative to those of others within the family, it may be difficult to maintain one's familial identity while assuming new roles. As shown by Hockey & James (2003), "while a child may in terms of 'age' become an adult, they remain genealogically the offspring of their parents however old they are" (p.164-5), suggesting that when a daughter assumes roles left open by her ill mother, it may be difficult for her to maintain her role as daughter as well. The disruption of age or generational order can have profound implications on family relationships. Parents and children must therefore negotiate their family roles in order to preserve aged-based identities and ensure the provision of care and social support.

The family is also recognized to play an important role for those coping with illness. The illness experience often includes changes to individuals' physical and mental well-being, among others. Research suggests that during times of illness the family becomes a resource for the ill, as it is the primary site of social support for those coping with illness-related disruptions (Pierret, 2003, p.13; Steinglass, 2000, p.6). This demonstrates that family members look to other family members for social support during illness experiences. It is also believed that family support has the ability to influence adjustment and outcome of illness (Steinglass, p.6). One way this occurs is through helping the ill to make sense of their experience and providing hope for the future (Chesla, 2005, p.376-7); thereby illustrating the importance of including the family in research about the social aspects of illness because it is the primary site in which illness experiences are managed.

Within the family, relationships among family members are important to day-to-day events, as well as during crises. In particular, mothers and daughters often form bonds which differ from other family relationships. The mother-daughter relationship is characterized by mutual support, caring and interdependence across the life cycle (Shawler, 2004, p.151). This relationship becomes especially valuable as daughters mature and the relationship becomes based on reciprocity, rather than unilateral care and support (Donorfio & Sheehan, 2001, p.46; Henman, 1997, p.255). This illustrates the significance of the mother-daughter relationship, as many mothers and daughters form unique and long-lasting bonds with each other. Although not all mother-daughter relationships assume these characteristics, it is recognized that "by late life, mothers and



daughters may have learned how to manage interactions to maximize enjoyment and minimize overt negativity and conflict” (Fingerman, 2003, cited in Shawler, p.150). Therefore, mothers and daughters negotiate their differences as they get older and commonly look to one another for companionship and social support.

The focus on the mother-daughter relationship in later life has also identified factors which may significantly influence the quality of the relationship, as well as the provision of care during health crises. For instance, Donorfio & Sheehan (2001) identify societal, familial, attitudinal and psychological dimensions that form the basis of the caregiving relationship. These include cultural expectations and values, as well as familial norms regarding the nature, extent, and explicitness of care (Ibid, p.40). The inclusion of several dimensions shows the complexities involved in the initiation of caregiving into a relationship. Daughters’ sense of obligation and the extent to which they feel they should be involved in their mother’s lives will vary depending on these dimensions. Consequently, it is important to recognize the multitude of experiences daughters have and how these affect the care given to their mothers.

There is significant evidence that the family plays a substantial part in illness experiences. As discussed earlier, the family is the site in which gender and age-based identities are often learned. These identities influence the distribution of roles and responsibilities within the family on a regular basis, as well as during times of crisis. When a family member becomes ill, families may be required to re-distribute the roles and responsibilities left open as a result of illness-imposed limitations in order to maintain family functioning. This re-distribution of family roles and responsibilities can affect family relationships, as previously held gender and age-based identities may be disrupted. Within the family, the mother-daughter relationship has particular significance, as this relationship often involves companionship and interdependence during the daughter’s adult years. I propose that the family provides crucial care and support during times of illness, especially daughters who may take on an important role because of the influence of gender socialization and the common interdependence of the mother-daughter relationships.

## **2.4 Caregiving: Connecting Sociological Domains**

The significance of care and social support for individuals who experience illness is widely acknowledged. It is thought that social support “can enable and enhance adaptive coping with a health problem through tangible or informational aid, as well as through enhancement of self-esteem and self-confidence that bolster one’s courage to face the problem” (Schaefer et al., 1981; Holahan et al., 1997, cited in Dukes Holland & Holahan, 2003, p.19). Dukes Holland & Holahan identify the significance of social support to those going through illness experiences. Ill individuals, along with their families, must also negotiate care-related issues, which can affect many aspects of their lives. While women with breast cancer may receive social support from various sources, it is evident that their daughters play a significant role in providing social support and care. Therefore, it is beneficial to draw upon existing literature on social support and caregiving in the family context.

The importance of one’s social support system in times of illness has been demonstrated by several studies (see Bloom et al., 2001 for a thorough review). Social support most commonly comes from those with whom one has formed close relationships, such as family members and friends (Bolger, Foster, Vinokur, & Ng, 1996). Family members are of particular importance to the social support system of women with breast cancer because of the illness-imposed limitations breast cancer often causes. For instance, breast cancer and its treatment may impose physical limitations on women, such as fatigue, pain, and arm problems, leading to diminished contact with others outside the family unit (Bloom et al.; Bloom & Kessler, 1994). This requires that family members to assume a major role in the provision of social support and care for women with breast cancer.

Social support refers to “the functions performed for the individual by significant others, such as family members, friends, and coworkers” (Thoits, 1995, p.64). Social support includes types of support such as: emotional, appraisal, informational, and instrumental (Bolger et al., 1996, p.286). Typically, different people provide different types of social support. Petersen et al. (2003) identify the way in which gender-role socialization may affect how family members provide social support. The authors believe that “[t]he family’s ability to meet the instrumental and emotional needs of a

women with cancer is, in part, influenced by gender-role socialization” (p.104). This statement proposes that gender plays a part in determining who is responsible for providing specific types of social support. Thus, it may fall on daughters to provide emotional support and care, while spouses and sons provide instrumental support and others outside the family, such as doctors or nurses, provide informational support.

Evidence supporting differences in social support based on gender is found in a study that reports communication avoidance by partners as a common theme for some younger women with breast cancer (Walsh et al., 2005). A significant number of women in this study found that their partner could not provide the emotional support they desired (Ibid., p.86). The lack of emotional support from their partners required these women to turn to others for emotional support. Research suggests that after a woman’s husband, daughters are the next largest support group (Bolger et al., 1996, p.286), which indicates that daughters are often called upon to provide emotional support. These findings illustrate the notion that emotional support is thought of as a feminine task.

Daughters may also be important in providing social support to those women who do not have a partner on whom they can rely. In a study performed by Holmberg et al. (2001), partnered women stated that their instrumental support needs were met, as partners took over household chores and provided transportation to treatment appointments (p.56). The women without partners in the study found it necessary to look elsewhere for this type of support. These women also received little emotional support from former partners and needed to look elsewhere for this type of support (Ibid., p.56). Holmberg et al.’s findings demonstrate the importance of family members, who after the spouse, provide greater amounts of affective support than friends or others (Dukes Holland & Holahan, 2003, p.17). Therefore, daughters appear to be an integral part of the social support system for women who are single, divorced or widowed.

Research on caregiving also emphasizes the importance of daughters to ill or aging parents. It has been shown that women typically perform care-related tasks more than men, as caregiving is portrayed as feminine in nature (Aronson, 1994; Kayser & Sormanti, 2002; Raveis & Pretter, 2005; Roberts et al., 1999), demonstrating one way in which daughters may have different experiences of their parent’s illness than sons. Assuming the role of caregiver to ill or aging parents can affect various aspects of

daughters' lives. Specifically, caregiving may cause daughters to experience stress, fatigue, financial hardship, and isolation (Brewer, 2001, p.218). It also may necessitate that daughters adjust their perceptions of their ill parent, take on new roles, balance old responsibilities with new ones, and negotiate the provision of care with their ill parent (Germino & Funk, 1993). Each of these outcomes is likely to affect the relationship that the caregiving daughter has with her ill parent. Thus, it is necessary to investigate how a daughter's involvement in providing care and social support during her mother's breast cancer experience has shaped their relationship.

In particular, research on caregiving has focused on relationships between aging mothers and caregiving daughters. One study proposes that the principle of "attentive love" is applicable to the relationship between caregiving daughters and aging mothers, in that "the practice of caring for a frail elderly mother parallels the work that mothers do in caring for their dependent, growing children" (Allen & Walker, 1992, p.285). Allen and Walker's assertion supports the belief that the mother-daughter relationship begins as a relationship based on maternal care for the child, shifts to become more interdependent, and is lastly based on care for the parent. While some studies focus on negative outcomes of the caregiver experience, such as burden, stress, and strain, many others identify positive outcomes, such as a sense of purpose, feelings of mastery, and increased emotional closeness (see studies cited in Donorfio & Sheehan, 2001, p.39). These studies illustrate the variety of experiences of daughters who care for their aging mothers. The literature on caregiving daughters and their aging mothers provides insight into the distinctiveness of mother-daughter relationships, which is also applicable to mothers with breast cancer and their adult daughters.

When a daughter assumes a caregiving role or observes her mother in a formerly unseen way, this has the potential to affect their relationship. One study identifies that changes in roles were an important concern to adult children who had a parent with cancer, especially if "adult children found themselves dealing with *role changing* in which they felt more like parents" (Germino & Funk 1993, p.103). This finding illustrates one major change that can occur in families when a parent has cancer. The reversal of family roles may create tension within the mother-daughter relationship or affect the daughter's own perception of the future (Germino & Funk; Raveis & Pretter,

2005). Thus, a mother's experience of cancer causes a confusion of age-based roles within the family that can be difficult for her daughter to manage.

Daughters may also have problems dealing with the added task of caregiving while trying to manage their own lives. This is especially relevant for daughters who have their own families. Daughters with this problem are described as the "sandwich generation", in that they are caught between the needs of their own families and those of their parents (Germino & Funk, 1993, p.104). Daughters without families of their own may also experience difficulties with the added task of caregiving. Having to care for or provide support to a mother with breast cancer has the potential to disrupt the daughter's attempts at becoming independent and creating a separate identity outside the family. This is certainly true for adolescent daughters, who are commonly pulled back toward the family rather than being allowed to develop autonomy and individual identity (Spira & Kenemore, 2000). Daughters may then face decisions about whether they should meet their own needs or those of their mothers.

In some cases, it may not be the children who have difficulty dealing with the role shifts brought about by a parent's illness experience, but the parent who cannot accept relinquishing the role of caregiver and allowing their children to help them. In a study of women diagnosed with cancer who had children living at home, many women expressed that they needed to find "new ways of maintaining the role of mother" while dealing with illness-imposed restrictions (Elmberger, Bolund, & Lutzen, 2000, p.494). This study suggests that mothers may seek alternative ways of providing for their children, in spite of sometimes being physically and emotionally restricted. While the experiences of mothers with adult children may differ, it is probable that they also wish to maintain the role of parent as long as possible and work to do so throughout their illness experience, demonstrating one of the hurdles that mothers encounter when faced with illness. Specifically, women with breast cancer often experience limitations in their physical capability and psycho-social problems that can constrain their ability to preserve their role as a parent.

Research has also identified that the extent to which mothers want and need children to assume caregiving roles varies. Specifically, societal expectations regarding caregiving by adult children are not always accepted by aging parents, who often wish to

maintain their independence and autonomy (see studies cited in Donorfio & Sheehan, 2001, p.41). The extent to which care is needed also varies with individual circumstances. Accordingly, it is important to realize that daughters' involvement in caregiving is linked to their own feelings of obligation, their availability, their mothers' desire for care, as well as the actual need for care. Therefore, mothers and daughters must negotiate issues related to care and social support in order to maintain previous features of their relationship as well as create new ones.

Another issue related to caregiving within families experiencing cancer is that of mortality. Research identifies that parents often do not want their children to see them as vulnerable or mortal. In a study of men with prostate cancer, an illness with a similar hereditary component as breast cancer, it was stated that "tension arose from a desire to share their concerns with their adult children and the preference not to be perceived differently" (Arrington, 2005, p. 153). Arrington identifies a dilemma faced by parents who desire support from their children at the same time as they do not wish to give up their familial position. This finding is echoed by a study of women with ovarian cancer, in which the women experienced a need for support from family members at the same time as a desire to maintain roles within the family (Ferrell et al., 2003). Both social support and maintenance of family roles were beneficial to these women's psycho-social well-being, but were difficult to uphold because of their conflictual nature.

Although there are differences in the experiences of those with prostate, ovarian and breast cancers, there are also similarities in the issues that arise. As demonstrated above, allowing one's children to observe a parent's vulnerability and mortality is commonly unwanted. Another common concern reported in a study of young women with breast cancer is "feelings of guilt about the distress your family and friends experience because of your breast cancer diagnosis" (Dunn & Steginga, 2000, p.141). This concern explicates that women with breast cancer do not want to be a burden or create extra work and anxiety for their family and friends. Thus, women with breast cancer may have difficulty accepting help from family members, especially those who already have busy schedules or a heavy workload such as adult daughters with children of their own.

Research on ill or aging mothers and caregiving daughters provides a valuable starting point for studying the mother-daughter relationship in relation to a mother's breast cancer experience. Adult daughters whose mothers are diagnosed with an illness that can be life threatening or have chronic effects, such as breast cancer, may feel similar obligations to their mothers as those felt by daughters with aging mothers. In other words, a health crisis may evoke feelings of responsibility in daughters to provide care and social support to their mothers. Again, many factors influence whether, and to what extent, daughters act on these feelings. While it is likely that daughters of ill mothers will play some sort of role in their mother's illness experience, research has neglected to explore the experiences of daughters who are young or middle-aged adults whose mothers are ill but not necessarily elderly. It is also valuable to take into account the roles and responsibilities that daughters hold previous to their mothers' diagnosis in order to understand their involvement in caring for and supporting their mothers.

My review of the caregiving and social support literature indicates the vital role the family plays in the provision of support and care. There is persuasive evidence that daughters take on key support roles for their mothers, as support and caregiving activities are often seen as a feminine in nature. Thus, daughters face a number of issues related to the provision of social support. These issues include: negotiating care-related issues, taking on new roles, balancing responsibilities, and adjusting perceptions of their mothers. Mothers also face issues related to the receipt of support and care. These issues involve: negotiating care-related issues, desiring to maintain independence, attempting to fulfill past roles and responsibilities, resisting changes in perceptions, and not wanting to burden others. Each of these issues may have profound implications for the mother-daughter relationship. Therefore, it important to undertake an exploration of breast cancer and the mother-daughter relationship in order to illuminate the ways in which these and other possible issues are managed by mothers and daughters and how they affect their relationship. Further, the exploration of caregiving occurs at the intersection of key sociological domains, namely health and illness and the family.

## **2.5 Summary**

The existing literature on breast cancer indicates that there are a number of implications which result from diagnosis. In particular, women may experience

limitations in their physical, psychological, and social functioning. As illustrated previously, these limitations may lead to changes in women's psycho-social well-being, which can include changes in social relationships. The hereditary component of some breast cancer cases adds another layer of complexity to this already multifaceted illness. A woman's diagnosis may bring about increased perceptions of risk for her daughter and other female relatives, which may have psychological and social ramifications. Comparable to women with breast cancer, female relatives often face biographical disruption and uncertainty, which may generate changes in behaviour and psycho-social well-being. Thus, it is apparent that breast cancer can have substantial consequences for women and their family members.

As I demonstrate in the health and illness section, there is a continuing need to highlight individual experiences of illness in order to emphasize their subjective nature. It is evident that family members' experiences should be included in this focus on individual experiences, as they too are profoundly affected by illness. By recognizing and sharing individual experiences, ill persons are able to give meaning to their experiences and help others to understand what it means to be ill. This may be especially helpful for those who experience biographical disruption as a result of illness and must reconfigure their sense of identity in order to reconcile it with their illness. Family members, particularly daughters who face issues related to "chronic risk", can also experience biographical disruption as a result of their mother's breast cancer diagnosis. Thus, there is a need to explore breast cancer experiences within the family in order to assess to whether, and the extent to which, biographical disruption occurs.

Research suggests that the family plays a vital role for those experiencing illness. As I mentioned earlier, the family is a resource for those who are ill because it is typically the primary site of social support and care. Illness may require families to re-organize roles and responsibilities in order to provide support, fulfill those left open by the ill individual and maintain family functioning. The management and distribution of support and caregiving tasks are often influenced by gender and aged-based identities, which are usually learned through socialization within the family. Thus, daughters may be called upon to provide support and care for their mothers because of the feminine



nature of these tasks, as well as the interdependence that commonly exists in mother-daughter relationships.

Finally, existing literature on caregiving illustrates the importance of social support during times of illness, as it is beneficial to adjustment and endurance. Throughout the literature, it is apparent that daughters play crucial roles in supporting ill or aging family members. This may require that daughters take on new roles within the family and balance their own responsibilities with support-related tasks. These requirements may have both positive and negative effects on daughters. Research also indicates that mothers may experience difficulties resulting from the need for social support and care, as they may wish to maintain their autonomy and current roles. Thus, it is apparent that the provision and receipt of social support may lead to changes in the mother-daughter relationship. However, it is unclear to what extent and in what ways changes occur within their relationship.

Throughout the literature review, I have demonstrated the need for further research on illness and the family and, in particular, breast cancer and the mother-daughter relationship. While previous research identifies a variety of issues related to breast cancer, there is a paucity of research on the social impact of breast cancer on women and their families. There is ample evidence that daughters play an important role in their mothers' breast cancer experiences, but it is not clear how this affects daughters' perceptions of themselves and their mothers. My research highlights the experiences of women diagnosed with breast cancer and their daughters in order to improve our knowledge of the issues they face. Exploring their experiences will contribute to a greater understanding of how breast cancer affects family roles and responsibilities, as well as the mother-daughter relationship.

## **CHAPTER THREE: METHODOLOGY**

The methodological approach informing this study of mothers and daughters' experiences of breast cancer is a blend of feminist and interpretive perspectives. In the first section, I identify key characteristics of each perspective and their correspondence to one another. I also emphasize the suitability of this blended approach for research about women's experiences of illness. The next two sections focus on the design of the research study and the recruitment and selection of participants. Mothers and daughters participated in one semi-structured qualitative interview together, as well as separate follow-up interviews. Mothers and daughters were recruited using a snowball sampling technique, which utilized advertisements and word of mouth. The fourth section of this chapter describes the data analysis process, which involved the coding and development of themes. The next section highlights aspects of the study that determine its credibility. Finally, I conclude with a discussion of some ethical considerations involved with this study.

### **3.1 A Feminist-Interpretive Approach**

The blended feminist-interpretive approach utilized in this study draws on principles shared by the two perspectives. In this section, I describe the basis of each perspective and how they correspond to one another. First of all, it is important to recognize that, while there are several feminist approaches to research, they all share a common feature. According to Harding (1987), all feminist research stems from a focus on women's experiences (p.7). In a discussion of feminisms and models of qualitative research, Olesen (1998) elaborates on Harding's claim stating that, although there are many feminisms, they share the view that "it is important to centre and make problematic women's diverse situations and the institutions and frames that influence those situations" (p.300). Thus, Olesen argues that all feminist research shares a mutual focus on the unique experiences of women and the social structures that shape them.

Harding and Olesen's assertions illuminate the belief that women experience the social world in distinctive ways.

The interpretive approach corresponds to feminist epistemology in that it draws upon individual experiences as a source of data. Interpretive approaches to research can be thought of as "the study of lived experience [which] aims to describe and interpret experiences of everyday life" (Jansen & Roe Davis, 1998, p.290). Specifically, interpretivists attempt to understand "the complex world of lived experience from the point of view of those who live it" (Schwandt, 1998, p.221). Schwandt emphasizes that interpretivist research is grounded in individual experiences of social phenomena. Interpretivists argue that everyone has an individual understanding of the social world that reflects the social processes in which they are engaged. Thus, interpretive researchers focus on describing and understanding individual experiences, rather than attempting to determine causality.

Interpretivists aim to explore subjective experiences in order to better grasp the social structures that liberate and constrain the individuals affected by them. Jansen and Roe Davis (1998) propose the need to focus on "understanding (how), rather than obtaining explanations (why)" (p.292). They assert that interpretivist approaches do not concern themselves with the reasons that social phenomena occur in so much as they are interested in the effects that certain experiences have on social beings. In order to access individual's "lived experience" (van Manen, 1990), it is necessary to utilize "how questions" during qualitative interviews as a way to invite "the inclusion of context and process" (Jansen & Roe Davis, p.292). Jansen and Roe Davis suggest that understanding is gained through the exploration of how an experience occurs within a certain social structure.

The focus on lived experience makes interpretive approaches suitable for research about sensitive issues. For instance, the use of qualitative methods by interpretivist researchers allows for the generation of data through interaction between the researcher and participant in a manner that allows for understanding. According to Jansen and Roe Davis (1998), qualitative methods are best for researching sensitive topics because they offer "more personal and interactive communication [which] has the potential to diminish the typical power relationships present in conventional research"

(p.289). This observation identifies the capability of qualitative methods to create an intimate and egalitarian relationship between researcher and participant, which is essential when discussing personal experiences. Qualitative interviewing is characterized as “empathetic”, in that the interview is a collaborative effort in which “the researcher and the respondents... work together to create a narrative... that could be beneficial to the group studied” (Fontana & Frey, 2005, p.697). Thus, interpretive approaches advocate an intimate and interactive interview format that allows experiences of sensitive issues to be discussed.

Feminist research also proposes that there is a need to diminish power differentials between the researcher and the participant. While it has long been thought that the researcher holds a position of power within the interview setting, Olesen (2005) refers to several studies that indicate that the researcher’s “power” is “partial, illusory, tenuous, and confused with researcher responsibility” (see studies cited in Olesen, p.255). While the researcher may wield control over some aspects of the interview, the participant is also powerful in that she/ he determines which experiences are shared with the researcher and to what extent. Thus, there is support for Thompson’s proposal that “the relationship between researcher and researched is founded on equality” (Thompson, 1992, p.14). Adhering to feminist and interpretivist preferences for qualitative research will influence the outcome of the research, as interviews hinge upon an effort to equally distribute and recognize dimensions of power between the researcher and the participants.

Feminist methodology also aims to ensure a focus on certain epistemological concerns which are significant to the study of women’s experiences of breast cancer. Primarily, feminists “reject any notion of objectivity founded on the possibility of knowledge untainted by history, culture, politics, and personal beliefs” (Thompson, 1992, p.9). This statement raises two issues related to feminist research. One issue is related to the distinctiveness of individuals’ experiences and perspectives. In order to emphasize that no two individuals will have identical experiences of a social phenomenon, it is imperative to acknowledge the context in which individual experiences occur. Thompson recognizes the need to access the contextual and personal aspects of women’s experiences, as well as the factual ones. Therefore, researchers must

engage with many aspects of participants' experiences in order to fully understand how they are affected by certain events.

Although there may be similarities in individual experiences of breast cancer, there is also variability in all aspects of the way individuals encounter the social world. The subjective nature of the breast cancer experience and its impact on social relationships emphasizes the suitability of a qualitative approach, in that it allows for the exploration of how individuals give meaning to the experience. Kasper (1994) proposes that the subjective data emerging from qualitative studies are useful because "they enable us to know how individuals arrive at meanings which sustain them, live as social beings among many, interact with social conventions and institutions, and maintain the boundaries which help define them as individuals" (p.278). Accordingly, qualitative research methods focus on the unique experiences of individuals with the hope of improving understanding of how individuals experience certain social phenomena. In order to comprehend the impact of breast cancer on the mother-daughter relationship, it was necessary to include both mothers and daughters, as they each contributed one side of the story.

The exploration of individual experiences is often best accomplished by using unstructured or semi-structured interview formats with open-ended questions, which allow the participants to determine the course of the interview. DeVault (1986) describes interview techniques that allow women to address issues they feel are important, rather than imposing certain topics on them. In her own words, she encourages interviewing that is "closer to 'woman talk' than to survey research" (cited in Kasper, 1994, p.268). DeVault indicates that participants have more influence over qualitative research than they do in quantitative studies. Qualitative interviews also permit "researchers to make full use of differences among people" (Reinharz, 1992, p.19). Therefore, unlike quantitative methods which attempt to predict outcomes based on patterns and frequencies, qualitative research engages with similarities and differences because both contribute to understanding of social phenomena. As mentioned previously, the goal of interpretivist research is to emphasize how or what, rather than why.

A second issue related to the rejection of objectivity in social research pertains to the recognition that researchers cannot remove their personal views from the research

they perform. Olesen (1998) points out that a common criticism of qualitative research is the seeming presence of the researcher's biases in data generation and analysis (p.314). Addressing this concern, Harding (1987) argues that, "we need to avoid the 'objectivist' stance that attempts to make the researcher's cultural beliefs and practices invisible" (p.9). She continues by stating that acknowledging the subjective element of feminist research "increases the objectivity of the research and decreases the 'objectivism' which hides this kind of evidence from the public" (Ibid., p.9). Harding's argument proposes that it is impossible to be completely neutral and, therefore, personal biases and agendas should be made explicit in order to avoid deception. Interpretivist approaches to research correspond to feminist calls for transparency, as the outcome is based on the researcher's subjective interpretation of the data. Schwandt (1998) recognizes that subjectivity is an inescapable part of social research because interpretation is a fundamental part of all social interaction (p.228). In summary, the feminist and interpretivist approaches advocate that researchers be aware of the context in which their research occurs, as well as how her/ his personal experiences shape the research outcome. The rejection of objectivity in qualitative research also removes authority from the researcher and elevates individual perceptions to an equivalent level.

In response to calls for transparency in social research, researchers are encouraged to be reflexive in their work. Olesen (1998) claims that with sufficient reflexivity a researcher can "uncover what may be deep-seated but poorly recognized views on issues central to the research and a full account of the researcher's views, thinking, and conduct" (p.314). Olesen suggests that reflexivity allows the researcher's subjective views to become apparent in the research process. Reflexivity involves attempts "to explain the grounds on which selective interpretations [have] been made by making explicit the processes of decision making which produce the interpretation and the logic of the method on which these decisions are based" (Holland & Ramazanoglu, 1994, cited in Olesen, 2005, p.251). Reflexivity involves reflecting upon and acknowledging the background of the researcher and how interpretations of the data were arrived at, as well as the circumstances in which the research takes place. Reflexivity is crucial in qualitative research that results in the authentic understanding of social phenomena.

Finally, the use of a feminist-interpretive approach to the study of breast cancer and the mother-daughter relationship attempts to present the perspectives of women whose voices may be overshadowed by biomedical accounts of breast cancer. Much of the literature regarding breast cancer is derived from scientific discourse surrounding the diagnosis and treatment of the disease. This literature prioritizes scientific information over the experiences of individuals who actually live and survive breast cancer. One of the fundamental objectives of feminist methodology is to privilege the perspectives of the marginal and less powerful. Olesen & Clarke (1999) state that feminist research “generates new ideas to produce knowledge about oppressive situations for women, for action or further research” (cited in Olesen, 2005, p. 236). Feminist research focuses specifically on circumstances affecting women in order to demonstrate the discrepancy that exists between women’s experiences and those presented as the dominant perspective in society, which are typically put forth by men (Kasper, 1994). Thus, feminist researchers attempt to identify evidence of power differentials in society and how they influence women’s experiences. Thompson (1992) contributes further support for researching individual experiences by noting that, “to speak from experience has authority” (p.11). Highlighting the perspectives of women who have experienced breast cancer, as well as their daughters who must deal with both their mother’s illness and their own feelings of vulnerability to the illness, produces vital information which adds to our understanding of how illness experiences are shaped by women’s positions in the social world.

In this section, I have outlined some of the epistemological principles underlying feminist and interpretive approaches to social research and have demonstrated the compatibility of the two. For instance, both approaches emphasize the need to focus on individuals’ lived experiences in order to gain a better understanding of social phenomena. Both approaches also support the use of qualitative methods such as interviewing, as data is generated collaboratively by the researcher and the participants. The collaborative nature of qualitative interviews allows for power differentials to be lessened and sensitive issues to be broached. In addition, feminists and interpretivists emphasize that subjectivity is an inescapable aspect of social research. Thus, a blended feminist-interpretive approach advocates reflexivity in social research, meaning that the

researcher should be aware and make participants aware of personal biases or agendas. The blended approach utilized in this study is suitable for the research topic because it enables the exploration of how the participants construct and interpret changes in their social relationships within individual breast cancer experiences.

### **3.2 Research Design**

In order to explore the impact of breast cancer on the mother-daughter relationship, qualitative interviews with four mother-daughter dyads were carried out. This resulted in a total of twelve interview transcripts that were analyzed for emerging themes. Qualitative methods have justifiably been used in other cancer-related research studies, as “the impact of cancer and its treatment cannot be fully captured by using predetermined scales” (Luoma & Hakamies-Blomqvist, 2004, p.729-30). This claim demonstrates the need to utilize a method that captures the uniqueness of the participants’ experiences. Qualitative interviews allow participants to address aspects of their experiences that they deemed to be significant. Hence, mothers and daughters were able to focus on the issues they felt were important to understanding how breast cancer affected their relationship. Therefore, qualitative interviews are suitable for the study of individual perspectives of the impact of a mother’s breast cancer experience on mothers and daughters’ roles, responsibilities, relationships.

The interviews were semi-structured with open-ended questions that allowed the pair to discuss the issues presented to them, as well as to identify any topics they deemed essential to understanding the dynamics of their relationship. An initial interview was carried out with both mother and daughter to discuss the details of the mother’s breast cancer experience, their family composition, and their relationship. The interview guide used in the initial interviews was common to all of the dyads, although the interviews differed based on their experiences and what they felt was significant. The initial interviews were audio-recorded and transcribed in order to identify emerging themes that highlight the impact of breast cancer on family roles, responsibilities, and relationships.

After the transcription and preliminary analysis of the initial interview, follow-up interviews were arranged with the mother and daughter separately, at which time further discussion of major themes from the first interview occurred. The interview guides used



in the follow-up interviews were unique to each participant, as they were based on preliminary analysis of the initial interview. The follow-up interviews allowed participants to elaborate and reflect on their previous comments, highlighting the effects of breast cancer that they felt had significantly affected their family relationships. The follow-up interviews were valuable because they allowed for validation of the researcher's interpretations by the participants. Consultation with participants regarding the researcher's interpretation of their experiences is useful in order to avoid misinterpretation. Borland (1991) acknowledges the importance of recognizing one's own subjective interpretation of qualitative data as well as the usefulness of post-interview consultation in her work on oral history (p.71). Accordingly, discussion of the researcher's interpretation with participants was beneficial, as was the use of open-ended questions and a semi-structured interview format.

### **3.3 Selection and Recruitment of Participants**

In order to carry out the research study, participants were recruited in the province of Saskatchewan. Participants were selected based on a number of criteria. Mother-daughter dyads consisted of a mother, who had experienced breast cancer, and a daughter over the age of nineteen. This study included women who were diagnosed with and treated for breast cancer in the past, not those women currently undergoing treatment. Daughters in this study were those who had not experienced breast cancer themselves at the time of recruitment. Participants were also required to be willing to share personal experiences and participate in audio-recorded interviews. I wished to recruit participants of a variety of ages, geographic locations, and marital statuses, in order to access a diverse range of perspectives. The sample was also varied based on time since breast cancer diagnosis.

Participant recruitment took place largely in the Saskatoon area through advertisements and a snowball sampling technique (i.e., word of mouth). Advertisements were distributed at a provincial survivorship conference in Saskatoon, a beauty salon, and with the assistance of support organizations, such as Breast Cancer Action Saskatchewan and the Hope Cancer Centre. This method of recruitment was successful because of the continuing involvement of many breast cancer survivors in the cancer community. Their involvement included attendance at conferences,

communication with support organizations, and personal interactions with those aware of the study. Participants who were interested in the study contacted me for information about the study and to volunteer to participate. Once interest was confirmed, I determined if the women met the criteria for participation and sought possible interview times.

### **3.4 Data Analysis: Coding and Development of Themes**

After the first interview with a mother-daughter dyad took place, preliminary analysis was done in order to create interview guides for the follow-up interviews. The preliminary analysis involved: reading notes from the interview, transcribing the interview, making notes during the transcription process on possible follow-up questions, reading the transcript one or two times to confirm the topics that needed to be explored further, and consulting with my thesis supervisor on follow-up interview guides. The preliminary analysis facilitated the creation of interview guides that were unique to each participant in order to better understand their experiences. Each subsequent interview guide, after the first set, was revised to include topics that emerged during the previous interviews. I found that introducing topics that the other participants expressed as significant assisted me with recognizing the similarities and differences in their experiences. In this way, data analysis took place throughout the study, beginning after the first dyad was interviewed. Preliminary analysis was supplemented by an ongoing review of relevant literature as possible themes emerged during the interviews.

Once all of the interviews were completed and transcribed, a cross-sectional organization of the data took place. Cross-sectional organization refers to “devising a consistent system for indexing the whole of a data set according to a set of common principles and measures” (Mason, 2002, p.150). This technique allows researchers to identify themes across the data, which allows for the recognition of similarities and differences. Drawing upon the preliminary analysis, I examined the transcripts in order to determine themes emerging from the interviews. Each transcript was read twice to develop a more concrete idea of themes. Next, the transcripts were coded by theme. At this stage, major themes and sub-themes were decided on and organized into three thematic sections.

Transcripts were then coded again using the qualitative software program QSR NVivo. This program helped me to organize sections of text into categories based on theme, which constitute the basis of the findings of this study. The process of analysis and coding involved reading over the interview transcripts several times and interpreting what was said by the participants. Each stage of coding involved further decisions about which quotations fit with which theme. According to Mason (2002), performing interpretive readings of research data involves “constructing or documenting a version of what you think the data mean or represent” (p.149). Therefore, the themes of the interviews resulted from the application of my own interpretations of what was said by the participants. Interpreting the data also involved comparing experiences, identifying similarities and differences, and deciding if certain quotations were representative; all actions based on my interpretive reading of the data.

Although I applied my own interpretation to the participants’ words, it is not without awareness that this was done. Applying one’s own interpretation to interview data is acceptable for those adhering to the interpretive approach, as interpretation is “a fundamental grounds of our being-in-the-world” (Schwandt, 1998, p.228). Thus, if the basis of social existence is interpretation, then it is an inescapable part of social interaction. As mentioned earlier, feminist and interpretivist researchers encourage reflexivity in the research process in order to ensure an authentic account of individual experiences. In order to incorporate reflexivity into the research process, I have attempted to locate my own role in the data generation and interpretation processes, as advocated by Mason (2002, p.149). By recognizing the part I played in constructing the data, I hope to illuminate ways in which the data was shaped by my research interest and personal characteristics. Specifically, I acknowledge that the use of social science terminology on occasion may have been confusing, as the participants sometimes misinterpreted the meaning of my questions. However, my emphasis on the exploratory nature of the study helped participants to understand that I was interested in hearing about their experiences in general, rather than finding out about particular events. Incorporating reflexivity into the research process is also a way to ensure the credibility of qualitative research.

### 3.5 Credibility

Determining credibility in qualitative research is highly contestable, as the applicable criteria vary widely among research studies. In order to present findings that were authentic and useful, I made an effort to ensure the research data accurately resembled what was said by participants. One method of ensuring trustworthiness surfaced in the process of transcription of the audio-recorded interviews. Seale (1999) argues the importance of:

...recording observations in terms that are as concrete as possible, including verbatim accounts of what people say, for example, rather than researchers' reconstructions of the general sense of what a person said, which would allow researchers' personal perspectives to influence the reporting (cited in Silverman, 2001, p.227).

Accordingly, I transcribed all interviews verbatim, in order to focus on participants' exact words in the analysis process. I also recorded all thoughts shared by the participants, whether they were relevant to the topic of the interview or not. Silverman advocates the use of precise methods of transcription, as "a failure to transcribe apparently trivial, but often crucial" information weakens the reliability of the analysis (p.230). In some cases, these seemingly trivial comments or stories were helpful in gaining a more complete understanding of the participants' experiences. Although I went to great lengths to ensure the accuracy of the data, some quotations presented in the findings chapter have undergone minor editing to improve clarity. Despite this, many of the 'filler' words, such as 'like' or 'so', have been included in order to preserve the participants' voices.

The follow-up interviews served as a way to authenticate my interpretations of the initial interview. In order to verify authenticity, I presented the participants with a statement of what they had said previously on a specific topic and asked for elaboration or clarification. This approach often led to a further description of the participant's experience, which helped me to better understand the noteworthy aspects. In some cases, the participants merely echoed what was said in the first interview. This repetition was taken as confirmation of what was said previously and its significance to the participants' experiences. The follow-up interviews provided a valuable opportunity to seek feedback from the participants, as well as to delve further into their experiences.

Although follow-up interviews were a prime opportunity to verify my interpretations of the initial interviews, respondent validation in qualitative research is often depicted as unattainable. Namely, participants usually do not understand or do not read the interpretations that the researcher has applied to their experiences (Bloor, 1978, cited in Silverman, 2001, p.236). Mason (2002) also suggests that respondent validation is impossible because participants do not have epistemological privilege, as they cannot confirm that their experiences speak for others (p.193). Despite this, attempts for validation are useful in that they generate further data and “should be treated as yet another source of data and insight” (Fielding & Fielding, 1986, cited in Silverman, p.236). Thus, the follow-up interviews allowed me to explain my interpretations to the participants, which helped them to elaborate or clarify their experiences.

While the validity of qualitative research is difficult to discern, Mason (2002) proposes two ways that validity can be assessed. First, qualitative research should be evaluated in reference to the validity of data generation methods (p.189). In other words, were qualitative interviews an appropriate method to explore the social impact of breast cancer on the mother-daughter relationship? Most importantly, the objective of this study was to explore the experiences of those who live illness firsthand in order to determine how they have been affected. Qualitative interviews were suitable in fulfilling this objective because they accessed the experiences and perspectives of mothers and daughters who were directly affected by breast cancer. In addition, the suitability of qualitative interviews for sensitive topic research has been described earlier, as has the compatibility of feminist-interpretive methodology and qualitative interviews. Lastly, qualitative interviews also allow a range of experiences to be explored, as generalization is not a concern to the same extent that it is in quantitative research. Therefore, qualitative interviews appear to be a valid method in exploring mothers and daughters’ experiences of breast cancer.

Mason (2002) also suggests that qualitative research can be evaluated in terms of the validity of interpretation (p.191). In other words, what measures have been taken to ensure that data analysis is of good quality and rigorous? One indication of the validity of interpretation in this study emerged from the thorough analysis of the data. As described earlier, the analysis of the data took place over several months and involved

reading and coding the data several times. On several occasions, I discussed the follow-up interview guides and the emerging themes with my thesis supervisor, which yielded useful feedback. The data was organized cross-sectionally by theme in order to illustrate specific ways that mothers' breast cancer influenced family roles, responsibilities and relationships. Also, the analysis process involved considering alternative explanations. For example, I was careful to note whether mothers and daughters felt that growth in their relationship was a result of the breast cancer experience or a consequence of something else. Thus, interpretations were made based on the consideration of multiple possibilities, as well as their relation to existing research. Although the validity of interpretation is important to assess, it is nonetheless difficult because of the subjective aspects of interpretation and the impossibility of reaching a universal truth (Mason, 2002, p.191). Consequently, I have attempted to show here some aspects of the research process that contribute to the validity of my interpretations.

It is also important to recognize how the method and design utilized in this study affected its outcome. Performing the initial interview with both mother and daughter has a number of implications. For instance, it is possible that being interviewed together made mothers and daughters more comfortable and willing to share personal experiences. On the other hand, interviewing mothers and daughters together may have placed greater pressure on them to control their emotions or not talk about difficult situations in front of one another. For example, mothers may not have wanted to express vulnerability in front of daughters. The separate follow-up interviews may have also had an influence on the data. The follow-up interviews allowed participants to broach topics that participants may have omitted during the initial interview. They also provided an opportunity for participants to reflect on their experiences and remember details they may have forgotten in the first interview. In addition, the participants also may have felt more comfortable during the second interview because they were familiar with me and the interview format. These observations illustrate some ways that choice of method and research design influenced the data generated in this study. Additionally, there were several ethical considerations that also had an important impact on the outcome of this study.

### 3.6 Ethical Considerations

This section focuses on the measures taken to ensure that this study was performed on ethical grounds, which contributes to its credibility. Before entering the data generation phase of this research study, ethics approval was gained from the University of Saskatchewan Review Ethics Board for behavioural research. This process included submitting a summary of the proposed research design, a consent form template, and the interview protocol for ethical review. Ethical concerns in qualitative research often differ from those in biomedical or quantitative research. This is recognized by van den Hoonaard (2002), who argues that “codes of ethics [are] designed for other types of research” and usually neglect the flexible design of qualitative studies (p.15). This comment resonates with this study in particular because the interview guides were revised throughout the data generation process. Therefore, I could not submit each interview guide for review prior to beginning data generation. Despite this, the questions asked during the interviews were similar to those in the interview protocol that was submitted for review. Although the ethical review largely focuses on biomedical issues of risk or harm, there are some ethical considerations which are imperative for qualitative researchers to ensure. As Punch (1998) argues, “a professional code of ethics is beneficial as a *guideline* that alerts researchers to the ethical dimensions of their work, particularly *prior* to entry (emphasis in original, p.171). Subsequently, some aspects of the review process may not be helpful, but considering the ethical implications of research remains important.

One important ethical issue underlying all social research is that of gaining informed consent from the participants. Although the issue of consent is contested by some qualitative researchers (van den Hoonaard, 2002, p.10), the need to inform participants of the objective or purpose of the study is essential when conducting interviews. Informed consent involves giving participants information about the research, ensuring that they understand it and that their participation is voluntary (Silverman, 2001, p.271). In this study, no advantage would have been gained by myself if the objective had not been disclosed to the participants beforehand. Also, I felt it was necessary to follow the University’s ethical guidelines and gain verbal and written consent from participants at the beginning of each interview before turning on the audio-

recorder. All participants willingly gave written consent after a review of the consent form and acknowledgement of their right to withdraw at any point of the study. As the participants of this study are not part of an oppressed or marginalized group in society (besides being women), participating in this study and providing written consent did not pose harm or risk to them.

Another issue that is significant to qualitative interview research is that of confidentiality. Maintaining confidentiality relates to ensuring that “identities, locations of individuals and places are concealed in published results, data collected are held in anonymized form, and all data [are] kept securely confidential” (Bulmer, cited in Punch, 1998, p.175). This is important to researchers performing qualitative interview research, no matter the sensitivity of the participants’ position in society or experiences shared. In this study, confidentiality was assured through the use of pseudonyms, the deletion of personal information from transcripts, and the removal of any other identifying factors, such as the names of doctors or organizations participants were affiliated with. Because of the relatively small size of the province participants were recruited from, steps were taken to ensure the confidentiality of participants, despite their willingness to share personal stories with others and a general lack of hesitation about their publication.

Although the stories shared by participants related to a sensitive issue, they did not generally involve issues that required a high level of privacy with respect to legal or moral issues (see van den Hoonaard, 2002 for examples of research subject to legal ramifications). Despite this, the researcher took steps to ensure confidentiality of participants’ personal information in order to respect their right to privacy. Transcripts and recordings of participants were labelled with an alpha-numeric code in order to avoid identification by others and stored in a different location than consent forms and the pseudonym/ coding reference. Personal information such as addresses and phone numbers were also stored in a secure, alternate location from the transcripts and recordings. Participants were also asked to review the transcripts of their interviews at which time they could alter or delete any or all of their comments. Once a review of the transcripts was completed, participants signed a transcript release form allowing for the publication of any information given to the researcher which had not been withdrawn. These efforts demonstrate my belief in the assurance of confidentiality in qualitative



research, in order to avoid any potential risks involved with the disclosure of such information (i.e. embarrassment of participant or others associated with them, withdrawal of medical services, controversy over comments on topic, influence on academic standing, etc).

### **3.7 Summary**

In the preceding section, I outline the methodological approach and research methods utilized in this study. First of all, I justify the use of a blended feminist-interpretive approach and show how the two perspectives correspond to one another. It is primarily the shared focus on individual experiences and the recognition of subjectivity in the research process that enable the two approaches to be blended. I also demonstrate the suitability of qualitative interviews to the exploration of women's experiences of breast cancer. The suitability of the chosen research method contributes to the validity of the study. Next, I describe the design of the study, as well as the recruitment and selection of participants. The data analysis section summarizes the preliminary analysis performed, as well as the process of developing themes and coding the interview transcripts. The description of the steps involved in analyzing the data demonstrates the thoroughness of the analysis, which supports the validity of interpretation applied to the data. The assessment of validity makes up a substantial part of the section on credibility, in which I attempt to show the measures taken to ensure the validity and trustworthiness of the findings of this study. Finally, I conclude this chapter with a discussion of the ethics approval process and specific ethical considerations that were relevant to the study. As a whole, this chapter identifies several aspects involved in the development of this study and demonstrates their influence on the findings and outcome.

## CHAPTER FOUR: FINDINGS

In this chapter, I begin by introducing each of the mother-daughter dyads and give some background information about their family composition, living arrangements, and personal responsibilities. Each of the mother-daughter dyads were given pseudonyms starting with the same letter so they can be easily identified. Participant demographics are also summarized in Table 1. Next, I describe the three major themes that emerged from the interviews with mothers and daughters. The first theme focuses on shifts in roles and responsibilities that resulted from the breast cancer experience, demonstrating how mothers and daughters' lives were affected during the mother's treatment for breast cancer. The second theme identifies issues involved in the ongoing process of coping with breast cancer, illustrating that both mothers and daughters utilized various coping resources and strategies in order to cope with breast cancer and the threat it posed to their well-being. The third theme describes growth that occurred in family relationships during the illness experience, as well as a possible negative outcome that illness may have for relationships within the family. This theme highlights the lasting impressions that breast cancer had on daughters' perceptions of their mothers and relationships within the family. Each section of this chapter provides evidence of how mothers, daughters, and other family members were affected by the illness experience at various stages of the illness process, from diagnosis to treatment and beyond. The findings described in this chapter serve as evidence that mothers and daughters experience some degree of biographical disruption as a result of mothers' breast cancer.

### 4.1 Profiles of Participants

*Judith and Jane:* Judith was the first woman to respond to my advertisement at a workshop for breast cancer survivors. I met her and her daughter, Jane, at her house two weeks later to perform the first interview. The three of us sat around the dining room table during the interview, drinking tea and eating cookies.

Judith was in her sixties at the time of the interview and had been diagnosed with breast cancer twelve years earlier. Her diagnosis occurred while she was in the hospital having surgery for calcifications in her breasts. One of the suspected calcifications turned out to be cancerous. After surgery, Judith had radiation therapy, driving herself to treatment and then going to work afterward. Judith is married and has two children: Jane, who lives in the same city, and another child, who lives in a different province. Judith told me that she talks to both of her children several times a week, if not everyday. At the time of her mother's diagnosis, Jane was twenty nine years old and had just returned to work from maternity leave after having her second child a few months earlier. Judith's mother (Jane's grandmother) also had breast cancer, surviving it and living nineteen years longer. During the interviews, Judith was able to comment on both her experiences of supporting her mother during breast cancer, as well as having the illness herself. Jane stated that she did not remember very much about her grandmother's breast cancer, so it did not influence the role she took when her mother was diagnosed.

***Diane and Darcy:*** The second dyad I interviewed was Diane and Darcy. Darcy had told her mother about my study after hearing about it from a friend. Diane was a bit unsure about participating because she felt that her illness experience was atypical and may not relate to other women's stories of breast cancer. I assured Diane that her story was valuable however atypical it was.

Diane's diagnosis occurred nineteen years ago when she was forty-five years old. She was divorced at that time and had recently started a new job. When Diane found a lump in her breast, she went to the doctor and was diagnosed with breast cancer. She was later referred to a haematologist after her pre-surgery blood work caused concern. She was later diagnosed with hairy cell leukemia, a chronic form of cancer. Although her double diagnosis was somewhat confusing, the lump in Diane's breast was treated as breast cancer; she had a lumpectomy followed by radiation therapy. Diane and her daughters lived in a small town a few hours away from where she received treatment. Her schedule was also complicated by the fact that she worked in a different city. This required Diane to do a lot of driving during that time. Despite this, she continued to work throughout her treatment, which she was able to do because she received support

from her extended family. Diane continued to be treated for leukemia intermittently over the next ten years. Darcy was five years old when her mother was diagnosed and her sister was nine. Her memories of this time are quite vague, but Darcy does remember going to the hospital with her mother once to see why her mother was always away. Darcy's memories of her mother's leukemia treatment are much clearer, but it was not until after they ended that she realized the extent of her mother's illness(es).

***Sally and Sarah:*** The third dyad I interviewed was Sally and Sarah. Sally had left me a message requesting more information about my study. When I returned her call, it was apparent that she was very interested in participating, but her daughter, Sarah, who was in her early twenties, was unsure about what she could contribute to the study. I assured Sarah that her perspective was important and that it might help other daughters whose mothers have breast cancer to hear about her experiences. A month later, Sally called back to say that they were interested in participating. The next week, I drove to the house they both lived in to do the initial interview.

Sally had been diagnosed only a few years prior to the interview. She had been having health issues for sometime before that, but doctors had not been able to identify a cause. Sally's breast cancer was discovered when she was in her late forties, after having a mammogram as part of a check-up. Although her diagnosis was unexpected, Sally explained that it was a relief to know what was causing her health issues. At this time, Sally was also experiencing marital problems, which were supplanted by her breast cancer diagnosis. Sally is the mother of four children. She was very open in the interviews, at times talking uninterrupted for several minutes. It was obvious to me that Sally was still adjusting to life after breast cancer, as she was still feeling the physical effects of treatment, deciding on reconstructive surgery, and setting new goals for her future. Sally's daughter, Sarah, was quiet, requiring me to direct specific questions to her. She was in high school when her mother was diagnosed with breast cancer. I could tell that Sarah was still trying to make sense of her mother's breast cancer.

***Charlotte and Christine:*** Charlotte and Christine were the fourth mother-daughter dyad I interviewed. After doing a presentation at the University, a student told me she had a friend whose mother had had breast cancer and might like to participate. The student passed on my contact information and, a week later, Charlotte called me. She and her

**Table 1: Participant Demographics**

	Marital status of mother	Location of mother & daughter	Time since diagnosis	Other siblings in the family? In the same area?	Daughter's responsibilities at time of diagnosis?	Family history of breast cancer?
<b>P1</b> Judith Jane	Married	-Both live in same city	12 years	-Yes, 1 sibling in different province	-Daughter had 2 children and was employed	-Mother's mother survived breast cancer
<b>P2</b> Diane Darcy	Divorced	-Both lived in same house	19 years	-Yes, 1 other daughter in same house	-Daughter was in elementary school	-Maternal aunt survived breast cancer
<b>P3</b> Sally Sarah	Married	-Both lived in same house	2 years	-Yes, 3 other siblings in same house	-Daughter was in high school	-No other known cases
<b>P4</b> Charlotte Christine	Married	-Lived in rural town -Lived in city a few hours away	6 years	-Yes, 1 other sibling in same city as daughter and 1 other sibling in different country	-Daughter had 1 child and was employed	-No other known cases

daughter were interested in participating and were wondering if I could drive to her house for the first interview because Christine was there visiting for the weekend. Charlotte lived about two and a half hours outside of the city where her daughter, Christine, and I both lived. After car troubles on my first attempt to drive there, I successfully reached her house the next day. After having a delicious lunch with their family, I interviewed Charlotte and Christine in Charlotte's sitting room.

Charlotte's diagnosis had occurred approximately six years prior to the interview. She told me that she had found a lump and went to the doctor. Charlotte had a mastectomy three days later. Later, she had her other breast removed and had reconstructive surgery. Charlotte had retired a few years before her diagnosis and lived in a small town with her husband, who was Christine's step-father. Charlotte also had two other children. Christine was in her early twenties when her mother was diagnosed. Her days were kept busy by her job and her five year old son.

#### **4.2 Shifting Roles and Responsibilities**

One major theme emerging from the interviews was shifting family roles and responsibilities. Family roles refer to the positions that members in a family occupy in relation to one another, whereas responsibilities refer to tasks performed by individuals that are necessary for successful personal and family functioning.

The breast cancer experience led to changes in family roles and the re-distribution of duties among family members. Specifically, the distribution of roles and responsibilities was influenced by the provision of social support by family members. It was apparent that family members provided several types of social support that were beneficial during the illness experience. These included instrumental, emotional, and financial support. The mothers who had experienced breast cancer strongly emphasized the significance of social support to their adjustment to and survival of the illness. Although mothers received support from outside of the family as well, all four mothers cited their families as the foremost source of support.

As a result of mothers' breast cancer, family members also assumed new positions and duties within the family. In addition to the extra tasks involved with providing social support, family members were required to take over duties that mothers were unable to fulfill. The way in which roles and responsibilities were re-distributed

varied because the roles left open by each of the mothers differed, as did the availability of family members to take over these roles. In some instances, role reversals occurred between parent and child. These role reversals took place between mother and daughter, daughter and father, and mother and son. The idea of filial responsibility also emerged in some of the interviews, as mothers and daughters described their perspectives on children's obligation to provide social support to their parents. Mothers and daughters were required to negotiate care and social support with respect to their expectations regarding filial responsibility as well as practical considerations.

As a result of their mothers' illness, daughters often assumed their mother's roles and responsibilities. Consequently, some daughters had to maintain their current responsibilities while taking over their mothers' responsibilities and providing social support. Responsibilities that daughters balanced with the provision of social support included: work, school, and childcare. Although the number of responsibilities that daughters had during that time seems overwhelming, their mother's need for support prompted daughters to do what was necessary to balance their responsibilities. One way that daughters were able to manage their numerous responsibilities was by seeking support from others. This finding indicates the need to support those involved with caring for ill family members.

During the breast cancer experience, mothers also faced issues with respect to their fulfilling their former responsibilities. While mothers tried to maintain their former roles and responsibilities, they were sometimes required to relinquish them to other family members because of the physical side effects of their treatment. A number of factors influenced mothers' ability to maintain or return to former responsibilities including: physical well-being, number of duties, and financial need. Thus, the ability and desire to fulfill past responsibilities varied for each of the mothers. This sub-theme illustrates some of the issues that women must negotiate with respect to fulfilling former responsibilities.

In this section, I describe many of the shifts that occurred in family roles and relationships during the breast cancer experience. Changes in the distribution of family roles and responsibilities illustrate the impact that illness can have on the family. In particular, the breast cancer experience required family members to negotiate their

position in relation to one another and to manage added responsibilities. Although the distribution of family roles and responsibilities did not appear to be permanently changed by the breast cancer experience, it is evident that shifts in roles and responsibilities left lasting impressions on mothers and daughters, as well as family relationships. The impact that the illness experience had on mothers, daughters, and family relationships will be explored in the two upcoming sections.

#### ***4.2.1 Seeking Social Support***

Here, I direct attention to the provision and receipt of social support as well as the sources of social support. As mentioned previously, social support refers to “the functions performed for the individual by significant others” (Thoits, 1995, p.64). Throughout the interviews, it was apparent that the family was an important source of social support to the women in this study. Each woman described how various family members supported them throughout their breast cancer experience. Types of support offered by family members included: emotional support, childcare, financial support, transportation, household tasks, and providing accommodation during treatment. Although family members played prominent roles in mothers’ illness experiences, they also sought support outside of the family. With the help of family members, two of the women found breast cancer support and exercise groups that met their support needs. It was apparent that groups specifically for women with breast cancer offered a different form of social support than family members did. Three of the women also expressed the idea that their religious faith and community provided significant social support. The stories of these women illustrate the prominent role the family plays in providing support, even when external sources of support are utilized. As a result of providing social support to mothers with breast cancer, family members went through shifts in their roles and responsibilities.

All four mothers overwhelmingly recognized the social support that their families had given them during the illness experience. While mothers were offered many types of support during the illness experience, they acknowledged that the dependability of their family members appeared to have the greatest benefit. In particular, mothers emphasized that they knew they could rely on family members to be there in times of need. This idea is shown by Judith, who acknowledged the unfailing support of both of



her daughters. She stated: *“I know even with our other daughter, the few times I’ve ended up in the hospital, our daughter from another city, she has come home right away too. So, you know, they’re there when you need them.”* This comment illustrates Judith’s belief that she can count on the support of her daughters. It also demonstrates the dedication that her daughters have shown to her by being there to support her during health crises. In some ways, knowing that she could rely on her family was more important to Judith than actually receiving social support.

Diane also stressed the importance of her family in supporting her through the cancer experience. Since her daughters were young children at the time of her diagnosis, Diane looked to other family members for social support. She described the support offered by various family members:

*I had support from, the fact that my sister would, you know, quite readily look after the girls, there were no hesitation there... and there was certainly a financial concern too ‘cause I was the sole provider and there again, I had help from a family member... Actually my mother came and spent some time too after I had my second surgery because I couldn’t really do so much, um, there for a while. So she came to stay for a week.*

Diane’s comments illustrate the variety of ways that she was offered social support while she underwent treatment. As a single mother, Diane faced challenges that married women may not experience. Her family members’ instrumental and financial support was crucial in that it allowed her to focus on coping with her illness.

It is also apparent that social support helped mothers to cope with and adjust to their illness. The value of social support was emphasized by both Charlotte and Sally. When asked about her ability to cope with breast cancer, Charlotte stated that she attributes coping to *“getting lots of support from [her] daughters and family and good friends.”* For Charlotte, it was her family and good friends that provided her with social support and played a part in her coping with breast cancer. Her belief that support helped her to cope with breast cancer is significant because it expresses the value of social support for those facing illness. Similar to Charlotte, Sally also acknowledged her need for social support and the importance of family by saying, *“how do you take care of your health? You need support and you let people be aware that you need their support... your immediate family is really crucial. You need some family... it doesn’t have to be*

*like blood family, but it has to be a group.*” She indicated that social support is a crucial aspect of the healing process and that the availability of support from her family enabled her to focus on getting through her breast cancer treatment. This comment illustrates the weight that Sally placed on support from family members during the illness experience. By re-distributing family roles and responsibilities, Sally’s family was able to provide her with support and continue to function successfully.

Social support from family members was highly significant to Charlotte, who lived in a rural area where alternative support services were not available. She said, *“because I live out here, I’ve never had anyone from the outside. I only have my family who supported me and a little bit my neighbours and stuff, but I never had help from anybody else really.”* Charlotte’s experience illustrates how critical support from family members is to those living in rural areas. The social support she received included family members coming to her home to provide care and instrumental support, as well as transportation to the city for her treatments. Charlotte also believed that being able to stay with her oldest daughter in the city during treatment gave her great comfort, which she would not have felt if she were staying in an unfamiliar place. Charlotte’s experience demonstrates that support from family is vital for those living in rural areas, as they may not have other readily available sources of support or people willing to go out of their way to provide support.

While family members played a significant role in each woman’s experience of breast cancer, the women also looked elsewhere for social support. Sally indicated that the support of other women with breast cancer was beneficial to her, but that she would not have sought that support without encouragement from family members. This is evident in the following quotation:

*[My husband] wouldn’t understand. He’s not in that situation, [but] at least he got me there, ‘cause I needed a support person to get me there to see if, ‘cause I’ve never been to [a support group] in my life, I didn’t know what they were about... it was the first time people understood what I was going through... I knew I found what I needed to help me through. Plus my family helped a lot... for being there all the time, but you need to be with people who are going through what you are going through.*

Here Sally recognizes the different types of support that were available to her from various sources. She emphasizes the importance of her family's presence during that time, as well as the support her husband provided her by accompanying her to the first support group meeting. Attending a breast cancer support group gave Sally an opportunity to identify with other women facing issues similar to her own. While the support group proved to be invaluable to Sally, she needed the initial support of her family in order to find that out.

In addition to family members and breast cancer support groups, some other sources of social support utilized by the women in this study were: friends, other types of support groups, religious faith, medical professionals, and fitness groups. The satisfaction with various sources of support differed among the women. For instance, Judith found a breast cancer support group that she attended to be more burdensome than supportive. She recalled that, "*when you get into a group like that it is depressing. I even said to [my husband] when I got home, I said 'I can't go to that group.' And he said 'Well, you don't have to go. If you feel that way, there is no sense going'.*" This illustrates that, rather than assisting Judith to cope with her illness, the support group made this more difficult. While she did not identify with members of that support group, she did find another group that better suited her needs. Judith stated: "*The best support group I had was with [an exercise group]. I was in that for 5 years and those girls are a very good support group. They didn't dwell on themselves. They just were out for fun.*" Thus, she desired support that focused on moving beyond the breast cancer experience and being healthy at that point in time. Judith's experience demonstrates that individual preferences for social support will vary and that family members can be helpful in finding the right type of support.

Unlike Judith and Sally, Diane did not look to breast cancer support groups to help her through the breast cancer experience. Diane was forced to balance childcare and work responsibilities while undergoing treatment. Her many responsibilities left her with little time to seek support outside of her family and groups she already belonged to. Diane related: "*my main support is from my faith... that was always my main support. I mean, we support each other.*" This comment shows that she drew upon her religious faith during that time. Diane also indicated that she received support from the religious

community to which she already belonged. Doing so was the result of her time limitations as well as her support preferences. As mentioned previously, Judith and Sally sought the support of other women with breast cancer. However, comparable to Diane, they emphasized the impact that their faith and support from their religious community had on their ability to cope. The support received by these three mothers from their faith and religious community suggests that religion is an important source of support for some women coping with breast cancer.

The stories of each of the four mothers in this study provide insight into the importance of social support to those experiencing illness. It is apparent that the family played a significant role in providing support to the mothers, and also helped to ensure that the additional support they needed was found. A prominent idea emerging from the mothers' experiences was that their family's presence during their time of illness was beneficial to their adjustment and survival of breast cancer. The mothers' experiences also demonstrate that geographical location can influence the availability of social support, making support from family members more crucial to those living in rural areas. While mothers drew upon various sources for social support, the type of support and the number of support sources utilized varied. It is important to recognize that women's support needs vary depending on their support preferences, geographic location, and time constraints. Therefore, the influence a mother's breast cancer has on her family's roles and responsibilities may depend on the extent to which external sources of support are available and drawn upon.

#### ***4.2.2 Taking on New Roles and Responsibilities***

Throughout the interviews, I observed that the illness experience led to family members taking on new roles and responsibilities within the family. In particular, daughters often took over positions and tasks that their mothers were unable to continue due to the physical effects of the treatment they were receiving for breast cancer. New roles and responsibilities that daughters assumed included providing leadership and emotional support, as well as performing household duties and other instrumental tasks. Some mothers and daughters indicated that the re-distribution of roles and responsibilities caused role reversals to occur, in which there was a perceived switch in positions between parent and child. Role reversals involved mother and daughter (Judith

and Jane, Sally and Sarah), daughter and father (Jane, Judith), and mother and son (Sally). However, it is important to keep in mind that providing social support and care to mothers did not always constitute a role reversal, as some participants (Charlotte and Christine) rejected the idea of role reversal. Nonetheless, daughters' assumption of new roles and responsibilities is an important finding because it identifies that significant change may occur within families as a result of illness.

As a result of being ill, mothers could not always fulfil their former roles within the family. This meant that other family members needed to assume the position left open by the mother. A clear example of taking on a new role in the family was described by Jane, who said: "*I started taking charge where my mother would have taken charge. I guess it's that following in your mother's footsteps kind of thing. I started doing the things that I know she would have done.*" This comment makes it apparent that Jane felt that the leadership role she took after learning of her mother's diagnosis was comparable to the leadership role her mother usually took within the family. Specifically, she acted as a support person to her father and gathered information to assist her mother. Because her mother was in the hospital, Jane assumed the role of providing leadership to the rest of the family. Jane's experience demonstrates one way that her mother's breast cancer resulted in her taking on new roles within the family.

Jane's recollection of the reaction her father had to her mother's breast cancer diagnosis also demonstrates that she took on new roles within the family. Jane indicated that her father's emotional response led to a reversal of roles between her and her father. She recalled:

*When dad phoned me at work... [mom] was in the hospital, um, and he completely fell apart, so, it's almost like our roles changed, I was the parent and he was the child at that point. Um, because he was so emotional and so sensitive about it, that I had to get to the bottom, and make calls to [the] surgeon, and to the hospital and find out more details... I had to find out, you know, how bad was it, had it spread, you know all of that kind of stuff. So, yah, where were we going to go from here? What sort of treatment would there be? and that kind of thing. Dad just sorta fell apart without knowing the full story.*

This quotation illustrates the role reversal that took place between Jane and her father. As described above, she took on the leadership role that her mother would have normally taken. Since her father was upset, Jane assumed responsibility for obtaining

further information about her mother's diagnosis and assessing the gravity of the situation. It is evident that she acted as a parent to her father, in that she provided guidance and support to him during this difficult time.

Interestingly enough, Jane took on a role with her father that was similar to the role her mother, Judith, had taken with her own father. Judith's mother was diagnosed with and treated for breast cancer several years before her own diagnosis. She remembered her father's reaction to her mother's diagnosis by saying: "*he cried like a baby, just like my husband did... when I found out that, ah, Mom had cancer, he was sitting in the living room and I told him 'Oh Dad, we'll get through that and we'll go on'.*" This quotation illustrates that Judith responded to her father's emotional reaction by providing him with reassurance. In doing so, she took on a parental role toward her father and took control of the situation. Without knowing that her mother had acted similarly, Jane took on a role that was analogous to the one her mother had taken in her family.

Sarah also took on new roles and responsibilities as a result of her mother, Sally's, breast cancer diagnosis, as did her siblings. She related: "*it used to just be my mom doing everything and now we help.*" Sarah went on to describe how her and her siblings took over the tasks that their mother had formerly performed. She said:

*Once it happened we started helping my mom a lot more. When she was in the hospital for the surgery, we had to, yah, cook our own meals, we had to drive her to appointments because she couldn't drive, and take, we took her to chemo. We all took turns 'cause it wouldn't be fun to go alone.*

In this quotation, Sarah describes the instrumental tasks that her and her siblings took over from their mother during her treatment. While she describes her actions as "*helping*" her mother, it appears that Sarah took responsibility for tasks she had not in the past; thus, she assumed new roles and responsibilities during this time. The provision of social support to her mother also required Sarah to assume new roles and to take on greater responsibility within the family. As she was a teenager at the time of her mother's diagnosis, Sarah did not take over her mother's roles and responsibilities completely, but shared the tasks that her mother normally would have performed with her siblings.

Sally confirmed her daughter's statement that she and her siblings took on new roles during their mother's breast cancer treatment. While her daughter saw it as helping out, Sally recognized that her children were taking on new roles and responsibilities within the family. She expressed:

*The roles changed because of the surgery. I couldn't drive, right? So all of a sudden, they were taking charge. You know, like I remember going into the first surgery and we went for groceries and we got the house all set, you know, cause I didn't know how long I'd be in bed and it was just like 'Okay, I'm in bed now and...' I'm the kind of mom that does everything. I'm not working. I was substitute teaching as a job while they were growing up, so if I didn't have to go in, I didn't, right? So they're so used to things done... and they were driven places and, ah, I thought 'How are they going to do this without me?' Well, it worked really well.*

In this passage, Sally acknowledges that her role within the family had involved doing “everything”, including instrumental tasks such as cooking and driving her children places. As she was not able to perform these tasks during her treatment, she encouraged her children to take on these roles and look after themselves. In a way, Sally's children switched roles with her, as they performed the tasks that she used to and took care of her in ways she had previously taken care of them.

Sally also felt that she experienced a reversal of roles with her oldest son. After learning that she had breast cancer, her oldest son was the first person Sally talked to. She described this experience:

*I needed that support, yah, and he was very intuitive and he is that kind of person. He supported me in a real, like, 'It's okay, mom. Everything will be okay.' It's, you know, like he focused the conversation on other things, maybe he was uncomfortable with the conversation about breast cancer, but it seemed like he was carrying me through it, you know? Like 'let's just go for something to eat' and we chatted about other things, and I needed that 'cause I had to focus on something else.*

Here Sally expresses the significant role played by her oldest son in supporting her during the difficult time following her diagnosis. Similar to Judith and Jane, Sally's oldest son acted like a parent to her by providing reassurance and guidance. It is apparent that her son's willingness to play a supportive role was beneficial to and appreciated by Sally. This provides another example of how illness may bring about

changes in family roles and responsibilities. Sally's oldest son was prompted to take on a supportive role toward her as a result of her diagnosis.

While Christine took on new roles and responsibilities during her mother, Charlotte's, breast cancer treatment by providing her mother with care and social support, neither she nor her mother felt that a role reversal occurred. Christine described her role in her mother's illness experience and how it related to other times she assumed a 'mother' role:

*I cleaned a lot, you know, I took care of her, but no, it's not the same. Like, you know, I know when my boyfriend gets sick then sometimes I have the motherly role of putting him to bed and... [making him] take [his] medication and that was never the case with Mom... I wouldn't say there was ever a switch in roles.*

Despite providing various forms of support to her mother, Christine did not believe that she had assumed a parental role as she did for her son and sometimes for her boyfriend. Charlotte agreed with her daughter that she never felt like they had switched roles with one another. Christine's words emphasize the differences between caring for her mother and others loved ones she has cared for. Her recollection challenges the notion of role reversal in favour of maintaining the existing roles within their family. Thus, Charlotte and Christine's experiences differ from those of Judith, Jane, Sally and her children in that a role reversal did not occur.

My research shows the ways that family members took on new roles and responsibilities during the breast cancer experience. Due to their mothers' illness, daughters commonly assumed new roles within their families. For instance, Jane took on a leadership role, comparable to her mother's role during her grandmother's breast cancer experience. Sarah, along with her siblings, took over instrumental tasks within the household that their mother had previously performed. Judith, Jane, Sally and Sarah described the assumption of new roles and responsibilities during this time as constituting a role reversal in which parent and child switched roles. The role reversals occurred across gender lines, as they involved mother and daughter, daughter and father, and mother and son. While these two dyads believed that role reversals had taken place, Christine felt that supporting and caring for her mother did not constitute a role reversal. However, the assumption of new roles and responsibilities by some daughters and sons enabled them to assist their mothers through a difficult time and maintain family



functioning. Their experiences highlight one way that family members were affected by mothers' breast cancer experiences.

#### **4.2.3 Beliefs about Filial Responsibility**

In some of the interviews, the theme of filial responsibility to parents during illness experiences emerged. Filial responsibility is a concept used by Donorfio (1996) to describe "an attitude, belief, or sense of personal responsibility that adult children are responsible for addressing aging parents' needs" (cited in Donorfio & Sheehan, 2001, p.40-1). Participants discussed this idea in relation to their beliefs regarding filial expectations and the ability of daughters to fulfil these expectations. It was apparent that mothers and daughters believed that children should be expected to play some sort of role in providing care and support to ill or aging parents. However, three of the mothers, Judith, Charlotte, and Sally, indicated that care was unnecessary or that their daughters, Jane, Christine, and Sarah, had other responsibilities which should be given priority. Daughters' responsibilities included: caring for their children, work, school, and personal activities. Consequently, the extent that daughters cared for their mothers was determined by their mother's need for care as well as their expectations of filial responsibility. Daughters also expressed their views on filial responsibility and its relation to the role they played in supporting their mother. In particular, Sarah and Darcy indicated their feelings regarding filial obligation to care for their ill or aging parents. In this section, I demonstrate that mothers and daughters' feelings of filial responsibility influenced the extent to which daughters took on new roles and responsibilities.

The idea of filial responsibility emerged in the interviews with Judith, who discussed the role that she played in supporting her own parents while they were ill. It was apparent that Judith's beliefs regarding filial responsibility had implications for her daughter, Jane. Judith mentions that the support role she played was a combination of her geographic location and her feelings of filial responsibility towards her parents. Judith said:

*I think because I was the closest here, like I have two brothers in a nearby town, you know, they were fine too when she got home [from her breast cancer treatment], but here was always me because when they had medical appointments or Dad had heart problems, he was in the hospital here, and Mom was in the hospital, she had surgeries and stuff, and it was always, well, I just*

*took it for granted that that's what I had to do. And I'm sure my daughter would do the same for me... I know she would.*

In this quotation, Judith expresses the responsibility she felt to support her parents when they were ill. She recognizes that residing in the city put her in a better position to offer her parents support during medical appointments and treatments in comparison to her brothers. However, Judith's words demonstrate that she also felt expected to support her parents. In the above quotation, Judith also acknowledges the filial expectations that she has for her daughter, Jane. Judith's statement that her daughter would take on a support role similar to the one that she did indicates that she expects her daughter to take on a support role when necessary. It is also evident that Judith believes that Jane feels a sense of responsibility to support her during health crises. Thus, Judith thinks she and her daughter share the same attitude toward filial responsibility.

Despite the beliefs about filial responsibility expressed above, Judith emphasizes that she did not need the same kind of support her mother had needed. This was because Judith lived in the city and could get to treatment on her own. She recalled:

*I drove myself to the treatment, then I went to work, and my husband came with me once. That was the only time that he came with me, and nobody else came with me. I don't know if my daughter wanted to come or not... She was working, she had a family too, so you know, you can't put any stress on them when they've got that, her family. I didn't expect her to be right there with me, anyway. I knew if I needed her, she would be there. But she had her kids too. 'Cause her second one was born when I was diagnosed, so that kind of, you know, she was busy with her kids.*

This quotation illustrates that Judith felt she did not need to be supported in the same way her mother had. She also stresses that her daughter had other responsibilities at the time, but that she would have supported her if needed. Although Judith emphasizes the importance of filial responsibility in her previous comments, she states that her daughter's assistance was unnecessary while she was in treatment. This suggests both that Judith did not require support and that she believed her daughter to have other priorities at that time.

The idea of filial responsibility also emerged in the interviews with Charlotte. It was apparent that she appreciated the support her daughters, Christine and her older sister, had offered her given their various responsibilities. However, Charlotte felt that

parents should not expect their children to leave other responsibilities unfulfilled in order to support them. This belief was demonstrated when Charlotte said:

*You gotta do something yourself too, and you cannot expect to totally lean on your children either and so, therefore, you know, I do not expect when I grow old to be living in their homes or something like that. If I get sick, you know, I'm sure they'll do their utmost and I think that's very important.*

This passage illustrates her belief that aging parents should not solely depend on their children for care and social support. It is evident that Charlotte appreciates her daughters' support but does not want them to feel obliged. She makes it clear that she does not want to depend on her daughters for support as she grows older; however she presumes that they will offer her support if needed. Thus, Charlotte expresses her belief that filial responsibility is valuable, but at the same time she does not want to interfere with her children's lives.

Sally's views on filial responsibility were similar to Charlotte's; Sally did not want her children to feel burdened by supporting her. Sally described situations in which her children had supported her, but emphasized that she did not want them to do so on a regular basis. For instance, she said: *"because he's the oldest, [my son has] supported [me] before. I don't generally ask my kids to support me though. But now that he's an adult, I suppose it's a different situation again."* This comment illustrates that Sally does not like to depend on her children for support, although she did accept her oldest son's support when she learned of her cancer diagnosis. She also recognizes that because her oldest son is now an adult, she feels it is more appropriate to seek his support. Sally's emphasis on age is significant because it suggests that children's age plays a part in determining the extent to which they are expected to take on supportive positions.

Sally also described a time when her youngest son supported her by accompanying her to the hospital in an ambulance. This recollection demonstrates once more that she did not want to depend on her children, but nonetheless appreciated her son's support. Sally related: *"in my mind, I was happy to see that he was really mature about it, but I didn't think that kids should be in that role. You know, I wouldn't want him to be there all the time. But I could see that he could handle it if he needed to in the short term."* In this quotation, Sally expresses her beliefs about filial responsibility.

Because her children were teenagers at the time of her breast cancer diagnosis, Sally was

more reluctant to expect them to support her. Sally's desire to avoid creating additional responsibilities for her children may explain why she utilized a number of sources of support outside her family.

Sally's daughter, Sarah, felt responsibility to support her mother at the same time she felt pressure to fulfil her own responsibilities. Sarah was in Grade 12 at the time of her mother's diagnosis and had many things going on in her life. Despite her busy schedule, Sarah said that her and her sister felt "*we had to [take on more responsibility]. We didn't pout about it at all, you know, 'Why do I have to do this?' We realized 'we have to 'cause our mom can't.' It wasn't a big deal.*" This comment illustrates Sarah's feelings of filial responsibility that emerged during her mother's illness experience. Although she had many responsibilities of her own, Sarah believed it was up to her and her sister to take on new responsibilities in order to support her mother and the rest of the family. Sarah's comment acknowledges that she and her sister did not see it as a choice, but as part of their responsibility to their mother and the rest of the family.

While Darcy was too young at the time of her mother, Diane's, breast cancer diagnosis to offer her care and support, she emphasized the feelings of filial responsibility she has at the present. Although her mother recognizes that she and her sister are busy with school and their own families, Darcy states that she would provide her mother with support if another health crisis were to arise. She said: "*you know how much hell [our mothers] went through to put up with our shit? And they put up with that and they love you anyways, so it's like, you know, 'I'll do this for you too.'* And that's I think how society is meant to be." In this quotation, Darcy characterizes filial responsibility as part of an exchange between parents and children. She expresses her feelings of filial responsibility, stating that supporting her mother is like returning the care and support her mother gave her as a child. It was apparent that Jane, Sarah, and Christine felt similarly, as they wanted to show appreciation to their mothers for years of care and support.

The idea of filial responsibility was expressed by several of the participants throughout the interviews. The illness experience brought out mothers and daughters' feelings regarding filial responsibility, which influenced the provision of care and social support by children. While the support their children offered them was appreciated,

mothers either did not feel support was essential or did not want to place too much burden on their children. All four of the mothers stated that they did not expect their children's support, but they knew they could count on it if necessary. The daughters in the study all expressed their willingness to support their mothers to some extent, as they wanted to express their gratitude for years of being supported. This theme identifies the influence that beliefs about filial responsibility have on the provision of social support. It also illustrates one way that a mother's illness may affect her relationship with her daughter. As shown, mothers had to negotiate their desire to avoid creating added responsibility for their children, while still expressing their appreciation for and faith in their ability to support.

#### ***4.2.4 Balancing Responsibilities***

For some of the daughters, their mother's breast cancer diagnosis created new responsibilities for them. Specifically, providing care and support to their mothers as well as taking over tasks their mothers had previously performed resulted in a greater number of responsibilities for daughters. The increase in duties required that daughters balance new tasks with past responsibilities. Although successfully balancing responsibilities involved some negotiation, the daughters who performed new tasks did not express any difficulties fulfilling their many responsibilities. Despite the fact that some of the daughters were at points in their lives where they had several other responsibilities, it is apparent that they still provided valuable support to their mothers. Here, I illustrate one of the key issues faced by daughters of women with breast cancer: they must seek a balance between their previous responsibilities and those resulting from their mother's illness.

Of the four daughters, Christine appears to have taken on the most additional responsibilities during her mother, Charlotte's, illness experience. She had a young son at the time of her mother's diagnosis, was employed, and had the added difficulty of living a few hours away from her mother. Christine described her schedule during that time: "*I worked in [the city], I worked in one job, and then I worked another job [in the town my mom lives in] so I could be there on weekends... I worked in the bar... in the evenings and I would take care of her during the day.*" This quotation demonstrates some of the responsibilities that Christine needed to balance during that time. In addition

to her job in the city and supporting her mother on weekends, she needed to get a second job in order to pay for costs associated with travelling to her mother's house every weekend. Thus, in addition to the added tasks involved with supporting her mother, Christine took on the responsibility of a second job. Christine's experience demonstrates that she had to manage considerable responsibility during her mother's breast cancer treatment.

Despite the many responsibilities she already had, Christine expressed that she was able to balance the new ones with her past ones. One way she managed her responsibilities was by seeking support from others. Christine said: "*near the end of her treatment, [my mom] started getting worse. I stopped bringing my son here. I started leaving him in [the city] with friends.*" She relates that she drew upon the assistance of her friends in order to be available to support her mother. Without the childcare assistance of her friends, Christine may not have been able to do so, as she worried that her son would be a disturbance to her mother during this difficult point in her treatment. This quotation is significant because it demonstrates the social support required by people involved in the provision of support to the ill or aging. Accordingly, it is important to recognize that family members also may require social support during times of illness, as they have various responsibilities to deal with.

When asked how she managed her multiple responsibilities, Christine expressed that it was not something she had thought about at the time. She believed that "*when you need to, you just do, you know? You just do and you don't even think about it and later on you kind of look back and go 'Oh my god, where did I get that energy from?'*" This comment indicates that Christine is unsure of how she dealt with the numerous responsibilities that she balanced while her mother was ill. During her mother's breast cancer treatment, she felt strongly about supporting her mother and, therefore, did whatever was required in order to do so. Although the number of responsibilities Christine had appear to be overwhelming, she indicated that "*[my schedule] kind of became normal after a while*". This comment shows that Christine adjusted to her hectic schedule over time and was successful in balancing responsibilities during her mother's health crisis.

Judith related that her experiences of support provision during her mother's breast cancer treatment required her to balance past responsibilities with new ones. Judith had to negotiate her work responsibilities with her mother's treatment schedule, as she drove her to the majority of her appointments. Comparable to Christine's comments in the previous paragraph, Judith believed that she had no choice but to manage her numerous responsibilities. Judith expressed her thoughts on balancing responsibilities: *"when you think of it now, you wonder how you did it. But you know, at the time, there was, you had no choice."* This demonstrates the inevitability of the situation that Judith faced. She felt that it was her responsibility to support her mother during this time, just as she needed to continue to perform career duties. The experiences of Judith and Christine illustrate that feelings of filial responsibility to ill or aging parents may contribute to daughters taking on new responsibilities, thus creating a need for daughters to balance their responsibilities.

Judith's experience is also comparable to Christine's in that she sought the support of others in order to aid her in fulfilling her responsibilities. Specifically, she solicited her sister's assistance with support duties. Judith recalled:

*I phoned my sister in the East and I said, you know, she wasn't working, I said 'Could you come out and help with Mom.' So she came out for a week or so and, um, she took her to her treatments and we just went away for a night or two and came back.*

Judith drew upon support from her sister in order to take a break during this busy point in her life. Although it was only for a short duration, her sister was able to help Judith balance her responsibilities by taking over the support tasks. As a result, her mother received the support she required and Judith was able to take a break from her many responsibilities. Judith and Christine's experiences emphasize the value of support for those who are caring for ill or aging parents.

Similar to Christine and her mother, Judith, Jane had many other responsibilities at the time of her mother's diagnosis. As described previously, Jane took on an important leadership role during that time, offering her parents instrumental and emotional support. Despite this, Jane felt that she had other responsibilities at the time that took precedence. She recalled: *"I was just going back to work and my daughter was 3 and my son was 4 months old, so it's kinda a blur, 'cause that was such a blur in my*

*life at that point anyway, with other things going on.*” This quotation illustrates Jane’s personal responsibilities at the time of her mother’s diagnosis, which included looking after her young children and returning to work from maternity leave. However, as shown earlier, she was able to perform her family and work responsibilities as well as provide her mother and father with valuable social support. Although she does not acknowledge it in this comment, the support that Jane provided her parents has been described previously in the discussion of taking on new roles and responsibilities. Therefore, it is apparent that Jane was required to balance multiple responsibilities during her mother’s illness experience, which she appears to have done successfully.

In this section, I illustrate the need for daughters to balance support-related tasks with their pre-existing responsibilities. This sub-theme demonstrates one issue faced by daughters of women with breast cancer. Specifically, daughters have to negotiate school, work and/or childcare responsibilities while taking on various other duties in order to support their mothers. Although they were uncertain of how they accomplished the tasks they did during that time, Christine, Judith, and Jane appeared successful in managing their various responsibilities. Both Christine and Judith stressed that balancing responsibilities was not done consciously because performing support-related tasks was essential, rather than optional. Receiving support from other people was one way that daughters were able to manage their responsibilities. By utilizing support from others, daughters were able to fulfil various responsibilities. This finding emphasizes the need to support individuals who are involved in support provision, as it may help them to balance previous responsibilities with those resulting from the provision of support to their mothers.

#### ***4.2.5 Fulfilling Former Responsibilities***

While daughters were often required to take on new responsibilities as a result of their mother’s diagnosis, their mothers focused on trying to maintain or return to past responsibilities. Although the duties that each of the mothers held prior to diagnosis varied, each mother discussed how their past responsibilities were managed. Their success in maintaining or returning to past responsibilities was related to: the number of responsibilities they had, the extent to which their illness inhibited their ability to carry out tasks, and their personal or financial need to do so. Therefore, maintaining or



returning to former responsibilities was not necessarily a freely made decision, but often depended on other factors. With this theme, I illustrate one way that women's roles and responsibilities are affected by their breast cancer diagnosis, as well as the unique situations that women encounter as a result of breast cancer.

Of the four mothers interviewed, Diane appears to have faced the most difficult situation because it was necessary for her to maintain past responsibilities. At the time of her diagnosis, Diane's daughters, Darcy and her older sister, were young children. Diane had also just begun a new job. In addition, she lived in a rural area, requiring her to commute a few hours to work and medical treatments. Diane recalled what she went through in order to fulfil her responsibilities while receiving treatment:

*I just got this job, and I was really quite concerned that I wasn't going to be able to keep it, and then I would have no job, ah, so that was very stressful, that part. Um, so then what I had to do, um, while I was getting the radiation treatment, I had to come in to [the city] for that. The routine that I had going there was extremely stressful and I still don't know how I managed to get through that, but anyway I did, ah, 'cause I had to. Um, I would go to, this was my weekly routine: I'd go to [work], I was teaching, it was a teaching job for a nursing program, ah, to [small city] and teach on Monday mornings, um, then drive to [the city], have my radiation treatment, stay over night, ah, have the next one the next morning, then drive back home, so that was Monday, Tuesday. In the mean time the girls were at their aunt's house, so Tuesday when I came home from [the city], I picked them up, they'd spend one night at home and then we'd do the whole thing over again for Wednesday and Thursday, and then on Friday I would, ah, drive to [work], do my half day of teaching and come to [the city], have my treatment and go home all in the same day. And so I did that for 6 weeks.*

Diane's story demonstrates the difficult situation that she faced as a result of her illness. Her financial concerns and responsibility to provide for her daughters required her to continue working, despite her demanding treatment schedule. Diane's sister played a crucial role in her illness experience by providing childcare while she received treatment. Diane's experience indicates that some women may have no choice but to maintain their former responsibilities because of financial concerns. This is especially necessary for women without partners because they may not have another source of income. Diane's experience also demonstrates that family members play an important role in helping women to fulfil past responsibilities by providing them with social support.

Judith also maintained her occupational responsibilities during her breast cancer experience. Unlike Diane, Judith's children, Jane and her sister, were grown up and she lived in the city where she received her treatment. Judith discussed the maintenance of her past duties during her treatment:

*I went [to work] while I was taking [radiation therapy]. Yah, I would go, take my little cup of tea and go have my treatment, and go off to the store we had. But I don't think that was such a smart idea. I think I should have rested more, I know now that [I] should have probably rested more. But I wanted to be that macho, big person.*

This comment shows that Judith was able to fulfill her work-related duties during radiation treatment because she was physically well enough to do so. Despite this, Judith acknowledges that she missed out on rest, which is vital to recovery. Judith and Diane's experiences illustrate that women may continue to work during their breast cancer treatment because of financial need or a desire to maintain past responsibilities. While Diane felt a financial need, Judith appears to have used work as a means of maintaining normality in her life. Also, it may have been less difficult for Judith to continue to work because she did not have young children to look after or a long distance to commute.

In the interviews, Sally also discussed her former responsibilities, which involved working as a substitute teacher and looking after the household. Upon completion of her treatment, Sally re-assumed many of her household duties, including cooking, cleaning, and looking after her four children. But after talking with others, she decided not to return to work immediately. Sally stated:

*When I got the consultation at the hospital and the nurse said 'You know, you've got four kids at home... That's a big enough job.' Like, and it's kind of nice because you can [look after your family] in your own time, whereas if you're at a job, you've gotta be there at a certain time, you've gotta leave at a certain time. Then when I finished the, um, chemo last January... I said 'Can I go back to work next month, cause I'd like to get back into work and make some money?' and [the oncologist] said 'Wait six months to a year, because you're recovering' ... Now I'm a year out of it, I can see why. I'm starting to get my energy back.*

In this quotation, Sally relates the advice that she received from health care professionals about returning to work. While she felt that she probably could return to work, this responsibility was of lesser importance than her recovery. Her decision was related to

her physical well-being, as well as her family responsibilities. Thus, Sally returned to some of her past responsibilities upon completion of breast cancer treatment, but wanted to ensure her full recovery before returning to work.

As a result of illness, mothers' former responsibilities were affected in various ways. While physical well-being was a determining factor in the maintenance or re-assumption of past responsibilities, the mothers' stories emphasized that other factors were also taken into account. For instance, Diane's financial need required that she continue to work during her treatment, causing her added stress. On the other hand, Judith continued to work during her treatment because she felt able to do so. She did not feel her treatment inhibited her from maintaining her responsibilities, although she recognized later that she should have taken some time to rest. Sally decided to resume her responsibilities within her family, but not to return to work, taking time to focus on physical recovery. Thus, women face many issues when it comes to managing former responsibilities. The variety of experiences shown in this section emphasizes the unique situations faced by women with breast cancer in relation to their responsibilities.

### **4.3 Coping With Breast Cancer**

An important theme that emerged in the interviews with mothers and daughters was related to coping with breast cancer. Coping refers broadly to resources and strategies involved with managing stressful or difficult situations. Specifically, coping resources are "social and personal characteristics upon which people may draw when dealing with stressors" (Pearlin & Schooler, 1978, cited in Thoits, 1995, p.59), while coping strategies are "behavioural and/ or cognitive attempts to manage specific situational demands which are appraised as taxing or exceeding one's ability to adapt" (Lazarus & Folkman, 1984, cited in Thoits, 1995, p.60). It was apparent that the mothers and daughters in this study utilized various coping resources and strategies during the breast cancer experience. For mothers and daughters, coping with breast cancer was both an individual and interactive process.

Coping with breast cancer entailed different things for each of the women. Throughout the interviews, I observed that coping was related to three main ideas: maintaining optimism, making sense of breast cancer, and assessing future risk. As shown in the previous section, social support was beneficial in helping the mothers to

cope with their illness. However, mothers also discussed coping in relation to their personal attributes. All four of the mothers emphasized the value of an optimistic outlook and setting goals for the future. The positive attitude that mothers had toward their recovery from breast cancer helped them to cope with the physical and psychosocial implications. Maintaining optimism also influenced the way that daughters and other family members dealt with the illness. This sub-theme demonstrates the inner strength and resiliency that mothers drew on in order to cope with breast cancer.

Another aspect related to coping was associated with making sense of breast cancer. In order to deal with their illness, mothers needed to give meaning to the experience and understand why they had developed breast cancer. Some mothers and daughters made sense of breast cancer by searching for potential causes. Determining a possible cause of breast cancer facilitated coping because it helped women to feel a sense of control over an illness surrounded by uncertainty. Three of the women also found meaning in the illness experience through the recognition that breast cancer encouraged them to acquire new insights on life. In this sense, these women came to understand the positive effects that breast cancer had on their lives. While not all women agreed that their outlook on life changed as a result of breast cancer, making sense of breast cancer was a significant aspect of the coping process for the majority of the participants.

A third issue related to coping with breast cancer that arose for mothers and daughters involved assessing future risk. Assessing future risk was one aspect of coping with breast cancer that the mothers and daughters continue to face after treatment ended. This sub-theme is extremely important because it identifies the “chronic risk” that women experience as a result of breast cancer (Kenen et al., 2003). Mothers and daughters reflected on their concerns regarding recurrence and future risk. They also discussed the influence that breast cancer had on their awareness of health and their health behaviour. Half of the mothers and daughters indicated that they had made changes in health behaviour as a result of breast cancer, while the other half felt their health behaviour remained unchanged. Although seven out of the eight women expressed concerns regarding recurrence or risk, only four of the women translated these

concerns into health behaviour changes. The findings described in this section illustrate the varying effect that chronic risk can have on women.

#### **4.3.1 Maintaining Optimism**

In order to adjust to and survive breast cancer, mothers and daughters needed to cope with the illness and its potential ramifications. While the breast cancer diagnosis may have been unexpected, mothers expressed from the outset that they would endure the illness and its treatment. For Judith, Charlotte, and Diane, maintaining an optimistic outlook and focusing on a positive outcome were of primary importance. When mothers adopted a positive attitude towards their illness, others in the family appeared to do so as well. Judith and Charlotte also emphasized that staying positive helped their bodies to heal physically. Another way that Sally and Judith got through this difficult time was by focusing on the future and setting goals for themselves. The theme of optimism demonstrates that mothers drew upon strength from within, which helped them and their families to maintain optimism and cope with breast cancer.

Approaching the breast cancer diagnosis with a positive attitude was a coping resource highlighted by the women in this study. Maintaining optimism and hope for the future provided the women with a sense of control over an uncertain situation. This coping resource was demonstrated by Judith, who described the personal attributes that helped her to cope with breast cancer:

*I actually am a strong individual, like it takes quite a bit to knock me down and, um, like there's bumps in the road and you just take them as you go along and there's nothing you can do. You have to face them and, ah, keep going. And think positive. Thinking positive is a big thing too. 'Cause if you are going to give up right away, you are not going to, ah, get over the bump.*

By saying this, Judith emphasizes that her inner strength and positive approach helped her to persevere during that difficult time. Judith's comment portrays breast cancer as one of life's challenges, which must be dealt with as they arise. Thus, Judith believed that her optimistic attitude toward life would help her to endure this crisis, just as she had endured other crises.

Charlotte also emphasized the importance of maintaining a positive outlook during difficult situations. She clearly expressed her optimistic approach to life and

demonstrated how it emerged when she was diagnosed with breast cancer. Charlotte stated:

*I'm such a positive type of person that I just, it never occurred to me that anything else could happen but what is happening now- that I'm well, you know? So I've always been a positive person... I was by myself when the doctor told me and he sat with me for a minute, but I mean, I drove back to the lake and I knew it was fine. I knew.*

Charlotte's words communicate her belief from the outset of her illness that she would be able to cope with breast cancer. Her optimistic nature was a coping resource that she drew upon in order to avoid thinking about possibilities other than recovery. Comparable to Judith, Charlotte attributed her ability to cope with breast cancer to maintaining optimism throughout the experience.

Similar to Judith and Charlotte, Diane stressed that she had only considered a positive outcome to her illness experience. Her focus on survival helped Diane to deal with her the complications of her illness. Despite the confusion of being diagnosed with breast cancer and then hairy cell leukemia, Diane did not feel her future was uncertain. She related that *"through all the different treatments I had, I've never really, ah, been that worried about [dying]... I've just always had a deep down feeling that I was going to be okay."* This quotation identifies that Diane maintained an optimistic outlook toward her illness during the many treatments she received over the years. Her inner strength and resiliency allowed her to cope with being ill and to continue to fulfill her family and work-related responsibilities. Thus, believing that she could successfully cope with being ill helped Diane to endure this difficult time.

In addition to helping Judith and Charlotte to cope with breast cancer, they asserted that a positive outlook was an essential part of physical recovery from illness. This idea was expressed by Charlotte, who said: *"I'm a firm believer in healing within yourself. You know? If you constantly dwell on the fact that you have [an illness], it's probably not going to do you any good."* This comment illustrates her belief that in order to recover physically, one needs to maintain a positive outlook. This idea is echoed by Judith, who stated that being upset puts *"a lot of pressure on the body and the body doesn't heal when it's under a lot of pressure. It's true, you know, the more upset you get, it takes a lot more out of [your body] and it's not going to heal as quickly as if you*

*are thinking positive.*” Judith’s words communicate the idea that negativity is detrimental to physical well-being and hinders recovery. Thus, Charlotte and Judith’s comments illustrate their beliefs that a positive attitude helped them to successfully coping with breast cancer.

The optimistic approach that mothers had toward being ill appears to have influenced their families’ ability to cope with breast cancer. Jane described her mother, Judith’s, attitude to breast cancer and how it affected the rest of the family:

*From the start she said ‘I’m gonna beat this. This is a piece of cake’ and she always maintained that to the rest of us, to my sister and to myself, and my family, my husband and kids, and to my dad. She always maintained that, so she, even though she was sick, she was still the leader of the family. She was still saying ‘Okay, this is no problem. We’re going to get through this’.*

In this quotation, Jane indicates that her mother’s unflinching optimism shaped the manner in which the rest of her family dealt with her illness. It is apparent that Judith’s attitude encouraged her family members to adopt a positive outlook as well. Despite the significant health threat that breast cancer posed to her mother, Jane followed her mother’s lead and approached the situation with the belief that her mother would be all right.

Christine also found that her mother, Charlotte’s, attitude influenced her ability to cope with her mother’s breast cancer. Christine was about to go on vacation when her mother phoned to tell her she had been diagnosed with breast cancer. She remembered that her mother said: *“she was going to go for surgery and she would be fine and we weren’t to worry about her and she didn’t want me to cancel my vacation.”* Charlotte’s insistence that her daughter go on vacation as planned demonstrates her optimistic attitude toward her diagnosis. Had she felt that her well-being was in jeopardy, Charlotte would likely have asked her daughter to cancel her vacation. Although Christine was concerned for her mother, she went on vacation because her mother had emphasized that she would be all right. Christine recalled: *“having gone on the vacation and coming back, I had enough time to really sit back and, and think ‘okay, what’s the next step’, rather than worrying and worrying.”* This shows that Christine used this time to think rationally about her mother’s illness and arrived at her mother’s house with a plan of

how to support her. By following her mother's request that she go on vacation, Christine was better able to adopt a positive outlook and cope with her mother's illness.

Maintaining optimism during and after the breast cancer experience also involved focusing on the future. Mothers were able to focus on the future by trying to move beyond their illness and set goals for themselves. Sally, who had completed treatment most recently of the four women, demonstrated an aspiration she had for the future. She said: *"I definitely want to be a breast cancer survivor. I wrote that right into my goals."* By saying this, Sally expresses that one of her goals for the future is to be a survivor, someone who has moved beyond illness and into the next phase of her life. It was important for Sally to set goals for herself because it gave her something to look forward to and helped her to cope with her breast cancer.

Judith also emphasized that she wanted to move forward from her breast cancer experience. She believed that once she was finished her breast cancer treatment, she and her family put the illness behind them. Judith said: *"I just felt that it's done with and I'm not gonna dwell on it now. I'm going on with my life."* This quotation illustrates Judith's desire to focus on the future, a sentiment that was shared by the other three mothers in this study. One way Judith concentrated on her future was by setting goals for herself, as shown in the following comment: *"I was 55 [when I was diagnosed] and I said 'If I can only make it to 60'. That was in the back of my head all the time, and then I thought, when I was 60, 'I want to make to 70.' So I'm only a couple years away from 70..."* Judith set a goal for herself as a way of giving herself something to strive for. Reaching her goal of age 60 validated Judith's positive outlook and encouraged her to set more goals for herself. As demonstrated by Sally and Judith's experiences, setting goals gave them something to focus on and was beneficial to moving beyond the breast cancer experience.

Thus, the theme of optimism provides an illustration of one of the coping resources utilized by the mothers in this study, which pertained to maintaining optimism throughout the breast cancer experience. It is apparent that mothers' perception of breast cancer as an illness they could overcome assisted them in doing so. Staying optimistic during this time required mothers to draw upon their inner strength and resiliency. While a positive attitude assisted the mothers in coping with breast cancer, it also helped their



daughters and other family members to maintain optimism. Jane especially felt that her mother's attitude dictated the rest of her family's approach to the illness. Judith and Sally believed that focusing on the future helped them to stay optimistic during and after their breast cancer experience. Focusing on the future involved moving beyond their illness and setting goals for the future. This section provides important insight into the coping process and how a mother's approach to coping can impact her family.

#### ***4.3.2 Making Sense of Breast Cancer***

In order to cope with breast cancer, mothers needed to make sense of their illness. This process was unique for each of the women, as they gave meaning to breast cancer in different ways. Making sense of their illness was a coping strategy that helped the mothers to maintain an optimistic outlook during and after treatment. Finding meaning in illness sometimes involved searching for the cause of breast cancer. Whereas the women could not be positive why they got breast cancer, attempting to find a cause helped them to explain both to themselves and others why they were affected. Identifying the possible cause also enabled women to feel more certain about the future. For the daughters, it was important that their mothers contemplate possible causes, as their own thoughts regarding risk were influenced by this. Another part of making sense of breast cancer was related to realizing new insights on life. While not all mothers and daughters felt that the illness experience changed them or their perspective of life, it was apparent in some of their stories that new insights emerged as a result of breast cancer. This finding is significant because it highlights the idea that giving meaning to illness experiences is a necessary part of the coping process.

##### ***4.3.2.1 Searching for a Cause***

For some of the women in this study, attempting to find a cause was an important part of making sense of the breast cancer experience. Searching for a cause involved drawing upon cancer research, as well as identifying personal characteristics associated with cancer. Sally had considered several possible causes of breast cancer, any of which may have caused her illness. For instance, she recalled:

*I was 29 when I had my first baby, so I was pregnant at 28. So it's just, you know, it's not 30's, the magic number that they say in the information, but you just wonder if that might have something [to do with it]... but they don't know do they? They are looking at industrialized countries with the high rate of breast*

*cancer and non-industrialized and they're saying 'well, what's the difference?' and one is the date of first birth is lower. Also, nuns have a high incidence of breast cancer.*

In this quotation, Sally relates her personal background to research on a potential cause of breast cancer. Although she cannot be positive that her age at first pregnancy was associated with breast cancer, identifying possible causes helped Sally to explain why she became ill. It also enabled Sally to feel more in control of her health and to inform her daughters of preventive measures.

Judith also tried to make sense of her illness by recognizing possible causes. She reflected upon her own health behaviour and how it might be linked to her breast cancer diagnosis. She said: *"I tried to be active and, you know, exercise and eat properly before [my diagnosis] and I had quit smoking a long time, long before that, so... I did do that at one time... You know what? I'm sure [smoking] is a lot of the cause of breast cancer."*

This quotation demonstrates the process that Judith went through to make sense of her illness. She expresses that she has always been health conscious, but that she did smoke when she was younger. She justifies this behaviour to an extent by stating that *"everybody smoked"*, but acknowledges now that smoking may have contributed to her breast cancer. The belief that smoking was associated with her illness provided Judith with a reason for why she got breast cancer despite being healthy in general. Identifying a cause of her illness also helped Judith cope with feelings of future risk. Similar to Judith, Diane also suggested that smoking when she was younger may have contributed to her cancer diagnosis.

Understanding why she got cancer despite her healthy lifestyle was also an issue for Charlotte, who was the most concerned with identifying possible causes of breast cancer. While Sally and Judith discussed their illness in relation to their personal background and behaviour, Charlotte believed that her own actions were not to blame for her illness. For Charlotte, searching for a cause was not only about making sense of her illness, but also an attempt to gain recognition that she was not responsible for its occurrence. As someone who has been health conscious all of her life, Charlotte showed her displeasure with current healthcare practices in the following quotation:

*Why are doctors giving us medications when they do know, um, this might be a carcinogen? Anyway, if I am told 'you're running a risk.' Okay, then I run the*

*risk and I make the choice. But if I'm not told that medications or birth control pills I take, um, if I'm not told that this might be cancer-forming then I have no choice, right?*

By saying this, Charlotte asserts that the lack of information about cancer-causing products leads people to put themselves at risk without knowing, whereas unhealthy behaviours, such as smoking and inactivity, are choices that people make. Thus, some people willingly put themselves at risk for illness, which was not the case for Charlotte. Her strong feelings about the causes of breast cancer demonstrate the struggle that she has gone through to make sense of her experience. It is apparent that Charlotte finds it difficult to reconcile her own beliefs about the causes of cancer with the lack of information on cancer-causing agents.

Christine also sought to make sense of her mother's breast cancer by identifying possible causes. Her comments draw upon her mother's beliefs about the cause of breast cancer, but also recognize that there are many factors that contribute to health and illness. Christine related:

*[The doctors] said that it was the estrogen. She was taking hormone replacement therapy, so that's what they told her. Um, I don't know. There's so many aspects that make up our health and what could be healthy for us. If we think it's healthy for us, like if they said that apples are good for you one year and bad for you the next, you never really know? I think that, you know, sometimes these things just happen. You have the gene, the DNA, that predisposes you to these kinds of conditions and, I mean, the fact that she probably was in very good health was probably a good portion of what kept her going, not to mention her good spirit. The combination of that is probably what took her through. But I think maybe if you are just predisposed to getting it, then you are going to get it. That's it.*

In this quotation, Christine indicates that the doctors suggested a specific cause of her mother's breast cancer. However, she also explores the option that her mother was genetically predisposed to breast cancer. While she accepts these as potential causes, she acknowledges the complexity of health. Christine recognizes that what is considered healthy often changes because of continuing research on specific substances. Christine's thoughts suggest that in order to understand why her mother had breast cancer she must accept that illness is not necessarily linked to poor health in the traditional sense.

As mentioned previously, Judith believed that smoking was likely associated with breast cancer. Despite this, she also recognized the arbitrariness of the illness,

noting that no one characteristic determines who will get breast cancer. Judith expressed this idea by saying that “*one in nine women [are affected by breast cancer]...cancer doesn't pick the person who has the most money or the least money or whatever. It's just there.*” This comment refers to Judith's belief that cancer does not target certain people, but remains largely unpredictable. While she recognizes that environmental and genetic factors are associated with breast cancer, she emphasizes the prevalence of the illness by referring to breast cancer statistics. By acknowledging the high rates of breast cancer as well as its randomness, Judith is trying to make sense of why she was affected. While smoking in the past remains a possible cause of her breast cancer, Judith illness experience has prompted her to realize the arbitrary nature of health and illness.

This section describes how the mothers searched for possible causes in order to make sense of breast cancer. These mothers drew upon research that linked certain characteristics or behaviours to breast cancer as a means of explaining what had happened to them. In doing so, the mothers identified measures that their daughters could take to prevent breast cancer. Charlotte felt she had not been sufficiently informed about cancer-causing substances and, therefore, she was falsely blamed for putting herself at risk for something she was unaware of. Her experience illustrates the difficulty that women have in understanding why they get breast cancer. In order to reconcile the illness with personal characteristics, Judith and Christine spoke of the unpredictability of cancer. Recognizing the high incident rates and arbitrariness of breast cancer helped them to make sense of why someone in good health can be affected. This finding is significant because it demonstrates the process that some mothers and daughters go through in trying to make sense of breast cancer. Searching for a cause helped mothers to understand more about the illness they were affected by and gave daughters perspective on their own risk.

#### *4.3.2.2 Realizing New Insights on Life*

For some of the participants in this study, the breast cancer experience led to new insights on life. Realizing new things about themselves and their lives helped women to make sense of breast cancer. Acknowledging that something good came out of the illness experience was an important part of the coping process. For example, Judith communicated one of the positive aspects of having breast cancer when she said: “*I had*

*to have something like [breast cancer] to become a stronger person 'cause you're really going to fight and you're going to do everything in your power to stay healthy."* This quotation suggests that Judith believed that her illness made her stronger, as it required her to persevere during a physically and emotionally difficult time. She furthered this sentiment by saying: *"When I see the word 'cancer', I don't think of death right away. I think of it as another hurdle in life that we have to get through... cancer is not the worst thing that could happen."* This comment illustrates that Judith's illness experience has led her to view cancer as an obstacle which is not insurmountable. She recognizes that worse things could happen and therefore she is able to see her illness in a positive light. For Judith, the positive outcome of her illness experience was that it helped her to think of crises as challenges meant to make her stronger.

Sally also found new insight into life as a result of her breast cancer experience. She felt that her illness encouraged her to grow as a person and become more appreciative of her life. For instance, Sally expressed: *"Caring for yourself is the most important thing. Starting to love yourself more. I don't think I was nurturing myself enough and loving myself. I was nurturing everybody else but I didn't take time for me."* In saying this, Sally identifies the need for her to start putting herself first sometimes. As the mother of four children, she devoted most of her time to caring for her children and husband. The breast cancer experience prompted her to recognize that she needed to care for herself as well. Thus, Sally viewed the breast cancer experience as an indication that she was not nurturing herself to the extent she should be.

The illness experience also led to a new outlook on life for Sally. She felt that surviving a potentially life-threatening illness brought about a new appreciation for life. Sally stated:

*My priorities are more in line in life, you know? I'm not so lackadaisical about my goals and 'Oh there's gonna be lots more days ahead of me.' You know? I'm more 'Today is a really important day and I have to live it for today 'cause this is a gift from God and a blessing to see the sun come up in the morning and that I'm awake today. I'm alive'.*

This passage illustrates the changes that Sally underwent in her life as a result of her illness. Her new outlook on life involved appreciating each day and becoming more proactive in attaining her goals. One goal she had achieved by the time of the first interview

was returning to her pre-pregnancies weight, losing over 35 pounds. Her new outlook on life helped her to make sense of why she had had breast cancer; she believed that her illness was a sign that she needed to make changes in her life.

Sarah felt that her mother's breast cancer experience provided her with new insight on life as well. According to Sarah, her mother's illness altered her perspective on life and aided the transition from teenager to young adult. In her own words, she expressed: "*[my mother's illness] helped me to grow up which was good... I realize that I don't have it as hard as some people and how easy my problems are. It's wrong for me to be complaining.*" This comment articulates the changes that occurred in Sarah's outlook. In particular, she felt that she became more mature as a result of her mother's illness. Her greater maturity was a result of the improved perspective she had on life because of her mother's illness. Sarah acknowledged the triviality of her everyday problems in comparison to the threat that breast cancer had posed to her mother's well-being. Thus, as a result of her mother's breast cancer, Sarah realized that she should be careful not to take the good things in her life for granted.

The quotations discussed above illuminate ways that three of the mothers and daughters gained new insight on life as a result of breast cancer. The new insights that emerged from the illness experience affected how they approached their lives after the breast cancer experience. Judith began to see difficult situations as challenges meant to make her stronger, while Sally felt that the experience led her to care for herself more. The latter also felt more appreciative of each day and a greater urgency to achieve her goals. Sally's daughter, Sarah, also expressed new insight on life. She believed that it gave her a new perspective with which to approach her problems. The experiences of these women show how gaining new insight on life was a part of making sense of breast cancer. It also illustrates an aspect of their lives that was positively affected by the breast cancer experience. While their experiences are significant, they do not speak for all the women in this study, as some believed that their outlook on life remained unchanged by illness.

#### ***4.3.3 Assessing Future Risk***

Part of coping with breast cancer involved the assessment of risk by mothers and daughters. While some aspects of the breast cancer experience ended when treatment

was complete, feelings of risk continued beyond that time. In particular, mothers discussed thoughts of recurrence, worries for their daughters, as well as an increased awareness of health in general. Daughters discussed concerns for their mothers, personal risk, and changes in health behaviour. The extent to which mothers and daughters acted on their assessment of risk varied. Some women appeared to make changes in their health behaviour while others continued their past health behaviour, despite feeling at risk. I now introduce the concept of “chronic risk”, which mothers and daughters experienced because of the mother’s breast cancer. The degree to which mothers and daughters acted on their perceptions of risk varied. This sub-theme also demonstrates the ongoing nature of the coping process, as mothers and daughters continue to deal with risk even though the physical side-effects of the illness are no longer apparent.

#### *4.3.3.1 Reflecting on Recurrence and Risk*

In all of the interviews, mothers and daughters expressed their feelings regarding recurrence and risk. The mothers reflected on what it was like to be a cancer survivor. The uncertainty of the future for cancer survivors was captured by Charlotte. She related: *“when people say they’re free of cancer, you’re never free of cancer. So therefore that does bother me a lot at times because I don’t know if it’s the end [of the cancer], you know?”* This comment demonstrates the ongoing issues Charlotte faces with respect to her breast cancer. While she was declared to be *“free of cancer”*, she acknowledges that the possibility exists that the cancer has spread elsewhere in her body or she will be diagnosed with another type of cancer. Thus, despite being a survivor, her future remains somewhat uncertain. Charlotte’s experience demonstrates that she continues to cope with breast cancer six years after her diagnosis.

Although Judith was diagnosed with breast cancer twelve years ago, she continues to experience concerns regarding future risk similar to Charlotte. Judith articulated her concerns:

*8 or 6 years after, you get a pain in your breast and you think ‘Oh my god, I should have had my breast off’, and it always comes back. Like, you think, ‘Should have I or shouldn’t have I?’ But then the doctor said, ‘No,’ he said, ‘You don’t have to have it off.’ So, hopefully someday I won’t have to have it off.*

This quotation demonstrates the ongoing struggle Judith experiences with respect to her breast cancer. She recalled that, at the time of her surgery, the doctor assured her that a

lumpectomy was sufficient to remove the cancer. However, Judith intimates that she would feel less at risk of a recurrence had she had a mastectomy rather than a lumpectomy. However, Charlotte, who had a double mastectomy, continues to feel at risk. Thus, a mastectomy does not necessarily diminish perceptions of risk. Judith and Charlotte's experiences illustrate the continual doubt that exists for many cancer survivors as to whether or not the cancer was successfully treated.

Darcy expressed feelings of uncertainty for her mother's future. Although her mother's most recent treatment for hairy cell leukemia had been about 9 years prior to the interviews, she went for annual blood tests to ensure that she continued to be in good health. While her mother, Diane, did not indicate that she was concerned about becoming ill again, Darcy described being worried about her mother's health. She stated:

*I know [she is] fine now, but yah, it worries me for sure. 'Cause even when [she] had to go, I remember [she] had to go get [her] blood tests and stuff and I would be sitting there with [her] and I would be, you know, 'I hope she's still okay'.*

Darcy identifies her ongoing concern for her mother's health. Each time Diane returns for her annual check-up, Darcy is reminded of the fragility of her mother's health and must acknowledge that the cancer could have reappeared. This shows that Darcy perceives cancer to be a constant threat to her mother's well-being.

Although Christine was concerned about her mother's health, she felt that her and her sister's risk of breast cancer was greater. When asked about her perceptions of future risk, Christine stated: "[my mother has] taken a lot of preventive steps. So, I worry more about myself and my sister, if it would affect us." By saying this, Christine acknowledges that her mother, Charlotte, has actively sought to decrease her chances of recurrence and, therefore, it is her own risk that she worries about. Regarding her risk, she stated: "I have I think a slightly increased chance, a very slight, because she got it post-menopausal... I think it's like a ten percent increased risk over anybody else. But instances of women having breast cancer are still climbing anyways." Christine is concerned with her risk of breast cancer, whether she is at increased risk or not. She feels that she has reason to be concerned about her future risk because of the high rates of incidence as well as her mother's breast cancer experience. While she estimates her



risk to be only slightly increased, it is apparent that Christine is more aware of her risk as a result of her mother's breast cancer.

Similar to Christine, Sarah was also concerned about her risk of getting breast cancer because of her mother, Sally's, experience. Sarah felt that it was important for her to be aware of the possibility that it could occur. She expressed: "*I'm kind of concerned that it might happen to me so I'm always checking, which is good so I can catch it early. Yah, yah, I don't want it to happen to me.*" Sarah is concerned about her risk of breast cancer, which she handles through self-examination. Self-examination identifies one coping strategy that Sarah draws upon in order to manage her risk perceptions. Despite her concerns, Sarah felt that she should not become pre-occupied with her future risk. This is demonstrated by her comment: "*I try not to think about it 'cause you never know. It hasn't happened, why worry about it? But there's always that thought that it could happen.*" Again, she acknowledged her concerns regarding breast cancer, while also communicating her desire not to let them interfere with her life. Sarah's experience illustrates that she must balance her perceptions of risk with her desire to avoid disruptions to her outlook on life.

Similar to Sarah, Jane's comments regarding risk of breast cancer also indicated that she did not want the potential risk to affect her life. Although she acknowledged that she was concerned about her possible increased risk, Jane had not taken measures to confirm her actual risk. She said that "*knowing that [her] grandmother had it and then [her] mother had it*" made her conscious of her own risk of breast cancer. Despite her family history of breast cancer and the implications that it had for her, Jane had not sought genetic counselling in order to assess her actual risk. Her passivity regarding her risk illustrates her desire to avoid disruption to her everyday life, which a confirmation of increased risk would likely cause. Thus, both Jane and Sarah acknowledge their perceptions of risk at the same time they wish to avoid disruptions in their lives.

Despite Jane's passivity regarding her risk of breast cancer, her mother expressed concern for her and her sister. Judith suggests that her daughters are at an increased risk because she and her mother (Jane's mother and grandmother) both had breast cancer. Judith recalled:

*I mention it every once in a while and sometimes I feel maybe they're trying to, you know, think 'This isn't going to happen to me' sort of thing. But I tell them it's inevitable because Mom had it and I had it. But, Mom was 70 when she got hers and I was, well, 55, so, I don't know, they say if it is post-menopausal, it's okay... but I don't know?*

This quotation communicates Judith's concern for her daughters and her wish for them to acknowledge their risk. It also illustrates her attempt to assess her daughters' risk based on the family history of breast cancer and information about genetic transmission. In the end, Judith concludes that she is not certain that her daughters are at increased risk, but that a future diagnosis seems "inevitable". It is apparent that Judith feels much greater concern for her daughters than she does for herself. In her own words, she said that "if they get it, it would be worse than if I had it."

When talking about her daughter's risk of breast cancer, Charlotte took a similar approach to Judith's. Charlotte expressed concern for her daughter, Christine, but also used information regarding genetic risk to downplay the likelihood that her daughter would inherit breast cancer. She communicated:

*I am concerned for her, um, that, you know, she might inherit it, that sort of thing too. But then because I had the cancer at the age that I had it, the doctor assured me that it was not like if I was 30. You know, post-menopausal, so therefore her risks aren't very high at all. You know, so that's the one good side about it.*

Although it is evident that Charlotte is concerned for her daughter, she indicates that she does not believe that her daughter's risk is any greater because of her breast cancer. Acknowledging that her illness was post-menopausal provides Charlotte with a means of assessing her daughter's risk. Thus, Charlotte and Judith's comments suggest that as mothers they are concerned for their daughters, but they also do not want to cause their daughters additional distress.

The participants' thoughts discussed in this section illustrate that feelings of recurrence and risk commonly arise after the breast cancer experience. Judith and Charlotte believed that they would never truly be free of cancer because thoughts of the illness often re-surfaced. Darcy expressed concern for her mother's future health, while Christine, Sarah, and Jane focused on their own risk. Although all four daughters perceived themselves to be at risk of breast cancer, the degree to which they acted on their feelings of risk varied. Both Sarah and Jane expressed an awareness of their risk, as

well as a desire not to let worries about breast cancer disrupt their lives. Judith and Charlotte also expressed concern for their daughters, but attempted to minimize their estimated risk by citing information on hereditary breast cancer. While daughters did not actively seek confirmation of their actual risk, I show in the following section on health behaviour that some daughters took other steps to diminish the possibility of breast cancer. Mothers and daughters' reflections indicate that recurrence and risk are significant concerns for them. This finding suggests that dealing with perceptions of risk is one aspect involved in coping with breast cancer.

#### 4.3.3.2 *Changing Health Behaviour*

Although the participants in this study did not actively seek confirmation of their future risk of breast cancer, feelings regarding recurrence and risk did affect their lives in various ways. Specifically, the illness experience led four of the mothers and daughters (Sarah, Sally, Judith, and Christine) to make changes in their health behaviour. For instance, Sarah discussed the importance of being healthy in order to decrease her chances of getting breast cancer. She related: "*[breast cancer] is a concern to me 'cause I have heard all the facts and now I'm trying to do everything right, like have kids early and eat healthy and exercise and things like that. I don't know, I'll just try and hopefully it doesn't happen.*" Sarah is making attempts to reduce her risk of breast cancer. In particular, she feels that exercise and a healthy diet can lower her risk of getting breast cancer. In addition, she wants to have children as a young adult, a strategy advocated by some breast cancer researchers. Sarah's desire to lead a healthy lifestyle demonstrates the influence that her mother's breast cancer has had on her health behaviour.

Sarah's mother, Sally, also sought to make changes in her health behaviour as a result of her breast cancer experience. In the past, Sally had tried to incorporate exercise into her daily routine, but found that an exercise group for breast cancer survivors was the incentive she needed. She said:

*When my friend wanted me to go into this exercise program, I thought 'Well, I've gone to the fitness centre and I hardly get there enough anyway' and she said 'No, it's a really good group. All these women have had breast cancer', and she convinced me to go because she said 'At the end, we go out for a meal.' And I thought 'Alright, I'll go!'... when she said that, it sounded like more like a support group than an exercise group... So I knew that there must be more to it,*

*and I got there and I got stronger, I'm stronger in my upper body than I've been in my life cause of weight lifting, right? But we support each other.*

This passage makes it apparent that Sally found that the exercise group gave her motivation to become more active, as well as support from other breast cancer survivors. She articulates the benefit of the group by describing her improved upper body strength. Sally's more active lifestyle clearly illustrates one of the changes in her health behaviour that she has made since having breast cancer.

In addition to exercising more frequently, Sally began to take a more pro-active approach to her health. After completing treatment for her breast cancer, Sally wanted to ensure that she was in good health. She recollected: *"I asked the pharmacist over at [the drug store], I said 'Is there a list of tests that we should do?' and she gave me that list."* This comment illustrates Sally's desire to take better care of her and her family's health. She wanted to have medical tests done in order to verify that an illness was not being left undiscovered. Sally related: *"[I had] a gastroscopy and colonoscopy and I just had a pelvic ultrasound this week, I wanted to get all those reassurances that I'm healthy in other parts of my body."* It is apparent that Sally's breast cancer led her to realize that she may have other illnesses that have not been detected. Thus, she went for medical tests to ensure that she was in fact in good health. Sally's new pro-active approach to her and her family's health demonstrates another change that occurred in her health behaviour since having breast cancer.

Judith also experienced health behaviour changes after her breast cancer experience, as she became more physically active than before. While she believed that her diet was already healthy, Judith agreed that she exercised more than in the past. Her daughter, Jane, recalled her involvement in various forms of exercise since her illness. Jane said: *"You didn't do aqua-fitness three times a week, and walk everyday and all that kind of stuff... You're in way better shape than you were before."* Jane identified specific activities that her mother has begun since having breast cancer which have improved her overall health. Judith summed up the changes in her health behaviour: *"I think I'm more active and more observant in everything and you just kind of want to get all the information you can out of all the cancer centres."* This comment demonstrates that Judith has made an effort to be healthier by becoming more active and aware of her

health in order to reduce her risk of getting cancer again. Similar to Sally, Judith's breast cancer experience prompted her to lead a more active lifestyle.

One significant health behaviour change that Christine made as a result of her mother's breast cancer was to avoid substances thought to be cancer-causing. After her mother's diagnosis, Christine and Charlotte became more conscientious of medications and other factors thought to cause cancer. An example of this is described by Christine:

*Now I take steps to avoid [cancer], like I decided recently not to take birth control pills anymore. Now I just get a progesterone shot for birth control because it just seems safer. My doctor said 'Well, it may cause osteoporosis.' But osteoporosis is a lot more treatable than breast cancer.*

Christine wished to make changes in order to reduce her exposure to cancer-causing substances. In particular, she was concerned that birth control pills may contribute to cancer and, therefore, she has chosen an alternate form of birth control. In this comment, Christine acknowledges that most medications have side-effects, but that she wishes to avoid medications linked to cancer. While health behaviour changes for Judith, Sally, and Sarah involved more frequent exercise and a greater awareness of health, Christine became more conscious of the substances she put in her body.

Despite her increased awareness of cancer-causing substances, Christine did not feel that changes she has made in her diet were wholly because of her mother's breast cancer. She related:

*I think that [my diet] is changing, but I'm not sure if that's the breast cancer or if it might have been part of it. It's just, I'm getting older, my metabolism changed somewhere around when mom had cancer and I started, you know, not being able just to get away with everything I want to eat anymore. So, I guess as society is moving more towards a health-conscious way of life, I'm starting to see that that's something I'm going to have to incorporate into my life too. Furthermore, if I do get breast cancer, I should be healthy so that I can try and fight it like mom did.*

Christine identified a number of factors that have led to changes in her diet. She recognized that growing older, the increasing emphasis on obesity in society, and her mother's breast cancer have all contributed to her becoming more healthy. She also expressed that a family history of Alzheimer's disease has led to a greater number of diet changes than has breast cancer. In addition, Christine acknowledged that her diet is one aspect of her health that she is able to control and that, while it may not guarantee good

health, a healthy diet will be beneficial if she does become ill. Christine's experience identifies that her mother's breast cancer was not the only motivator for her to become healthier.

Christine's mother, Charlotte, did not believe that she had made any health behaviour changes since her breast cancer experience. However, she did acknowledge that having breast cancer made her more aware of the importance of a healthy lifestyle. She recalled:

*Now we are maybe more conscious of the effect [a healthy diet] has, which we did not think about before. Before [the breast cancer], we might have thought only that eating healthy was the thing. I mean, I grew up in Europe and people are always health conscious there, you know? Like, I grew up most of my life on my grandmother's country home and the only vegetables we ate were from her gardens and fruit and stuff. We always ate very little meat.*

Charlotte indicated that it was not necessary to make changes in her diet after her breast cancer because she has always made an effort to eat healthy. In the past, Charlotte had eaten healthy because it was emphasized in her upbringing and the culture. Since her breast cancer experience, Charlotte has realized how crucial a healthy diet is because it may have contributed to her surviving breast cancer. Similar to her daughter, Charlotte also became more aware of substances that potentially cause cancer as a result of her breast cancer. For example, she tried to avoid pesticides by eating organic meat and produce. Although Charlotte's diet did not necessarily change, her reasons for eating healthy became more evident after her breast cancer experience.

Similar to Charlotte, Diane and Jane also believed that changes had not occurred in their health behaviour as a result of breast cancer. When asked if her illness had led to changes in her health behaviour, Diane said: *"I don't think so, because I tried to be active and, you know, exercise and eat properly before that and... I had quit smoking long before that."* This statement suggests that Diane did not make any changes because she felt that she had already made an effort to do so previously. Jane also claimed that she had not made changes to become healthier since her mother's breast cancer. She stated: *"I haven't [made changes]. I don't exercise. [My mother] exercises for both of us. Um, we've always had a healthy life, like eating healthy foods and stuff like that, but, ah, no, it hasn't made me make any drastic changes."* While Jane indicated that her diet

has always been healthy, she did not make an effort to introduce exercise into her lifestyle despite the obvious health benefits. Jane's experience suggests that daughters may not be influenced by their mother's breast cancer to adopt a healthier lifestyle.

To summarize, some of the mothers and daughters changed their health behaviour as a result of the mother's breast cancer. Changes involved increasing exercise, altering diet, seeking medical testing, and switching medications to avoid those that might be cancer-causing. These mothers and daughters felt that introducing these lifestyle changes would benefit their health and diminish their future risk of illness. While four of the women made changes in their health behaviour because of breast cancer, Christine also acknowledged that other factors contributed to the changes, such as family history of other illnesses and the emphasis on health in the media. This finding implies that risk was not the sole motivator for women to make health behaviour changes. Three of the women did not make changes to their health behaviour because they believed that their lifestyles were already healthy. Jane felt that she made no changes in her health behaviour, despite recognizing that there was potential for improvement. The absence of change in this daughter's health behaviour suggests that a mother's breast cancer does not necessarily precipitate changes. Another daughter, Darcy, acknowledged that she had made changes in her health in order to decrease her risk of cancer, but that these changes were not associated with her mother's illness. Therefore, the experiences of the women in this study imply that women may or may not make changes to their health behaviour as a result of breast cancer. For instance, those who previously lived healthy lifestyles may believe it is unnecessary to make changes, especially if they think that cancer is linked to environmental factors. However, others may find that illness is a catalyst for changing their health behaviour.

#### **4.4 Growth in Family Relationships**

Throughout the interviews, participants discussed their family relationships with respect to the illness experience. Growth in family relationships refers to shifts or changes that occurred in their relationships as a result of the breast cancer experience. The first sub-theme discusses daughters' descriptions of how the breast cancer experience influenced their perceptions of their mother. It was apparent that daughters recognized and admired their mother's strength of character during the experience.

Daughters also realized the uncertainty of life during this time, as the breast cancer diagnosis was a reminder of their mother's mortality. Each of the daughters communicated that their mother's breast cancer was a reality check that brought about a greater appreciation of time shared with their mother. This sub-theme demonstrates that the illness experience can cause daughters to see their mother in a new way.

The second sub-theme focuses on growth in the mother-daughter relationship specifically. Mothers and daughters' experiences indicated that their relationship was affected by breast cancer. For two of the mother-daughter dyads (Judith and Jane, Charlotte and Christine), the breast cancer experience illustrated that reciprocity existed in their relationship. The support that Jane and Christine provided their mothers demonstrates that the breast cancer experience allowed them to reciprocate support that their mothers had given them in the past. Three of the mothers and daughters, Jane, Christine, and Charlotte, also expressed that the illness experience brought them closer to one another or confirmed past closeness. The intensified bond that developed for these women illustrates that the illness experience can positively affect the mother-daughter relationship. However, it is important to recognize that not all mother-daughter dyads expressed that growth occurred during this time.

There was also evidence that other family relationships changed as a result of the illness experience. Growth in family relationships included shifts within the entire family, as well as changes in relationships with siblings and step-parents. For Sarah, it was apparent that her mother's breast cancer led her family to be more caring and respectful toward one another, especially to her mother. Christine's mother's illness experience led her to better understand her step-father, but exacerbated tension between her and her sister. Thus, it is evident that illness can influence family relationships both positively and negatively. This sub-theme provides valuable insight into some of the ways in which family relationships are affected by a mother's breast cancer experience.

#### ***4.4.1 Altered Perceptions***

One theme that emerged throughout the interviews was related to daughters' perceptions of their mothers. In particular, daughters talked about how their mothers coped with the illness and the traits in their mothers that emerged as a result of their illness. Daughters recognized the inner strength their mothers had displayed during the



breast cancer treatment. Daughters' perceptions of their mothers did not necessarily change, but the illness experience prompted them to acknowledge attributes that they did not always notice. In addition to recognizing their mothers' strength, the breast cancer experience caused daughters to confront their mother's mortality. Confronting mortality led daughters to realize the fragility of life and develop a new sense of appreciation for their mothers. Thus, the breast cancer experience altered daughters' perceptions of their mothers and, in doing so, daughters gained a greater appreciation of their mothers and their time together.

#### *4.4.1.1 Recognizing Strength*

All four daughters discussed their mothers in respect to their inner strength and coping ability. For the daughters, the breast cancer experience either established new perceptions or confirmed past beliefs about their mothers. For instance, Jane recognized that her mother's inner strength became more obvious during that time. She articulated:

*I'd say that she is a fairly strong person, strong willed, very stubborn, and she's been sort of the leader of the family, um, and I think probably that's one of the reasons... Right from the start she said 'I'm gonna beat this. This is a piece of cake' and whatever, and she always maintained that to the rest of us, to my sister and to myself, and my family, my husband and kids and, ah, to my dad... even though she was sick, she was still the leader of the family. She was still saying 'Okay, this is no problem. We're going to get through this'.*

This quotation illustrates the traits in her mother to which Jane attributed her family's ability to cope with breast cancer. She indicates that her mother's strong will and leadership were important to maintaining optimism and helping them to cope with the unexpected threat that the breast cancer diagnosis posed. Jane recognized that her mother had always assumed a leadership role within the family, but her strength clearly emerged in her positive attitude and approach to her illness.

Sarah also emphasized that her mother's inner strength emerged during the breast cancer experience. When asked how her view of her mother was affected by the experience, Sarah related that “[my mother] is really strong, you know? [Breast cancer] would be pretty hard to go through and... she's gone through a lot and she's always smiling.” Sarah acknowledged the difficulties that her mother has gone through because of her breast cancer and her ability to stay positive. She continued to say that she has always been aware of her mother's strength, but that “it came out a lot more” during that

time. While this was not a new view of her mother, it was evident that her mother's ability to cope with breast cancer brought out admiration and respect for her mother in Sarah. Her comments indicate that the illness experience allowed her to recognize her mother's strength to a greater extent.

Christine expressed a similar sentiment as Jane and Sarah, believing that her mother's strength shone through during the breast cancer experience. Christine stated: "*I probably never realized really how strong she is beforehand... I probably may have eventually seen it with age, but this certainly, you know, I mean, she was going to beat it and that was all there was too it.*" Christine acknowledged that she became aware of her mother, Charlotte's, strong character during the breast cancer experience. She highlighted her mother's strength by emphasizing that she never let herself think that cancer was unbeatable. Although Christine feels this perception of her mother would have emerged over time, it is obvious that the breast cancer experience was a catalyst for viewing her mother as someone with great inner strength.

Similar to Jane, Darcy described how her mother's inner strength influenced her own ability to cope with her mother's illness. Although Darcy does not remember very much from when her mother, Diane, was diagnosed with breast cancer, her mother also had hairy cell leukemia, which required treatment throughout Darcy's youth and adolescence. Darcy believed that her own ability to cope with her mother's cancer was linked to the approach her mother had toward being ill. She recalled: "*[my mother] just stood strong and didn't really do any emotional stuff. 'Oh yeah, my mom's got cancer', you know, like, you're not going to cry 'cause it's not a big deal to her, so it's not a big deal to me.*" Darcy did not respond emotionally to her mother's cancer because her mother did not do so. It is apparent that she drew upon her mother's strength in order to cope with the uncertainties associated with illness.

This section provides evidence of one change that took place with respect to daughters' perceptions of their mothers. As a result of their mother's breast cancer, daughters recognized their mother's inner strength. It was evident that their mother's strength brought out respect and admiration in the daughters, who acknowledged that it would be difficult to maintain optimism when diagnosed with a life-threatening illness. Jane and Darcy's comments recognized that their mother's inner strength influenced

their coping ability. These two daughters expressed explicitly that their mother's strength during this time helped them to stay strong. This finding is important because it illustrates that the illness experience can influence daughters' perceptions of their mothers, which may lead to a new appreciation for one another or benefit their family's coping ability.

#### 4.4.1.2 *Confronting Mortality*

Another aspect of daughters' perceptions that was affected by their mother's breast cancer related to mortality. The breast cancer diagnosis forced the daughters to acknowledge the potentially negative outcome of the illness. Even though the mothers who participated in this study all survived breast cancer, daughters were confronted by concerns related to their mother's mortality and recognized that the illness could have had a different outcome. These sentiments were captured by Jane:

*I think you realize very quickly that, how quickly your life can change... she could have died ten years ago, rather than survived it, right? And so right now we could be sitting here, minus one person at the Christmas table, right? So, anything could have happened, um, so it's impacted all of us in the sense that you sort of live each day like it could be your last really. Um, because you always think that, 'Oh, it will never happen to us', right? And then all of sudden, bang, it strikes your family, and you think 'Wow, we are all human. It could happen to any one of us'.*

Jane articulated the idea that her mother's breast cancer diagnosis was unexpected and caused her and the rest of her family to acknowledge the fragility of life. Jane added: "Sometimes I think you feel like you are living on borrowed time... enjoying everyday that we've had since that time." This comment emphasizes that she is aware of how different life would be if her mother had not survived. She also communicated that this realization has changed her outlook on life, as she has learned to value each day.

Darcy also realized her mother's mortality as a result of her illness; however this occurred about a year after her mother, Diane's, cancer treatment had ended. When asked at what point she became aware of the implications associated with her mother's cancer, Darcy replied: "After about a year, actually realizing 'Oh my god, she could have died.'... But I was like 'You're invincible'... probably about a year, like, you know, 15, 16, when it actually registered." She did not fully understand the implications of her mother's cancer (both breast cancer and hairy cell leukemia) until she was 15 or 16 years

old. At this point in her life, Darcy became aware of the severity of cancer and the threat it had posed to her mother. This quotation also highlights Darcy's past belief that her mother was "*invincible*", a view that was shaken by the realization of the potentially negative outcome her mother's cancer may have had. Similar to Jane's comments, it is evident that her mother's cancer experience required Darcy to acknowledge that she could have lost her mother.

In order to make sense of the threat that the breast cancer diagnosis posed to her mother, one daughter related her mother's cancer to the experiences of other people she knew who had survived the illness. Sarah recalled that her mother, Sally's, breast cancer diagnosis came as a shock that she was not sure how to deal with. She said:

*At first, I wasn't sure how to respond, like 'Okay...' and then later that night, it pretty much hit me and 'cause I've, I've known people who have had breast cancer and they've survived so that's how I thought about it. But then there's always that idea that...*

This quotation illustrates Sarah's attempt to make sense of the potential threat breast cancer was to her mother's well-being. Although she does not explicitly talk about the negative outcome her mother's illness could have had, it is evident that this was something Sarah had considered. This quotation also demonstrates how she reassured herself by remembering the positive outcome of other people's cancer experiences. Specifically, Sarah thought about her godmother who had survived breast cancer several years earlier; she used her godmother's experience as a way of maintaining an optimistic outlook and keeping her fears in check. Comparable to Jane and Darcy, Sarah's comments indicate that her mother's breast cancer diagnosis required her to confront issues of mortality.

For the most part, daughters tended to talk only briefly about the possibility of losing their mother. They typically focused on the fact that the illness was in the past and that the outcome had been positive. Despite this, some daughters felt increased concern for their mother's well-being, which was related to issues of mortality raised by the breast cancer experience. Christine demonstrated her intensified concern: "*I think that I am a bit more protective of her, you know, when she decides to stand on a rickety chair and kind of stuff like that... if she falls off the chair, I'm going to have to catch her.*"

From this quotation, it is evident that Christine worries more about her mother now and

feels a greater responsibility for her well-being than she did previously. Her mother's breast cancer diagnosis caused Christine to recognize how quickly life can change as a result of illness or injury. Christine's comment illustrates one way in which she sees her mother differently since the breast cancer experience and emphasizes that there is a greater level of reciprocity in their relationship.

The four daughters in this study did not spend a great deal of time talking about mortality. However, it was apparent that their mothers' illness forced them to recognize the fragility of life. For Jane, this realization led to a greater appreciation of her mother and the time they spent together. About a year after her mother's final treatment, Darcy realized the severity of her mother's illness and the threat it posed. Christine expressed a greater concern for her mother's well-being as a result of breast cancer. In order to deal with fears about losing her mother, Sarah related her mother's illness to the experiences of other people who had survived breast cancer. This section provides an example of one way that daughters' perceptions of their mothers can be shaken by a breast cancer diagnosis. It also demonstrates that daughters may develop a new appreciation for their mothers, as illness forces them to confront issues of mortality.

#### ***4.4.2 The Mother-Daughter Relationship***

Another theme that emerged from the interviews was related to growth in the mother-daughter relationship. Both mothers and daughters reflected on how the breast cancer experience affected their relationship with one another. While they generally did not describe their relationship as changed by the mother's illness, the experience appeared to alter the relationship in some way. One aspect of growth discussed by two of the mother-daughter dyads (Judith and Jane, Charlotte and Christine) was the reciprocity which emerged in their relationship during that time. For Jane and Christine, their mothers' breast cancer experience provided them with an opportunity to demonstrate their ability to support their mothers, just as their mothers had supported them in the past. Another aspect of growth that was expressed by three of the women was related to the development of intensified bonds with one another. Jane, Christine, and Charlotte believed that the illness experience contributed to an increased sense of closeness between mother and daughter. The intensified bonds described by the women involved feeling closer to one another or solidifying their already close relationship. For

some of the mothers and daughters, two aspects of the mother-daughter relationship were positively influenced by the mother's breast cancer experience, which involved increased reciprocity and intensified bonds.

#### 4.4.2.1 Demonstrating Reciprocity

The existence of reciprocity in the mother-daughter relationship is confirmed by Charlotte and Christine. Until her mother's diagnosis, Christine felt that she had been the one in the relationship who had received support, as her mother had supported her while she was pregnant. During her mother's breast cancer treatment, Christine played a significant role by providing instrumental and emotional support to her mother. When asked about supporting one another, Charlotte and Christine responded:

Charlotte: *When it really comes down [to it], we know we can count on each other. You know, if there's any crisis, as there was, I knew I could depend on her.*

Christine: *Absolutely.*

Charlotte: *I don't have to ask. She'll know.*

In this passage, Charlotte emphasizes that she and her daughter can depend on one another. She acknowledges that her daughter supported her during her breast cancer experience and would do so again if another crisis arose. This exchange between Charlotte and Christine demonstrates the interdependency that exists in their relationship, which became evident during the breast cancer experience.

Reciprocity was also apparent in Judith and Jane's relationship, although it appears to have emerged before the breast cancer experience. When asked about the care and support her daughter offered during the illness experience, Judith said: "*I don't think she's given [me] any more care than normal, but I think that if I needed her, I'm sure that she would be there for me.*" Jane agreed that support was always available if her mother needed it. This quotation demonstrates that Judith and Jane's relationship involved ongoing reciprocity. It is evident that interdependency previously existed in their relationship and did not emerge solely during the breast cancer experience.

Although Judith may not have felt that she was offered any more support than usual, her belief that support was available to her reveals the reciprocity in their relationship. Thus, the illness experience provided confirmation of the reciprocity that existed in this mother-daughter relationship and also illustrated the close bond that existed between Judith and Jane.

These women's comments suggest that reciprocity was evident in the mother-daughter relationship during the illness experience. The mother-daughter relationship begins as a parent-child relationship in which the daughter is dependant on her mother (Henwood, 1997, p.255). Over time, this relationship often becomes increasingly interdependent and mother and daughter are mutually supportive (Shawler, 2004, p.151). The point at which this shift from dependence to interdependence takes place is influenced by many factors. Both daughters who reciprocated support to their mother during the breast cancer experience were young adults at the time. Christine's mother's breast cancer diagnosis was an opportunity for her to support her mother and establish interdependency in their relationship. For Jane, the breast cancer experience confirmed that reciprocity previously existed in her relationship with her mother. The experiences of these two mother-daughter dyads illustrate that the mother-daughter relationship may become more interdependent because of the illness experience.

#### *4.4.2.2 Developing Intensified Bonds*

Supporting their mother during the breast cancer experience brought some mothers and daughters closer together emotionally. While all of the daughters stated that they had close relationships with their mothers previously, Jane felt that her mother's breast cancer diagnosis resulted in an intensified bond with her mother, Judith. Jane expressed:

*It's probably made us closer and it's sort of been a reality check that, I mean, you read about it, and it always happens to other people, but when it hits that close to home, and my sister flew down too for it and so you feel really vulnerable... So, yah, it's just sort of a reality check, I guess.*

This quotation communicates the heightened sense of closeness Jane feels towards her mother because of the potential threat her mother's breast cancer posed. She felt that her mother's diagnosis was a "reality check", which helped her realize that nothing should be taken for granted. Thus, the illness experience prompted Jane to become more appreciative of the time she shared with her mother and the rest of her family.

Christine stated explicitly that her relationship with her mother, Charlotte, had always been close, but that the breast cancer experience intensified the mother-daughter bond. Similar to Jane, Christine felt that her mother's illness had encouraged her to value her mother more. She said:

*We're closer... I suppose I really realized how much she means to me... I probably would have come to the conclusion with age anyway. But [these feelings] probably got sped up and probably expanded because of her experience. I mean, a lot of these realizations just come with age and maturity. But [illness] has a way of making you grow up too.*

Christine recognized that her mother's breast cancer prompted her and her mother to become closer. However, she believes that this intensified bond would have developed over time anyway. Thus, it appears that the greater sense of closeness between Christine and her mother was accelerated by the illness experience. She also indicated that she matured during her mother's breast cancer experience, which contributed to her greater appreciation of her mother. Christine's reflections acknowledge that the illness experience had a positive influence on the mother-daughter relationship.

Charlotte also expressed an intensified bond with Christine and her other daughter because of her breast cancer experience. She emphasized that realizing how much her daughters care for her brought them closer. She expressed:

*I know I have loving daughters type of thing, but I also came to realize, because I was sick, how much they really love me, you know? Sometimes you go on in life and yet you don't always think about things like that... It's kind of assuring that, um, I could ask and I got support.*

Charlotte's illness led her to become aware of the love that her daughters feel for her. She articulates that her daughters' support during her breast cancer experience demonstrates how much they love and appreciate her. Charlotte's remarks illustrate the realization she made about her daughters because of the breast cancer experience, which resulted in an increased sense of closeness in the mother-daughter relationship.

For the mothers and daughters in this study, the breast cancer experience brought about some form of growth in the mother-daughter relationship. The dyads typically did not state explicitly that changes had occurred, but their stories identify growth in their relationships. Three of the women, Jane, Christine, and Charlotte, indicated that they developed a greater sense of closeness in the mother-daughter relationship as a result of the illness experience. Jane thought of her mother's breast cancer diagnosis as a reality check that prompted her to appreciate her mother more. Christine and Charlotte stated that breast cancer helped them to realize how much they mean to one another. For other mothers and daughters, the illness experience merely confirmed their former closeness.



For instance, Sarah expressed that the bond she had with her mother remained unchanged, as they had a close relationship beforehand. The intensified bonds that developed for the three mothers and daughters highlight the growth that occurred in their relationships as a result of the breast cancer experience, however subtle it may have been. This growth illustrates one way that the breast cancer experience positively affected the mother-daughter relationship.

#### ***4.4.3 Family Relationships***

The breast cancer experience also precipitated growth in family relationships. The growth described by two of the daughters related to changes in relationships with individuals or within the family as a whole. For example, Sarah expressed that there was a greater sense of respect among her family members, especially for her mother. The illness experience led to both positive and negative changes in relationships. In particular, Christine felt that the illness experience helped her to understand her step-father better, but negatively influenced her relationship with her sister. The theme of family relationships provides evidence of some of the positive and negative changes that can occur within the family as a result of illness.

While Sarah believed that the close relationship she and her sister had with their mother, Sally, was unchanged by the breast cancer experience, she asserted that changes had taken place within her family. In particular, Sarah believed that her family members had more respect for one another since the illness experience. When asked about changes in her family's behaviour, she responded: "*[We are] just saying nicer things to each other [now]. We were kind of, really rude to each other [before] and, yah, things that like.*" Sarah described the shift that took place in her family as a result of her mother's breast cancer. Specifically, the experience prompted Sarah's family members to appreciate and respect one another to a greater extent. Thus, her mother's breast cancer had a significant influence on how Sarah's family related to one another.

While Sarah spoke about the greater respect in her family in general, it was apparent that much of the increased respect was for her mother, Sally. Having had health issues for some time before being diagnosed with breast cancer, her mother was viewed as "*sick*" by the rest of the family and was often blamed when something went wrong. Sarah recalled:

*[My mother] had all these symptoms and something was wrong and we didn't know, we're like 'You're just sick. That's who you are. You get sick all the time and complain.' And then after [her diagnosis], we realized it was something serious and maybe we should have been a bit nicer.*

This passage illustrates that her mother's breast cancer diagnosis brought about changes in her family's behaviour. Sarah states that she and her family members had been inconsiderate toward her mother in the past because they did not understand the authenticity of her health problems. Once Sally's complaints of health problems were validated by her breast cancer diagnosis, the rest of the family recognized their legitimacy and approached her with greater compassion. In this way, positive growth clearly took place in their family relationships.

As a result of her mother's breast cancer, Christine experienced growth in the relationship that she had with her step-father. In particular, Christine expressed that she gained a better understanding of his feelings for her mother. She recalled:

*He grabbed me by my shoulders and he said 'You take care of your mother.' I was like 'Okay.' So, I guess at that point I really understood, you know, I mean he was quite rough and he was upset but, I mean, his caring, the caring was so obvious.*

According to Christine, this exchange with her step-father made her aware of his love and concern for her mother. While her step-father typically did not express emotion, she felt that her mother's illness prompted him to show his feelings for her mother. Consequently, Christine saw her step-father in a way that she had not before which helped her to better understand him. In that sense, her mother's breast cancer experience brought about positive growth in Christine's relationship with her step-father.

While Christine indicated that the breast cancer experience contributed to positive growth in her relationships with her mother and step-father, she felt it increased tension between her and her older sister. Although Christine and her older sister had disagreed about certain issues in the past, it was evident that their relationship deteriorated as a result of arguments about caring for their mother. Christine described their difficulties:

*My sister fought against me a lot... [She] told me I was interfering more than anything, so if anything I would say that the cancer brought me closer to my*

*mother, but probably, in some ways, pushed me further from my sister, which is unfortunate but she seemed to have some sort of a rivalry almost.*

Christine's relationship with her sister was adversely affected by disagreements related to supporting their mother. Christine also expressed that the tension resulting from that time has continued to plague their relationship. This finding provides insight into one of the potentially negative consequences that illness experiences can have for family relationships. Negotiating the provision of care and support may lead to disagreements among family members, resulting in relationship difficulties that may create stress for the ill individual.

This theme demonstrates some of the ways that family relationships were affected by the breast cancer experience. While growth may be common in family members' relationships with the ill person, it is also apparent that growth can occur within the family as a whole or in other family relationships. For example, Sarah expressed that her mother's breast cancer brought about change in her whole family. She stated that the change involved a greater sense of respect among her family members. Christine also experienced changes in relationships with family members. She indicated that her relationship with her step-father and her sister were altered during that time. In conclusion, the experiences of Sarah and Christine illustrate that illness has both positive and negative consequences for family relationships. While illness often brings about greater appreciation for life and time spent with one another, these feelings may not overshadow conflict between family members. Once again, this finding adds to the argument that illness has various implications for families.

#### **4.5 Summary**

I began this chapter by introducing the women who participated in my study. This background information, such as family composition, living arrangements, and personal responsibilities, will help readers to better understand the themes I describe in this chapter. The findings that I have identified resulted from my analysis of qualitative interviews with mothers and daughters. Three major themes emerged from the interviews, which were: *shifting roles and responsibilities, coping with breast cancer, and growth in family relationships*. As a whole, the findings demonstrate aspects of mothers and daughters' lives that were affected by the breast cancer experience.

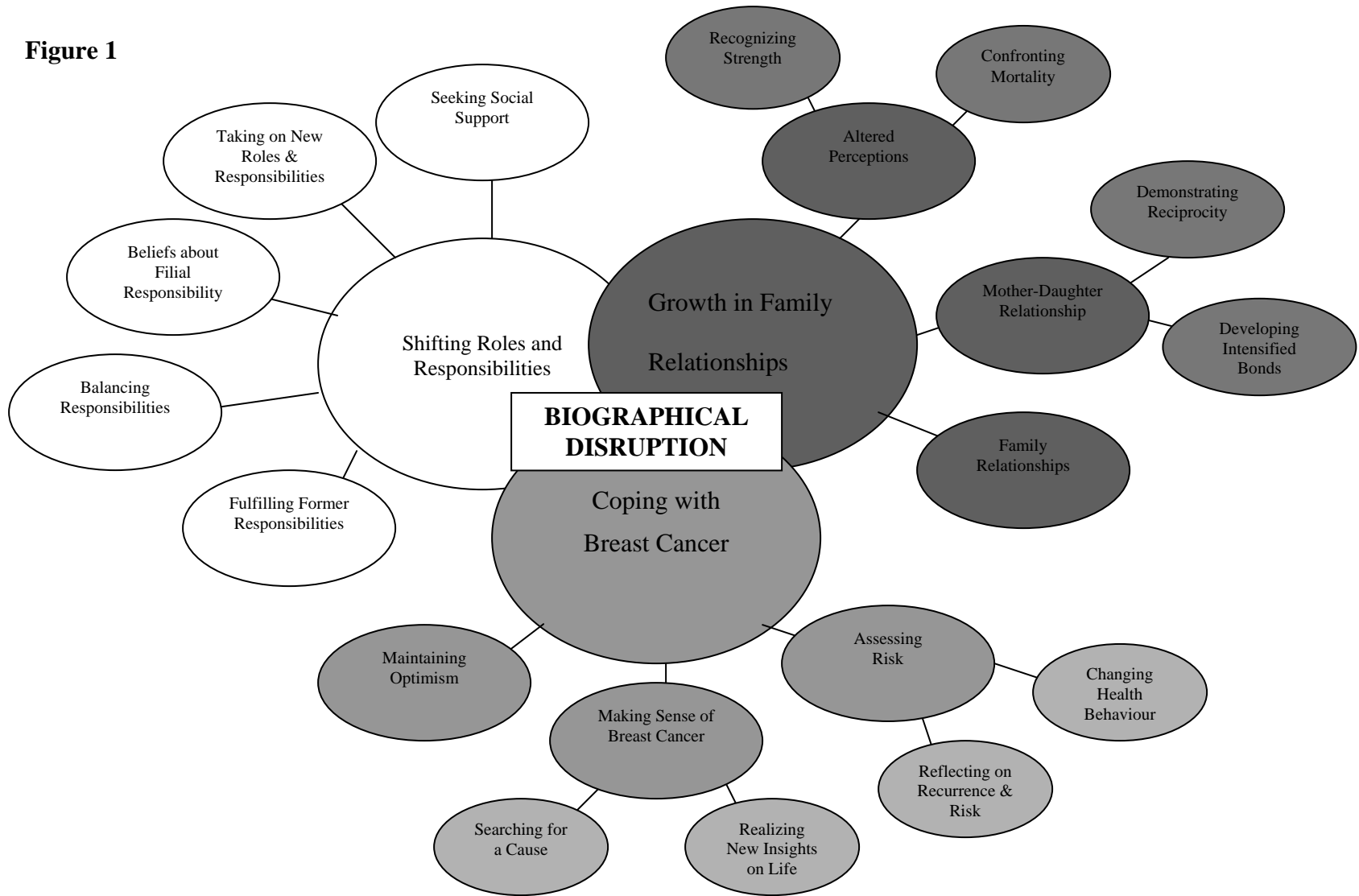
The theme *shifting roles and responsibilities* focuses on changes that may have occurred in the distribution of family roles and responsibilities as a result of the mother's breast cancer. I divided this theme into five sub-themes, each of which relate to shifts that took place for mothers and daughters. The first sub-theme, seeking social support, emphasizes the importance of family members in providing care and support during the illness experience, as well as in helping mothers to seek external sources of social support. The second sub-theme highlights the assumption of new roles and responsibilities by family members during the breast cancer experience. It was evident that families had to re-distribute tasks mothers had previously performed, in addition to allocating new tasks related to caregiving. For some mothers and daughters, the assumption of new roles and responsibilities led to role reversals, in which parent and child switched roles. The third sub-theme concentrates on mothers and daughters' beliefs about filial responsibility. This sub-theme suggests that mothers must negotiate their support needs with their desire to maintain autonomy, as well as their daughters' desire to provide care. The fourth sub-theme I identified is related to the balancing of responsibilities by daughters. During the breast cancer experience, daughters were required to manage their previous obligations while also assuming new caregiving tasks. One way that daughters were able to balance their responsibilities was by seeking support from others. The fifth sub-theme related to shifts in roles and responsibilities focuses on mothers' ability to fulfill former duties, which was related to: physical well-being, number of obligations, and financial need. As a whole, this theme contributes to our understanding of how family roles and responsibilities were affected during the mothers' breast cancer treatment.

The second major theme I identified is *coping with breast cancer*. This theme demonstrates coping strategies and resources that mothers and daughters used and continue to use in order to cope with the implications of breast cancer. The sub-theme of maintaining optimism indicates that mothers believed that an optimistic attitude toward their illness was key to successful coping. Two of the daughters felt that their mothers' optimism helped the rest of their family to deal with the illness. Another important aspect of the coping process involved making sense of breast cancer. I divided this sub-theme into two parts: searching for a cause and realizing new insights on life. Searching

for a cause involved attempts to determine possible causes of mothers' breast cancer in order to make sense of why they had developed breast cancer. It also helped mothers to feel a sense of control over their illness and allowed daughters to assess their own risk. Three of the women felt that they realized new insights on life because of the breast cancer experience. Their realizations demonstrate that they made sense of breast cancer by acknowledging that it had a positive effect on some aspect of their lives. The third sub-theme I identified was assessing risk, which focused on mothers and daughters' reflections on recurrence and risk, as well as changes in health behaviour. It was apparent that assessing risk was an ongoing process, as mothers and daughters faced "chronic risk" because of the potential threat that breast cancer posed to their futures (Kenen et al., 2003). Despite mothers and daughters' perceptions of risk, only half of them made changes to their health behaviour.

The third major theme, *growth in family relationships*, concentrates on changes that occurred in daughters' perceptions of their mothers, the mother-daughter relationship, and other family relationships. It was apparent that the breast cancer experience led to shifts in the way that mothers and daughters thought of one another. The first sub-theme I identified was altered perceptions, which discusses two aspects of daughters' perceptions of their mothers that were affected by the illness experience. First, their mothers' breast cancer led daughters to recognize the inner strength that their mothers drew upon during that time, which prompted daughters to have greater admiration and respect for their mothers. Second, the breast cancer diagnosis forced daughters to realize their mothers' mortality, bringing about a greater appreciation of their mothers. The second sub-theme focuses on growth in the mother-daughter relationship. I observed two important shifts in some mother-daughter relationships that occurred as a result of the breast cancer experience: the opportunity for daughters to reciprocate support to their mothers and the development of intensified bonds. Two of the daughters used their mothers' illness as a chance to show that they were able to support their mothers, just as they had been supported. Three of the mothers and daughters also expressed that they became closer as a result of the breast cancer experience. The final sub-theme discusses changes that occurred in other family

**Figure 1**





relationships because of the mothers' breast cancer. This sub-theme recognizes that illness may affect family relationships in both positive and negative ways.

Many of the themes are related to one another. The extent to which mothers and daughters' roles and responsibilities were affected may have influenced the degree to which other changes took place in their self concepts and family relationships. For instance, the illness experience provided an opportunity for daughters to take on new roles and responsibilities which prompted reciprocity to emerge in the mother-daughter relationship. Also, mothers' ability to maintain optimism during the illness experience contributed to daughters' recognition of their mothers' strength. Figure 1 demonstrates the inter-connectedness of the themes and sub-themes.

The findings discussed in this chapter demonstrate various implications that breast cancer had for mothers and daughters' family roles, responsibilities, and relationships. The three major themes, *shifting roles and responsibilities*, *coping with breast cancer*, and *growth in family relationships*, provide evidence that mothers and daughters experienced changes in their everyday lives and had to re-examine their expectations for the future. Thus, the themes have an overarching connection to the concept of biographical disruption. The themes also illustrate the idea that illness does not end with the completion of treatment and that families may encounter a variety of challenges throughout the breast cancer experience.



## **CHAPTER FIVE: DISCUSSION AND CONCLUSION**

In this final chapter, I discuss the significance of the findings, relating them to existing research. This discussion is followed by a section outlining conclusions that I have drawn from the findings. The conclusions highlight the biographical disruption that mothers and daughters experience as a result of the mother's breast cancer; however I feel it is necessary to acknowledge that biographical disruption for many of the women was partial rather than complete. This section also identifies the ways that daughters could be better supported by family, friends, and health care professionals. After summarizing the conclusions, I suggest the strengths and limitations of this study, as well as recommendations for future research. I then reflect on the methodological approach utilized in this study and its influence on the findings. Finally, I conclude with a short overview of the major outcome of this study.

### **5.1 Shifting Roles and Responsibilities**

As a whole, this theme offers important insight into the family as a source of social support and the ways that the provision of care and social support affects roles and responsibilities within the family. As discussed in the literature review, prior research indicates that social support is significant for individuals experiencing illness (Schaefer et al., 1981; Holahan et al., 1997, cited in Dukes Holland & Holahan, 2003, p.13; Roberts et al., 1999, p.77). I have demonstrated that family members were a valuable source of social support for the mothers diagnosed with breast cancer. Two of the mothers, Charlotte and Sally, explicitly stated that their coping ability and survivorship of breast cancer was the result of the unfailing support of their families. This finding reflects the claim made in the existing literature that family support has the ability to influence adjustment and outcome of illness (Ferrell et al., 2003; Steinglass, 2000, p.6). Recognizing the family as a major source of social support for women with breast cancer demonstrates that family members' lives are affected by the illness experience as well.

Although the degree to which each of the mothers required social support varied, mothers drew attention to the availability of support from their families. Mothers' emphases on the availability of support demonstrate that it had a significant effect on their well-being. This finding corresponds to research discussed by Thoits (1995), which suggests that the perceived availability of social support is more influential "on mental health than the actual *receipt* of social support" (emphasis in original, p.64).

Accordingly, mothers' belief that support was available had a positive effect on their well-being. The availability of support from family members was especially beneficial for the two mothers, Charlotte and Diane, who lived in rural areas, as their support options were fewer and treatment took place several hours away. While three of the women, Judith, Sally, and Diane, also sought sources of social support outside the family, it was evident that family members assisted them in doing so. The mothers' accounts indicate that the family played a crucial role in offering social support during the breast cancer experience. This finding confirms the claim made by other researchers that the family is the primary source of social support for those coping with illness (Pierret, 2003, p.13; Steinglass, 2000, p.6).

The theme of taking on new roles and responsibilities illustrates that a mother's breast cancer experiences has the ability to alter the allocation of duties within her family. For instance, it was apparent that three of the daughters, Jane, Sarah, and Christine, often assumed some of the roles and responsibilities that their mothers had performed in the past. This finding corresponds to previous research that suggests that families re-distribute family roles and responsibilities in order to maintain successful family functioning (Northouse, 1995; Petersen et al., 2003; Spira & Kenemore, 2000). Two examples of roles and responsibilities assumed by daughters included: assuming a leadership role within the family and performing household tasks, such as cooking and cleaning. Providing care and social support to their mothers was another way that daughters undertook new roles and responsibilities. Three of the daughters, Jane, Sarah, and Christine, also assumed some caregiving responsibilities and provided their mothers with instrumental, emotional, and informational support. Similar to the finding described by Raveis and Pretter (2005), assuming a supportive role during the illness experience situated daughters in unfamiliar positions (p.57). The shifts that took place in roles and

responsibilities during the breast cancer experience emphasize one aspect of daughters' lives that was affected by their mother's illness.

For four of the mothers and daughters (Jane, Judith, Sarah, and Sally), shifts in roles and responsibilities entailed role reversals during the illness experience. A role reversal involved the perceived exchange of roles between parent and child. The occurrence of role reversals among parents and their children was also found by Germino and Funk (1993), who observed that "role changing" occurred between adult children and their parents during their parent's cancer experience (p.103). The role reversals described by the participants in my study are significant because they involved reversals between mother and daughter, daughter and father, and mother and son, which suggest that gender roles within the family may not be as prevalent as stated in the social support and caregiving literature. It is thought that gender influences the distribution of caregiving and social support responsibilities within the family, as caregiving tasks and emotional support are commonly seen as feminine in nature (Aronson, 1994; Brewer, 2001; Kayser & Sormanti, 2002; Petersen et al., 2003; Raveis & Pretter, 2005; Roberts et al., 1999). However, my research shows that the re-distribution of family roles and responsibilities during times of illness is not necessarily based on gender, as daughters sometimes took on roles that were stereotypically masculine and sons provided emotional support.

For instance, Sally's experience contrasts with the existing literature, as her two sons and two daughters provided her with various forms of social support. In particular, her oldest son took on a parental role and provided her with emotional support in the form of reassurance. Judith and Jane's experiences with their fathers also reveal that role reversals can take place across gender lines. Petersen et al. (2003) propose that families experiencing illness benefit from flexible gender roles, as roles and responsibilities are re-distributed "among other capable members, regardless of gender" (p.104). It is possible that my participants' families were able to maintain functioning during the breast cancer experience because they benefited from gender role flexibility, which allowed them to successfully re-distribute roles and responsibilities.

For those involved in role reversals (Jane, Judith, Sarah, Sally), it was evident that they saw their family member in a previously unseen way. However, it does not

appear that this was detrimental to their relationships. Sally expressed that she was surprised and pleased by the new roles and responsibilities her children assumed during her breast cancer experience. Other studies have found that adult and adolescent children may be confused about how to relate to their ill parent, wish to avoid seeing their parents as vulnerable, or worry that role changes would alter their relationship (Germino & Funk, 1993; Raveis & Pretter, 2005; Spira & Kenemore, 2000). In contrast, the three women who took on parental roles did not indicate that it had a negative impact on their family relationships. Rather than influencing their perceptions of their parents, Sarah, Judith, and Jane believed that the illness experience was an opportunity for them to demonstrate their ability to provide support and leadership to their parents. Thus, the role reversals that took place had positive implications for family relationships, rather than negative ones.

While the provision of care and support by children during the illness experience can lead to role reversals, some parents and children may wish to ensure that their family roles are maintained. Charlotte and Christine provide an example of how, despite the care and support Christine provided her mother, they did not characterize this as a reversal of family roles. In Christine's description, she emphasized that the support she provided her mother was different from that which she has given her own son or her boyfriend when they are ill. It is possible that Charlotte and Christine wanted to ensure that their family roles remained unchanged. Existing research indicates that both children and parents may work to avoid changes in their roles and relationships during cancer experiences (Arrington, 2005; Ferrell et al., 2003; Germino & Funk, 1993; Walsh et al., 2005). Therefore, some parents and children may seek to ensure that their roles remain unchanged during the illness experience in order to preserve aspects of their past relationship. It is also possible that some daughters do not see performing social support and caregiving tasks as a reversal of roles because these tasks are typically characterized as feminine. Thus, daughters may see the provision of care and social support as expected behaviour for females. Consequently, it should be recognized that some families will experience role reversals during times of illness, while others may not characterize taking on new roles and responsibilities as such.

The stories of the mothers and daughters in this study also illustrate their ideas about filial responsibility. This concept refers to a belief that daughters should be responsible for caring for aging parents (Donorfio & Sheehan, 2001). Research on daughters who are primary caregivers to aging parents found that daughters feel a sense of responsibility to care for and support their parents (Abel, 1999, p.151; Aronson, 1994, p.181). The daughters in this study expressed similar sentiments, indicating that they felt it was important to care for their mothers during the illness experience. My participants did not see the provision of care and support as a burden, as other research has suggested (see Donorfio & Sheehan); instead caring for their mothers was something daughters wanted to do. This sub-theme contributes to our understanding of how daughters can be affected by their mother's illness. If daughters feel a strong sense of filial responsibility or are expected by parents to provide support, their personal responsibilities may be affected. Thus, daughters are required to negotiate their ability to provide support with their feelings of filial responsibility and the expectations placed on them by their parents.

The idea of filial responsibility was also acknowledged by the mothers, who believed that children were an important source of social support during times of illness. With the exception of Diane whose daughters were young during the breast cancer experience, the mothers in this study described the specific ways that their daughters and sons provided them with support. Despite appreciating the support they had received from their children, the mothers indicated that they did not want to burden them with extra responsibility during busy points in their lives. One study found that "feelings of guilt about the distress [their] family and friends experience because of [the] breast cancer diagnosis" is a concern to young women with breast cancer (Dunn & Steginga, 2000, p.141). Thus, it is possible that the mothers in this study felt similarly and did not want to support provision to be burdensome.

Mothers' claims that they did not want to depend on their children for support could also be related to a desire to maintain independence. A desire for independence might be especially relevant for mothers who are ill, but feel that they have not reached an age at which they need to be cared for. This idea is supported by Bury's (1982) work on chronic illness, in which he argues that illness might imply "premature ageing"

because it does not fit with societal expectations of the life cycle (p.171). In that sense, mothers may be less willing to depend on their children for support if they consider themselves to be 'middle-aged', rather than 'old-aged', at the time of their breast cancer diagnosis. However, several studies suggest that aging mothers also wish to maintain some degree of autonomy from their caregiving daughters (see studies cited in Donorfio & Sheehan, 2001, p.41). Thus, it is possible that age is not a determining factor in whether or not mothers wish to maintain independence; nevertheless age may influence the extent to which mothers assert their desire for autonomy. Ill or aging mothers may therefore need to discuss their expectations regarding filial responsibility with their children in order to ensure that they are able to maintain a certain level of independence.

Another issue that emerged during the interviews was related to daughters' need to balance support-related tasks with pre-existing responsibilities. The need to manage support-related tasks while maintaining past responsibilities is commonly expressed by adult children of parents who are ill or aging (Aronson, 1994; Germino & Funk, 1993; Rosenthal & Gladstone, 1994). For example, Christine was required to balance working two jobs, caring for her son, and providing her mother with support. Both Christine and Judith expressed that, during the illness experience, they felt they had no other option but to balance their numerous responsibilities, as supporting their mother was of primary importance. Despite recognizing that their responsibilities seem overwhelming now, the daughters succeeded in balancing school, work, and/or childcare with support-related tasks. One way that daughters were able to handle their various responsibilities was through the receipt of support from others. This finding emphasizes that individuals who provide support to others often require support themselves. Therefore, daughters could benefit from assistance with their other responsibilities, such as childcare, household duties, or other instrumental tasks. A flexible work schedule could also be helpful in balancing responsibilities.

The maintenance and re-assumption of past responsibilities described in this sub-theme identify some key issues that women with breast cancer face. First of all, the decision by some women to continue to perform past duties was based on their desire to do so. On the other hand, Diane's financial concerns appeared to override all other matters. Her experience suggests that financial concerns may be especially relevant to

women without partners, as their salary is likely the major or only source of income for the household. Second, the desire that some women with breast cancer feel to maintain or return to former roles insinuates that they wanted to avoid changes in their lives. This finding is comparable to the findings of a study of women with advanced breast cancer, in which women continued to work in order to lessen changes in their lives (Luoma & Hakamies-Blomqvist, 2004, p.734). Accordingly, women may maintain past responsibilities as a way to maintain familiarity in their lives during the illness experience. Finally, it appears that the women who were able to take a break from former responsibilities, such as work and household duties, did so in order to focus on their physical well-being, proposing that physical wellness may be a more immediate issue than psycho-social wellness. This section illustrates the need to acknowledge that women experiencing breast cancer have unique needs, which in turn affect their decisions regarding the management of past responsibilities in distinct ways.

## **5.2 Coping with Breast Cancer**

The second major theme that I have identified in the interviews involved coping with breast cancer. This theme illuminated several aspects that were involved in this process. It was apparent that coping with breast cancer was an ongoing process for the women, in that coping continued long after treatment was completed. First of all, in order to cope with their illness, mothers utilized various coping resources and strategies (Thoits, 1995). One coping resource utilized by the mothers in this study involved maintaining an optimistic outlook during and after breast cancer treatment. The mothers' belief that their illness was survivable helped them to endure the physical and psycho-social effects of breast cancer (see Luoma & Hakamies-Blomqvist, 2004; Remennick, 1998). While maintaining optimism was likely difficult at times, it may have been an attempt to exercise control over their illness. The optimism expressed by three of the women is comparable to the findings of a study performed with cancer survivors by McKenzie and Crouch (2004). They propose that "the desire to achieve control of emotion is very real for cancer survivors"; however control of emotion may be a response to "the contemporary faith in the power of optimism" (p.151). This argument suggests that some cancer survivors create a façade of optimism in order to appease people around them. It is unclear whether the mothers in this study felt compelled to

project a positive attitude in order to adhere to societal expectations, but it is certainly a possibility.

The need to maintain an optimistic attitude was also emphasized by Judith and Charlotte because they felt that physical recovery from illness was linked to their psychological outlook. In order to allow their bodies to heal, they felt the need to eliminate as much stress as possible from their lives. This finding suggests that these women believe in the “popular view that optimism, good humour and good health are closely aligned” (McKenzie & Crouch, 2004, p.151). Consequently, being upset and focusing on the possibility of death was thought by these two mothers to inhibit physical recovery. While the significance of optimism is described above as a “popular view”, research has shown that “dispositional optimism, or the tendency to expect positive outcomes, has been most consistently associated with lower symptoms of anxiety and depression and higher quality of life” (see studies cited in Compas & Lueken, 2002, p.112). Therefore, a positive attitude appears to have an actual influence on psychological well-being and, therefore, may also play a role in physical well-being.

It has also been suggested that women who are ill attempt to create a specific image of themselves through the telling of illness stories. Ochberg (1994) claims that women relate “self-idealized versions” of their illness that portray them in a positive light to others (cited in Werner, Isaksen, & Malterud, 2003, p.1037). In this sense, the mother’s emphasis on maintaining optimism during and after their breast cancer experience may demonstrate their efforts to gloss their illness stories. Women with breast cancer may feel that they are being compared to accounts of breast cancer publicized by the media (see Dunn & Steginga, 2000, p.144). Consequently, their stories become works of credibility, in that they are “methods for handling dignity in an appropriate moral way, both as women and as being ill” (Werner & Malterud, 2003, cited in Werner et al., p.1037). In other words, the mothers in this study may emphasize their inner strength because they feel pressured to live up to societal expectations regarding illness and femininity. These women may have also used stories of their positive attitudes to show that they were “deserving” of survival (Radley, 1999, cited in McKenzie & Crouch, 2004, p.151). The suggestion that women feel pressured to present a self-idealized version of their illness seems valid when time since diagnosis is



considered. Sally, whose breast cancer treatment ended the most recently, recounted the least idealized image of herself, while the other mothers focused on their optimism throughout the experience.

On the other hand, maintaining optimism could also have been a way to avoid upsetting their families further and to help them to cope. Whether genuine or not, it appears that the mothers' optimism aided their families in successfully cope with her breast cancer. Jane and Christine, who were both young adults at the time of their mother's diagnosis, indicated that their mother's positive attitude toward breast cancer prompted them to maintain an optimistic outlook as well. In this sense, daughters followed their mother's lead when it came to coping with breast cancer. This finding suggests that, despite being ill, mothers continued to influence their families' responses to the crisis. While mothers were unable to fulfill some of their other roles and responsibilities within the family, maintaining optimism during the illness experience was one way in which these mothers could support their families. Elmberger et al. (2000) identified that mothers commonly found "new ways of maintaining the role of mother" during their breast cancer experience (p.494). This assertion indicates that perhaps maintaining a positive attitude was one way that mothers were able to retain their role or assume a new role within the family, as it helped family members to cope with breast cancer. Therefore, maintaining optimism could be both a response to societal pressure to put forth a positive attitude, as well as the result of mothers' desire to support their families through the illness experience.

Making sense of breast cancer was another important part of the coping process for both mothers and daughters. In order to understand why mothers were affected by breast cancer, mothers and daughters sought possible causes of the illness. The uncertainty of the cause(s) of breast cancer made it difficult for women to ascertain a definitive cause (Aronson, 2003), but nonetheless they wanted to identify possible causes. Some of the causes that the women contemplated included: late age of first childbirth, exposure to cancer-causing substances, particularly hormone replacement therapy, and smoking, along with the possibility of genetic transmission. Identifying these potential causes helped the women to make sense of what had happened to them and move forward from the illness experience. In addition, being able to identify

potential causes of breast cancer also enabled mothers to encourage their daughters to take measures to avoid getting breast cancer. While searching for a cause appears to be part of the coping process, none of the mothers underwent genetic testing to confirm whether their illness was hereditary, although one mother expressed interest in doing so. This observation suggests that mothers do not believe that their breast cancer was genetically linked or that access to genetic counselling is limited in this province.

Searching for a cause helped one mother to realize that it was not her fault she got breast cancer. Charlotte was extremely concerned about the role that environmental factors played in the increasing incidence rates of breast cancer. Specifically, she felt that little effort was being made to bring about public awareness of the cancer-causing agents found in substances such as medications, pesticides, and cleaning products. Charlotte felt that she was being blamed for causing her illness, despite the fact that she was otherwise healthy and had not been informed of the risks of certain medications. This sentiment is similar to the plight of individuals with lung cancer who are stereotyped as smokers and, therefore, considered to be responsible for causing their illness (Chapple, Ziebland, & McPherson, 2004). Women who experience chronic pain are also commonly blamed for their illness, as chronic pain is often portrayed as psychological, rather than physiological (Werner et al., 2004, p.1043). For Charlotte, searching for a cause was not only about making sense of why she was affected by the illness; it was also an attempt to shift blame away from herself. Charlotte appealed to government and cancer agencies to promote a greater awareness of cancer-causing substances and to expand research on environmental contributors to breast cancer. The feelings of blame that Charlotte experienced illustrate a significant aspect of the coping process. In order to move beyond her breast cancer, she needed to understand and make other people understand that she was not accountable for her illness.

Another aspect related to making sense of breast cancer that was expressed by some of the participants in this study involved realizing new insights on life. In a sense, these women came to understand the illness experience as a positive experience. Consequently, breast cancer was depicted as a catalyst for personal growth, as it led to greater inner strength, increased focus on one's own needs, and an impetus to re-evaluate priorities and goals. The new insights on life that some women articulated

illustrate part of the coping process. As Charmaz (1999) describes, one aspect of coping with illness involves viewing the illness and oneself from a new perspective (p.78). While illness was unexpected and certainly unwanted, Judith and Sally came to see the positive impact that breast cancer had on their lives in order to make sense of it. Sarah also felt that her mother's illness gave her new perspective on her own life, as she realized the triviality of her everyday problems. This finding is comparable to other studies about illness experiences that indicate that illness prompts individuals to reflect upon their lives and adopt new values (Asbring, 2001; Kayser & Sormanti, 2002). The emergence of new insights on life as a result of the illness experience shows that some of the women saw it as an opportunity for personal growth which helped them to cope with the illness and its lasting effects.

The positive insights on life that were described by three of the mothers and daughters (Judith, Sally, and Sarah) indicate that these women may be adhering to culturally-prescribed illness narratives. As Frank (1995) proposes, individuals often frame their experiences as a "quest", in which illness is seen as a challenge and an impetus for change (cited in Thomas-MacLean, 2004, p.1649). Existing research on women with breast cancer proposes that this type of narrative, while utilized by some women with breast cancer, is commonly found in published accounts of breast cancer (Thomas-MacLean, p.1654). Thus, Judith and Sally may be drawing upon media portrayals of breast cancer in order to give meaning to their own illness experiences. It is interesting to note that Sarah framed parts of her experience of her mother's illness in the form of a quest narrative as well. Her experience demonstrates that her mother's breast cancer brought about changes in her outlook on life. The experiences of these three women demonstrate that they may have drawn upon culturally-prescribed illness narratives as a means of making sense of their illness, which was part of the coping process.

Another major aspect of the coping process involved assessing risk. Assessing risk was one aspect of coping with breast cancer that involved both mothers and daughters, as the possibility of recurrence and future diagnosis existed for each of them respectively. The continual fear of recurrence that many cancer survivors experience was described by Charlotte, who indicated that she will never feel free of cancer. Her

feelings reflect the uncertain position expressed by other cancer survivors, who emphasize that they live with “uncertainty, anxiety and heightened awareness of mortality” (McKenzie & Crouch, 2004, p.142). Despite having a double mastectomy, Charlotte was concerned that her cancer may have spread to other parts of her body. Judith also acknowledged that the possibility of recurrence was always in the back of her mind. Charlotte and Judith’s experiences demonstrate that some breast cancer survivors may have persistent worries regarding risk, as every ache or pain is a reminder of the possibility of recurrence. These mothers’ ongoing fear of recurrence illustrates one aspect of their biographies that was disrupted because of their illness (see Bury, 1982; Kenen et al., 2003). It is interesting to note that Diane did not express concern regarding recurrence, which is probably because this research occurred nineteen years after her diagnosis.

Daughters also shared concerns regarding their mother’s and their own future risk. While Darcy hoped that her mother was “*still okay*”, the daughters tended to focus on their own risk of breast cancer. Daughters expressed an explicit awareness of the fact that their mother’s breast cancer could place them at a higher risk. Their acknowledgement of risk is comparable to adult women caring for mothers with breast cancer, who felt that their mother’s diagnosis brought about major changes in their estimated risk (Raveis & Pretter, 2005, p.56). In order to cope with the new sense of vulnerability that they felt, the daughters I interviewed attempted to minimize the affect breast cancer had on their lives. Christine downplayed the likelihood of being at increased risk in comparison to other women, while Sarah indicated that vigilant self-examination would give her a better chance of survival if she were to get breast cancer. These comments, among others, make it evident that daughters wanted to minimize the extent to which their perceptions of risk interfered with everyday life. Although daughters may have felt more vulnerable to breast cancer because of their mothers’ experiences, they did not want to worry too much about something that could happen many years in the future. Daughters’ desire to minimize the affect that risk had on their lives relates to Kenen et al.’s (2003) claim that “women at high risk for developing breast/ovarian cancer do not necessarily spend *all* their time thinking about it” (emphasis added, p.316).

Although existing research indicates that women with a family history of breast cancer commonly overestimate their risk (Chalmers et al., 2003; Press et al., 2000; Rees et al., 2001), daughters' comments suggest that they did not perceive their risk to be greatly increased as a result of their mother's breast cancer. As Christine indicated, she felt her risk was ten percent greater than the average woman. Despite both her mother and grandmother being diagnosed with breast cancer, Jane related that she had not made an effort to find out her actual risk or make changes to her health behaviour. The lack of immediacy expressed by these daughters with regard to risk relates to a study by Sanders et al. (2003), which found that people with a first-degree relative with cancer felt that their relative's cancer was related to lifestyle factors rather than genetics (p.67). Applying this finding to the daughters in this study proposes that their efforts to downplay their risk could be associated with a belief that their mother's breast cancer was not inheritable. Thus, daughters' may feel that their risk can be minimized by healthy behaviour. This argument may also explain why daughters had not sought confirmation of their risk or looked into genetic testing. If daughters felt their mother's breast cancer was connected to lifestyle or environmental factors, genetic testing would not help them to diminish their risk.

Mothers also tried to determine the degree to which their daughters were at risk of getting breast cancer. The mothers all expressed concern for their daughters and wanted to ensure that they were aware of the potential threat breast cancer posed to them. As mentioned previously, mothers often attempted to determine the cause of their breast cancer in order to advise their daughters of possible risk factors. Despite making their daughters aware of potential risk, Judith and Charlotte attempted to minimize their daughters' perceived risk by drawing on information about genetic risk and the timing of their diagnosis. By doing so, mothers made an effort to diminish the psychological disruption that risk of breast cancer caused to their daughters. Thus, mothers appeared to ensure that their daughters were aware of their risk, at the same time as they tried not to exacerbate daughters' anxieties by emphasizing their increased risk.

While mothers and daughters did not seek an actual assessment of future risk, making changes to health behaviour was one way they coped with their potential risk. For example, Sarah discussed the importance of diet and exercise in minimizing risk of

breast cancer and Christine changed her type of birth control in order to decrease her risk. The changes made by some of the daughters in health behaviour were similar to the lifestyle practices emphasized by other women with a family history of breast/ovarian cancer (Kenen et al., 2003, p.323). In addition to becoming more active, mothers developed a greater awareness of their health in general. For instance, Sally became more pro-active about getting other tests done to confirm she was in good health. While Charlotte felt that she had not made health behaviour changes, she had a new awareness of the importance of good health. The ideas presented by mothers and daughters about health behaviour illustrate one aspect of their lives that was changed by the breast cancer experience. While not all of the women made changes in health behaviour, they became more aware of their health and gave it a higher priority than in the past.

### **5.3 Growth in Family Relationships**

The third major theme that emerged from the interviews pertained to growth in relationships. It was apparent that the breast cancer experience had a number of implications for mothers and daughters, their relationship, and their relationships with other family members. One noticeable outcome of the experience for daughters was the changes that occurred in their perceptions of their mother. This finding is comparable to Wellisch et al.'s (1996) claim that "daughters of breast cancer patients appear to [perceive] changes in their mothers after diagnosis and treatment of breast cancer" (p.280). In my study, all four daughters felt that breast cancer brought out their mother's inner strength. Although daughters may have viewed their mothers as strong in the past, they emphasized that their respect and admiration for their mother grew as a result of their mother's fortitude throughout the breast cancer experience. The acknowledgement by daughters of their mother's inner strength is significant because it identifies one way that daughters came to see their mothers differently than before their breast cancer diagnosis. In addition, this finding suggests that daughters may also attempt to present idealized versions of their mother's illness. As discussed previously, there is pressure on women to "reflect a positive image of self" in order to maintain dignity during illness (Werner et al., 2004, p.1037). Thus, the emphasis that daughters placed on their mother's strength during the illness experience may be evidence that daughters are trying to portray their mother's breast cancer experience in a positive light.

Another aspect of daughters' perceptions of their mothers that was influenced by the breast cancer experience involved becoming aware of their mothers' mortality. Specifically, daughters were forced to consider the possibility of losing their mothers and how life would be different if that happened. As a result of this realization, all four daughters came to understand the fragility of life and Christine became more protective of her mother. This change in daughters' perceptions was also found by a study of daughters whose mothers had breast cancer, in which daughters felt that the breast cancer diagnosis caused thoughts of losing their mother to arise prematurely (Raveis & Pretter, 2005, p.54). While children typically acknowledge the fact that their parents will die at some point, it is likely that these daughters had not considered that their mother's death could occur at this point in their lives. Age at diagnosis may well be an important factor in how daughters react to their mother's breast cancer. The older mothers grow, the more likely it is that their daughters become aware of their mortality and do not see illness as unexpected. Recognizing that daughters' perceptions of their mothers may be affected by the illness experience is important, as shifts in perceptions may contribute to changes in relationships.

Daughters expressed that the changes in their perceptions of their mothers led them to develop a greater appreciation for their mothers. The increased appreciation contributed to growth that occurred in the mother-daughter relationship. First, the illness experience illuminated that reciprocity was evident in two of the mother-daughter relationships (Judith and Jane, Charlotte and Christine). As described in the literature review, several studies on the mother-daughter relationship indicate that this relationship becomes increasingly interdependent as the daughter matures (Donorfio & Sheehan, 2001; Henman, 1997; Shawler, 2004; Spira & Kenemore, 2000). It was apparent that supporting their mothers during the breast cancer experience was an opportunity for daughters to demonstrate the interdependency in their relationship. For Christine in particular, her mother's breast cancer was her initial chance to reciprocate support to her mother. Christine's experience is similar to the experiences of other daughters of women with breast cancer, who felt that a shift took place during this time in which they found themselves in the unfamiliar role of support person (Raveis & Pretter, 2005, p.57). The

evidence of reciprocity in the mother-daughter relationship for two of the dyads demonstrates growth that took place as a result of illness.

Although the breast cancer experience provided daughters with an opportunity to reciprocate support to their mothers, it does not appear that this support was in exchange for support they had previously received. Prior research suggests that daughters take care of their mothers in order to “re-pay parents for the care they received when young” (see studies cited in Abel, 1999, p.159). While daughters in this study willingly provided their mothers with care and support, it does not appear that they did so in order to “re-pay” their mothers. In contrast, the illness experience put daughters in a position to show their mothers that they were able to reciprocate support. For mothers, being ill led them to realize that they could rely on their daughter’s support. Thus, the experiences of two of the mother-daughter dyads contrast with notion that support provision is merely repayment for past caregiving.

Another aspect of growth that occurred in the mother-daughter relationship involved the development of an intensified bond. While mothers and daughters believed that they had been close beforehand, the breast cancer experience led some mothers and daughters to express an increased sense of closeness. The intensified bonds between these mothers and daughters were the result of realizations they made because of the mother’s breast cancer. For instance, recognizing her mother’s mortality led Jane to appreciate her mother more and value the time they spent together. Christine felt that the illness experience caused her to realize how much her mother meant to her. Her mother, Charlotte, expressed an increased sense of closeness with her daughters because the care and support they provided her during her treatment demonstrated their love for her. This finding is comparable to other research in which mothers and daughters articulated an increased closeness because of the breast cancer experience (Raveis & Pretter, 2005; Walsh et al., 2005). The intensification of the mother-daughter bond during the breast cancer experience signifies a positive outcome that illness can have for families. While a sense of closeness existed prior to the illness experience, the mothers’ breast cancer had a number of implications for mothers and daughters which brought them closer together.

The breast cancer experience appeared to bring about growth in other family relationships as well. One daughter believed that her family members acquired a new



sense of caring and respect for one another as a result of the negative possibilities that illness brought up. Sarah indicated that her family members also had greater compassion toward her mother since her diagnosis. This growth that occurred within Sarah's family was the direct result of the illness experience. Having had health problems for some time before her breast cancer diagnosis, Sally's family saw her health complaints as a burden to the rest of them. Bury (1982) notes that it is difficult to gain recognition of illness when the symptoms are similar to those commonly experienced in society, such as aches and pains (p.170). Sally's breast cancer diagnosis provided her family with confirmation that her complaints were valid. The realization that their mother was legitimately ill led Sarah and her siblings to have greater respect and compassion for her. This example demonstrates that breast cancer had a definite influence on Sally and Sarah's family relationships.

Christine's relationships with her step-father and older sister were also affected by her mother's breast cancer. As a result of her mother's illness, Christine became more understanding of her step-father and aware of his feelings for her mother. It is likely that their mutual concern for her mother created common ground for Christine and her step-father. The growth that took place in this family relationship is indicative that both Christine and her step-father realized the possibility that they could lose Charlotte. The intensified bond that Christine had with her mother as a result of her illness probably contributed to the growth as well. Thus, the positive influence that illness had on Christine's relationship with her step-father is significant because it demonstrates how mutual concern for a family member can bring about greater care and understanding in family relationships. Christine's experience is also valuable because relationships between adult children and step-parents during times of illness appear to have gone unexplored. Therefore, future research is needed on step-parent-child relationships during illness experiences.

On the other hand, the illness experience can also be detrimental to family relationships. Christine and her sister disagreed about the extent to which they should offer their mother care and social support. Their disagreement created increased tension and has damaged their relationship in the long term. The negative effect that their mother's breast cancer had on Christine and her sister's relationship provides evidence

that children may have differing opinions of how they should support their ill parents. While Aronson (1994) found that some caregiving daughters and their brothers disagreed about the role that each should play in providing care, there is no mention of disputes between sisters regarding caregiving. The disagreement between Christine and her sister identifies that sisters may not share beliefs regarding filial responsibility and caregiving and, thus, must negotiate issues related to support provision with one another. The growth that Christine experienced as a result of her mother's breast cancer indicates that illness can have both positive and negative effects on family relationships.

#### **5.4 Conclusions and Implications**

The experiences of mothers with breast cancer demonstrate that the illness causes "biographical disruption", as women are forced to re-examine their everyday lives, expectations and plans for the future (Bury, 1982, p.169). While the ongoing physical effects that women experienced varied, the psycho-social implications the illness had are certainly evidence of biographical disruption. The processes involved in coping with breast cancer, such as making sense of the illness and assessing risk, indicate the need for women to integrate new ideas and beliefs into their self concept. For example, some of the women in this study identified having to incorporate fear of recurrence and risk of other illnesses into their conception of self. For some women, the illness experience brought about new insights on life, which helped them to see their lives in different ways. In this sense, the women experienced disruptions to their former selves and were required to re-examine their relationships with others and their expectations for the future. It is important to recognize that the degree to which women experience biographical disruption will vary depending on the extent to which their everyday lives are altered by breast cancer.

Breast cancer also constitutes biographical disruption for women diagnosed during middle-age. According to Pound et al. (1998), those in their 70s, 80s, 90s may be better prepared to deal with hardships such as illness (cited in Williams, 2000, p.51). It is also suggested that older people have "lower expectations of health and may anticipate illness as *inevitable* in old age" (emphasis in original, Ibid., p.51). The average age at time of diagnosis for the women in this study was 53 years old, placing the mothers in middle- or late middle-age. Consequently, women in this age group may feel that a

breast cancer diagnosis is unexpected and, therefore, they experience greater disruption to their lives because of it. Having to face the possibility of death earlier than expected required these women to re-examine their lives; specifically, who they are, what they do, and how they spend their time.

As a result of breast cancer, I found that families needed to re-organize roles and responsibilities during the mother's treatment. However this re-distribution of roles and responsibilities appeared to be temporary, as the mothers re-assumed most of their past duties once treatment was completed. For the most part, family members did not continue to perform the tasks they assumed during the mother's treatment because it became unnecessary. In this sense, the illness experience brought about changes in family roles and responsibilities that were episodic, rather than ongoing. Despite the fact that most family members returned to their past roles and responsibilities, some changes in families were evident. In particular, the changes that occurred during that time often had a lasting influence on family relationships.

Evidence of the growth in family relationships that occurred is demonstrated by the changes in perceptions that daughters had of their mothers. Daughters realized that their mother's inner strength allowed them to persevere during the cancer experience. Daughters also developed a greater appreciation for their mothers, as the breast cancer diagnosis led them to acknowledge that they could have lost her. These revelations contributed to growth in their relationships, sometimes in the form of increasing interdependence and an intensified bond with one another. Growth also occurred in relationships with other family members, which involved both positive and negative outcomes for family relationships. Building on the work of Bury (1982), the changes in family relationships that occurred provide evidence that, comparable to those with chronic illness, family members of ill individuals must also revise their expectations, relationships and plans for the future as a result of illness.

The potential threat that breast cancer posed to mothers caused disruptions for daughters in particular. As mentioned previously, recognizing their mothers' mortality prompted daughters to realize the fragility of life and develop greater appreciation for their mothers. Daughters saw the breast cancer diagnosis as unexpected and felt that the possibility of losing their mothers had come too soon. The realization of their mothers'

mortality also triggered thoughts regarding their own risk. Feeling at risk caused Sarah and Christine to make changes in their health behaviour and to become more aware of suspected causes of breast cancer. The idea that they might have an increased risk for the illness brought about changes in daughters, as they too experienced a threat to their present expectations and future plans. In this way, daughters were faced with “chronic risk”, meaning that they face an uncertain future, similar to their mothers (Kenen et al., 2003). Therefore, daughters’ worries regarding their own risk indicate one aspect of biographical disruption that they experienced. The daughters did and continue to negotiate their perceptions of risk of breast cancer with their previous outlook on life. The accommodation of this risk with time brought about varying degrees of change in the daughters’ lives. For instance, Jane and Sarah emphasized that they tried not to let their risk affect their everyday lives. The differing degree to which daughters were affected by their mother’s breast cancer corresponds with the argument put forth by Asbring (2000) that biographical disruption resulting from illness is often partial, rather than complete.

Although daughters had multiple responsibilities to fulfill already, they expressed a sense of filial responsibility that led them to play an important role in their mother’s illness experience. For example, Christine and Jane both had young children and were employed, but nonetheless provided significant social support to their mothers. Their experiences emphasize the need to recognize that feelings of filial responsibility may overshadow other responsibilities and personal needs, requiring daughters to balance their various commitments. In order to assist daughters in caring for their mothers, support should be available to them. Friends and other family members should be aware of the added responsibilities that daughters have assumed and try to offer their support. For example, assistance with childcare, household duties, and a flexible work schedule would benefit daughters. In conclusion, it is important to recognize that daughters who provide support to ill or aging parents may also benefit from support themselves, as it can help them balance their responsibilities.

Daughters are also in need of support services when it comes to assessing their own risk. While the daughters in this study had considered the possibility of being at increased risk of breast cancer, they had not sought confirmation of this. During their

mother's treatment, it is unlikely that daughters wish to determine their actual risk through genetic testing because their mother's well-being takes precedence. However, daughters should be provided with basic information about their likelihood of getting breast cancer based on personal characteristics and knowledge about hereditary breast cancer. For example, the daughters in this study who expressed concern about inheriting breast cancer were not aware that only five to ten percent of all breast cancer cases are hereditary (Armes & Venter, 2002; Bouchard et al., 2004; Chalmers et al., 2003; Press et al., 2000; Rees et al., 2001). This finding suggests that it would benefit daughters to meet with a health care professional who was familiar with their mother's breast cancer profile, research on genetic transmission of breast cancer, and genetic counselling options, as well as ways to decrease risk for breast cancer in general. The availability of this type of resource would allow daughters the opportunity to seek more information and help them to assess their actual risk. While daughters may talk to their own doctors about risk, it would be helpful to speak with someone who is familiar with their mother's profile and who specializes in breast cancer. Thus, informational support for daughters of women with breast cancer would be beneficial in helping daughters assess personal risk without having to decide if they wish to undergo genetic testing.

In summary, it is important to recognize that women with breast cancer and their daughters experience some degree of biographical disruption as a result of the illness experience. The preceding discussion demonstrates some of the aspects of women's lives that were affected by breast cancer. Specifically, families were required to redistribute roles and responsibilities during this time in order to fulfill duties left open by mothers and to provide her with care and social support. Three of the daughters in this study played a significant role in their mother's illness experience and took on new responsibilities as a result. In addition to negotiating new duties within the family, daughters discussed their need to balance their new and old responsibilities. Thus, three of the daughters' everyday lives were altered by their mother's breast cancer. The fourth daughter was not affected to the same extent because she was young at the time of her mother's diagnosis and initial treatment. However, other aspects of this daughter's life were influenced and shaped by her mother's cancer.

Throughout the interviews, I observed that coping with breast cancer introduced changes into mothers and daughters' lives, some of which are still being managed at the present. Although the coping process varied for each of the women, some common coping resources and strategies were utilized. For instance, all four mothers discussed the importance of maintaining optimism during and after the breast cancer experience. Another part of the coping process involved making sense of breast cancer, which the women did in two ways. Four of the mothers and daughters gave meaning to their illness by searching for a cause, while three of the women came to see their illness as the source of new insights on life. Another sub-theme related to coping with breast cancer that mothers and daughters broached was related to assessing risk. Two of the mothers expressed the precarious position of cancer survivors because of the constant risk they live with. It was apparent that daughters also faced uncertainty because of their mother's illness. In order to cope, mothers and daughters tried to understand the likelihood of future risk. In addition, four mothers and daughter made changes in their health behaviour in order to decrease their risk or better prepare them for fighting breast cancer. As a whole, this theme illustrates aspects of mothers and daughter's lives that were, and continue to be, altered by the breast cancer experience.

Finally, the changes that occurred because of shifts in family roles and responsibilities and coping with breast cancer affected the mothers and daughters' family relationships. Most apparent were the changes that occurred in daughters' perceptions of their mothers. While some of the daughters had viewed their mothers as strong in the past, all four of them expressed that the breast cancer experience brought out their mother's inner strength. At the same time, daughters were also faced with the possibility of losing their mother, something that had gone previously unconsidered. These changes in daughters' perceptions contributed to greater admiration and appreciation for their mothers. Growth also occurred in two of the mother-daughter relationships in the form of increased reciprocity and intensified bonds. These changes in the mother-daughter relationship demonstrate the positive influence that breast cancer had on their relationship. Lastly, growth also occurred in some of the mothers and daughters' family relationships. Sarah believed that her entire family had become more caring and respectful. Christine grew closer to her step-father during her mother's illness

experience, but became more distant from her sister. This theme is important because it demonstrates some of the effects that the breast cancer experience can have for family relationships. Specifically, shifts in family roles and responsibilities and issues related to coping that emerge during the illness experience may leave lasting impressions on family relationships.

### **5.5 Limitations, Strengths, and Recommendations**

In order to validate my findings, I now address some of the limitations and strengths of this study and suggest possibilities for further research. In particular, this study involved four mother-daughter dyads who were from the dominant group in society and were of middle class backgrounds. Their stories may share similarities with others who occupy comparable positions in our society's stratification system, but do not necessarily represent the multiplicity of backgrounds in our society. This possible discrepancy indicates a need to expand research on breast cancer and the family to include women from more diverse social backgrounds in order to determine whether their experiences differ. Although the participants occupied similar social positions, the study sample was varied because each family form was unique. Family forms included mothers who were: married, divorced, re-married, and experiencing marital difficulties at the time of diagnosis. Thus, the four mothers each brought a unique perspective to this research because of their differing family composition. The number of children in each family ranged from two to four. The participants also brought unique perspectives to this study because of the differences in location of residence and household composition. At the time of diagnosis, one dyad lived in the same city, 1 dyad lived in the city in the same house, 1 dyad lived in the same house in a rural town, and the fourth dyad lived within a few hours of each other. Each of the dyads had distinctive experiences with respect to negotiating the provision of social support. Further research might compare the experiences of mothers and daughters who live in rural areas with those who reside in urban centres. This comparison could identify whether location of residence influences the ways in which a mother's breast cancer affects her family. Lastly, the women each brought a unique perspective to the study because the time since diagnosis differed, as did the age of their daughters. Therefore, their experiences demonstrate that women have both similar and different concerns related to the time since their diagnosis.

It was also apparent that daughters concerns also varied according to their age and the length of time since their mother's diagnosis.

### **5.6 Methodological Reflections**

It is necessary to evaluate the methodological approach utilized in this study with respect to the conclusions I have drawn. First, feminist approaches to research focus on the experiences of women, which are thought to be distinct from men's (Harding, 1987; Olesen, 1998). In order to investigate issues related to breast cancer, women's experiences of breast cancer must be researched. In other words, a feminist approach suggests that being ill involves different things for women than it does for men. As noted in the above discussion, some of the women's stories appeared to be "self-idealized versions" (Werner et al., 2004), which emphasized the mothers' dignity during the illness experience in order to ensure adherence to cultural standards of femininity. This observation demonstrates that women may work to present a certain image of themselves during the breast cancer experience in order to avoid "the medical narrative about [women's] hysteria", which portrays women as "crazy, lazy, illness-fixed or weak" (Ibid., p.1043). While it is likely that men must also negotiate their illness with respect to cultural standards of masculinity, it is important to recognize that this is done differently because of the distinctive standards placed on women and men. Utilizing a feminist approach helped me to recognize aspects of women's illness experiences that were related to gender.

A feminist approach also helped me to identify aspects of women's experiences that reflect power differentials associated with gender. During the interviews, it was evident at times that the women struggle with certain ideas put forward by biomedical research, which is "developed from a predominantly white masculinist perspective" (Gustafson, 2005, p.266). Specifically, the idea that individuals "are personally responsible for [their] state of health" was difficult for women to make sense of given the ubiquity of cancer and the uncertainty of its cause(s) (Ibid, p.266). Charlotte's experience most noticeably reveals the oppression that women can be subjected to because of a breast cancer diagnosis. Her experience corresponds to the argument put forward by Rail and Beausoleil (2003) that "the focus on making healthy choices shifts responsibility from external to internal control where 'the desire to achieve health has



become a new form of corporal (self) control and guilt has become intimately tied to an individual's failure to achieve it" (p.3, cited in Gustafson, p.268). Specifically, Charlotte felt that she was being blamed for engaging in behaviour that caused her illness. Other feminist research on breast cancer also identified that women felt blamed for their illness, while environmental and other extracorporal causes were ignored (Yadlon, 1997, cited in Olesen, 2005, p.260-1). Utilizing a feminist approach aided me in recognizing that the women's experiences were often shaped by power differentials that privileged biomedical perspectives.

The outcome of the study confirmed the importance of researching individual experiences as a way of gaining a better understanding of social phenomena (Jansen & Roe Davis, 1998; Schwandt, 1998). It was evident that each of the women had a unique perspective to contribute to the study of breast cancer and the mother-daughter relationship. Their stories indicate that there were both similarities and differences from biomedical and media accounts of breast cancer. The focus on individual experiences also provided a better understanding of how families are affected by illness, which is one of the goals of interpretive research (Jansen & Roe Davis). Thus, the interpretivist approach's emphasis on "lived experience" (Schwandt; Van Manen, 1990) was beneficial in improving understanding of how mothers and daughters are affected by breast cancer.

Feminist-interpretive methodology also shaped the outcome of the study because it influenced the approach taken to the topic. Most significantly, the semi-structured, qualitative interviewing technique enabled participants to focus on what they saw as important to understanding their experiences. Data generation was a collaborative effort by the participants and me (Fontana & Frey, 2005). In that sense, the participants influenced the findings of the study. Despite this claim, I acknowledge that I made several decisions throughout the research process, including the interpretation of the data. However, I believe that my interpretation of the data is valid because of the thorough analysis process, as well as the inclusion of sufficient reflexivity (Mason, 2002; Olesen, 2005).

Finally, I must acknowledge that the findings of this study, while they do compare to much of the existing literature, cannot be thought of as representative of a

larger population (Mason, 2002). However, the findings of this study are still useful for a number of reasons. First, the themes emerging from this study provide a basis for future research on breast cancer and the mother-daughter relationship, as well as research on other illnesses in the family setting. Next, it is apparent that, although a small number of participants participated in this study, the selected themes illustrate many of the implications that a mother's breast cancer has for her and her daughter. In other words, the findings are evidence of possible ways that women can be affected by breast cancer. Finally, the thoroughness of the analysis process indicates that the findings are useful. As shown in chapter three, efforts were taken to ensure the accuracy of the data, as well as the validity of both the method and interpretation (Ibid., p.196). Therefore, the conclusion that mothers and daughters experience some degree of biographical disruption as a result of a mother's breast cancer is credible and could be used to shape health care practices and policies.

### **5.7 Conclusion**

In conclusion, the unique situations and backgrounds of the women in this study reveal a range of illness experiences which represent varying degrees of biographical disruption and re-configuration of the self. Using the work of Bury (1982), Asbring (2000), and Kenen et al. (2003) as a starting point, I have demonstrated that both mothers and daughters experience partial biographical disruption as a result of a mother's breast cancer. Evidence of partial biographical disruption is found in the effects that breast cancer has on family roles, responsibilities, and relationships. Thematic analysis of the interviews indicated that family roles and responsibilities were affected by the provision of social support during the mother's breast cancer treatment. Analysis also showed that coping with breast cancer involved attempts to make sense of breast cancer and negotiate future risk. This process required mothers and daughters to draw on personal strength, seek information on breast cancer, and make changes in health behaviour. Thirdly, the analysis of the interviews revealed that growth took place in family relationships because of the illness experience. The most evident changes that emerged from the interviews were in respect to daughters' perceptions of their mothers and the mother-daughter relationship. Some daughters also discussed growth in other family relationships being related to their mother's breast cancer. Finally, it is important

to recognize that the changes, realizations, and growth that occurred as a result of the illness experience were not always characterized as such in the interviews with mothers and daughters. The explanation for this lies in the fact that the shifts which occurred as a result of the illness experience have been incorporated into the self concept over time and, thus, go unnoticed when mothers and daughters reflect on their experiences. However, mothers and daughters' accounts illuminate many aspects of their lives that were affected by breast cancer. Therefore, the thesis that mothers and daughters experience biographical disruption to some extent as a result of the mother's breast cancer is substantiated by the thematic analysis of the stories that they shared. This research also demonstrates the importance and utility of a feminist-interpretive, qualitative approach to social research, as the approach was beneficial to understanding women's experiences.

## REFERENCES

- Abel, E.K. (1999). The caregivers' perspective. In *Health, illness, and healing: Society, social context, and self*, K. Charmaz & D.A. Paterniti (Eds.). Los Angeles: Roxbury Publishing Company, 150-164.
- Allen, K.R. & Walker, A.J. (1992). Attentive love: A feminist perspective on the caregiving of adult daughters. *Family Relations*, 41, 284-289.
- Armes, J.E. & Venter, D.J. (2002). The pathology of inherited breast cancer. *Pathology*, 34(4), 309-314.
- Aronson, J. (1994). Women's sense of responsibility for the care of old people: "But who else is going to do it?" In *Aging: Canadian Perspectives*, V. Marshall & B. Marshall (Eds.). Peterborough, ON: Broadview Press, 175-194.
- Aronson, K. (2003). Alcohol: A recently identified risk factor for breast cancer. *Canadian Medical Association Journal*, 68(9), 1147-1148.
- Arrington, M.I. (2005). "She's right behind me all the way": an analysis of prostate cancer narratives and changes in family relationships. *The Journal of Family Communication*, 5(2), 141-162.
- Asbring, P.(2000). Chronic illness- A disruption in life: Identity-transformation among women with chronic fatigue syndrome and fibromyalgia. *Journal of Advanced Nursing*, 34(3), 312-319.
- Balter Blume, L. & Blume, T.W. (2003). Toward a dialectical model of family gender discourse: Body, identity, and sexuality. *Journal of Marriage and Family*, 65, 785-794.
- Bloom, J.R. & Kessler, L. (1994). Emotional support following cancer: a test of the stigma and social activity hypotheses. *Journal of Health and Social Behaviour*, 35(2), 118-133.
- Bloom, J.R., Stewart, S.L., Johnston, M., Banks, P., & Fobair, P. (2001). Sources of support and the physical and mental well-being of young women with breast cancer. *Social Science & Medicine* 53, 1513-1524.
- Bolger, N., Foster, M., Vinokur, A.D., & Ng, R. (1996). Close relationships and adjustment to a life crisis: the case of breast cancer. *Journal of Personality and Social Psychology*, 70(2), 283-294.
- Borland, K. (1991). "That's not what I said": Interpretive conflict in oral narrative research. In *Women's words: the feminist practices of oral history*, S.B. Gluck & D. Patai (Eds.). New York: Routledge, 63-75.

- Bouchard, L., Blancquaert, I., Eisinger, F., Foulkes, W.D., Evans, G., Sobol, H., & Julian-Reynier, C. (2004). Prevention and genetic testing for breast cancer: variations in medical decision. *Social Science and Medicine*, 58(6), 1085-1096.
- Brewer, L. (2001). Gender socialization and the cultural construction of elder caregivers. *Journal of Aging Studies*, 15, 217-235.
- Bury, M. (1982). Chronic illness as biographical disruption. *Sociology of Health & Illness*, 4(2), 167-182.
- Bury, M. (2001). Illness narratives: fact or fiction? *Sociology of Health & Illness*, 23(3), 263-285.
- Canadian Cancer Society. (2006). Canadian Cancer Statistics 2006. Retrieved Oct. 19<sup>th</sup>, 2006, from [www.cancer.ca](http://www.cancer.ca)
- Chalmers, K., Marles, S., Tatrjn, D., Scott-Findlay, S., & Serfas K. (2003). Reports of information and support needs of daughters and sisters of women with breast cancer. *European Journal of Cancer Care*, 12(1), 81-90.
- Chapple, A., Ziebland, S., & McPherson, A. (2004). Stigma, shame, and blame experienced by patients with lung cancer: Qualitative study. *British Medical Journal*, 328(7454), 1470-1473.
- Charmaz, K. (1999). 'Discoveries' of self in illness. In *Health, illness, and healing: Society, social context, and self*, K. Charmaz & D.A. Paterniti (Eds.). Los Angeles: Roxbury Publishing Company, 72-82.
- Chesla, C.A. (2005). Nursing science and chronic illness: Articulating suffering and possibility in family life. *Journal of Family Nursing*, 11(4), 371-387.
- Compas, B. & Luecken, L. (2002). Psychological adjustment to breast cancer. *Current Directions in Psychological Science*, 11(3), 111-114.
- Donorfio, L.M. & Sheehan, N.W. (2001). Relationship dynamics between aging mothers and caregiving daughters: Filial expectations and responsibilities. *Journal of Adult development*, 8(1), 39-49.
- Dukes Holland, K. & Holahan, C.K. (2003). The relation of social support and coping to positive adaptation to breast cancer. *Psychology and Health*, 18(1), 15-29.
- Dunn, J. & Steginga, S.K. (2000). Young women's experience of breast cancer: defining young and identifying concerns. *Psycho-Oncology*, 9, 137-146.

- Elmberger, E., Bolund, C., & Lutzen, K. (2000). Transforming the exhausting to energizing process of being a good parent in the face of cancer. *Health Care for Women International*, 21, 485-499.
- Ferrell, B.R., Smith, S.L., Ervin, K.S., Itano, J., & Melancon, C. (2003). A qualitative analysis of social concerns of women with ovarian cancer. *Psycho-Oncology*, 12, 647-663.
- Fontana, A. & Frey, J.H. (2005). The interview: From neutral stance to political involvement. In *The SAGE Handbook of Qualitative Research*, N.K. Denzin & Y.S. Lincoln (Eds.). Thousand Oaks: Sage Publications, 695-727.
- Forrest, G., Plumb, C., Ziebland, S., & Stein, A. (2006). Breast cancer in the family- Children's perceptions of their mother's cancer and its initial treatment: Qualitative study. *BMJ: Online First*, April 13<sup>th</sup>, 2006, doi:10.1135/bmj.38793.567801.AE
- Fox, B. & Luxton, M. (2001). Conceptualizing family. In *Family Patterns, Gender Relations*, 2<sup>nd</sup> ed., B. Fox (Ed.), Ontario: Oxford University Press, 22-33.
- Frank, A. (2000). The standpoint of storyteller. *Qualitative Health Research*, 10(3), 354-365.
- Frank, A. (2002). Why study people's stories? The dialogical ethics of narrative analysis. *International Journal of Qualitative Methods*, 1(1), Article 6. Retrieved Sept. 9<sup>th</sup>, 2006, from <http://www.ualberta.ca/~ijqm/>
- Germino, B.B. & Funk, S.G. (1993). Impact of a parent's cancer on adult children: role and relationship issues. *Seminars in Oncology Nursing*, 9(2), 101-106.
- Gustafson, D.L. (2005). Understanding women and health. In *Feminist Issues: Race, Class, and Sexuality*, 4<sup>th</sup> ed., N. Mandell (Ed.), Toronto: Pearson Prentice Hall, 266-286.
- Hallowell, N., Foster, C., Eeles, R., Ardern-Jones, A., & Watson, M. (2004). Accommodating risk: Responses to BRCA1/2 genetic testing of women who have had cancer. *Social Science & Medicine*, 59, 553-565.
- Harding, S. (1987). *Feminism and methodology: Social science issues*. Bloomington, IN: Indiana University Press.
- Henman, K.L. (1997). Adult mother-daughter relationships: Two phases in the analysis of a qualitative project. *Feminism & Psychology*, 7(2), 255-263.
- Hockey, J. & James, A. (2003). *Social identities across the life course*. New York: Palgrave Macmillan.

- Holmberg, S.K., Scott, L.L., Alexy, W., & Fife, B.L. (2001). Relationship issues of women with breast cancer. *Cancer Nursing*, 24(1), 53-60.
- Jansen, G.G. & Roe Davis, D. (1998). Honouring voice and visibility: Sensitive-topic research and feminist interpretive inquiry. *Affilia: Journal of Women and Social Work*, 13(3), 289-299.
- Kasper, A.S. (1994). A feminist, qualitative methodology: A study of women with breast cancer. *Qualitative Sociology*, 17(3), 263-281.
- Kayser, K. & Sormanti, M. (2002). Identity and the illness experience: issues faced by mothers with cancer. *Illness, Crisis & Loss*, 10(1), 10-26.
- Kenen, R., Ardern-Jones, A., Eeles, R. (2003). Living with chronic risk: healthy women with a family history of breast/ovarian cancer. *Health, Risk & Society*, 5(3), 315-331.
- Lowenstein, A. (2003). Contemporary later-life family transitions: revisiting theoretical perspectives on aging and the family. In *The Need for Theory: Critical Approaches to Social Gerontology*, S. Biggs, A. Lowenstein, & J. Hendricks (Eds.). New York: Baywood Publishing Company, Inc., 105-125.
- Luoma, M.L. & Hakamies-Blomqvist, L. (2004). The meaning of quality of life in patients being treated for advanced breast cancer: a qualitative study. *Psycho-Oncology*, 13, 729-739.
- Mason, J. (2002). *Qualitative researching*, 2<sup>nd</sup> ed. Thousand Oaks, CA: Sage Publications, Inc.
- Marx Ferree, M. (1990). Beyond separate spheres: feminism and family research. *Journal of Marriage and the Family*, 52, 866-884.
- McKenzie, H. & Crouch, M. (2004). Discordant feelings in the lifeworld of cancer survivors. *health: An Interdisciplinary Journal for the Social Study of Health, Illness and Medicine*, 8(2), 139-157.
- Northouse, L.L. (1995). The impact of cancer in women on the family, *Cancer Practice*, 3(3), 134-142.
- Olesen, V.L. (1998). Feminisms and models of qualitative research. In *The landscape of qualitative research*, N.K. Denzin & Y.S. Lincoln (Eds.). Thousand Oaks, CA: Sage Publications, Inc., 330-332.
- Olesen, V.L. (2005). Early millennial feminist qualitative research. In *The SAGE handbook of qualitative research*, N.K. Denzin & Y.S. Lincoln (Eds.). Thousand Oaks: Sage Publications, 235-278.

- Petersen, L., Kruezek, T., & Shaffner, A. (2003). Gender roles and the family life cycle: the case of women with cancer. *Journal of Feminist Family Therapy*, 15(2/3), 99-119.
- Pierret, J. (2003). The illness experience: State of knowledge and perspectives for research. *Sociology of Health & Illness*, 25(Silver Anniversary Issue), 4-22.
- Press, N., Fishman, J.R., & Koenig, B.A. (2000). Collective fear, individualized risk: The social and cultural context of genetic testing for breast cancer. *Nursing Ethics*, 7(3), 237-249.
- Punch, M. (1998). Politics and ethics in qualitative research. In *The landscape of qualitative research*, N.K. Denzin & Y.S. Lincoln (Eds.). Thousand Oaks, CA: Sage Publications, Inc., 156-184.
- Raveis, V.H. & Pretter, S. (2005). Existential plight of adult daughters following their mother's breast cancer diagnosis. *Psycho-Oncology*, 14, 49-60.
- Rees, G., Fry, A., & Cull, A. (2001). A family history of breast cancer: women's experiences from a theoretical perspective. *Social Science and Medicine*, 52(9), 1433-1440.
- Reinharz, S. (1992). *Feminist methods in social research*. New York: Oxford University Press.
- Remennick, L.I. (1998). Living with cancer: A patient perspective. *Current Sociology*, 46(1), 115-127.
- Roberts, C.S., Baile, W.F., & Bassett, J.D. (1999). When the care giver needs care. *Social Work in Health Care*, 30(2), 65-80.
- Rosenthal, C.J. & Gladstone, J. (1994). Family relationships and support in later life. In *Aging: Canadian Perspectives*, V. Marshall & B. Marshall (Eds.). Peterborough, ON: Broadview Press, 158-174.
- Sanders, T., Campbell, R., Sharp, D., & Donovan, J. (2003). Risk constructions among people who have a first-degree relative with cancer. *Health, Risk & Society*, 5(1), 53-69.
- Schwandt, T.A. (1998). Constructivist, interpretivist approaches to human inquiry. In *The landscape of qualitative research*, N.K. Denzin & Y.S. Lincoln (Eds.). Thousand Oaks, CA: Sage Publications, Inc., 221-259.
- Shawler, C. (2004). Aging mothers and daughters: Relationship changes over time. *Ageing International*, 29(2), 149-177.



- Silverman, D. (2001). *Interpreting qualitative data: Methods for analysing talk, text and interaction*, 2<sup>nd</sup> ed. Thousand Oaks, CA: Sage Publications, Inc.
- Spira, M. & Kenemore, E. (2000). Adolescent daughters of mothers with breast cancer: impact and implications. *Clinical Social Work Journal*, 28(2), 183-195.
- Spira, M. & Kenemore, E. (2002). Cancer as a life transition: A relational approach to cancer wellness in women. *Clinical Social Work Journal*, 30(2), 173-186.
- Steinglass, P. (2000). Family processes and chronic illness. In *Cancer and the family*, 2<sup>nd</sup> ed., L. Baider, C.L. Cooper, & A. Kaplan De-Nour (Eds.), John Wiley & Sons, Ltd., 3-15.
- Thoits, P.A. (1995). Stress, coping, and social support processes: Where are we? what next? *Journal of Health and Social Behaviour*, Extra Issue, 53-79.
- Thomas-MacLean, R. (2004). Understanding breast cancer stories via Frank's narrative types. *Social Science & Medicine*, 58, 1647-1657.
- Thompson, L. (1992). Feminist methodology for family studies. *Journal of Marriage and the Family*, 54(1), 3-18.
- Turner, B.S. (1987). *Medical power and social knowledge*. London: Sage Publications.
- van den Hoonaard, W. (2002). *Walking the tightrope*. Toronto: University of Toronto Press.
- van Manen, M. (1990). *Researching lived experience: human science for an action sensitive pedagogy*. London, ON: Althouse Press.
- Walsh, S.R., Manuel, J.C., & Avis, N.E. (2005). The impact of breast cancer on younger women's relationships with their partner and children. *Families, Systems, & Health*, 23(1), 80-93.
- Werner, A., Isaksen, L.W., & Malterud, K. (2004). 'I am not the kind of woman who complains of everything': Illness stories on self and shame in women with chronic pain. *Social Science & Medicine*, 59, 1035-1045.
- Williams, S.J. (2000). Chronic illness as biographical disruption or biographical disruption as chronic illness? Reflections on a core concept. *Sociology of Health & Illness*, 22(1), 40-67.
- Wellisch, D.K., Schains, W., Gritz, E.R., Wand, H. (1996). Psychological functioning of daughters of breast cancer patients. Part III: Experiences and perceptions of daughters related to mother's breast cancer. *Psycho-Oncology*, 5, 271-281.

## APPENDIX A: CONSENT FORM

**Researchers:** Dr. R. Thomas-MacLean, Department of Sociology, University of Saskatchewan, (306) 966-1489  
Meridith Burles, Department of Sociology, University of Saskatchewan,  
(306) 665-1314

**Purpose and Procedure:** The purpose of this study is to explore the impacts a mother's experience of breast cancer has on the mother-daughter relationship and any changes that occur in family roles and relationships. In order to do so, tape-recorded interviews with mothers and daughters will be carried out. These interviews will allow for the identification of how mothers and daughters feel that the breast cancer experience has changed their relationship. Interviews will last approximately 60 to 90 minutes, and each participant will be asked to take part in 2 interviews in total (1 with both mother and daughter, and 1 separately). The total time commitment will be approximately 2 to 3 hours. The two interviews will take place a few weeks apart to allow for further reflection by the participants.

**Potential Risks and Benefits:** This study poses no known risks or benefits to participants. Being a part of this study may help to increase the understanding of women's experiences of breast cancer and its impact on family and mother-daughter relationships. If anything discussed in the interviews is upsetting, information on local breast cancer support groups is available.

**Storage of Data:** All information collected for this study, including tapes and transcripts of interviews and contact information, will be stored in a locked filing cabinet by Dr. R. Thomas-MacLean at the University of Saskatchewan for a minimum of five years after the study is completed.

**Confidentiality:** The findings of this study will be used as the basis for a Master's thesis, as well as in reports to support groups, conference presentations or academic journal articles; however, your identity will be kept confidential. Although direct quotations from the interview will be reported, you will be given a pseudonym, and all identifying information will be removed from the report. After your interview, and prior to the data being included in the final report, you will be given the opportunity to review the transcript of your interview, and to add, alter, or delete information from the transcripts as you see fit.

**Right to Withdraw:** Your participation is voluntary, and you may withdraw from the study for any reason, at any time, without penalty of any sort. As well, you may refuse to answer any questions which you do not feel comfortable with. If you do choose to withdraw from the study, any data you have contributed will be destroyed at your request.

If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researchers at the numbers provided if you have questions at

a later time. Please do not hesitate to contact the researchers with any questions about the research or results.

You can contact either: Dr. R. Thomas-MacLean, Department of Sociology, 9 Campus Drive, University of Saskatchewan, S7N 5A5, Phone: (306) 966-1489 or Meridith Burles, Department of Sociology, 9 Campus Drive, University of Saskatchewan, S7N 5A5, Phone: (306) 665-1314. This study has been approved on ethical grounds by the University of Saskatchewan Behavioural Research Ethics Board on (insert date). Any questions regarding your rights as a participant may be addressed to that committee through the Ethics Office (306) 966-2084. Out of town participants may call collect.

I have read and understood the description provided above; I have been provided with an opportunity to ask questions and my questions have been answered satisfactorily. I consent to participate in the study described above, understanding that I may withdraw consent at any time. A copy of this consent form has been given to me for my records.

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(Name of Participant)

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(Date)

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(Signature of Participant)  
Researcher)

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(Signature of

## APPENDIX B: INITIAL INTERVIEW GUIDE

### Introduction and Explanation of the study

- Description of study: interested in the social impact of breast cancer on the mother-daughter relationship with a focus on how family roles and relationships are affected by the illness.
- Explain consent form, pseudonyms will be used for confidentiality.
- Explain questions will be open-ended with no right answer.
- Feel free to ask questions and answer which ever questions you feel are relevant.
- Mention that I might take notes to remind myself of things to bring up later.

### Brief social and personal characteristics

Can you tell me a bit about your breast cancer experience?

How long has it been since your diagnosis?

Can you tell me a bit about your family composition? (the members of your family?) who makes up your family? (does daughter have children, etc.?)

Is your family spread out or do they all reside in the same area?

### Possible Questions

#### *Family Roles and Relationships*

1A Can you tell me about the relationships within your family?

-Can you tell me about your relationship with each other specifically?

What types of changes do you feel have occurred since your diagnosis?

Can you tell me about roles within your family?

-What were family roles like before your diagnosis?

Do you feel there have been changes in who assumes what role within the family since your breast cancer experience?

-Has daughter taken on any new roles as a result?

1B During or since the breast cancer experience, do you feel that your daughter has provided care for you?

-What type of activities did this involve? Or What type of activities do you believe can be labelled 'caregiving'?

-Do you feel that your daughter/you were in a position to provide care? (geographically, practically?)

-What kind of responsibility did you feel for providing your mother with care?

-Was assuming a caregiving role a natural occurrence? Or did it require some negotiation between mother and daughter?

Do you feel that you switched family roles at any time during the breast cancer experience?

-In what ways were roles switched or different than before?

-Do you feel that they have remained this way, or have they returned to the way they were before the breast cancer experience?

How would you say that role changes which resulted from the breast cancer experience have impacted your relationship?

1D Before the breast cancer experience, what are some of the ways you offered your daughter social support? (childcare, emotional support, instrumental/ financial support, etc.)

-How have the ways you offer social support to your daughter changed since the breast cancer experience?

1C If care was provided, how did you deal with care provision as well as your own responsibilities? (work, family, etc).

-How has caring for your mother affected your roles and responsibilities in your own family?

-Do you find they have changed? Did they only change during the breast cancer experience?

-How has this affected your roles or responsibilities with regards to work or school?

-Do you find they have changed?

1F How do you think that your illness (your mother's illness) has impacted your family?

-Have there been any changes to the way your family functions?

How would you say your family member's responsibilities have changed since your breast cancer experience?

-Can you give me an example?

1G During your breast cancer experience, did you find that you needed to rely on others more so than in the past?

-How did you feel about this?

Would you say that previous to the breast cancer experience, you/ your mother were the member of the family that others relied?

-How has that changed?

-Can you tell me how you reacted to this shift?

-Did it take a while to adjust to? Was it difficult to get used to?

1H Has your experience of breast cancer resulted in a change in what you can and cannot do?

-What are some examples of this?

Once treatment was completed, did you return to your previous roles and responsibilities?

-Within the family?

-Outside the family?

### *Social Support*

3A/D During your illness experience, did you receive social support?

-What are some of the sources of this social support? (i.e. people or places)

What are some of the ways in which you were offered support?

-Can you give me some specific examples?

Do you feel that social support was readily available to you/ your mother during your breast cancer experience?

-Why is it that you think that?

Do you feel that social support continues to be available to you?

From what source or sources do you feel support was most available? Family, friends, work, medical system?

-Why do you feel this way?

Do you feel like your support needs were met?

-Can you give me an example?

What importance do you place on social support in the completion of your treatment for breast cancer?

-What kind of differences did it make?

3B Do you think that different people offered support in different ways?

-Can you give some examples of this?

Do you feel that some people are more able to offer social support than others?

-emotional? -instrumental (availability, financial well-being, etc.)?

-informational?

Why do you think that there are sometimes differences in the types of support people offer?

3C Were there particular people that you feel played important roles in your breast cancer experience because of the social support they offered?

-Why do you think they were so important?

-Do you feel that their support was helpful in your adjustment to and survival of breast cancer?

-Can you give me a specific example of how it may have helped your adjustment?

Do you feel that having a good support network makes a difference to women with breast cancer?

-What factors make up a good support network?

-In what ways is a good network important?

#### *Risk and Health Behaviour*

Mother: Do you feel that your daughter or other female relatives are at risk of getting breast cancer?

-Why do you feel this way?

-Is this because of your own experience?

Do you feel that it is hereditary (breast cancer runs in the family) or that it is because of similar body types or health behaviour?

-Can you give some examples?

Daughter: Do you feel you are at risk of getting breast cancer?

-What are the reasons for this?

-genetic inheritance? – similarities in body composition? –health behaviour?

Have you made an effort to learn more about your risk of breast cancer?

-Can you give me an example?

Both: Have there been any changes in your health behaviour since your breast cancer experience? –exercise, nutrition, etc.

-Do you feel that health behaviour or lifestyle plays a role in getting breast cancer?

-What do you feel is the role of genetics in getting breast cancer? (was it inherited?)

-Do you think that any changes you have made in health behaviour are because of the influence of each other?

Do you feel more aware of your health than before you had breast cancer?

-How has this awareness impacted your health behaviour or resulted in changes to your life?

#### *Other thoughts on discussion or changes in family relationships*

-ask for other stories, expansion on what was talked about, things that haven't been mentioned, other things that play a role in the experience, etc.

-Thank you for your participation and time!