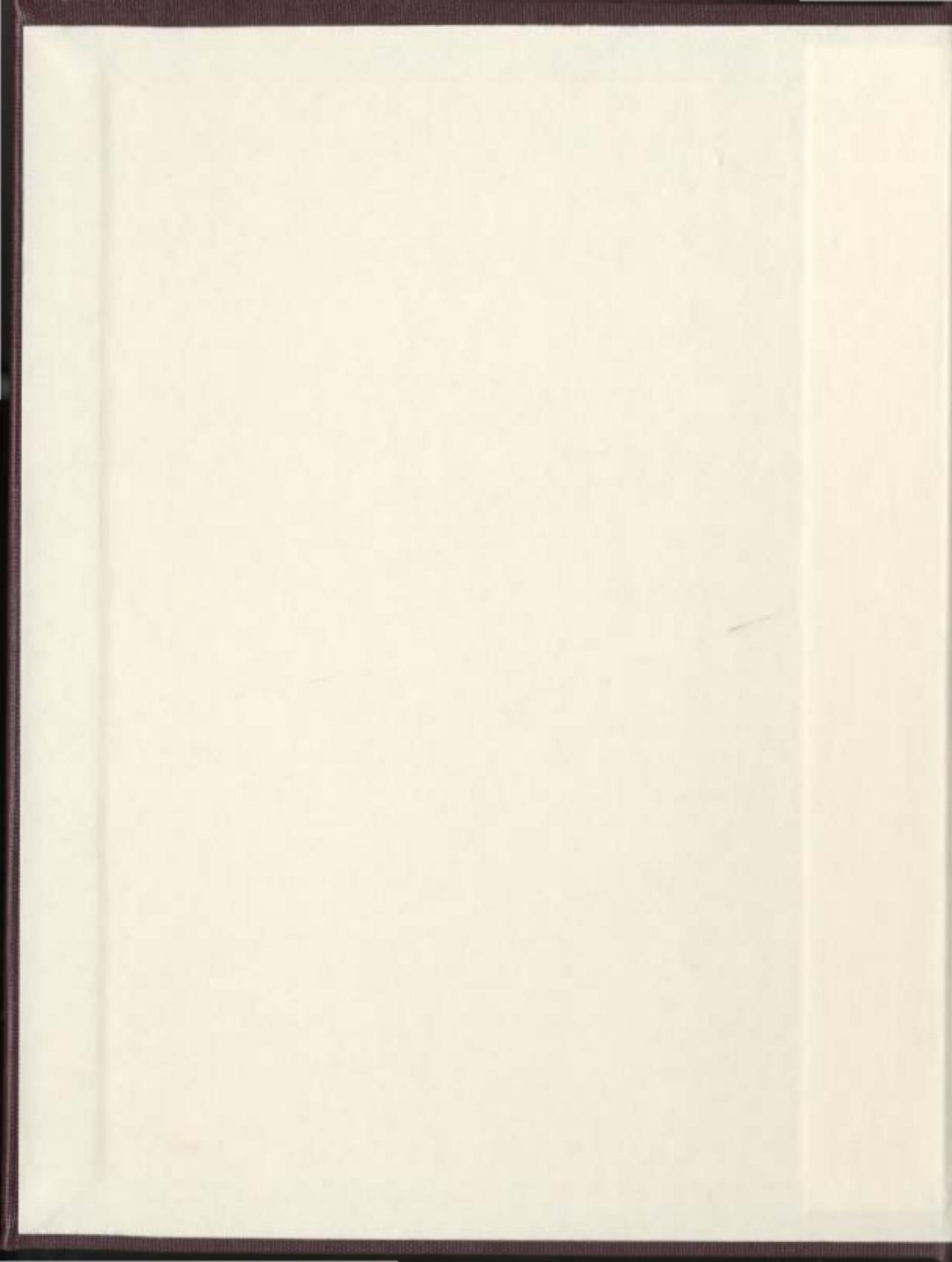# DAUGHTERS' NARRATIVES OF MOTHERS' LIFE THREATENING ILLNESS

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DAUGHTERS' NARRATIVES

OF MOTHERS' LIFE THREATENING ILLNESS

By

©Kimberly Adrienne Bonia

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Abstract

This qualitative study investigates the narratives of six women from an urban area of Newfoundland whose mothers have life threatening illnesses. Using individual and focus group interviews, the purpose of the study is to explore the impact of mothers' illness on the mother-daughter relationship. Interviews were audio taped, transcribed, and analyzed using Mauthner and Doucet's (1998) voice-centred relational analysis. The women's narratives reveal that their relationship with their mothers during the illness is influenced by their relationship before the illness. Feelings of needing to provide support, understanding, and care for their mothers as well as the impact on the daughter's relationships with other family members are discussed. The results indicate that the daughters are concerned with issues of caregiving as it relates to issues of gender, pressures, homecare, and access to services and policies. I also found that although the women in my study indicated that they are familiar with the symptoms of their mother's illness and would be able to detect symptoms in themselves, they are not overly concerned with developing the illness themselves. This study provides a unique view of the impact of illness on the mother-daughter relationship because it is reflexive in nature. I share my own experiences as a daughter of a mother with a life threatening illness. My study begins to fill the gap in literature on the impact of a mother's life threatening illness on the social and economic lives of daughters, the changing definition of life threatening illness, and the similar experiences of caregiving across different types of illnesses. . My research also demonstrates the need for gender-based analysis of health policies and benefit programs relating to the support given to caregivers.

To the women who shared
personal stories
of their relationships with their mothers.

To my mother,
who has inspired me
through her
determination, strength,
and accomplishments.

I would also like to dedicate this work
to the memory of Shaina M.Glassman (1983-2007).
Shaina has opened my eyes
to the meaning of care and compassion.

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Chapter One: Introduction

1.1 Purpose and Overview

The purpose of my study is to understand the impact of a mother's life

threatening illness on the life of her daughter. The focus is on daughters' perspectives

and experiences in their relationship with their mothers, the impact of a life

threatening illness on the relationship, and daughters' concerns for their own health.

My study takes a collaborative feminist narrative approach in data collection

and analysis. Collaboration between the participants and myself produced knowledge

through critical reflection and mutual discussion. Through collaborating with the

women in my study, there was a shift in position of power (usually held by the

researcher), which empowered the women and directly involved them in the telling of

their stories, the construction of themes, and the value of their experiences and

knowledge (Gustafson, 2000). Drawing on the work of Charmaz (1995, 2000) this

research assumes three things: a) multiple realities exist, b) the researcher and

participant mutually construct the narrative, and c) the researcher journeys with and

enters into the experience of suffering, loss, and transcendence with the daughter

facing her mother's life threatening illness. The study explores how participants

construct meaning from their own realities within time, place, social context, culture,

religion, ethnicity, and circumstances. Each narrative was co-constructed by the

participant and me as both were affected by the other. The final result is one

interpretation of a reality rather than an exact truth (Charmaz, 1995, 2000; Guba &

Lincoln, 1994; Mathieson, 1999; Schwandt, 1994). A collaborative understanding,

involving the exchange of stories and experiences, between the participant and myself, develops the richness of the narrative (Ellis & Berger, 2002).

Humm (1989) reports that feminist methodology is useful in describing and improving the everyday lives of women. Feminist researchers use narrative as an opportunity to bring women into the co-construction of their life stories in order to provide a view of private experiences in the larger context of the social world. Although many women may consciously construct versions of their own life stories without the involvement of a researcher, researchers bring the narrative from private to public.

Rosenthal (1993) makes the distinction between *life history* and *life story* by clarifying that *life history* is the actual experience of the events. In contrast, the *life story* is the share construction and interpretation of the life history. Through the use of narrative women are able to convey the reality and understanding of their experiences. In this research, a narrative approach was used to communicate how daughters perceived and made sense of their relationship with their mothers and illness experience at a given point in time. This is neither the exact truth nor fiction. It is a personal view of how the women understand and construct meaning in their lives (Bailey, 2001; Brody 2003; Murray, 1999; Ricoeur, 1981; Wengraf, 2001).

Narratives may provide an understanding of the illness experience in the relationships of those surrounding the ill person (Thomas-MacLean, 2004). The illness and suffering may not be explainable, but through the sharing of stories the experience may become understandable (Charmaz, 1999; Schweizer, 1995). This study includes narratives about the relationship between mother and daughter, illness, and concern for the daughter's own health. I also include my own narrative in an

attempt to reflexively bring together the experiences told by the women in my study and to deepen my understanding of my own story and experiences. Ellis and Bochner (2000) state that with the reflection of one's own story, the researcher can then begin to understand the experiences of others.

The daughter's interviews and focus group narratives were analyzed through Mauthner and Doucet's (1998) voice-centred relational method. This voice-centred method was used in striving to keep the women's voices and perspectives in focus while recognizing my own role in shaping the research and its final outcome.

1.2 Rationale and Relevance of Study Problem

In particular, my research examines the daughters' perspectives of the mothers' experience of life threatening illness and the impact it has on the daughter's lives and relationships with others. My study provides an account of family dynamics during a life threatening illness, from the specific standpoint of the daughter. Therefore, my research explores daughters' narratives of their mother's illness. There is a need for future research in gender-based analysis on health policies and benefit programs; my research demonstrated this gap in gender equality. My research provides an understanding of how a life threatening illness shapes a daughter's relationship with her mother and her own life, society's influence on private lives, the relationship between one's private and public worlds when faced with a seriously ill mother. The stories told by myself and participants are meant to build meaning and understanding of experiences.

1.3 My Personal Narrative of My Mother's Illness and Our Relationship

As I sit here writing, my mother is probably in her physiotherapy session at the rehabilitation unit at a local hospital. Although I know she is in capable hands and there is 24 hour nursing care at the hospital I somehow feel guilty in being here and not at her side. Again my mother is hospitalized, but this time it is more serious. When she arrived at the emergency room my mother's physician admitted she was "on death's door."

Illness has always been a part of my mother's life and consequently a part of my life. My mother was diagnosed with Type I diabetes at the age of four and has been dependent on insulin injections since then. As a child, she was also diagnosed with asthma. In 1992, at the age of 40 my mother was diagnosed with multiple sclerosis (MS). All three major illnesses have caused life threatening and debilitating complications throughout my mother's life including a tracheotomy, a heart attack, eye hemorrhages, chronic pain, nerve damage, and digestive problems.

Looking back at my childhood, I now realize that my life was different from that of other children because of my mother's illnesses. I sometimes resented my mother because she was ill and we could not do many of the things other mothers and daughters would do. For example, my mother and I did not go shopping or to restaurants as some of my friends did with their mothers. I sometimes felt jealous of my mother because all of the attention would be on her and her illnesses. So, although my relationship with my mother was close we often argued because of my feelings of resentment and jealousy. I also behaved and acted selfishly to get attention.

As I matured and entered my 20's, I realized that my mother's illness had a major impact on our relationship throughout my childhood and teenage years. I

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understood that nobody was at fault for the situation. It was during this time, I was able to reflect on our relationship when my mother had a life threatening experience.

I can still feel the weight of emotion pushing on my chest. I can feel the stillness, the sense of being alone, and the fear. I remember the tears, uncontrollable tears that fell, not being able to catch my breath, and the fear of losing my mother. I also remember the guilt of having just returned from a March break road trip adventure to Maine with a friend. We had laughed, joked, sang along with the radio, stopped at shopping malls and restaurants. Unbeknownst to me, at the all same time my mother was in indescribable pain. She was suffering while I was playing and enjoying life. And still as my father broke the news to me over the telephone, "Kim, your mom had a heart attack today," I was unable to do anything. I was in another province, miles away. I was not even able to speak with her to tell her to be strong and that I loved her. That night I did not sleep. I cried. In between sobs, I prayed. I am not an overly religious person, but during this time I turned to God and asked him to send strength to my mother because I still needed her. I was 22 years old and I still needed my mom.

In September of 2005, as I was planning the second focus group for this study, my mother was once again hospitalized. She had been nauseated, vomiting, and experiencing back pain for several days before my father and I decided to take her to the emergency room. The emergency room doctors decided to give her intravenous fluids to prevent dehydration, anti-nausea medication, morphine for the pain, and subsequently, she was sent home. After another two weeks of caring for my mother, doctor appointments and telephone calls, her condition had not improved. We decided to take her to the emergency room once again. This time, she was admitted to the

hospital. My mother was in serious condition without having eaten for almost 30 days. The side effects from the medications caused my mother to sleep most of the day and have hallucinations when she was awake. The three of us discussed memorial arrangements and decided to donate my mother's body to medical science. My mother had expressed her wish to die; she was in severe pain and wanted the doctors to leave her alone.

As I sat next to my mother's bed and held her hand I watched her chest rise and fall. I saw my own face in hers. I noticed our similar cheek bones and thought of times when strangers would say, "You look just like your mother." My mother would joke and say, "Oh, the poor girl." But as I sat next to my mother in her hospital room, I was proud to be her daughter. I wanted to be just like my mother; I felt a bond with her that day. I felt honored to be just like the strong, determined, brave woman who lay before me. My mother opened her eyes and looked at me. I told her "Mom, I want you to know it's okay for you to let go. You have been through enough and it's okay for you to go now. I love you." I held her hand and a tear ran down my face. She whispered, "Thank you."

A few months later, I sit in front of my computer while my mother is at her daily physiotherapy session at the unit of the rehabilitation hospital. I feel guilt for not being there with her as she learns to stand and walk again. I feel guilt for not being able to make everything alright. I feel anger, but I am not exactly sure who or what is to blame. Anger because she is too young, at 53, to be at a rehabilitation unit learning to walk again, wearing a pull up for incontinence, needing help to feed herself, get dressed, go to the washroom, or wash her face. I feel anger because of what it has done to her life, but I also feel angry about what it has done to my life. Caring for my

mother and our relationship has had an impact on decisions in my life including education and career paths and in my relationships with others.

Neufeld and Harrison (1995) found that some women describe caring for a family member as a responsibility, a duty, or an obligation. I do not like to use such terms to describe how I feel about caring for my mother because I denote negative associations of feeling burdened by her need for care. I describe caring for my mother as a bond or caring relationship. It is not something that I am forced to do but something I enjoy doing. Although there are many days when we both feel frustrated and angry about everyday activities and the impact it has had on life decisions, I understand that caring for my mother has influenced who I am today. The rewards are felt in the closeness of our caring relationship. I admire my mother's strength and determination and I accept those traits I have learned from her.

1.4 Research Question and Objectives

The objective of my study was to examine the narratives of women whose mothers are living with a life threatening illness. The main goals of my study were:

a) to examine the daughter's perspectives and experiences in the mother-daughter relationship;

b) to explore the impact of a mother's life threatening illness on her relationship with her mother;

c) to identify a daughter's concerns for her own health.

This thesis is organized into six chapters. The introduction states the purpose, the qualitative approach to the study, the rationale of the study, my personal narrative, as well as the research questions and objectives. Chapter Two describes relevant

literature on mother-daughter relationships, mother-daughter relationships and illness, caregiving, and women's health issues. In Chapter Three, I discuss ethical considerations, recruitment of participants, data collection, and data analysis. In Chapter Four, I present the women's stories, and describe the findings from the interviews and focus groups. In Chapter Five, I discuss my reflections on the women's narratives, limitations and strengths of my study, and recommendations for future research. And, in Chapter Six, I give a summary of my research study.

Chapter Two: Literature Review

2.1 Introduction

This chapter reviews the literature on mother-daughter relationships, the impact of illness on mother-daughter relations, and women's health issues. There is an abundance of literature on issues surrounding illness and relationships, caregiving, and women's health issues. This literature review is organized in separate sections based on themes relevant to my study. I describe the literature on mother-daughter relationships in section 2.2. In the next section, I describe the research that has been done on illness and mother-daughter relationships. I review the literature on women as caregivers in section 2.4. Finally, I describe women's health concerns and health issues. This literature review presents a theoretical background and provides some context regarding the mother-daughter relationship and illness, caregiving, and women's health issues. It provides a framework for my research on the impact of illness on daughter's relationships with their mothers.

2.2 Mother-Daughter Relationships

Gender plays an important role in the relationship between parent and child. Female parent and child bonds are often stronger than bonds between a male parent and child (Fingerman, 2001). Previous research on mother-daughter relationships has focused mainly on mothering and the psychoanalytic theory of separation. Throughout their lives, daughters are continuously trying to escape from their mothers and build their own identity as women (Chodorow, 1978). Caplan's (1989) research focuses on the tendency to blame the mother for daughter's problems or inability to

separate from their mothers to build their own lives. Such studies focus on the negative aspects of mothering and mother-daughter relationships and offer little room for social, cultural, and political influences.

Porter and Porter (1999), a mother-daughter research team, suggest that power imbalances are present between mother and daughter throughout the daughter's childhood. They noticed that at a point in the daughter's adult life the power imbalance that had once been present was no longer visible. The daughter had learned to use her power as she matured while the mother had learned to lessen her power. Porter and Porter (1999) believe that this type of learning and sharing of power enabled them to maintain a close relationship.

Fingerman's (2001) study examines the relationship between mother and daughter while both are in good health. She conducted interviews, questionnaires, and joint interviews with 48 pairs of mothers and daughters. The mothers were between the ages of 69 and 93 years of age and the daughters between 32 and 58 years of age. All pairs were from a European American background and were middle to upper class with a high degree of education. Fingerman (2001) reveals that the early relationship between mother and daughter shapes their relationship in later life. The later life relationship is influenced by the daughter's need for separation from her mother and the mother's need (as she grows older) for involvement in the family. After the relationship matures, daughters see themselves as having separate lives and families of their own. They sometimes resent their mother's advice and concerns for them, but still grieve for it when it is no longer there. Daughters often became preoccupied with what might happen in the future of their mother's lives rather than concerning themselves with the present. In general, mothers and daughters were

satisfied with their relationship, but conflict was occasionally reported. Conflict usually occurs when communication, the larger family dynamic, and individual well-being is disrupted.

According to Fingerman (2001), mothers are more likely to bring their personal problems to their daughter's attention than daughters are to bring their problems to their mother's attention. Daughters cite their partners as the person they chose to discuss their problems. Fingerman (2001) explains that this may be due to generational differences in which men in older generations are less likely to be open in discussing concerns and problems than younger generations of men. Thus, mothers in this situation were unable to share problems with their husbands; therefore, were more likely to share with their daughters. Whereas, the daughters were more likely to share their problems with their partners.

Fingerman (2001) uncovers that daughters often feel intruded upon by their mothers. They feel that their mothers are demanding and dominating. As a result, many daughters describe their relationship with their mothers in negative terms. Mothers feel ignored and left out of their daughters lives. The mothers feel they are trying to improve their relationship with their daughters by becoming involved in their lives, but the daughters feel this was an intrusion.

As mothers and daughters age, their descriptions of their relationships changed with the changing roles of each individual in the relationship. Fingerman's (2000) research reveals that mothers tend to be more involved in their relationship with their daughters throughout their lifespan. In the daughter's early adulthood the focus of the relationship is on the daughter's development in adulthood. As daughters enter midlife the focus of the mother-daughter relationship tends to be on family and the

daughter's children and familial responsibilities. In later adulthood, mothers often

focus less attention on the individual daughter and more on the family as a whole.

Daughters begin to provide a caring and nurturing role for their mothers. Although

the mothers did not need daily assistance from their daughters, they reported an

appreciation of their daughters' concern and offers of care. Cicirelli (1989) uses the

term *filial anxiety* to describe adult children's worries about future caring for their

parents. In Fingerman's (2000) study, mothers tend to describe *parental anxiety* over

the future and the possibility of needing care from their daughters.

Blieszner, Usita, and Mancini (1996) reveal that contact and support or

companionship is reciprocated between mothers and daughters. Open communication

is needed to maintain close relationships, but it adds strain sometimes to already

conflicted relationships (Blieszner, et al.,1996). In another study, daughters agreed

that it is important to have open communication in their relationships with their

mothers, but they report that they purposely try to avoid conflict (Fingerman, 2001).

In doing so, they admit that they often mask their emotions as a way of protecting

their mothers as their mothers grow older. Additionally, daughters who purposely

avoid conflict and mask their emotions report more satisfaction from their relationship

with their mothers.

2.3 Mother-Daughter Relationships and Illness

Blackford (1998) conducted qualitative interviews with 18 families in Ontario

regarding mother and daughter experiences when the mother has a chronic illness.

Individual interviews were conducted with mothers who have MS and their daughters.

The daughters were between eight and 16 years of age. The focus of the study is to

understand the experience of transition from being healthy to being chronically ill and the importance of a mothers influence in shaping her daughter's values. Grounded theory methodology was used to code and analyze the data. The daughters express feelings of resentfulness, rejection, and separation when asked about their emotions concerning their mother and their mother's illness. Caregiving roles are also briefly mentioned as a source of internal burden and resentment.

Blackford (1998) reports that the social, historical, and economic impact on mothers with chronic illness and their daughters has not been explored in earlier studies, because it was assumed that there would be negative outcomes for the child if this phenomenon was studied. Recent research has shown the impact of chronic illness often leads to feelings of uncertainty for daughters, but Blackford (1998) reveals it also provides strength, resilience, and hopefulness for mothers and daughters.

Tarkan (1999) interviewed more than 70 women in the United States whose mothers have breast cancer. Some of the mothers of the daughters interviewed had died from the illness at the time of the interview; others were receiving treatments, while others were survivors of breast cancer. The women ranged in age, social, and economic status. Tarkan (1999) discloses four themes that developed from the interviews: feelings of helplessness, fear, responsibility for providing support to other family members, and sadness about the role reversal in taking on the role of caring for their mothers. Daughters in Fingerman's (2001) study are often overwhelmed with feelings of anger, depression, fear, frustration, and anxiety.

In Fingerman's (2001) study which includes daughters of healthy mothers and

Tarkan's (1999) study, some of the women keep their feelings of sadness, fear, responsibility, and helplessness to themselves. This leads to problems in other parts of their lives including their relations with their mothers, careers and other family relationships.

In Davidman's (2000) study of motherloss, her goal is to examine how early motherloss is reflected on social contexts. Sixty men and women were interviewed over a period of three years. The age at which they had lost their mothers was between 10 and 15 years of age. At the time of the interviews, the participants ranged in age from 20 to 80 years. The majority were white middle-class Euro-Americans. Most of the participants were children when their mothers died. When looking back they remembered being embarrassed by their mother's illness and silenced when they tried to talk about it. The participants said they felt guilt over feeling this way as their mothers were not in control of the illness or their deaths.

Bassoff (1992) indicates that when a mother is diagnosed with a life threatening illness, this may be a time for growth and spiritual healing in the relationship. It can also provide an opportunity to put things into perspective and to make meaning of their relationship. If this does not occur, and in many cases it does not, the daughter may feel guilt and disappointment. According to Cicirelli (1989), while adult children care for an ill parent, there is a need to resolve conflict between the parent and child, as well as, other family members. Tarkan (1999) interviewed more than 70 daughters of women with breast cancer and found that most women felt both estranged and close to their mothers at different stages throughout the illness. If conflict occurred, most women felt the need to talk openly in order to resolve any issues so that there was no unresolved issues. Often the relationship became

disengaged because of the need for the daughter to protect her mother from her feelings and to keep her own problems hidden from her mother.

Ward-Griffen's (in press) study reveals that mother-daughter relationships deteriorate in the face of illness. She explores the experiences of daughters of mothers with Alzheimer's disease before and after the diagnosis. Daughter's experiences of caregiving are not only influenced by the current situation of illness, but also by a life long relationship between mother and daughter, family relationships, and past health and illness. The relationship deteriorates because of the stress of caregiving, negative emotions related to caregiving, and also because of the nature of the mother-daughter relationship prior to the illness diagnosis. Other scholars agree with Ward-Griffen's (in press) findings (Finch, 1989; Fingerman, 2001; Phillips, 2000; Pohl, Boyd & Given, 1997; Poirer & Ayres, 2002).

Ward-Griffen (in press) identifies five themes in describing the mother-daughter relationships of mothers with dementia and their caregiving daughters. Daughters in Ward-Griffen's (in press) study were between 36 and 64 years of age, most were Canadian, married, employed, and their range of incomes varied. Half of her participants had some post secondary education. The daughters had been caring for their mothers for less than one year to over six years.

Ward-Griffen (in press) uses the metaphor of a journey to illustrate these themes. The first theme is of "becoming aware" (p. 9) of changes within the relationship during the diagnosis and first symptoms of the illness. Some daughters in Ward-Griffen's (in press) study, describe being aware of changes within their relationship, due to the speed of the evolving illness, while others describe it as a gradual change. Reminiscing and thinking about the past relationship often brings

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about feelings of sadness. It is often while being aware the daughters realize that they have to become involved with their mother's care.

The second theme, "finding the balance" (p. 11), describes the changing degree of care needed from the daughters. Ward-Griffen (in press) demonstrates that daughters are willing to help mothers with household duties that are becoming more difficult for mothers to do. In the early stages of the illness, mothers are often still able to do most household duties and therefore often decline the assistance. Finding a balance between needing assistance, independence, negotiation and respect is dominant within this theme of the relationship. Daughters often report the need for the fathers' emotions and opinions within the balance.

Ward-Griffen (in press) identifies another theme, "leading the way" (p. 12), which is when daughters protect their mothers by taking on much of their mother's lives. This theme is sometimes described as a role reversal by some of the daughters. Feelings of guilt and concern are described by daughters as they take on the leadership role. Another theme is "carrying the load" (p. 13). This is when daughters take on more of the caregiving while balancing other responsibilities such as careers and family responsibilities. Some daughters describe a stronger bond between siblings while caring for their mother, whereas others felt resentful because of the obligation and little help from siblings. Some daughters comment on the lack of recognition and support from siblings, in particular brothers. The need for formal support (for example, homecare) and accessibility to that support is described by many of the women.

The final theme presented by Ward-Griffen (in press) is "holding on/letting go" (p. 16). She asserts that as the illness progresses, daughters often reminisce about

their past relationships with their mothers, although their mothers are still alive. They grieve for their mothers and the lost relationship.

As in Ward-Griffen's (in press) study, Edelman's (1994) study of women who have lost their mothers during childhood, shows that daughters reminisce about their mother's diagnosis of a life threatening illness and that they felt it was a pivotal point in their lives. Some daughters describe it as being more life altering than other events such as the first menstrual period. Daughters describe feelings of anger, resentment, and fear, but at the time they were unable to express these emotions because they did not want to upset family members. Edelman (1994) interviewed 92 motherless women and surveyed 154 women through mail. The women were from a variety of racial, ethnic, socio-economic areas of the United States. Participants ranged in age from 17 to 82 years of age and were between infancy and early thirties when their mothers died or abandoned them. Although a specific method of analysis is not clearly defined, Edelman states that her interviews were anecdotal and retrospective. She supplements the narratives with psychological theories on loss and bereavement. She includes information obtained by interviewing therapists, researchers, and professors specializing in mother-daughter relationships, bereavement, parent loss, and the sociology of death.

My research differs from previous research on mother-daughter relationships and illness because it focuses on the experiences of daughters only, I do not include narratives from mothers. My study also focuses on a variety of illnesses; I am not concerned with the illness itself, but rather the impact of the illness on the lives of daughters. A lot can be gained from examining daughters of mothers who have different illnesses, for example the emotions felt by daughters (guilt and feeling the

need to protect their mothers) and experiences of accessing caregiver supports were similar despite the different illnesses. Much of the preceding research has focused on specific illnesses such as alzheimer's disease or breast cancer. My research also differs from previous studies due to my own involvement as a participant and the co-creation of the narratives between myself and the women in my study.

2.4 Women and Caregiving

As the life expectancy of Canadians is increasing, so is the shift in focus of healthcare from institution to community and informal home based care (Canadian Caregiver Coalition, 2003; Kramer, 2005; National Coordinating Group on Health Care Reform and Women, 2003). In an attempt to reduce costs and shift to informal care rather than medicalized formal care, there has been a decrease in hospital admissions and length of hospital stay which Ginzberg (1996) and Vladeck (1996) suggest will continue in the future. Kramer (2005) indicates that this shift to informal care places family members in a compromising position where they do not have the education, training, and preparation necessary in caring for family members.

Historically, women provide much of the care to the sick, in both home and in health care facilities. The family is recognized as an organization within a hierarchical society. Familial and household duties are unequally distributed along gender and age lines among family members, which reflects and reinforces the gendered division of labor in the public sphere (Baines, Evans, & Neysmith, 1991; Blackford, 1998; Bullock, 1990). Neysmith suggested that women are forced to care because of the lack of support from other family members (Baines et al., 1991). Blackford (1998) agrees that women often feel a responsibility or obligation to care

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for members of the family while juggling responsibilities of paid work, family life, and extracurricular activities.

Women who are expected to care for family members often fall into a *caring tricycle*, which Doyal (1995) describes as a lifetime of caring for children, elderly parents, and finally an ill partner. Fast, Keating, Otfinowski, and Derksen (2004) and Aronson (1998) affirm that the type of caregiving tasks also reflect gender assumptions. Women tend to provide more personal, emotional, and housekeeping care while male caregivers tend to provide household repairs and outdoor work.

The management of family relationships and well-being is often the responsibility of the women in the family. Doyal (1995) describes this as emotional housework. The responsibility of emotional housework becomes burdensome. The need for care and support for the caregiver is overlooked. Women are often afraid to ask for help because they do not want to burden others. Even with the support of extended family, women feel rivalry from other family members rather than support (Doyal, 1995). Doyal (1995) indicates that women are responsible for cooking, cleaning, and caring. Caring for dependents includes both child care and adult dependents. Domestic work often requires 24 hour duties, which does not allow for rest and presents an emotional and physical burden to the caregiver. The expectations and assumptions put on daughters creates strain and conflict within intergenerational relationships (Aronson, 1991). According to Ward-Griffen (in press), most mother-daughter caregiving research has found that daughters experience caring for their mothers as burdensome and stressful. As Doyal (1995) describes, there are some women who consciously chose to care for a sick family member and who find great

rewards from this, but often there are women whose family members expect them to do the caregiving.

Connidis and McMullin (2002) and Luescher and Pillemer (1998) define ambivalence as opposing feelings due to societal and individual expectations of how one should behave and act. Women who combine employment with caring for family members may experience a conflict of roles due to social expectations. Aronson (1992) suggests that societal expectations are forced upon women, and pressure women to feel rewarded and satisfied in caring for family members. Influences such as economic status and class may increase ambivalence. For example, negotiating working hours in order to provide care for a family member may increase stress for women who are in lower paying jobs. Such women may be dependent on the income provided by paid employment. A professional woman may be less reliant on the income from her job, but she may rely on the sense of identity provided by her work (Connidis and McMullin, 2002).

In comparison to Connidis and McMullin's (2002) study, Fingerman, Chen, Hay, Cichy, and Lefkowitz (2006) report that gender or the number of social roles do not have an impact on reported ambivalence within parent and adult-child relations. Fingerman, et al. (2006) explains that the degree of investment in each social role (for example, mother, employee, caregiver) impacts the amount of ambivalence felt by daughters. Increased investment in social roles coincides with lower reports of ambivalence in parent and adult-child relationships. Individuals' beliefs and feelings of being in control over their situation and relationships influence their experiences of ambivalence (Fingerman, et al., 2006).

Connidis and McMullin (2002) suggest that confrontation, conflict, and acceptance are outcomes of ambivalence. In order to attempt to resolve ambivalence, one must confront the problem and actors involved in the situation. There is potential for conflict, but there may also be compromise in an attempt for resolution. Those with fewer options, for example female caregivers with lower paying jobs and little assistance from other family members, may resort to acceptance rather than confrontation (Connidis & McMullin, 2002).

Allen and Walker (1992) interviewed mothers and daughters regarding their relationship - particularly when the daughters were caring for their mothers. The study identifies positive outcomes of daughters caring for their mothers rather than negative views of caregiving, which has been described in much of the literature (see Barer & Johnson, 1990; Matthews, 1985; Stueve, 1982). Allen and Walker (1992) reveal that both the daughters and mothers describe their relationship as a companionship or friendship in which they both feel comfort from the other's affection, respect, and mutual participation in activities. The care provided by the daughters is described as being out of respect for their mothers, not a burdensome duty. The mothers express their appreciation for the household chores, errands, financial support, and personal care provided by their daughters. The daughters describe a sense of satisfaction from caring for their mothers and from their contribution to the relationship.

Employed daughters, in Keefe and Fancey's (2002) research, describe the stress of juggling time constraints of work and caring for their mothers as well as other family members. Some of the daughters report that their careers had helped

them become more assertive and develop skills needed to care for their mothers, including nursing skills, knowing where to go and how to ask for assistance, and being comfortable in advocating for their mothers. When referencing DiLeonardo's (1987) study, Hines Smith (1998) describes women's roles in "kinkeeping" as "tasks related to communication and support of relatives, including ritual gatherings, gift-buying, nurturing, and economic and emotional exchanges between households" (p. 36-37). The roles described by Hines Smith (1998) are often used to describe society's expectations of women.

Hines Smith's (1998) study looks at the mother-daughter relationship, specifically the consequences of the mother's death on the daughter's role within the family. She interviewed 30 African American women ranging from 39 to 68 years of age in the Philadelphia and New Jersey areas. Fifty percent of the women she interviewed were low income and the other half were mid to high income. She indicates that kinship plays a role in determining who will care for an ill parent. Most often it is a wife, daughter or daughter in-law who provides the care (Brody, 2003).

Feminist research emphasizes a different standpoint in which caregiving is another element of the life long relationship between mother and daughter. Instead of looking at caregiving as a negative weight upon daughters, some feminists strive to attain change in viewing caregiving as a positive aspect of the mother-daughter relationship (Poirer & Ayres, 2002; Ward-Griffen, in press). Daughters in Pohl et al. (1997) study describe their experience of caregiving as an expansion of their past relationship. Other daughters describe caregiving as a chance to develop bonds in their relationship with their mothers. Walter's (1991) study shows that mothers and daughters, who describe their relationship as a friendship before the need for

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caregiving, have positive experiences of caregiving.

The term *role reversal* is often used to describe the change in the direction of care within the parent-child relationship. The term *role reversal* may be problematic to some because they suggest that rather than a reversal, the relationship becomes an exchange of care. Patsdaughter and Killien (1990) suggest that rather than experiencing role reversal, daughters who care for their mothers experience a reciprocal relationship. Daughters often provide more care to their aging mothers than in previous years of their life, but mothers continue to provide support and care for their daughters as well.

Keefe and Fancey (2002) investigate the reciprocal exchanges between mothers and their daughters (who are employed full-time) from the perspective of both the mother and daughter. The daughters were involved in two focus groups and the mothers were interviewed in a semi-structured interview style. Keefe and Fancey (2002) suggest that past studies have focused on the burdens of juggling care for a parent and careers. In their study, they focus on the reciprocity of caregiving. Mothers receive help from their daughters through daily assistance, but mothers also give back to their daughters. Gerstel and Gallagher, (1993) and Norris and Tindale (1994) refer to this reciprocity as "kin work" that may occur over time through familial relationships.

Keefe and Fancey (2002) state that although the daughters provide the majority of the care and assistance in their relationship with their mothers, most of the daughters felt satisfied with the care they gave because of the past help they received from their mothers. Examples of past care include childcare and/or financial support. The current help mothers provide to their daughters includes emotional support. The

type of care changes as the mother became more dependent on the daughter; the mother is no longer able to provide practical care, but could provide emotional support such as love and advice.

Norris and Tindale (1994) suggest that if the mother-daughter relationship is strong previous to the illness, then the reciprocity will be positive, but if the past relationship was strained, the reciprocity will remain strained. Hines Smith (1998) has similar findings; African American daughters and mothers emphasize reciprocity in their relationships. Daughters describe a give-and-take type of relationship with their mothers. This reciprocity also includes mutual respect, unconditional love and commitment in the relationship. Hines Smith's (1998) research reiterates that daughters who chose to care for their mothers are guilt free and those who do not, feel guilt after the death of their mother.

In Keefe and Fancey's (2002) study of mothers and their caregiving daughters, they discovered that the degree of reciprocity is often downplayed by mothers. Talbot (1990) confirms this assertion. Indeed, mothers describe giving more to their daughters while receiving little in return. Neufeld and Harrison (1995) interviewed mothers of premature infants and women caring for older adults with cognitive impairments to examine reciprocity in relationships with other family members as well as with the care recipient. This research indicates that reciprocity between caregivers and other family members or friends is determined by a balance between give and take. If the balance is unequal within the relationship, the relationship often broke down.

Neufeld and Harrison (1995) describe the closeness of the relationship and the expectation of reciprocity. For example, in close relationships the expectation of

reciprocity is not expected but in less close relations the expectation of reciprocity is emphasized. Women who feel an obligation to care for a family member view the relationship as negative with little reciprocity. Neufeld and Harrison (1995) describe reciprocity within the relationship, between caregiver and care receiver, as constructed reciprocity. Observation, waiting, and remembering made up this type of reciprocity. Cues given by the care recipient such as hand holding, eye movements, or smiles are described as reciprocity.

Care is the foundation of the reciprocal relationship between mother and daughter. Waerness (1984) states that "caring encompasses that range of human experiences which have to do with feeling concern for and taking charge of the well-being of others" (p. 68). As Ward-Griffen (2002) and Tronto (1989) suggest, caring for and about someone includes physical, emotional, intellectual, and psychological aspects as well as affection. Based on these definitions, caring includes all aspects of one's self.

Many of the informal family caregivers in Ward-Griffen's (2002) study report that physical care, such as preparing and assisting with meals, dispensing medications, suctioning tracheotomies, changing dressings, and catheter irrigations, are a routine part of everyday life. Such tasks become repetitive and automatic and are described as household duties. Participants rarely consider emotional care as an aspect of caregiving. Participants view emotional support as part of the mother-daughter relationship, and is not thought of as caregiving work, although some participants agree that emotional work is not always easy to provide. Ward-Griffen (2002) describes another type of caregiving – intellectual caregiving. Intellectual caregiving includes record keeping of medications, symptoms, and side effects. Although this is

a practical aspect of a caregiver's responsibility, it is an important and detailed task.

Ward-Griffen (2002) concludes that family caregiving is often viewed as less important than formal caregiving. Family caregiving is described as being undervalued, and as a continuation of household chores. Emotional caregiving is often described as being an obligation, or an aspect of the relationship between family members.

Fast et al. (2004) examine the distribution of care, and organization of care in groups of caregivers, as opposed to a single caregiver. Fast, et al. (2004) reveal that characteristics of caregiving networks are similar to single caregivers. The groups of caregivers were small, predominately female, made up of family members, middle aged or younger, and lived separately from the older adult. Although this research focused on caregiving networks, Fast et al. (2004) note that the majority of care received by older adults is often provided by an individual female.

Fast et al. (2004) concludes that large caregiving networks provide more time for care, and additional help in caregiving than single caregivers. While most of the networks are made up of family members, it is important to note that this does not reflect the amount of care given to older adults. Friends and neighbors provide the same amount and quality of care as family members. Fast et al. (2004) reports that networks comprised of both family members and non-family members provide the best quality, and the largest amount of care to recipients.

The Canadian government has implemented a number of caregiver support programs, such as the federal caregiver tax credit, which protects the jobs of caregivers who take time from work in order to care for an ill family member (Fast, Eales, & Keating, 2001). Such programs tend to emphasize the individual caregiver,

and do not provide assistance for caregiving networks. Therefore, caregiver support programs tend to encourage individual caregiving rather than supporting caregiving networks.

The Compassionate Care Benefit Program was put into place in January 2004, by the Government of Canada, for caregivers who leave work in order to care for a seriously ill family member. The program is intended to provide job and income security for employees who take time off from their work to care for a seriously ill family member. The maximum amount of paid leave from work allowed by the Compassionate Care Benefit is six weeks. An additional two weeks of job security is allowed without pay. A seriously ill family member includes a child, child of partner, partner, mother, father, mother of partner, or father of partner who is at risk of dying within 26 weeks. A medical certificate, signed by a physician, is needed to verify risk of dying. In addition, a physician examination and date of diagnosis is needed. Caregiving is defined by The Compassionate Care Benefit Program as "providing psychological or emotional support, or arranging for care by a third party, or directly providing or participating in the care" (Government of Canada, 2007).

Although there is a need for the compassionate leave benefit, it was considerably underused in its first year (Osborne & Margo, 2005). The Health Council of Canada (cited in Osborne & Margo, 2005) determined that its under use may be due to several reasons. The first possible reason may be credited to the structure of the program. In order for a family member to qualify for the program, the individual must have employment insurance benefits. This criteria, unfortunately, ignores many caregivers who do not have employment insurance (Osborne & Margo, 2005). The second proposed reason for the under use of the program is the narrow

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definition of "family member." The diverse structure of family in Canada often includes extended family such as aunts, uncles, grandchildren, cousins, and step-children. The Compassionate Leave Benefit does not acknowledge extended family in their description of "family member"(Osborne & Margo, 2005).

The six week time period has also been criticized as being too short a period, and inconsistent with the unpredictability of illness. Also, the 26-week prediction of estimated time left to live is hard to determine especially in the case of children and non-cancerous patients. Although more than one family member can apply for the care leave benefit, only six weeks of paid leave can be claimed per family (Osborne & Margo, 2005). Osborne and Margo (2005) suggest that the general public are not aware of the benefit and more publicity is needed to benefit eligible individuals. Finally, Osborne and Margo (2005) suggest that all provinces and territories make use of The Compassionate Care Benefit. Currently, British Columbia, Alberta, and the Northwest Territory do not offer the program to its residents.

2.5 Women's Health Concerns and Health Issues

Tarkan's (1999) study reveals that daughters of deceased mothers (who had died of cancer) describe their mother's illness experience as more distressing than daughters whose mothers are still living. They also share an intense anxiety about developing cancer. Fear of getting the illness often lead daughters to avoid routine exams, doctor appointments, and preventative measures (Tarkan, 1999). Edelman (1994) reports that a mother's life threatening illness affects the daughter's view of physicians, hospitals, and her body and health.

Edelman (1994) indicates there is a frightening point when daughters become

aware of their mother's mortality, and they realize their mothers are not heroines. Daughters often wonder what their mothers were feeling when they went for treatments and tests. Daughters experience their own mortality as they watch their mothers go through the illness. This mortality is often felt when the daughter reaches the same age as her mother when her mother was diagnosed, or when her mother died. Edelman (1994), Hines Smith (1998), and Moss and Moss (1995) also describe fear and panic of daughters who believe they will develop the same illness as their mothers, even when the illness is not genetically linked.

Even when juggling household work, emotional work, kinkeeping, and working full-time is balanced with caring for an ill mother, caregiver support is often overlooked. As Doyal (1995) reports, the responsibility of caring for dependents can cause strain on the caregiver's emotional and physical health. Briggs and Oliver (1985) in Doyal (1995) relay a participant's experience:

> The tiredness associated with looking after someone disabled was the hardest thing for me to adjust to...the tiredness is, of course, due to different causes for each carer, but the exhaustive effect is the same – for me, the tiredness comes from the physical exertion of caring for someone with severe multiple sclerosis, and from the mental stress of seeing the person you love best in the world suffering from such a disease. (p.39)

Tarkan (1999) and Edelman (1994) indicate disagreement between whether daughters become more concerned about their health, or if they choose to ignore their health after their mother is diagnosed with an illness. There is agreement, however, in the importance of the physical, mental, social health, and well-being of the caregiver.

2.6 Conclusion

This body of literature has raised my awareness of the experiences and obstacles facing daughters who care for their mothers and the health concerns of daughters of mothers who have a life threatening illness. These theories influence the framework I use in my research, which I will discuss in the next chapter. I describe process of ethics approval, ethical considerations, the recruitment of my research participants, data collection, and data analysis in the following chapter.

Chapter Three: Methodology

3.1 Introduction

Qualitative research was used in my study in order to make sense of the everyday experiences of women whose mothers have life threatening illness and to situate myself within the research as both the researcher and self as participant. Lyons (1999) supports the notion that qualitative research aims to find meaning and understanding in the lived experiences of the social world. Denzin and Lincoln (2000) use the term "thick description" to describe the experience of an individual in terms of the emotions and understanding from the individual's point of view, and how meaning is derived from such an experience. The rich accounts told by the daughter's in my study supports Denzin and Lincoln's (2000) concept of "thick description," and the daughter's understanding and meaning of their experiences in their everyday lives.

The methodology used in my research takes a feminist collaborative approach. Gustafson (2000) defines a feminist collaborative approach as:

> concern for the kind of knowledge produced (knowledge that is woman centered and transformative) and a concern for how that knowledge is produced (emerging from a partnership with peers working to uncover, clarify, and negotiate meaning through critical reflection, discussion, and reciprocity). (p.718)

Denzin and Lincoln (2000) describe the qualitative researcher as a bricoleur or quilt maker, who chooses techniques in an attempt to understand the world of the participant, through the use of mixed methods, as each sheds a different interpretation. In order to develop a rich understanding of the personal narratives, and the

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experiences of the everyday life of my participants, I chose to combine interviews and focus groups as a way to interpret the stories of the women in my study.

My research was conducted in three stages of data collection: individual interview, interviews of focus group, and follow-up interviews of the focus group. Six participants took part in an individual interview. When all six interviews were completed five of the six participants became the focus group. Three of the five focus group participants took part in the follow up focus group. The purpose of the follow-up focus group was to share my analysis and to provide an opportunity for the women to review what they had said, to clarify any misinterpretations or misunderstandings, to remove anything they wished to disregard, to add any relevant or new experiences that were not discussed in previous conversations, to talk about their experience of being involved in the research, and to review the first focus group transcript. As well, participants had the opportunity to review their individual interview transcript in order to edit or add to their individual discussions.

3.2 Ethics Approval

My project was granted ethics approval by Memorial University of Newfoundland's Human Investigation Committee (Appendix A) and by Clinical Trials and Research at the Cancer Care Program Eastern Health (formally known as the Newfoundland Cancer Treatment and Research Foundation). I submitted the appropriate forms and a copy of my proposed research to the Human Investigation Committee and was granted approval. In the latter case, I submitted a copy of my research proposal, a copy of the Human Investigation Committee forms, the and letter of approval.

In compliance with the Tri-Council Policy Statement article 2.4 (2003), before asking for consent from potential participants, I explained the following: the research project and the possible harms and benefits that might occur during the study. Every effort was made to ensure participant confidentiality and privacy. Pseudonyms were used in transcriptions and written results. All identifying details were removed. I explained that if the discussion became uncomfortable, the tape recorder could be turned off at any time and that by request, particular statements made during interviews or focus groups could be kept off the record.

Participation in this research was voluntary. Participants were made aware that they might not receive any immediate benefit in choosing to participate. I explained that they were free to withdraw from the study at any time. Each participant signed a consent form (Appendix D) before the interview. Prior to each focus group, participants also signed an undertaking of confidentiality (Appendix I). I also signed an undertaking of confidentiality before the interviews and focus groups (Appendix J). Tapes, transcripts and notes were kept in a locked cabinet, in my supervisor's office at Memorial University. The data was stored on a password-protected computer. Only my supervisor and I had access to the original data. Data will be kept for five years as required by Memorial University of Newfoundland.

Due to the sensitive nature of the study - the possibility of emotional pain, unresolved conflict, and uncomfortable issues - Dr. Rick Singleton, a professional grief and bereavement counsellor agreed to be available, if needed to provide counseling services (Appendix K). Memorial University's Counselling Centre was available for my use during my research. I availed of the Counselling Centre's

services during the last few months of writing my findings, it was during this time that my mother was hospitalized.

A thank you letter was sent to participants after the completion of the interviews and focus groups. Participants were offered the opportunity to make comments, on their individual interview transcripts, the initial focus group transcript, and their role within the research, during a second focus group. Participants will be able to access the final thesis once it is complete.

3.3 Recruitment of study participants

A recruitment package, including a letter of information for community organizations (Appendix B), a letter of information for potential participants (Appendix C), a consent form (Appendix D), an interview discussion guide (Appendix E), a focus group discussion guide (Appendix F), a second focus groups discussion guide (Appendix G), and a poster (Appendix H), was forwarded to the following community organizations: The Canadian Cancer Society, Health and Community Services, the AIDS Committee of Newfoundland and Labrador, the St. John's Women's Centre, the Cancer Care Program Eastern Health (formally known the Newfoundland Cancer Treatment and Research Foundation), and the Women's Studies and Sociology programs at Memorial University. I asked that the study be introduced to members and clients of the organization (through posters and email lists). I also distributed posters at the Health Sciences Centre and the Dr. H. Bliss Murphy Cancer Centre. My contact information was provided in the recruitment package. I asked potential participants to contact me, if they had any questions, concerns, or were interested in participating in the study.

The purpose of the recruitment package was to engage daughters of mothers living with a life threatening illness. For the purpose of my research, I define "life threatening illness" as a non-curative illness, which may lead to death. As many non-curative illnesses, which may lead to death, often remain chronic for months or even years, the participant's mothers could be at any stage of the illness. Potential participants were free to decide whether their own mother's illness met this description.

The definition for palliative care, terminal illness, life threatening illness, and chronic illness are often confused. *Palliative care* is defined by the World Health Organization (2000) website as "Care for people with chronic or life-threatening diseases from which they will not recover. Its focus is on symptom control and family support to help people have the best quality of life they can, given their medical condition"

Terminal illness has traditionally been defined as having a life expectancy of six months or less (Lorenz, Shugarman, and Lynn, 2006). There has been scholarly debate over the limitations of defining end-of-life care in rigid time constraints because of the varied nature of the course of illness (Lorenz et al., 2006). *Life threatening illness is* defined on the World Health Organization's (2000) website as "illnesses where it is expected that death will be a direct consequence of the specified illness...[and it]might be expected to shorten an individual's life.". In comparison to life threatening illness, *chronic illness* is defined on the World Health Organization's (2000) website as having a "significant impact on the patient's abilities and quality of life, there is likely to be a less direct relationship between the illness and the person's exacerbations death."

Lorenz et al. (2006) suggest that end-of-life care be defined by the trajectory or course of care, instead of putting a time limit on illness. They suggest that there are three trajectories of care: the first trajectory is terminal decline in which the patient's health declines rapidly in a short period of time. An example of this includes most cancers. The second trajectory is chronic illness with exacerbations, which includes progressive long-term limitations that will eventually lead to death. An example of this is chronic obstructive pulmonary disease (COPD). The third trajectory is prolonged dwindling illnesses. An example of this is dementia.

All of the daughters in my study describe their mothers as having a life threatening illness that falls into the categories of terminal decline or chronic illness. Such illnesses require intermittent care. Although the mother's illnesses ranged from cancer to MS, I did not intend to focus on the illness itself but rather the impact of the illness on the relationship between mother and daughter and on the life of the daughter.

During the period of January to March 2005, I was contacted (via telephone) by seven women who have a mother living with a life threatening illness. On initial contact, the daughters would often give me a summary of their mother's illness and after some discussion, I would ask if she was interested in participating in my study. If so, I emailed her a copy of the interview and focus group discussion guides to review, and scheduled a convenient date, time, and place for the interview. One of the women who contacted me, asked for more information about the research, and later decided not to participate in the study. In addition to the before mentioned seven women, I received five emails and telephone calls from women who were interested in participating in my study, but did not meet the criteria of having a mother still living

with a life threatening illness. With the volume of inquiries from women whose mothers had already died, I had initially considered including such women in my research. After careful consideration, I decided that such a group of women may have similar experiences to daughters whose mothers were still living but the experiences might have been altered by the death of the mother, and would involve different kinds of loss. I did not include women whose mothers had already died in my study but with the interest from such women, support in this area may be needed.

The age range of participants was between 24 and 49 years of age. The age range of the participants' mothers was between 48 and 72 years of age. All participants were Caucasians. All but one participant had completed or was in the process of completing a graduate degree or higher. Four of the six women were employed full-time. Two of the six were employed part-time. Four of the six women were married and living with their partners. Three of those four were married with children. Two of the six participants were single. Two of the six participants lived in the same house as their mothers. Only two of the six participants identified themselves as being the primary caregiver for their mothers. All participants lived in an urban area of Newfoundland. Five of the six participants' mothers lived in the same province. The mothers were living or have lived with the following major illnesses: COPD, organic brain disease, cancer, MS, and Parkinson's disease (PD). Participants' mothers were diagnosed with their life threatening illness between 1990 and 2003.

3.4 Data Collection

3.4.1 Interviews

Data was collected by using in-depth, semi-structured interviewing techniques. Topics of discussion were given to participants prior to each interview (Appendix E). I first asked each woman to tell me about her relationship with her mother as she was growing up. I also asked her to describe her mother, the things they do together, and her present relationship with her mother. This part of the interview was intended to explore the daughter's relationship with her mother. I then asked about her mother's illness, the diagnosis, changes in her relationship with her mother since the illness, her mother's treatments, and how she copes with the illness. This set of questions was meant to describe and discuss the impact of the illness on the mother-daughter relationship. Finally, I asked questions about her concerns for her own health, if she has any health problems, if she is concerned about developing the same illness that her mother has, and about her health care needs. I was interested in discussing any concerns the daughters may have had for their own health, and if they were fearful of developing the same health problems as their mothers. The outline was a flexible list of topics and was used as a guide. Particular issues or themes that were not on the discussion guide, but were relevant to the daughter's experience, were explored. The interviews flowed as a conversation, rather than a set of questions and answers.

As I asked participants to tell me about their relationship with their mothers, and their mothers' illness, some told a story with a beginning, middle, and an end. I did not have to use many prompting questions as the story flowed easily. This type of narrative is referred to by Frank (1995) as the restitution narrative, which describes an illness story involving a beginning (being in good health), a middle (sickness), and an

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ending (free of illness). Some narratives, however, seemed to jump around in a chaotic array. In these cases, I would intervene and ask questions about the timeline. As Frank (1995) describes, the chaos narrative is often without a clear sequence of events and with no hope of an ending. There are pauses and silences. Often, silences occur when the story becomes emotional. I allowed such pauses and gave the participant time to reflect. I reinforced that it was okay to pause and the participant moved on when she was ready.

VICTORIA: Um [pause] well this is going to sound really bad...

KIM: No, no.

VICTORIA: [laughs] but like I can't even hug her anymore [pause, tears in her eyes, crying]. I know that sounds so bad because it's not her fault.

KIM: No, no, it's okay.

VICTORIA: But I just hates what it's doing to my life [pause, crying].

KIM: Yeah.

The benefit of having all interviews before the focus groups was to build a rapport, and comfort level with each individual woman. It also provided me with a profile of each woman's experience with her mother's illness, and the impact of the illness, on her own life. In building a connection, and learning about each individual before the focus groups, I felt that I could facilitate each focus group while considering each woman's situation and needs.

The interviews took place between January and March 2005. I gave each participant the choice of where the interview would take place, and a convenient time and date was set. Interviews took place either at Memorial University, in the participant's homes, or at the participant's place of work. Interviews were

approximately one and a half to two hours in length, and were audiotaped and then transcribed. At the beginning of each interview, I asked the participant to read and sign a consent form (Appendix D) and information form (Appendix L). I introduced myself, and gave a brief background and summary of my interest in this topic of research, which included the story of my mother's illness and how it has impacted our relationship. I began the conversation by asking the participant to tell me about her background, her family, and her work. The interview guide (Appendix E) was followed, but I allowed further topics to be explored if they arose and were relevant to the discussion. Toward the end of each interview I asked if there was anything else she would like to add. Each interview was conducted in a similar nature.

3.4.2 Focus Groups

Focus groups are an ideal method for exploring sensitive issues such as the meanings of health, illness, and death. As Wilkinson (1998) describes, participants are connected by their common situations. Wilkinson's (1998) study demonstrates that focus groups provide a warm, understanding environment, in which disclosure is welcome, participants feel comfortable offering detail of their experiences, particularly when their emotions and experiences are reinforced by others in the group (Farquhar & Das (1999), Firth (2000), Kissling (1996), Madriz, 2000; Wilkinson, (1998, 2004); and Zeller (1993). As Madriz (2000) describes, focus groups offer both "vertical interaction" and "horizontal interaction" (p. 840), meaning that discussion is formed between the researcher and participant, as well as between participants themselves (Madriz, 2000; Wilkinson, 1998).

The first focus group was held in March 2005, in a conference room at Memorial University. The focus group was approximately two hours in duration, it was audiotaped, and then transcribed. Before starting the group, I reviewed the consent form, which was previously signed at the individual interview, and asked the participants to read and sign an undertaking of confidentiality (Appendix I). I thanked each participant for coming, and asked them to briefly introduce themselves (pseudonym names were used). I also introduced myself, and again reminded participants of my interest in the research topic. I followed the topics of conversation as they were determined by the flow of participant discussion. I felt that areas of importance, as well as topics from the discussion guide, were naturally explored by the women through the course of the conversation. The discussion guide outlined questions around how the illness has impacted the daughter's relationships with their mothers, supports that are available to caregivers, and coping strategies or activities that help them deal with their mother's illnesses and the emotions they are experiencing. These questions were explored in order to gain insight into their relationships with their mothers and the impact of illness on the mother-daughter relationships.

The second focus group took place one evening in November 2005, in a conference room again at Memorial University. Three of the six original participants (Mayzee, Naomi, and Marie) took part in the second focus group. Brooke, Victoria, and Jennie were unable to attend due to conflicting schedules and unexpected emergencies. I had given each participant a copy of the first focus group transcript. I explained that the purpose of the focus group was to share my findings from the

previous focus group, to get feedback from the findings and transcript, to share recent relevant experiences, and to discuss their involvement in the research.

Although I had asked the women to read the first focus group transcript, before the second focus group, they reported that time restraints and other commitments did not allow them to do so. I started the focus group by discussing social themes that I had found in the first focus group transcript. As I described each theme, participants offered relevant updates and experiences from their own lives to expand upon the themes I had found. As I shared the findings of the first focus group, the women in the group drew upon the social themes, and instead of me, as the investigator, asking the participants questions, the women asked me questions about my expectations and responses to the findings.

> NAOMI: Did you find anything that you weren't expecting in this research? Did anything come out and you thought "Oh, that's different or interesting from the literature?"
>
> KIM: Yeah, when I first went into it - this is from my own [experience], not from the literature or anything – but I was thinking, Oh everything is going to be okay, like, if you had a bad relationship with your mother before she was ill it casts this seriousness into it and everything will be all happy again because maybe there is a certain amount of time left and I just thought that maybe [the relationship] would get closer.
>
> MAYZEE: Hmm.
>
> KIM: But yet, I don't know there's a lot more to it in each person's story.
>
> NAOMI: Yeah.
>
> KIM: That's what I found. Like, there's a lot more to it than just the illness, you know?
>
> MAYZEE: Um hum.
>
> KIM: And I guess maybe I was living in this little world you know [laughter] of make believe. You know what I mean?
>
> NAOMI: Yeah.

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KIM: I didn't really.

NAOMI: What does the literature say about that? Does it talk about how people have different expectations first when it happens?

KIM: Yeah, it really depends on the situation. Usually the illness brings in a different type of conflict and conflict of family members, you know?

NAOMI: Guilt and stuff like that.

KIM: Yeah, yeah.

NAOMI: That's really interesting.

The women in the focus group were also interested in knowing how I would organize my thesis. After giving the women an update on my mother's health, Naomi asks me if I was planning to include my own narrative in my thesis. Marie asks how I will include my own story in my thesis. She explains that she comes from a science background, is unfamiliar with including herself within her research.

I was interested to learn if being involved in my research had had an impact on their lives, their thinking, or how the participants felt about being involved in a research study. All women admitted that participating in my study had a positive impact on understanding their own situations and feelings.

KIM: I was just wondering if there was anything that you thought about being involved in the research, how it's had an impact on you? How you felt about participating in the focus group and the interviews?

MAYZEE: Well, I used to work as a counselor, and I always liked doing group work with people because I find the support helpful. Because we're all dealing with our own stuff, in our heads, and that can be so isolating. And so difficult to deal with in terms of your self-esteem and your own ability to cope. It was really good, like Victoria said, to sit with a group of women who are dealing with similar challenges, and realizing that I may be having a bout of guilt because I can't be all, I can't do all the things that I'd like to be for mom. And that I have a life, and I feel that I should have my life even though mom is not well. And I had dad in my face when dad called, and I had tickets for the premiere night and I said "no, I'm busy tonight." [Laughter] and that's ok.

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And to hear that other women are challenged with the same thing. It was very affirming, and it helped me. As much as Miranda has been saying that to me, to hear it from somebody else makes it more valid. I hear it so often from her it's like a broken record. It was validated outside of our family, you know? It was very helpful in that way.

NAOMI: Yeah, I found it helped solidify my ideas around things like that. I think I came out of it feeling a lot luckier because everybody else had much more serious issues around them. But, my mother is doing much better now, although she's disabled. I realized how lucky we are.

MARIE: I came out with the same sort of thing. It was nice to hear the stories coming from [other women in the same situation]. So, it was nice too, and I feel kind of lucky to be able to learn from everyone. And to feel already that yes, I'm going to come up with feelings of guilt, but that's totally normal. Like, my father is the primary caregiver, so, to recognize that in him, so I can help him. So, no, I enjoyed this. And it really raised some awareness for the issues.

Although it was impossible to predict benefits from talking to others about their relationships with their mothers and the impact of illness, I was encouraged by the positive responses of the focus group participants in regard to their involvement in participating in the study, and talking to others in similar situations.

3.4.3 Talk as Action

The interaction between focus group participants, including discussions, disagreements, and debates, are unique to focus group conversations. I have entitled this section, Talk as Action (Wilkinson, 2004), in order to describe the group dynamic of interaction between participants, or how people talk to one another within a particular context. Much of the first focus group conversation began by one participant taking the initiative of giving an example of a situation within her relationship with her mother. Another participant would then share a similar experience as a reflection or comparison to the previous account. For example,

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Mayzee begins discussing her relationship with her mother, before her mother's illness. She says that she was not close to her mother, and she describes their relationship as a "love-hate" relationship. It was not until she moved out of the province, that they became closer during their telephone calls.

Jennie shares similar sentiments, she says that she thinks of her relationship with her mother as a "love-hate" relationship as well. Further, their relationship became stronger when she moved away from home. Marie expands the conversation by agreeing that distance helps in making a relationship intimate, and says that her relationship with her mother has become closer since she moved to Newfoundland. Marie admits that she considers her relationship as being a "normal relationship," she gets along well with her mother, but they are not particularly friendly. Victoria agrees with Marie, and also says that her relationship with her mother was a "normal relationship," before her mother's illness. Naomi says she had a good relationship with her mother before the illness, but it was a relationship in which her mother turned to her for protection from her abusive husband.

Naomi describes her role, as protector in her relationship with her mother. Likewise, Jennie admits that she protected, and cared for her mother during her childhood. Jennie had not described this aspect of her relationship until Naomi addressed the issue. Naomi's description may have made Jennie feel comfortable in disclosing that she had to act as an adult, although she was a child, in her relationship with her mother. Wilkinson (1998) suggests that focus groups are a preferred method for use in research, that may bring forth personal information and discussion of intimate experiences. The dialogue between Naomi and Jennie affirms Wilkinson's

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(1998) assertion that focus groups are the best means of eliciting this type of personal information.

The collaborative nature of the second focus group was useful because it allowed me to give back to the participants, by sharing what I had found, and also allowed the participants the opportunity to discuss, and make suggestions. It also gave power to the participants – giving control over the presentation of their stories. In a qualitative feminist study on a sensitive subject area, such as relationships between mothers and daughters through life threatening illness, I believe it was beneficial to provide an opportunity to the women to have control over what was shared, and how I presented the women in my thesis (Gustafson, 2000; Wilkinson, 1998, 2004).

3.5 Data Analysis

The individual interview and focus group narratives were analyzed through Mauthner and Doucet's (1998) voice-centred relational analysis. The voice-centred method strives to keep women's voices and perspectives in focus, while simultaneously recognizing my own role in shaping the research. I have chosen to use this type of analysis because of its focus on how the participants speak about their own experiences, their relationships with others, the world around them, and my own reflexive experience as a researcher and self participant. Mauthner and Doucet (1998) recognize that data analysis is an ongoing process and occurs throughout the research process. Voice-centred analysis is based on Brown and Gilligan's (1992) work, which is summarized in their book, *Women's Psychological and Girls' Development.* Mauthner and Doucet (1998) attempt to build upon this model, in order to explore the

broader social and cultural contexts, rather than the individual and psychological focus of Brown and Gilligan's (1992) model.

Mauthner and Doucet's (1998) voice-centred relational analysis follows the narrative, in terms of relationships and the social and cultural contexts that surround the participant. Unlike grounded theory, as described by Charmaz (2000), Mauthner and Doucet (1998) recommend viewing the data with specific objectives through numerous readings of the interview transcript. By contrast, grounded theorists' interpretations of the data are used to create themes (Charmaz, 2000). Using Mauthner and Doucet's (1998) voice-centred relational analysis, I read the first reading of the transcript for the overall plot and story (see section 4.2). A reflexive focus on the researcher's involvement and response to the narrative is also highlighted in the first reading. Reactions and interpretations, of the researcher, are examined to discover the participant's narrative in relation to the researcher's interpretation (Mauthner and Doucet, 2003). I will include my own thoughts and reactions to the narratives throughout chapters four and five. The second reading focuses on how the participant speaks about herself. Personal pronouns (for example, 'I' or 'you') are particularly important to determine how the participant experiences and understands her surroundings and herself (Brown and Gilligan, 1992; Mauthner and Doucet, 1998). This step of analysis gave me an outline, and it focused my attention in finding themes, based upon how the participants understood themselves within their experiences. The third and fourth readings focus on how the participant talks about relationships with others around them. This step focused my attention upon how the women described their experiences with their mothers, and the feelings surrounding their changing relationships with their mothers. The social world, and its impact on

the participant's experiences are highlighted in these readings (Mauthner and Doucet, 1998). I found that social issues, such as caregiving supports and ambivalence felt dues to societal expectations, were discussed in the focus groups. Themes, such as coping and feelings of guilt in response to societal and family pressures, were found in the focus of this reading.

Mauthner and Doucet's (1998) voice-centred relational analysis allowed me to hear the daughter's stories, of their relationships with their mothers, from their own perspective. This approach to analysis allowed the linkage of the daughter's experiences of her mother's life-threatening illness to her own personal meanings of illness within the social context of those around her. Instead of a grounded theory approach of coming up with themes, as described by Charmaz, (2000), the voice centred analysis allowed me to direct my attention to viewing the data through a specific lens in order to come up with further themes, based on the objectives of each reading.

Originally, I began using N-Vivo, a qualitative data analysis software, to aid in coding and analyzing the transcripts into categories of the 'voice of I', 'relationships', and social/cultural themes. After entering sections of transcripts into these categories, I felt uneasy about cutting the transcripts into sections and assigning portions into categories. I felt as if my analysis was becoming similar to a thematic analysis rather than keeping with a voice-centred, narrative style analysis. As I had originally planned, my analysis would keep each individual's story in each women's own voice as a whole and not divide her narrative into themes and categories. I then returned to Mauthner and Doucet's (1998) suggestion of using coloured pencils and physically underlining the voice of I, and examples of how each participant talked about her

relationship with her mother. Although this took a fair amount of time, I felt as if I had accomplished my intent of keeping each daughter's voice as an individual, rather than adding my own interpretation, and placing her story within categories. I also felt that I was able to keep each narrative as a whole by not cutting the story into sections. The narrative provided an account of each woman's experience of her mother's illness, and her relationship with her mother through her own words and voice.

3.6 Conclusion

In this chapter I discussed the steps taken for ethics approval from the Human Investigation Committee at Memorial University. I outlined the process of recruitment. I discussed my approach to data collection through the use of collaborative methodology in interviews and focus groups. I concluded the chapter by discussing the voice-centred relational analysis as a way of keeping the narratives separate, and providing an account of each woman's experience in her own voice. The next chapter examines theses experiences.

Chapter Four: Caring for Mother and Oneself in Everyday Life

4.1 Introduction

I begin this chapter by first giving a brief description of each of the women I interviewed. I have entitled this chapter, Caring for Mother and Oneself in Everyday Life, because the women in this study describe caring for their mothers, which often includes relationships with other family members and emotional hardships, but also includes concerns about caring for themselves. This was apparent by the personal stories of friendship, frustration, guilt, anger, laughter, and hope. I have identified nine major themes that came out of my research: gender expectations and caregiving, juggling caregiving with other responsibilities, guilt, protecting mother, illness stigma, supports and self-care, and daughter's concerns for their health, (re)defining life threatening illness, and personal stories with larger social issues. This chapter presents these eight themes.

4.2 Women's Stories

At the time of her interview, Mayzee was 49 years of age. She was employed in the healthcare field, and called herself a feminist activist. Mayzee's mother was 70 years old, and had been diagnosed with COPD in February of 2003. Mayzee was born, and lives with her partner, in an urban centre of Newfoundland. She has one sister. Mayzee's father acts as her mother's primary caregiver. She says that her mother is a hard working woman who worked outside of the home when Mayzee was a child. Her mother has always been involved in activities such as bingo and knitting. Mayzee's mother loved to drive before her license was revoked, due to her illness.

The illness has forced her mother to readjust to her loss of independence. She explains that her relationship with her mother has changed, since her mother's illness. Their relationship was strained and distant before her mother was diagnosed with COPD. Mayzee says that she now tries to be patient with her mother, and she tries to understand what her mother is going through. She also expresses concern for her father. Although her parents decided they no longer need homecare, Mayzee is concerned that her father's health will be affected by the stress of caring for her mother.

Naomi was 48 years old at the time of her interview. She was employed at a university, and was also a graduate student at the time of her interview. Her mother was 72 years of age, at the time of Naomi's interview, and was diagnosed with a tumor on her spinal cord in January of 1996. Naomi was born in Central Canada, but now lives with her partner outside of an urban area in Newfoundland. She has two children. Naomi has one brother, who lives outside of the province. Her step-father is her mother's primary caregiver. Naomi grew up in an abusive household, where she often felt the need to protect her mother. During her mother's illness, she says that she still feels as if her mother turns to her the truth about her illness. She feels as if she needs to protect and comfort her mother from the illness, similar to when Naomi protected her mother during the abusive period in her childhood. She admits there has been a change in her relationship with her mother since her mother's illness. She explains that she used to communicate openly and share her problems with her mother, but, since the illness, she does not like to put extra stress on her mother by telling her her own problems.

At the time of her interview, Brooke was 36 years of age, and was working with the government. She holds a graduate degree. Her mother was 62 years of age, at the time of the interview. Brooke's mother was diagnosed with colon cancer and lung cancer in August of 1994. Brooke lives with her partner in an urban centre of Newfoundland. She has one brother and one sister, and has two small children. Her father is the primary caregiver for her mother. She says that since her mother's illness, she tries to support her mother's decisions and understand the importance of family. It was hard for her mother to accept her diagnosis of colon cancer because her mother believed in the importance of nutrition. Her mother continues to believe the cancer is genetically linked. Brooke believes this is her mother's way of coping with the illnesss. Although Brooke says she is not overly concerned with her health, she has regular colonostomies and medical check-ups.

Marie was single and 24 years of age at the time of her interview. She was working on a graduate degree. Her mother was 48 years of age, at the time of the interview, and she was diagnosed with MS in approximately 1990. Marie is from an urban centre in Western Canada, but she was living in Newfoundland at the time of the interview. She has one brother. Her father is her mother's primary caregiver. She says that her mother's illness impacts the way she relates to her mother and her family, and also the way her mother relates to her. She says that she feels guilty about living in another province, wanting things in her own life, and doing things that her mother cannot do. For Marie, the life threatening aspect of MS is the realization that her mother's illness is degenerative, her mother's quality of life will continue to decline, and Marie's own life will continue to be affected by the illness.

At the time of her interview, Victoria was 29 years of age, and she was employed as a teacher. She has completed a graduate degree. Her mother was 68 years of age at the time of the interview, and she was diagnosed with parkinson's disease in April of 1997. Victoria lived just outside an urban centre of Newfoundland, and has seven brothers and sisters. She was single and living with her mother at the time of the interview. She is her mother's primary caregiver. She is unhappy about caring for her mother at a time in her life when she feels as if she should be developing her career and social life. Victoria feels guilt and pressure to take care of her mother, and feels as if she has no other choice. She says that her career and life decisions have been influenced by her mother's illness. Frustration and anger has impacted her relationship with her mother. She knows the illness is not her mother's fault, but she blames the illness for the changes within her life. She does not talk to her mother about her frustrations, and purposely tries to keep her feelings to herself, in an attempt to protect her mother.

Jennie was 42 years of age, employed in the health care field, and taking graduate studies at the time of her interview. Her mother was 68 years of age at the time of the interview, and was diagnosed with COPD in January of 2002. Her mother also lives with substance abuse problems. She has one brother. Jennie's mother lives with her, and her partner, and their children in an in-laws apartment in an urban centre in Newfoundland. She considers herself to be the primary caregiver for her mother. When Jennie was a young adult she attempted to get away from her mother's substance abuse problems by moving to another province. For a brief period, she says that she had a "normal" relationship with her mother before moving back to Newfoundland. She relies on the support of her partner and two sons to help her in

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caring for her mother, but she admits the stress takes its toll on her family. Her partner has taken leave from his job because of the stress at home. Their children have also been under stress from the situation. Jennie's children suggest that she should not worry so much about her mother's health and decisions. Her mother's illness has impacted not only herself, but also her marriage and family life.

4.3 Gendered Expectations and Caregiving

Normative family care refers to care that is expected within family relationships (Forbat, 2005). Four of the women in my study agreed that women are often the assumed caregivers to other family members. This responsibility is established through family messages that have been encoded since childhood (Bumagin and Hirn, 2001). Finch (1989), Forbat (2005), and Twigg and Atkin (1994) suggest this assumption of women's involvement in caregiving may be due to past government policies surrounding care benefits. From the 1950's to the 1990's benefits were originally linked to the gendered division of labour, and the gendered family roles of women.

Although there have been changes in the ideological pressures on the gendered division of labor, and the increased involvement of men in caregiving (Kramer, 2005), the women in my study still emphasize the responsibility of care that is felt among women. As Neysmith indicates, women feel a responsibility to care because of the lack of support from other family members (Baines et al., 2001). Mathiowetz and Oliker (2005) explain that women's cultural ideals of femininity regard caring as a natural attribute of women.

The participants in my study echo the literature. They too, as women, expressed feeling responsible for providing care. Mayzee introduces the issue of her father's caregiving expectations of the women in the family. Jennie suggests that women accept caregiving as a natural responsibility of being a woman.

> MAYZEE:...And it's his sister and my sister and mom's sister. It's the women that they rely on. Dad has *never* called on his brother who only lives up the street to help him.
>
> MARIE: Yeah.
>
> MAYZEE: He's a single man, he doesn't have a family or anything.
>
> JENNIE: Um hum.
>
> MAYZEE: But it's always the women that they turn to for that support, and it's expected of the women. And they don't even think of asking the men.
>
> JENNIE: That's interesting because well, I have a brother who's absolutely not involved in any of this.
>
> MAYZEE: Um hum.
>
> JENNIE: Only when he feels [breaks off].
>
> MARIE: Um hum.
>
> JENNIE: Although my mother would prefer his company more than mine. So, it's interesting how the women [breaks off]. And they take readily, we accept the burden maybe? I don't know. We're genetically coded I guess? I don't know.

The responsibility of caregiving is automatically placed upon women. But, as Mayzee and Naomi explain, it is often the single women who feel as if they have no other choice than to comply with society's expectations that they will care for their ill family members.

> MAYZEE: And if there's a single woman, you're *doomed*. You're *doomed* [laughter]. If there's another sibling who has children, "well she has a family." And I worked with a woman in another province whose parents became ill here. And because she was single, the kids here got off the hook, like her

sisters and brothers in Newfoundland. But, no, she had to take leave from work, and come to Newfoundland for six months.

NAOMI: That happened to my sister in-law when her grandparents got ill outside of the country. Her father and his wife, who were retired, doing nothing, and were perfectly healthy, phoned her up, because she was the single grandchild, and she was working full time - "why don't you go down and take care of these old people?" She has a life, you know? She didn't know them anymore than anybody else did. It's just amazing.

As the primary caregiver for her mother, Victoria says that she often calls upon her siblings to stay with her mother, while she does errands or goes out with friends. Just as Mayzee's father often calls upon the women in his family for extra help, Victoria's requests for assistance are often met by other women in the family.

VICTORIA: ...I have a couple of nieces that I'm extremely grateful for because otherwise I wouldn't have a social life [laughs]. But, it's my *nieces*; it's not even my brothers. Like, they'll get their daughters to come up and stay with mom.

MARIE: Interesting, interesting.

VICTORIA: [laughs] You know? It's true.

In Canada there has been an increase in men as primary caregivers (Kramer, 2005). Four of the six women interviewed in my study state that the primary caregiver for their mothers is their father, or step-father. Although the primary care is being done by their fathers, the women still feel an obligation to provide care for their mothers. The women feel pressure, from their fathers, to assist in caregiving responsibilities. All of the daughters describe gendered assumptions placed upon women to provide care. These assumptions often place stress on women, as they juggle their careers, social, and families lives. As a result, the women express feelings

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of guilt, anger, and frustration while attempting to fulfill the pressures and obligations upon them.

As with most of the women in my study, my father is the primary caregiver for my mom, and although most of my mother's personal care and medical care is done by my father, I feel an obligation to assist with care, household chores, and to be there for both my parents. As a woman, I feel as if I am a buffer between my parents. I listen to their frustrations, fears, concerns, and struggles. I try to provide support by offering my interpretations and opinions. I often feel torn between what I know is best for my father, as he struggles to keep his own life, but also be there as a caregiver for my mother, and my mother's daily frustrations of living with a mix of chronic illnesses and related consequences. I believe, that as a woman, I am expected to offer emotional support for both my father and mother. I am attempting to build my education, career, and personal life, while similtanously, I struggle with the responsibility, I feel, to provide solid emotional support for my father as a caregiver, and my mother who is in need of both physical and emotional care.

4.4 Juggling Caregiving in Everyday Life

The women in my study have careers, personal and social relationships, children, and lives outside of caring for their mothers. Three of the women's mothers rely on homecare workers to come into the home for personal and household care. Jennie and Mayzee both agree that homecare is as much for their mother's care as it is for the family caregiver. Mayzee explains to her father that while a homecare worker is with her mother, he can take time for himself, go for a walk, go for coffee, or shop for groceries.

Although a homecare worker can provide the opportunity for the primary caregiver to take a break, and have time for themselves, a homecare worker can also put stress on the household. Mayzee explains that shortly after being accepted for homecare, her parents asked the homecare worker to leave. Her mother and father were uncomfortable with having a stranger in their home, doing their cooking, and cleaning their laundry. Mayzee is upset about this decision, but says that she realizes she has to accept her parent's decision.

Victoria explains that the issue of having a stranger come into their home, and doing her mother's personal care is uncomfortable, but it is necessary. All of the women express the importance of finding a homecare worker who gets along with their mothers, and makes their mothers feel less threatened by the loss of their independence.

> MAYZEE: And that's why I was saying to dad that this thing about a stranger coming into the house...
>
> NAOMI: Yeah my mother said the same thing.
>
> MAYZEE: And cooking in mom's kitchen, and doing their laundry that was way off the wall. ...But, when the thought was *a stranger,* and you know it was "we can't."
>
> VICTORIA:...it's hard, it's very hard to get homecare, or any other support system. But, we had to go and get something because I was just trying to start my own career, I teach, and I have my own life. I can't build it around, well I mean I am in some respects, I'm still building it around mom. Like I couldn't give up working too.
>
> NAOMI: It's hard.
>
> VICTORIA: ...but then it went back to just as you mentioned about not wanting a stranger coming into your house. Not wanting a stranger doing all these things. Now we're after going through two or three [homecare workers] and now we finally have one that works well with mom and stuff.
>
> NAOMI: When my mother first came home from the hospital my step-father wouldn't have homecare either, but he was very healthy and able to take care

of her. But, he needed a break every once and a while. So he would [breaks off], he was having people from his church come in and take care of her and she just *hated* that [laughs]. So, I think that's one of the things that spurred her on to take care of herself and getting better. She just couldn't stand the thought of dealing with people who she didn't really know to take care of her.

The acceptance of homecare is a difficult transition for those who need care. The Grenfell Regional Health Services (2003) reports that the adjustment to homecare may be difficult for those needing care, because of changes in health, a sense of losing control over one's own life, changing self-image, a fear of becoming a burden to others, losing independence, and becoming isolated.

All of the women in my study describe their struggle with juggling caregiving, feeling pressured to care, careers, social lives, and family responsibilities. Naomi describes the juggle, also known as *carrying the load* in Ward-Griffen's (in press) study, between work and being there for her mother. Her mother calls upon Naomi to take her to the hospital, and stay with her while she waits. Naomi works full-time, but has some flexibility in her work, which allows her to go to the hospital and stay with her mother.

Doyal (1995) describes expectations that women face in caring for children, older parents, and their partners while taking on other responsibilities of household and paid work as the "caring tricycle." This is illustrated by Jennie's experience.. Jennie cares for her children and mother, and although, she does not care for an ill partner, she feels pressure from her partner. This is an example of the negative impact of Jennie's mother's illness on her relationship with her family and her everyday life.

> JENNIE: I've raised two sons and I'm raising my mother. There is nobody, *nobody* except my husband who, this has taken a major toll on him and he's saying now "Jennie I married you, I didn't marry all this baggage." And

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we've been married 20 years and he's never said that to me before until this past year. So, he feels like he's trapped sometimes. While he was off sick he said "I feel like I'm trapped in my own house because I can't determine our lifestyle because your mother is bringing this into our lives all the time."

The struggle to attend to daily responsibilities puts pressure on daughter's relationships with other family members, partners, careers, and their relationships with their mothers.

At the time of my interview with Mayzee, I had not experienced the impact of having a homecare worker come into our home. After my mother's lengthy hospitalization, in February of 2006, we accepted the need for homecare. I agree with Mayzee and Victoria, homecare is just as much for the primary caregiver, and family as it is for the care receiver. I agree with Mayzee, when she says that having a homecare worker in the home can cause stress on the household. During the time we had homecare, my father would often help the homecare worker with chores. When he did take time for himself, he confessed that he would often worry about my mother and the new homecare worker. Although the homecare worker was capable of doing personal care, my mother only allowed my father to assist her with such care. We presently do not have homecare within our home because we agree that my mother is capable of doing most household chores herself. My father still takes time for himself, which is much needed, and beneficial for him. I feel pressure from my parents to perform the household tasks once done by the homecare worker. Victoria says that she believes her mother is closer to her homecare worker than herself. She believes her mother shares her emotions and feelings with her homecare worker. Since we have had homecare, my mother and her homecare worker have become close

friends. Since we no longer have her as a homecare worker, she remains a close friend of the family.

The stress of balancing the responsibilities and roles in the daughter's lives puts strain on their own emotions. The next section will explore feelings of guilt, which often arises from attempting to balance responsibilities of everyday life.

4.5 Guilt

The effects of policies that are based on gendered family roles and the notion of normative family care was discussed in my interviews and focus groups. The problem in referring to family caregiving as normative family care is that referring to is as such has a negative impact on family members who choose not to, or cannot cope with, caring for a family member (Forbat, 2005). Phillips (1994, 2000) reports that guilt is felt by women who juggle responsibilities, which may lead to depression, anxiety, and stress. All of the women in my study describe feelings of guilt when pressured to care for their mothers. Guilt results from the stress of struggling to care, and also from choosing not to become involved in primary caregiving.

> MAYZEE:...I'm not going to do *everything*. I have a life too. I started a job because first I wasn't working, I had no excuse, I could be there. But you know I got a job and it was part-time so I was flexible on hours and then I got full-time. My hours aren't flexible anymore. I have to be there full day...But, the guilt is there. You know I feel that I should be doing this.

Opposing feelings are simultaneously experienced due to societal and family pressures. This is described by Connidis and McMullin (2002) as sociological ambivalence. Feelings of guilt and anger are simultaneously felt by the participants in my study. The feelings are not only psychological emotions, but are shaped by the

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structured social relations, and social expectations of women's roles in family

caregiving.

> VICTORIA:...I was in the process of getting ready to move out *on my own* and then all of a sudden there was a major turn of events. Dad got really ill, and passed away, and mom was left there by herself. With a major illness herself and had to be cared for. And me, the youngest, and unattached, that left me with the homecare responsibilities. At first, you do what you have to do because if you don't, I felt guilty if I wasn't there for my mom.

> KIM: Um hum.

> VICTORIA: But, on the other side of the coin, there are some days where I feel so frustrated, and so angry because I feel like she's taking away part of my life. And it's really difficult.

Marie feels guilty because of her financial dependence on her parents. The

women in my study feel the need to protect their mothers and the need to support

them.

> MARIE: ...huge guilt. And I don't know what to do about that and they don't *want* me to feel guilty but I do. I feel guilty because of financial obligations sometimes. So, basically this Christmas I wasn't going to go home. And I was okay with this and little did I realize that my family was not okay with that [laughter]. So, mom was actually very adamant that I come home and I was glad I did, but they paid for that. Mom's not working, dad, it's not a high paying job. And my brother goes to school full time and has no job. I was funded to go to school so I'm a little less of a worry for them. He wants to retire and he can't because he doesn't know what's going to happen to mom. What if she needs some expensive treatment and eventually needs a new van so they can have the wheelchair lift thing, there's all these uncertainties. So, I feel guilty for being an obligation to them. I need to be free, and actually, you know, for the first time in my life I want to support them. Like I'd consider sending money to them even though I have nothing [laughs].

The normative family care model (Forbat, 2005) is problematic when applied

to Marie's situation, because she is not living in the same province as her mother and

therefore, she cannot fulfill the expectation of caring for her mother. She sometimes

questions her own decisions about not living at home, and caring for her mother.

MARIE: Some days are good, some days aren't. I don't know if you get this but some days it just hits you. And you're like what am I doing? Why am I not with my mom? Why am I not there? [Pause] and then other times it just sort of fades because life takes over, you know "oh my God I have everything else like thesis work" [laughter]. And then it just sort of fades and then I get a call from my mom "I haven't heard from you in a while." And I'm like *"oh"* [laughter].

MARIE: ... sometimes I just get so wrapped up in this disease that I'm always wrestling these issues and I feel so guilty, I feel so torn and I want to help.

The struggle of juggling caregiving with other responsibilities of everyday life, having lives of their own, and living separately from their mothers, places strain on the daughter's lives. All of the daughters in my study express feelings of guilt, as if they could, or should, be doing more to care for their mothers. In some instances, the daughters describe feelings of anger and frustration, as a consequence of attempting to balance their own lives, while caring for their mothers.

As I listened to the stories of the women in my study, I feel that I most identify with Marie and Victoria. Marie and Victoria were both in their 20's, at the time of their interviews, and they were completing their education and beginning careers. I identify with Marie, as she describes feelings of guilt, because she is away from home, completing her education. I too was away from home and attending university when my mother had a heart attack. I understand the feelings of guilt, of not being there to offer support, and of having my own life. Although, I know I am a capable young women with many opportunities to advance my education, career, and personal life, I sometimes feel guilty about concentrating my energies on something other than emotional and physical support for my parents. My education and career decisions have been influenced by my mother's illness. But even if I were given the opportunity to make the decisions again, I would not do things differently. As a result of the

influence of my mother's illness on my life decisions, like Victoria, I sometimes feel

angry. I feel as if the illness has taken away many opportunities in my life.

4.6 Protecting Mother

A number of the daughters in my study report that since their mother's

illnesses they purposely try to keep things from their mothers, as a means of

protecting their mothers from undue stress. In the following excerpt, Naomi describes

her relationship with her mother as being close and built on trust, but since her

mother's illness, their relationship has changed.

> NAOMI: ...I'll tell you one thing that did change - for your study - since it's about the relationship between mothers and daughters. All the time I was growing up I always felt that I could dump all my problems on her too. Whenever I have problems now, or something like that, I don't talk to her. And that's how things have changed...But that's sort of, I mean, I think that's the kind of relationship that we had before.
>
> KIM: Is it because of you don't want her to [interrupted]
>
> NAOMI: I don't want her to have to worry about me and my family anymore. I mean she's got enough to deal with...yeah you know. I think she's fine now and she doesn't need to be worrying about me and my family.

Fingerman (2001) concludes that daughter's who purposely avoid conflict and

mask their emotions report more satisfaction from their relationship. Naomi

purposely avoids discussing her problems with her mother and admits that this tactic

works in her situation.

Tarkan's (1999) study suggests that keeping things from their mothers leads to

conflict, and further problems in the mother-daughter relationship. In my study,

Victoria reports that she does not talk openly with her mother because she does not

want it to lead to further argument. Victoria supports Tarkan's (1999) conclusions in the following passage.

> VICTORIA: Mom I think, we don't talk a lot about it, I'll be honest. I think mom confides in her homecare worker a lot more than she do in any of the family.

> KIM: Uh hum.

> VICTORIA: But every now and then [pause] a couple of weeks ago this happened. It does happen every once in a blue moon. I'll break down and just start crying and then mom wants to know of course what's wrong with me. So then like I try not to tell mom really what's bothering me because I'm like "mom it's going to hurt you" to know what's wrong with me.

Whether the daughters avoid open communication with their mothers and receive satisfaction from doing so, or report further conflict from avoiding open communication, daughters keep their problems to themselves, in an attempt to protect their mothers from the negative impact of the illness on their lives, and the negative impact on their relationships with their mothers. The daughters in my study describe their attempts to protect their mothers from conflict, by the avoidance of discussing problems in their lives. The literature indicates that women who use this tactic report both positive relations and negative relations with their mothers. The women in my study also describe positive outcomes of avoiding conflict, but others report that the avoidance leads to further frustration of keeping their feelings inside themselves. Connidis and McMullin (2002) suggest that confrontation, conflict, and acceptance are ways of resolving ambivalence. The women in my study avoided confrontation and by doing this accepted the feelings of social ambivalence.

Another means of the daughters providing protection for their mothers is the protection from the stigma of illness. Marie reports that she feels the need to protect her mother from the awkwardness of using her motorized mobility scooter in public. I

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interpret this as a way of attempting to protect her mother's feelings surrounding her loss of mobility, and her loss of independence.

> MARIE: She wants to try as hard as she can so we used to go shopping together on her scooter. And we joke, we joke to keep it light. I'll give her a rough time like "Oh I can't keep up to you in that thing." [Laughter] "You're whipping around those corners." [Laughter]

Like Marie, I sometimes feel the need to protect my mom from the outside world. For example, when my mother goes to a social event, I often worry about the possibility that people around her will be rude to her because she's in a wheelchair, or that people will stare at her. As a teenager, I was embarrassed of my mother's illnesses because I could not do the same things with my mother as other teenager could do. I do not feel embarrassed anymore, but I do feel the need to protect her from feeling the impatience and rudeness that some people assert with people who have disabilities.

4.7 Coping with the Stigma of Illness

Goffman's (1963) work on stigma indicates that a person's appearance (their attributes and characteristics) may influence the way others identify them. A stigma refers to an assumption made based on a person's attribute. As Goffman (1963) describes, a stigma is "an attribute that is deeply discrediting within a particular social interaction" (p. 3). A stigmatized person may feel inferior to others, causing her or him to experience shame or self-hatred. The stigmatized person may become isolated from others because of avoidance of social situations, which, in turn, may lead to depression, anger, anxiety, and jealously (Goffman, 1963).

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Three of the five women in the focus group comment on their mother's feelings of shame or embarrassment of going out in public because of their illnesses. The root of this embarrassment, according to the daughter's descriptions, is the stigma of illness. Marie describes an incidence when her mother refused to go to church, on Christmas Eve with her family, because she was embarrassed due to her incontinence. Her mother was fearful that people would notice her going to the washroom and would know that she was ill. Naomi also discloses that her mother would need extra time to put her makeup on and have her hair done before she went out in public. Naomi says that her mother was never concerned with her appearance before she became ill, but during her illness her mother would pay more attention to her makeup and hair, so that people would not know she had a tumor and was undergoing treatment. One more example comes from Victoria in the following passage.

> VICTORIA: ...It's weird. And you mentioned the ashamed part. First when she was diagnosed with the disease, she'll stumble and she'll say "Oh I look like I'm loaded drunk." And she is ashamed. Like, she stopped going to church because she was so ashamed of the sickness, and she thought everybody would be staring at her... And that was a big issue. Right? And then it took years for her to get over that and start going back to church again, and go to the supermarket again...Because she was afraid that people would be looking at her. She was just so conscious of it.

The mother-daughter relationship may be influenced by the stigma of illness. Humour is a way of coping with the awkwardness caused by illness and the stigmas surrounding it. Marie and Jennie describe the humour that they share with their mothers. Both daughters say that they try to make their mothers laugh and keep the mood light. Although the stigmas surrounding illness may add anger and stress to the

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mother's life, the humour shared between mother and daughter may strengthen their relationship.

4.8 Support for Caregiver and Self-Care

The women in my study agree that there is not enough support services for caregivers. Further, the services that are available are difficult to access. Government employment insurance category for caregiver payment is only available if the caregiver and ill person meet certain criteria. For example, the care receiver must be in the last 10 to 15 weeks of life, or if applying for an income tax claim, the claimant must make a certain amount of income, or must be working a certain amount of hours. Daughters also state that services, such as homecare, are difficult to access. There is a large amount of paperwork, physician recommendations, assessments, and payments involved in applying for homecare services.

The women in my study also discuss the limited access to counseling and mental health services. All of the women in my study agree that such services have a complicated process of assessments, referrals, and waitlists. Some of the women have private insurance that provides coverage for mental health and counseling, while others who need such services do not have the means to pay for such out-of-pocket expenses. The following discussion describes the need for accessible mental health services.

> VICTORIA: ... I went and sought counseling from a psychologist through the university that was free to me as a student. Once I left university I don't even know now, even if I wanted to see a psychologist, how I'd go about doing it... I don't think you should have to wait six [months], you know what I mean? If you're in a situation where you need that kind of medicare, I don't think you should have to wait six months to go see somebody.

JENNIE: My husband and I have had intermittent counseling...And we went through EAP [Employee Assistance Program] at work. So, if you have a steady job, sometimes you have an EAP option. And we intermittently, over the past two years as we see a need, we go to counseling individually or together to the same counselor...Well, they'll refer you to a psychologist. I don't know if you have any insurance? A doctor's prescription will get you, if it's covered by a plan. But the plans are so variable [pause].

VICTORIA: I think that's such an important thing for somebody. Like when you're dealing with stuff like that it's hard...

MAYZEE:...I was looking and I was like "EAP, wow. This is amazing." And it's almost like [sigh] one of those life preserver rings you know, I can see it now. There's support available when I need it.

JENNIE: The fact that it is through EAP, there's 10 visits per year.

MAYZEE: Yeah.

JENNIE: So, I find I'm very selective now about how I'm going to use it.

Employee Assistance Program (EAP) is a confidential, short-term counseling service offered by some employers. A referral from an EAP trained person, within the workplace, is needed. Counseling services are provided for employees and their immediate family on issues such as job stress, relationship problems, eldercare, childcare, harassment, substance abuse, separation and loss, balancing work and family life, financial and legal issues, and family violence (Canadian Centre for Occupational Health and Safety, 2007). The major limitation to EAP is that not all employers offer EAP services to their employees. Such counseling services would be beneficial to employees who are struggling to maintain their work and family lives.

Although I am not in the work force, and do not have employee assistance, I have taken advantage of the counseling services available through Memorial University. My experience in availing of this service was positive. I telephoned the counseling office at the university and was asked if I needed immediate attention. I

was not in an emergency situation, therefore, I had to wait approximately a week for an evaluation appointment. Once I was evaluated, through the use of a questionnaire which addressed my feelings and the intensity of my feelings, my appointment was made approximately one week later. I went to weekly appointments, with a trained counsellor, for about 2 months. I decided to stop going because I felt as if I had explored and discovered emotions that I had not examined before. Although it took approximately 2 weeks, from the time I initiated contact with the counseling centre to the time of my first appointment, I am pleased with the wait time it took to see a counsellor, and the quality of care I received. I believe the waiting time would have been shorter if I had expressed an emergency. The wait time was also shorter than most counseling services, and is free of charge because I am a student.

The women of this study emphasize the importance of self-care and learning to cope with the frustrations and stress of their mother's illnesses. Mayzee admits that when her partner suggested she try writing her feelings down on paper, she did not think it would be useful. She finally tried it, and she says that it does indeed release some of her frustrations. She also says that if she does not want anyone to read what she has written, she burns the paper when she is finished. Jennie agrees that journaling is a way of releasing her frustrations. She says that she writes her thoughts rather than taking her frustrations out on her partner or children.. But, she admits that she tends to "spout and spurt things all over." Victoria reveals that she often keeps her feelings to herself and does not like to show her emotions. But, she says that journaling is a way of letting her feelings out on paper. She admits, "letting it all off your chest is good."

In terms of self-care, journaling is one way the daughters may deal with

frustrations in their lives. This was the only outlet discussed in the focus group. I believe that journaling, as a form of communication, may indeed be a way of releasing frustrations. As I have previously discussed, many of the women in my study revealed that they tend to avoid talking to their mothers about their problems. Journaling may act as a substitute for the open discussion they once had with their mothers.

4.9 Daughters' Concerns for Her Own Health

As a daughter watches her mother's physical deterioration due to illness, she may experience feelings of helplessness, lack of control, anger, and frustration. A daughter may respond by expressing a fear of medicine, physicians, the body, and illness (Edelman, 1994). A daughter from Edelman's (1994) study describes reading her mother's medical file and wondering what her mother was thinking about while she was undergoing tests and exams. It was at this point, that she realized her mother was not a heroine. It was then that she feared that she was just like her mother, not only in her physical features, but also in her vulnerability to illness. Watching her mother go through illness, treatments, and tests, a daughter may feel vulnerable, becoming aware of her own mortality.

In Edelman's (1994) and Tarkan's (1999) studies, many women begin to see a physician regularly, and read the current developments and news surrounding the illness, but others avoid regular physical examinations and visits to the physician in fear of developing the illness. Tarkan (1999) describes some women who obsessively check their breasts for lumps, and are so worried about developing cancer that they develop hypochondira. Edelman (1994) reveals that daughters whose mother's had

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passed away, increasingly worry when they reach the "magic number" (p.222), or the same age of the mother at the time of her death.

Unlike many participants in previously cited research, the majority of the women in my study report they are not overly concerned with their health, and the risk of developing the same illness as their mothers. Although most of the women admit they are not concerned with their own health, they all report that they attempt to eat healthy food and exercise. Some even avoid behaviours that are associated with specific illness risks (for example, not smoking and avoiding the use of pesticides). Two of the participants report that they keep up to date with research and developments of their mother's illnesses. All women admit to knowing the symptoms of illness, and are able to identify them if they develop such symptoms. Therefore, although the women state that they are not overly conscious of their health, their behaviour shows otherwise.

I was surprised that the women in my study revealed that they were not overly concerned with their own health. I undergo annual blood work and examinations to check for diabetes and heart disease. I think about what my life would be like if I develop MS. I would not like to burden my loved ones with caring for me, if I develop MS. I think about my career and wonder how it would be impacted by illness. Although I do not obsess with the uncertainty of developing this disease, certain situations have made me ponder the possibility. For example, if drop something, lose my balance, or feel shaky, I often think that it could be the early signs of MS. I believe the possibility of developing the illness will always haunt me, but it is up to me to be aware of changes within my body.

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4.10 (Re)Defining Life Threatening Illness

Life threatening illness is an illness that is expected to shorten the life of an

individual and impact the cause of death (World Health Organization, 2000). All of

the participant's mothers in my study fit into this description. Although in the case of

four of the six women's mothers, death will be a direct result of the illness, but in the

case of Marie and Victoria, their mothers deaths may be a consequence of a life

threatening illness. I asked Marie why she was interested in participating in my study

on daughters with mothers who have a life threatening illness, since MS is often

described as a chronic illness rather than life threatening. She explains that she

defines MS as being a "life altering" illness, which impacts her relationship with her

mother and her father, as well as their relationship with her.

> MARIE:...It eventually will end somewhere... its life threatening, it's
> something that's not as immediate as cancer, or a heart attack, or surgery,
> because you don't know what might happen but to me it is. It's life altering in
> that sense, it changes *everything*. It changes how you relate to your parents,
> how they relate to you, it changes what you do for the rest of your life.

Marie further explains MS as a life threatening illness by saying:

> MARIE: I consider it [the illness] to be life threatening - it changes the fact
> that I know that one day I may have to give up my career, and come back and
> be ok with that. Knowing that I may be faced with that moment of death, that
> you don't think about on a regular basis...but in that sense it's life threatening
> to me. Because I'm going to have to be there when she is completely
> incapacitated, when she's completely bed ridden. Maybe that's what I mean
> when I say it's life threatening. Being mentally prepared for that moment in
> advance. We don't know when it's going to happen, but I'm aware that this
> will happen, and I'll do what I can for now, and realize that when I feel that I
> need to drop everything, and be there for her then I will do it. So, that's the
> life-threatening part.

When I began my research, I had a difficult time in trying to define MS as a

life threatening illness. I knew that the illness itself was not a cause of death, but part

of me also thought of it as being life threatening. However, Marie describes MS in a

way that has clarified my definition of MS as a life threatening illness. The impact of the illness on family members and caregivers - knowing that the illness will slowly progress, is the defining factor of MS as a life threatening illness.

As with Marie, I asked Victoria how she defines PD as being life threatening. She hesitates and says that when she received my recruitment letter from an email listing she had given some thought into PD as a life threatening illness. Like Marie, Victoria says that the illness is not immediately life threatening, but it is life changing for both her mother and her own life.

> VICTORIA:...it's not immediately life threatening. It changes people's lives dramatically like 180 degree turn like it's changed mom's life, it has changed my life.

I had the sense that Victoria did not think of PD as being life threatening until she became involved with my study. When she expressed interest in my study, she emphasized that PD is a chronic condition, and her mother may live for many years with the illness. She asked me several times if I still wanted to include PD as a life threatening illness in my study. I agreed that I understood her hesitance in describing the illness as being life threatening, it is not an immediately life threatening illness such as cancer or AIDS (although there are many options available for such illnesses, and may not be as immediately life threatening as they were at one time). Although PD and MS are not generally considered to be life threatening, in terms of length of life, Victoria and Marie define their mother's illnesses as life threatening because the illnesses have threatened their way of living.

4.11 Personal Connections with Social Contexts

Fielding (1993), Wilkinson (1998, 2004), and Zeller (1993) reveal that participants who disclose personal stories within a group of people who have experienced similar situations feel that their feelings are reinforced, and accepted by those in the group. Intimate details are often exposed during focus groups because of the supportive environment that is created within the group setting. There is less pressure to be socially acceptable in a group, rather than in one-on-one interviews (Farquhar & Das, 1999; Frith, 2000; Kissling, 1996). Contrary to much of the literature on focus groups, the women in my study discuss social issues during the focus groups. As well, during the individual interviews, the women share personal narratives, rather than social issues.

In my study, the conversation often links the daughter's personal stories within larger social issues. For example, Marie suggests it is unfortunate that caring for an ill mother is not recognized, and is not supported and compensated by government. Jennie expands on this topic by explaining the regulations around the available tax benefits, and goes on to elaborate with her own experience in applying for this support. The personal and broader social connections, made by the women, may have been due to the women's high education levels, and their awareness of social issues. The dialogue between Marie, Naomi, and Jennie reiterates the need for government funding for caregivers.

> MARIE: It means that you're going home from work to work again at a different type of job. It's too bad that it's not recognized somehow.
>
> NAOMI: I guess there is a tax break that you get.
>
> JENNIE: There is a tax break and we do avail of it. It's about $3000.00 maximum per year, and we are eligible for that. And it can only be claimed on the higher income earners. So in my situation, that's my husband. But, we

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build that into our income tax every year. You can claim up to $3000.00 as a credit. So, you're not taxed on that. That only means that you see $1500.00.

NAOMI: Yeah it's not very much.

JENNIE: $1200.00 or $1500.00. But, that's built into how we do our income tax. What's that compensating? Absolutely nothing.

NAOMI: It's compensating your husband, and not you. And you're doing most of the work.

The interactive nature of the focus group allows for comfort in disclosure, as well as an opportunity to discover the topics of importance to the participants (Wilkinson, 1998). The women in my study disclose such topics by asking questions of each other. For example, Marie asks if there are any other supports available to caregivers. Naomi responds by suggesting the Alzheimer's respite adult daycare. Jennie continues by disclosing her experience about the strict criteria needed to meet the qualifications of such supports. The following excerpt confirms the need for caregiver support, and the difficulty in getting such relief.

MARIE: Is there anything else other than homecare? Is there any kind of temporary relief? Any kind of respite?

NAOMI: I know the Alzheimer's Society has adult daycare...I think if you're within a certain area you can pick up the person and bring them in for the day. It gives the caregiver a break.

JENNIE: There's a whole whack of hoops to jump through. I worked in healthcare over the past five or ten years. So I'm quite familiar with the things that are out there. There is very strict criteria for those things so some people match, and some people don't.

The group dynamics of a focus group allow for debate, discussion, and questioning among participants. The researcher can allow the participants to direct the flow of the conversation, and therefore, explore issues of importance to the

participants (Cooper, Diamond, & High 1993). Many feminists are in favor of this method, because of the shift in power balance (Wilkinson, 2004).

The one-on-one interviews that took place, prior to the focus groups, focused on the personal narratives of the mother daughter relationships, and the impact of illness. Johnson (2002) argues that in-depth interviews provide a greater opportunity for disclosure of information than focus groups. He refers to "deep conversation" which is the revealing of personal experience of going beyond the superficial details of the everyday, and into the meaning of lived experience. During the interviews with the women in my study, daughters share their personal accounts of their decisions, emotions, opinions, and experiences in their daily lives. For example, during my interview with Victoria, she discloses her reactions to her mother's illness and the impact it has had on her life. The emotions she describes are not typically viewed as being socially acceptable, but I feel that the trust and rapport that was built between Victoria and myself, made her feel comfortable in discussing her feelings. The following excerpt is an example of her description of how she feels her mother's illness has impacted her life and her reaction to the illness.

> VICTORIA: ...First when dad died and I was left to take care of her I used to hug her all the time [whispered, crying, pause]. When I'd make sure she was in bed, I used to make sure she was in bed...and settled away before I could even go to bed. It's like having a youngster [laughs]. And I'd give her a kiss goodnight. I just can't do it anymore [whispered, crying]. I'm to the point now where I just can't do it, and I know it's not her fault, she didn't ask for it, but [pause] I just *hate* what it has done to my life so much that I've been taking it out on mom.

As Johnson (2002) concludes, interviewing provides the opportunity for disclosure of perspectives from the participant's everyday life. This excerpt from my

interview with Victoria demonstrates the impact that her mother's illness has had on her life and her relationship with her mother. It also describes Victoria's emotions and understanding that her mother cannot be to blame for the illness, but she feels as if she is directing her anger and frustrations onto her mother.

After the tape recorder was turned off, and the interview was finished, Jennie and I chatted more about her strained relationship with her mother. She admits in the interview, that when she talks about the stress on her family it is "at a distant arm's length," which means she distances herself from the situation. When the interview was over, Jennie admitted that she had just told me things that she had never told anyone before. I believe that Jennie would not have described her relationship with her mother in such intimate detail, if she had been in a group setting. The one-on-one interview setting provided the comfort needed for disclosure of the participant's personal life.

The discussion between the women in my study highlights social or cultural issues, which are reinforced by examples from their own lives. The discussion of social issues – rather than personal issues - may have occurred because the women had not previously known each other before the meeting, and were not comfortable in disclosing personal information. Each of the daughter's relationships with their mothers are different and set within a unique life course. The nature of each of the mother's illnesses are different, therefore, the women may not have been comfortable in discussing the intimate details of the illnesses with the other women in the focus group. For example, a daughter may not feel comfortable disclosing information about symptoms or personal care involved in certain illness to women who are unfamiliar with the aspects of that illness. The women may have been hesitant to talk

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about personal issues in an attempt to protect their mothers' life stories. It may have been possible for continued openness and disclosure of personal narratives if the group of women had continually met over a period of time, and created a relationship with each other.

4.12 Conclusion

In this chapter, I introduce the women in my study, and the main themes that emerge from the interviews and focus groups with the participants. The themes include gender expectations and caregiving, juggling caregiving, guilt, protecting mother, coping with the stigma of illness, support services for daughters, concerns for their own health, defining life threatening illness, and personal stories within larger social issues.

Some daughters acknowledge that they took on more of the adult role throughout their childhood relationship with their mothers. Those daughters felt the responsibility to protect and care for their mothers during their childhood, because of abusive relationships within the family or because of illness. Some daughters describe their relationship with their mothers as well as the rest of their family as close.

Daughters often feel their mothers' illness has made them feel the need to be supportive for their mother. When trying to understand their mothers' emotional needs and wishes, daughters report the importance of patience and understanding. Some daughters indicate the need to protect their mothers from any discomfort. The need to protect may mean openness in the truth regarding their illness. Other daughters feel the need to protect their mothers from the stigmas of illness held by the general public. While some daughters notice their relationships with their mothers

had gotten closer throughout the illness, four of the women describe a negative change in the nature of their relationships with their mothers. All of the daughters also describe feelings of anger, guilt, pressure, and being trapped within their situation. Caregiving sometimes causes the daughters to feel anger toward the illness and the impact it has had on their family and social situations. The pressure to take care of their mothers, as described by some women, often leads to feelings of being trapped and, as a consequence, feelings of guilt arise when these expectations of caring for their mothers are not met. The daughter's agree that gender plays a role in caregiving expectations from their mothers and other family members.

All of the women in this study admit they are not overly concerned with their own health. They indicate the importance of regular physical tests and exams. All of the daughters convey that individuals are responsible for their own health. The daughters highlight the importance of eating healthy food, and getting regular exercise. All women state that there is a need for women to become proactive in their own healthcare. They explain that women's symptoms are often overlooked, both by themselves and the medical community, or are blamed on other factors such as age or menopause. The daughters indicate a need for women to put their own health first, to advocate for regular testing, and the need to be taken seriously when reporting their symptoms to physicians.

The women in my study define life threatening illness not in terms of time left to live, but in terms of the illness's impact on the life of her mother and herself. The daughter's in my study challenge the traditional definition of life threatening illness.

Chapter Five: Reflecting on the Women's Narratives

5.1 Introduction

In this chapter, I will provide a refection on the women's narratives and the impact they have had on my experience of conducting this research and on my understanding of having a mother with a life threatening illness. I will provide the limitations and benefits of this research. Finally, I will make recommendations for future research.

5.2 Reflection on the Narratives and My Own Thoughts

A collaborative methodology allowed me to share my own feelings and experiences with the women I interviewed at all stages of the research. When the women first expressed interest in becoming involved in my study, I shared the reason for my own interest and briefly told them of my experience of being a daughter of a mother who lives with a life threatening illness. I told my story as a way of disclosing my standpoint and to ground myself, so that there were no power imbalances between the daughters and myself. While reading the transcripts, I reflected on the narratives. I recorded my own reactions to what was being said by the daughters. This section will further reiterate and discuss my response to the daughter's narratives.

Although this study was collaborative in nature, throughout the course of writing this thesis, I struggled with separating my own experiences from the women in my study. My personal attachment to the study was both difficult and fulfilling. When I began writing the thesis proposal and throughout the stages of writing, it was often suggested by those around me (academics, family, and friends) that I take a break from writing or take some time to evaluate what I was doing because of the emotional involvement. At the beginning of this study, my mother's health was

stable. I had gone through stressful situations with my mother's health which I described as my personal narrative in the introduction of this study, but during the course of writing my mother's health deteriorated. I have spent many hours of writing this thesis while at my mother's bedside in the hospital. I do not try to separate myself from the women in my study because it is from my personal experiences that I chose to listen to other daughter's stories. I believe it was through my understanding of their emotions and struggles that I obtained such rich personal accounts.

When I reflect on my interview with Marie, I remember thinking that it was different from the other interviews. The conversation between Marie and I flowed easily. I had initially thought the easiness was because I was becoming comfortable in doing interviews, and hearing the women's stories of their mother's illness, but as I reviewed the transcript and recorded interview, I became aware that the experiences we share are very similar – not only did our mothers share the same illness, we are close in age, we lived in different provinces than our mothers when our mothers were seriously ill, we both feel guilt because we are furthering our lives while our mothers are not able to do the things we are doing, and our fathers are the primary caregivers for our mothers. During the interview, I felt that I could directly relate to her experiences and feelings. Instead of an interview style, it was as if we were comparing stories. It was amazing how many times we both said things such as "I'm sure you know exactly what I'm talking about" or "I know, that sounds so familiar." After this interview, I started to question the focus of the interview. I was worried that it was only a comparison of our mother's illness, symptoms, and treatments.

I was amazed by the complex situation that Jennie described about the discrimination her mother received from the health care system. As Jennie described,

her mother lives with a "self-induced" illness (substance abuse problems) as well as emphysema. Her mother abused both alcohol and prescription drugs which has threatened her mother's life several times. Jennie described a number of occasions when her mother was brought to the emergency room and was ignored, had to wait unreasonable hours for medical attention, or was refused treatment which Jennie attributes to her "self-inflicted" illness. I was surprised to hear of this discrimination. This discussion made me think about the nature of illnesses and the pressure that is put on the individual and self-induced behaviors. I began to question the future in physician's decisions in treating illnesses related to smoking and obesity, as such illnesses seem to be due to preventable behaviors or lifestyle choices. Often when considering such illnesses, there is a danger to put blame on the individual, rather than on social influences. If health promotion becomes the focus of healthcare, I believe we are in danger of creating a form of healthcare discrimination, due to blaming the individual for "self-induced" illness.

Through my experience in listening to the narratives told by the women in my study, I began to learn more about myself and my own feelings and responses to my mother's illness and the impact it has had on my own life. In particular, my interview with Victoria had a great impact on realizing my own feelings that I had repressed. Victoria read a speech she had given at a parkinson's disease conference on her feelings about the illness. She described the anger and hatred she felt about the things that her mother is no longer able to do, and how the illness has impacted her own life as the primary caregiver to her mother. She described her lifestyle as a single 28 year old woman, who manages a career of her own while living with and caring for her mother. At the time of the interview, she said that she could not give her mother a hug

because of the anger she felt. This anger has made her feel guilty and depressed over her life situation. The interview with Victoria left me thinking about my own life and feelings about illness. Several months later, I began to discover my own feelings of masked anger that I had perceived as depression. With the help of a counsellor, I examined my responses and feelings of guilt, depression, and repressed anger. The most surprising emotion I discovered within myself was of repressed anger. Women are often encouraged to hide and ignore their anger (Cox, Bruckner, & Stabb, 2003; Lerner, 2005). I had hidden my anger and resentment so much that I was in denial. I believed that I was not an angry person, and I did not see the purpose of expressing such an emotion. I realize that I was angry about the impact of my mother's illness on my life decisions. Like many of the women in my study, major decisions in my life (for instance, the decision not to move out of province to attend graduate school and moving back into my parent's house) have been influenced by my mother's illness.

5.3 Limitations and Strengths

The recruitment was based on voluntary participation, which means that women who are less comfortable talking about their concerns for their own health, their relationship with their mother, or their mother's illness and death are less likely to come forth, and are therefore, not represented in this study.

This study did not focus on the cultural aspects of deciding to become a primary caregiver. In Newfoundland and Labrador, the value placed on family relationships, caring for family members, and the ties that bind family members were not discussed in this study. It may be useful to further examine the cultural influence of caregiving in Newfoundland and Labrador because of the value placed on

independence, kinship, community, and the family (Anderson, Crellin, & O'Dwyer, 1998). Elder care in Newfoundland and Labrador has often been the responsibility of the family. Long-term care facilities are often viewed as places for older adults who do not have a family to care for them (Lewis, 1997).

Farquhar and Das (1999), Firth (2000), Kissling (1996), Wilkinson (2000, 1998), and Zeller (1993) suggest this type of study may be beneficial because many individuals find it cathartic and meaningful to talk about sensitive issues, especially when it is within the company of others who have experienced similar situations. During the second focus group, the women in my study admit that they found it reassuring and helpful to discuss their concerns and experiences with other women who understood their emotions and struggles while caring for their mothers.

This study provides an in-depth account of daughter's experiences of their mother's life threatening illnesses and the impact of illness on their relationship with their mothers. The design of the study was unique because of the number of methods used to examine the narratives – individual interviews and focus groups. This study also includes a unique reflexive piece. As a daughter of a mother who has a life threatening illness, I include my reactions to the participant's narratives with my personal experiences of the impact of illness on my relationship with my mother. This experience has allowed me to examine and express personal emotions that I had not acknowledged before this study.

This study provides a distinct contribution to the research on caregiving. Although the mothers described in this research were living with a range of illnesses, the daughters expressed similar reactions to the illness and its impact on their relationships with their mothers. All daughters expressed the frustrations of the

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gendered nature of caregiving, juggling caregiving with career and family responsibilities, feelings of guilt, and feeling obligated to protect their mothers from the stigma of illness. This study indicates that daughters experiences of having a mother with a life threatening illness were similar, although their mothers had different illnesses.

5.4 Recommendations for Future Research

During recruitment, I had five inquiries from women whose mothers had already passed away. Such women were interested in talking about their experiences and their relationships with their mothers during their mother's illness and death. Unfortunately, I could not include them in my study as they did not meet the criteria of having a mother still living with a life threatening illness. I did not include these women because their experiences may have included feelings of grief and bereavement which were not the focus of this study. This interest may suggest a need for community-based support in the area of motherloss.

The women in my study suggest that their male siblings do little of the caregiving for their mothers. It is often the women of the family who are responsible for taking care of an ill mother. The need for in-home care is increasing, consequently, the need for caregivers is also on the rise. Some scholars (Kramer, 2005; Thompson, 2005; Wagner, 1997) predict that male caregivers will become more prevalent in the future. There is a need for research focusing on men as caregivers, to improve and understand the role of all caregivers in order to provide better policies and services for the ill, the caregivers, and the families involved.

This study highlights the need for support for caregivers. I plan to continue with future study on the Compassionate Care Leave Benefit for women. There is a need for further research on the recently developed Compassionate Care Leave Policy and its use among women, particularly in the province of Newfoundland and Labrador. Due to the way the current policy is written, many women, in particular women living in rural areas, may not qualify for employment insurance benefits due to the sporadic nature of women's involvement in the paid workforce. For example, part-time work, seasonal work, women with little education, low income, single mothers, immigrant women, Aboriginal women, and women with disabilities may not be eligibile to receive this benefit (The Status of Women, 2004).

Further research on the effects of out migration of young people who leave their homes to find work in other provinces or countries and its impact on the future of family caregiving is needed. There is a concern that the future of caregiving in this province and in Atlantic Canada may be influenced by a shortage in family caregivers.

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Chapter Six: Final Thoughts

6.1 Summary of Study

This study focuses on the changes in the relationship between mothers and daughters in the face of the mothers' life threatening illness. I interviewed six daughters from an urban area of Newfoundland. Five of the six women took part in a focus group and three of these five women took part in a follow-up focus group. The interviews and focus groups were taped, transcribed and analyzed by Mauther and Doucet's (1998) voice centred relational analysis.

My objectives in conducting this study were: a) to examine the daughter's perspectives and experiences in the mother-daughter relationship; b) to understand the impact of the illness in relation to the daughter; and c) to identify daughter's concerns for her own health.

In listening to the daughter's narratives of their experiences in their mother-daughter relationships, the findings from this study reveal that the impact of a mothers' illness on the mother-daughter relationship is deeply embedded in an already evolving relationship. This relationship is influenced by the social and cultural assumptions that are placed on mothers, daughters, illness, and caregiving. Various scholars (Fingerman (2000, 2001), Finch (1989), Poirer and Ayres (2002), Phillips (2000) Pohl, Boyd and Given (1997), and Ward-Griffen (in press)) indicate that the mother-daughter relationship before the illness influences their relationship after the illness, caregiving, and the emotions that develop throughout the mother's illness. Family relationships, social and cultural issues (for example, sexual orientation, family violence, and substance abuse) factor into the experience of illness and relationships. When illness occurs, it acts as another aspect of an already complex,

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evolving relationship between mother and daughter. Personal issues are affected by the illness. Therefore, there are no concrete conclusions that can be made in regard to the impact of a life threatening illness on the mother-daughter relationship. Family relations, social and cultural issues such as violence against women, alcoholism, substance abuse, diagnosis and treatment of women's health issues are influential factors that affected the mother-daughter relationships and the illness narratives. The nature of the relationship before the diagnosis of the illness, the social and cultural factors surrounding the lives of the women, and the nature of the illness itself plays a role in the daughter's reaction to the illness and her relationship with her mother.

Illness is a feature of the relationship. Individuals use the tools they have developed over time to deal with the occurrence of illness. The unique characteristics and background of each woman's narrative plays out in her own description and analysis of her relationship with her mother. The illness is another opportunity to negotiate those stories of conflict and struggle between daughter and mother.

One of the major themes in my study is the struggle of juggling caregiving with other responsibilities. The struggle results in the women feeling stressed for time to concentrate on their relationships with their partners, children, careers, as well as ocial and leisure activities. As women, the daughters feel a responsibility to care for their mothers. As Bumagin and Hirn (2001) describe, this responsibility is established through the family's messages that have been encoded since childhood. Such messages or normative family care (Forbat, 2005) produce a feeling of social responsibility that if not met, may result in feelings of guilt. Although most of the women's fathers were the primary caregivers, the daughters were often called upon for support – to such a degree they are essential to the mother's care (two out of the

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six women I interviewed are the primary caregivers for their mothers. The other four women's fathers or step-fathers are the primary caregivers).

Another theme that arose from my conversations with the women in my study is of feeling the need to protect their mother's from undue stress. Fingerman (2001) and Tarkan (1999) both found that daughters who once had a close relationship with their mothers may distance themselves and their problems from their mothers in an attempt to avoid stress on their mother. In attempting to protect and avoid stress, one of the women in my study describes the need to keep her emotions from her mother. She tries to keep any public interactions her mother may as light and free from the awkwardness, that is sometimes felt due to the stigma of illness, as possible. As Goffman (1963) explains, illness stigma may lead the stigmatized person to feel inferior or shameful about their illness. The women in my study encourage their mothers to continue to do all of the activities they enjoyed before the illness.

The women in my study conclude that support services for caregivers have difficult qualification criteria, and the procedures for applying are complex. Several services were discussed, including leave benefit programs, mental health, and counseling services. The daughters cope with their mother's illness and strains put on their relationship by talking to others about their frustrations, journaling their thoughts, and using humor as a way to cope with the stress of everyday life.

Although much of the literature indicates that daughters of mothers with a life threatening illness often fear getting the same illness as their mothers (Edelman, 1994; Tarkan, 1999), the daughters in my study say they are not concerned for their own health in this regard. The women talk about health in terms of individuals being responsible for their own health. Ill health, therefore, is a result of an individual's

choices and lifestyle. Although the women in my study admit they are not concerned with developing illness, they all report they take on individual responsibility for their health by maintaining a healthy diet, exercise, staying informed on health issues, and know the symptoms of their mother's illness and would be able to detect if they develop the symptoms.

This study provides a unique contribution to the literature on the impact of illness on mother-daughter relationships and caregiving because of the reflexive use of self as participant, the changing definition of life threatening illness, and the similar experiences of caregiving and the impact of illness on the mother-daughter relationship, across different types of illnesses.

I would like to thank the six women who shared their personal stories of illness and relationships. Without their disclosure of their emotional narratives this study could not have been possible, the private would not have been brought into the public. I hope that my research may provide a glimpse of the private lives and the impact of illness on personal relationships.

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APPENDIX A

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December 15, 2004

Reference #04.220

Ms. Kim Bonia
C/o Dr. N. Beausoleil
Community Health
Faculty of Medicine
2nd Floor, Health Sciences Centre

Dear Ms. Bonia:

This will acknowledge your correspondence, dated December 9, 2004, wherein you clarify issues and provide a revised consent form for your research study entitled **"Daughter's narratives of a mother's life-threatening illness".**

At the meeting held on **November 18, 2004,** the initial review date of this study, the Human Investigation Committee (HIC) agreed that the response and revised consent form could be reviewed by the Co-Chairs and, if found acceptable, full approval of the study be granted.

The Co-Chairs of the HIC reviewed your correspondence, approved the revised consent form and, under the direction of the Committee, granted *full approval* of your research study. This will be reported to the full Human Investigation Committee, for their information at the meeting scheduled for **January 6, 2005**.

Full approval has been granted for one year. You will be contacted for annual update in **November 18, 2005.**

Modifications of the protocol/consent are not permitted without prior approval from the Human Investigation Committee. Implementing changes in the protocol/consent without HIC approval may result in the approval of your research study being revoked, necessitating cessation of all related research activity. Request for modification to the protocol/consent must be outlined on an amendment form (available on the HIC website) and submitted to the HIC for review.

For a hospital-based study, it is <u>your responsibility to seek the necessary approval from the Health Care Corporation of St. John's and/or other hospital boards as appropriate</u>.

This Research Ethics Board (the HIC) has reviewed and approved the clinical trial protocol and documentation as noted above for the trial which is to be conducted by you as the qualified investigator named above at the specified clinical trial site. This approval and the views of this Research Ethics Board have been documented in writing. In addition, please be advised that the Human Investigation Committee currently operates according to the Good Clinical Practice Guidelines, the Tri-Council

Policy Statement and applicable laws and regulations. The membership of this research ethics board complies with the membership requirements for research ethics boards defined in Division 5 of the Food and Drug Regulations.

Notwithstanding the approval of the HIC, the primary responsibility for the ethical conduct of the investigation remains with you.

We wish you every success with your study.

Sincerely,

John D. Harnett, MD, FRCPC   Richard S. Neuman, PhD
Co-Chair   Co-Chair
Human Investigation Committee   Human Investigation Committee

JDH;RSN\jd

C   Dr. C. Loomis, Vice-President (Research), MUN
     Mr. W. Miller, Director of Planning & Research, HCCSJ

APPENDIX B

APPENDIX C

APPENDIX D

Faculty of Medicine, Schools of Nursing and Pharmacy of Memorial; Health Care

Corporation, St. John's; Newfoundland Cancer Treatment and Research Foundation

Consent to Take Part in Health Research

TITLE: Daughter's Narratives of a Mother's Life-Threatening Illness

INVESTIGATOR: Kimberly Bonia, graduate student in Community Health

You have been asked to take part in a research study. It is up to you to decide whether to be in the study or not. Before you decide, you need to understand what the study is for, what risks you might take and what benefits you might receive. This consent form explains the study.

The researcher will:

- **Discuss the study with you**
- **Answer your questions**
- **Keep confidential any information which could identify you personally**
- **Be available during the study to deal with problems and answer questions**

If you decide not to take part or to leave the study this will not affect your status in any way. Taking part in this study is completely voluntary.

1. **Introduction/Background:**

There have been few studies done in the specific area of the impact of a mother's life-threatening illness on her daughter. Much of the existing literature focuses on motherloss, which involves the impact of the death of a mother, taking place after the loss; mother-daughter relationships in general; and the impact of a mother's chronic illness on her daughter.

2. **Purpose of study:**

The purpose of this study is to understand the impact of a mother's life-threatening illness on the life of her daughter. It will focus on the daughter's perspectives and experiences in their relationship, the impact of the illness, and concerns for her own health.

The general objective of this study is to examine the lives of women who are affected by a life-threatening illness. Specific focus will be on the daughter's

views of her mother's illness. The main goals of this study are a) to examine the daughter's perspectives and experiences in the mother-daughter relationship; b) to understand the impact of the illness in relation to the daughter; and c) to identify daughter's concerns for her own health.

3. Description of the study procedures and tests:

There will be approximately 6 participants. There will be 3 stages in data collection. Each participant will take part in each of the three stages.

Stage One: Interviews
An individual interview of approximately 1-2 hours in length will take place. Each interview will be audiotaped and transcribed. Topics of discussion will include the relationship between the mother and daughter, the story of the mother's illness, caregiving, and concerns for the daughter's health.

Stage Two: Focus Group

A 2 hour focus group involving the 6 participants will take place. The focus group will be audiotaped and transcribed. Topics of discussion will include dealing with emotions, supports, and the mother-daughter relationship. Benefits of using focus groups in examining the narratives of daughter's experiences of having a mother living with a life-threatening illness may be to meet other women in similar situations, and to share information and resources.

Stage Three: Follow-up Focus Group
A 2 hour focus group involving the 6 participants will take place once I have transcribed and made a preliminary analysis of my findings. The purpose of the follow-up focus group is to share my analysis and to provide an opportunity for the participants to review what was said, to clarify any misinterpretations or misunderstandings, to remove anything they may wish to disregard, to add any relevant or new experiences which were not discussed in the previous focus group, and to talk about the experience of being involved in the research.

4. Length of time:

The individual interview will take approximately 1-2 hours to complete. Each focus group will take approximately 2 hours.

5. Possible risks and discomforts:

Due to the nature of this subject area there may be a possibility of emotional pain or uncomfortable issues. A professional counsellor will be available, if the need should arise.

6. Benefits:
It is not known whether this study will benefit any of the participants.

Signature Page

Study title: Daughter's Narratives of a Mother's Life-Threatening Illness

Name of principal investigator: Kimberly Bonia

To be filled out and signed by the participant:

Please check as appropriate:

I have read the consent [and information sheet].	Yes { } No { }
I have had the opportunity to ask questions/to discuss this study.	Yes { } No { }
I have received satisfactory answers to all of my questions.	Yes { } No { }

I have received enough information about the study.　　　　Yes { } No { }

I have spoken to Kim Bonia and she has answered my questions　Yes { } No { }

I understand that I am free to withdraw from the study
- at any time
- without having to give a reason　　　　　　　　　　　　Yes { } No { }

I grant permission to audiotape interviews/focus groups and I understand that the recording may be stopped at any time.　　　　　　Yes { } No { }

I have agreed to and signed an undertaking of confidentiality for participation in the focus group.

　　　　　　　　　　　　　　　　　　　　　　　　　　Yes { } No { }

I understand that it is my choice to be in the study and that I may not benefit.

　　　　　　　　　　　　　　　　　　　　　　　　　　Yes { } No{ }

I agree to take part in this study.　　　　　　　　　　Yes { } No{ }

_____　　　　　_____
Signature of participant　　　　　　　　　Date

_____　　　　　_____
Signature of witness　　　　　　　　　　　Date

To be signed by the investigator:

I have explained this study to the best of my ability. I invited questions and gave answers. I believe that the participant fully understands what is involved in being in the study, any potential risks of the study and that he or she has freely chosen to be in the study.

_____　　　　　_____
Signature of investigator　　　　　　　　　Date

Telephone number: _____

APPENDIX E

Interview Discussion Guide

Topics for discussion will remain flexible; I do not intend to explore every question, this guide is a possible list of topics. Additional themes or topics of interest may arise during the interview and will be explored during the natural progression of the discussion.

Background and Family Life

1. Tell me something about your background (where you were born, when you were born, education, occupation, siblings, etc.)
2. How would you describe your relationship with your mother as you were growing up?

Relationship with Mother

3. Tell me about your mother (what does she like/dislike, personality, interests, activities, looks, etc.)
4. What kinds of things do you do with your mother?
5. How would you describe your relationship with your mother?
6. What kinds of things do you talk about with her?
7. Do you resemble your mother? (looks, personality, interests)

Illness

8. Can you tell me what your mother's health was like before the illness?

9. What was your relationship with your mother like before the illness?
10. Tell me about the changes in your mother's health.
11. Tell me about the diagnosis (when, what was it like hearing? Who told you? What do you remember about it? Etc.)
12. What was your relationship with your mother like at that point?
13. Has your relationship with your mother changed since the diagnosis? How?
14. Tell me about any treatments she underwent or may be undergoing.
15. How do you cope with the illness? How do you feel about the illness?

Health

16. Are you concerned about your own health?

17. Do you share any of the same health problems as your mother?
18. Do you do anything to prevent illness? Has this been influenced by your mother's health?
19. Do you talk to your mother about your own health? Is she concerned about your health?
20. Do you have any children of your own? (If yes, what are your concerns about their health?)
21. Do you feel you are getting proper health care? Does it attend your needs?
22. Do you believe women receive adequate health care?
23. What do you think could be improved for women's health?

APPENDIX F

Focus Group Discussion Guide

Topics for discussion will remain flexible; I do not intend to explore every question, this guide is a possible list of topics. Additional themes or topics of interest may arise during the focus group and will be explored during the natural progression of the discussion.

Relationship and Illness
1. What was your relationship with your mother like before the illness?
2. How has your relationship with your mother changed since the illness?

Caregiving and Supports
3. What supports are available? Do you take advantage of them? What could improve the support?

Emotions & Getting Through
4. Describe the emotions you are feeling through your mother's illness.
5. Are there any particular moments, prayers, saying, memories that help you get through?

APPENDIX G

2nd Focus Group Discussion Guide

The purpose of the follow-up focus group is to share my analysis and to provide an opportunity to review what has been said, to clarify any misinterpretations or misunderstandings, to remove anything the participant may wish to disregard, to add any relevant or new experiences which were not discussed in the previous focus group, and to talk about the experience of being involved in the research. Topics for discussion will remain flexible; this guide is a possible list of topics. Additional themes or topics of interest may arise during the focus group and will be explored during the natural progression of the discussion.

Your Role in Research

1) After reading your interview transcripts and focus group transcript, is there anything you would like to clarify?
2) Is there anything you would like removed from the transcripts?
3) Are there any new experiences, which were not discussed in the interview or previous focus group that you would like to add or discuss?
4) Has this research benefited you in any way?
5) How would you describe your experience in taking part in this research?
6) Is there anything else you would like to add?

APPENDIX H

APPENDIX I

Undertaking of Confidentiality

I understand that as a participant in the research study entitled, "Daughter's Narratives of a Mother's Life-Threatening Illness," I must maintain strict confidentiality of information shared from other participants in the research.

I understand that a failure to abide by this requirement could cause other individual participants embarrassment. Breach of confidentiality could have serious personal, social and legal consequences for other participants and for theirfamily, friends and associates.

Printed name of participant:

Signature of participant:

Witness name:

Witness signature:

Date:

APPENDIX J

Human Investigation Committee
Undertaking of Confidentiality

I understand that as an investigator or member of a research team, I must maintain strict confidentiality of information obtained from participants in research studies and/or their health and study records.

I understand that not all members of a research team will require confidential information about research participants and that the principal investigator will limit the number of persons on the team who require such information to as few as possible.

As an investigator I agree not to disclose or discuss any confidential information to which I have access except with the appropriate members of the research team.

As a staff member of the research team I agree not to disclose or discuss such information unless specifically authorized to do so by the investigator to whom I am responsible.

I understand that a failure to abide by this requirement could cause individual participants embarrassment. Breach of confidentiality could have serious personal, social and legal consequences for the participant and for the participant's family, friends and associates. I appreciate that an unauthorized disclosure could have consequences for the participant in his or her employment.

I also acknowledge that as part of my employment relationships, if I should make an unauthorized disclosure of information about a participant in a research study, I may be dismissed from my position or suffer formal reprimand. I appreciate that I shall be legally responsible for my actions and, in the event of litigation for my unauthorized disclosure of information, I agree to indemnify my employer for any damages incurred by him.

Printed name of research team member:

Position on the research study:
    [ ]   Investigator
    [ ]   Staff member

Signature of research team member:

Witness name:

Witness signature:

Date:

APPENDIX K

APPENDIX L

Daughter's Narratives of a Mother's Life-Threatening Illness
Participant Information

DATE OF INTERVIEW:

NAME:

PSEUDONYM:

AGE:

MAILING ADDRESS:

EMAIL ADDRESS:

TELEPHONE NUMBER:

MOTHER'S AGE:

MOTHER'S ILLNESS:

DATE OF DIAGNOSIS:

WHERE DID YOU HEAR ABOUT THIS STUDY?