BREAST CANCER EXPERIENCE: MOTHERS, ADOLESCENT DAUGHTERS and the MOTHER-DAUGHTER RELATIONSHIP

by

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This interpretive descriptive study explored the meaning and lived experience of breast cancer for 5 mothers and their 5 adolescent daughters, and for these mother-daughter relationships. Mothers had been diagnosed with breast cancer between 2 and 6 years ago, and their daughters were between 11 and 13 years old at the time of the diagnosis. A series of six in-depth interviews with mothers and daughters, conducted both jointly and separately, afforded a view of aspects of experience that were shared and privately held. Interview data were supplemented with participants’ drawings of their experience, and the researcher’s observations.

The interpretive descriptive framework employed was augmented with the lens of portraiture in the conduct of study, data analysis, and composition of the product of inquiry. Portraiture utilizes five essential features: voice, relationship, context, emergent themes, and aesthetic whole. Individual and relational experience and meaning were described in four themes: (a) Inhabiting Another Landscape, (b) Intending and Acting, (c) Acquiring Wisdom, and (d) Enduring Mother-Daughter Relationships.

The theme of Inhabiting Another Landscape described a trajectory of experience and meaning that began with diagnosis, persisted through prolonged effects of treatment, and continued in the present and into imagined futures. Mothers and daughters had privately held concerns about the mothers’ breast cancer and the possibility that breast cancer might one day visit daughters as well. The most prominent reminder of vulnerability was recurrence among friends in the social networks of breast cancer.

The theme of Intending and Acting described the mutual caring and protectiveness of these mothers and daughters. Mothers and daughters described actions
and strategies to minimize the threat of breast cancer for themselves and for the other person. Actions included attempts by both persons to create and maintain a sense of normalcy. Conversations between mothers and daughters on the experience of breast cancer were limited, in particular around prognosis and the possibility of death.

The theme of Acquiring Wisdom described personal growth and change after the diagnosis of breast cancer. For both persons, realizations of mortality brought a new perspective on what was important in life. Mothers passed on the wisdom gained from their experience either directly in what was said to daughters or indirectly in the attitudes and behaviours they modelled.

The theme of Enduring Mother-Daughter Relationships described the quality of mother-daughter relationships and the import of breast cancer for these relationships. Mothers and daughters described their relationships as close. Daughters described their relationships as closer than most, in part because of their experience with breast cancer. Parenting and being parented was in some cases complicated by breast cancer. Friction between mothers and daughters was described as par for the course during the teen years, but one source of friction was the unexpected and prolonged effects of treatment.

The findings in this study indicate the value in attending to the voices of teenage daughters, which remain largely absent in the literature. Mothers and daughters have needs for information and support that are not being met. The emotional landscape of breast cancer, which entails prolonged uncertainty for both mothers and daughters, deserves further study. Personal growth described by both mothers and daughters provides an alternative view of the largely problem-focused perspective in the literature of the meaning and experience of breast cancer.
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The completion of this thesis represents an end and a beginning. It is the end of years of study and hard work. It is the beginning of how I may contribute to theory, research, and practice on an important health issue touching too many women, and the daughters who are to become women.
CHAPTER I

INTRODUCTION

Breast cancer is almost exclusively a disease of women. It is estimated to develop in one of every nine Canadian women in her lifetime and is currently the leading cause of death in women aged 35 to 54, an age group which will constitute 51% of Canadian women by the year 2001 (Canadian Cancer Statistics, 1995). Thus, breast cancer touches large numbers of women in their child rearing years. Given the trend for women to delay childbirth until later in life when they are at greater risk for breast cancer (Howes, Hoke, Winterbottom, & Delafield, 1994), and the increased risk for women with a familial history of the disease (Olivotto, Gelmon, & Kuusk, 1994; Slattery & Kerscher, 1993), this disease will touch increasing numbers of women and their daughters.

From a psychosocial perspective, cancer is a disease that invades the family as much as it does the patient (Lewis, 1993). This study was designed to contribute to a holistic understanding of health in a natural social unit by looking at the individual and relational experience of mothers and their adolescent daughters whose lives are touched by breast cancer. Although breast cancer is among the most well researched forms of cancer there is a paucity of research on how breast cancer affects the health of the family.

Psychological studies of breast cancer have focused on the individual with the disease for several reasons, among them: (a) psychology's predilection for studying individuals as opposed to relational systems; (b) medicine's view of health and disease primarily as biological states of individuals (Cunningham, 1986); (c) psychology's role in
oncology as adjunctive to that of medicine, which remains a pre-eminent stakeholder in our health care system and in oncology; (d) the problem-focused role many psychologists have developed in oncology, for example, symptom management during treatment that complements the role of physicians prescribing treatment regimens. Psychological studies considering cancer as an illness experience affecting the family in concert with the individual who has the disease are therefore relatively few in number.

The bulk of psychosocial research in oncology has tended to focus on individual differences in adaptation to cancer. Individual differences in adaptation have been conceptualized as core resource variables that fall into two categories: (a) personal resources, such as perceived control, coping, and more recently, religion and spirituality, and (b) social resources, such as social support and family functioning (Curbow & Somerfield, 1995). In accord with psychological studies developed from a positivist framework, one line of research is moving towards the application of hierarchical modelling to investigate causal relationships among psychosocial resource variables. In the area of breast cancer, researchers who have focused on the relationships among social support, personality traits, and coping responses are being encouraged to move from global measures of social support to more specific processes occurring in relationships that affect well-being (Irvine, 1996).

A complementary line of reasoning calls for increased attention to ecological validity of the phenomena targeted in psychosocial research in oncology, that is, the study of meaning-making processes among family members (Spiegel, 1995). This study
was crafted in accord with that line of reasoning. It was focused on understanding experience and meaning in a shared illness experience, apprehended concurrently from individual and relational perspectives. In this study, I attempted to respond to women’s concerns about the impact of breast cancer on their children (Hoke, 1996), and to give a voice to their adolescent daughters whose psychological health has been viewed to be at special risk (Lichtman, Taylor, Wood, Bluming, Dosik, & Leibowitz, 1985; Wellisch, 1981; Wellisch, Hoffman, & Gritz, 1996). To date, literature on the psychosocial aspects of breast cancer has been relatively silent on the import of this illness for daughters, and for the mother-daughter relationship.

The next section offers an ecological perspective on myself as researcher. It documents my orientation to inquiry in terms of theoretical orientation, professional interests, and personal experience.

Orientation to This Inquiry

This section orients the reader to the personal commitments, interests, and experience of the author. The first portion of this section, Constructivist Approaches, describes constructivist approaches to inquiry, which emphasize the constructive process in creating the product of an inquiry. Because my theoretical commitments to, and experience in, the practice of counselling psychology influenced the construction of the research questions and the design of the study, they are included in this section. The second portion, Personal Knowledge, includes the process and product of an exercise in reflexivity that speaks to my axiological commitments. Fieldwork that served as
Constructivist Approaches

Constructivist approaches to research tend to overlap with other orientations to inquiry such as *constructivism, interpretivist, interpretivism, and naturalism* (Schwandt, 1994). Thus, constructivist approaches to inquiry are marked by multiple uses of the term and are shaped by the intent of those that use it. In this segment my intent is to identify aspects of constructivist thinking that capture ideas that were important to me in this study.

The overall goal of constructivist inquiry is to understand “the complex world of lived experience from the point of view of those who live it” (Schwandt, 1994, p. 118). The task of understanding meaning entails interpretation, elucidating meaning construction, and clarifying what and how meanings are embodied in language and action. Constructivist approaches to inquiry are characterized by “an attention to context-embedded meanings, acknowledgement of the contributions of the observer and observed, utilization of tacit knowledge, and preference for interactive modes of knowledge construction” (Hoshmand, 1994, p. 27). A constructionist perspective favours meaningfulness, authenticity, and pragmatic utility construed as utility for problem solving as criteria for inquiry (Hoshmand). Because constructivist inquiry is concerned with matters of knowing and being, as opposed to methods per se, methods are adopted or created to honour the purpose of inquiry. Purpose, in turn, turns back to epistemological and methodological commitments.
Constructivist inquiry takes a particular interest in how people create knowledge and truth. It emphasizes the pluralistic and plastic nature of reality, expressed in a variety of symbol and language systems, and shaped to fit purposeful actions of people. However, for the most part, constructivist inquiry remains restricted to expressions of reality in verbal accounts of experience. In respect of counselling practice, it has been my experience that much of what is valuable in coming to an appreciation of experience is conveyed in symbolic representation outside of verbal dialogue. For example, emotional tone, kinesthetics, proxemics, and the artistic expression of felt experience are important channels of communication that are largely unexplored in research literature focused on the expression and elucidation of meaning.

In this study, one of my goals was to honour the complexity of experience by expanding the space for symbolic expression. In this research, I was interested in expanding the dialogue with participants to include a space for art because I viewed it as a potentially rich source of data. Sandelowski (1994) has described the purpose of qualitative inquiry in nursing as the business of “rendering the lives of people in crisis, transition and illness in ways that can inform, evoke, provoke, do justice, and above all matter.” As a student of counselling psychology and nurse these sentiments were apropos for my study. They capture the flavour of the intended process and product of an inquiry that invites artistic expression.

A psychologist working from constructivist theory understands people as self-organizing, developing, knowing systems that rely heavily on mediating knowledge
structures for growth and change. Because an important facet of human knowing is understood as operating at an implicit or tacit level, meaning-making may be explored through symbolic forms of communication such as dreams and art, and the symbolism of metaphors that infuse our everyday discourse. In this study I was attuned to the possibility of apprehending experience through art and metaphor.

Although most cognitive approaches endorse a view of humans as proactive human knowing systems, cognitive constructivists emphasize a view of persons as active agents that individually and collectively or jointly co-construct meaning in experience. This study was focused on the individual and joint construction of experience and meaning. The constructivist approach to understanding human experience also emphasizes the place of emotions in a different, and higher order knowing system (Mahoney, 1991).

In constructivist cognitive practice, the emotional distress that accompanies problems is embraced as a vehicle for transformation of meaning. From this perspective, crises arise as natural precursors to change and self-organization in an open system of organism and the environment (Mahoney, 1991). One of my assumptions in this study is that the experience with breast cancer constitutes a crisis that may give rise to change. Breast cancer may be considered as a problem in living, which from a constructivist perspective, is a discrepancy between an individual's current developmental challenges and his or her adaptive, meaning-making capacities. Research inspired by the tenets of constructivism aims towards understanding and reconstruction of the constructions held by all research participants, including the researcher (Guba & Lincoln, 1994).
Personal Knowledge

As a student of counselling psychology, my clinical experience and research interest in relationships encourage an inquiry into the social, relational nature of experience. Because constructivist approaches favour engagement in a social, dialogic form of inquiry that affords a better understanding of the issues or concerns of all participants, they are well suited for inquiry that is intended to have relevance for health psychology.

Research inspired by constructivism also engenders a strong obligation for disclosure of intent (Guba & Lincoln, 1994) and a challenge to maintain an open reflective stance. As Sandelowski (1989) has noted, there is a need for researchers “to come clean about their present orientation to the subject of inquiry” to facilitate an assessment of the trustworthiness of any claims to knowledge resulting from the inquiry process. Exactly how to construct such an orientation, what to include and what to omit, appears to vary by a fair number of factors, such as professional membership, topic of study, theoretical orientation, and philosophical commitments. I have chosen to structure this personal orientation to inquiry on the basis of personal and professional values and experience.

Approaching the task of discovery and documentation of my own orientation to inquiry in a straightforward and open manner seemed to offer two immediate advantages. It seemed the best way to generate feedback from my committee on my assumptions and values. It also seemed an opportunity for me to actively consider the personal and tacit
ways of knowing that are important constituents in the construction and validation of knowledge (Hoshmand, 1994). I approached this inquiry as a nurse and as a student of counselling psychology interested in making a contribution to the health of families touched by a disease that affects large numbers of women, sensitized to my own vulnerability to this disease by a process of reflection and fieldwork.

The Person of the Researcher

The person who conducted this study is a mother of a daughter, a nurse, and a student of counselling psychology. As a mother of a daughter I have come to appreciate the depth and complexity of the mother-daughter relationship. Although it has been a long cherished goal to integrate nursing and counselling psychology in the practice of health psychology, I was initially uncertain as to why I felt drawn to oncology for my doctoral research. Through nursing I have had the opportunity and privilege of caring for many people with various forms of cancer, but I did not specialize in oncology nursing. The combination of uncertainty and strong inclination to follow a particular stream of inquiry prompted a period of prolonged questioning, intense reflection, and discovery.

As a student of counselling psychology, I was predisposed to consider my sense of problem as an opportunity for development and growth (Myers, 1992). As a person who works from a constructivist framework in counselling practice, I was encouraged to do some self-exploration by writing narratives of my most memorable encounters in working with people with cancer in nursing practice. My intent in this exercise was twofold: (a) to unearth my tacit understanding of value and purpose in working with
people with cancer, and (b) to begin to engage in a dialectic of analytic and intuitive aspects of knowing that would inform knowledge construction with study participants.

My criteria for writing narratives of my work experience with cancer were that they be vivid memories that seemed to have relevance for what I might be able to contribute to the health field, that felt important to acknowledge at this time, or that left me with unanswered questions. Four stories resulted. All were concerned with cancer, but only one dealt with breast cancer. Upon reflecting on these stories of encounters with patients with cancer, and after sharing them with faculty members for feedback on the import of these stories, caring stood out as a unifying theme. In one sense, this result might be expected because caring has been regarded as a central if not defining concept in nursing and these stories were based on my experience in nursing.

To move beyond my personal constructions of caring my next step was to develop a conceptual map of caring, and to then look into the literature on caring. In the process of exploring discourse and research on caring in philosophy, psychology and nursing, I was moved to examine the axiological assumptions in my personal and professional life. During this time I made a commitment to my faith, and became a member of a pastoral care team. From a spiritual, psychological, and embodied view of human life, focusing on caring in my doctoral research seemed to make eminent sense. The initial draft of my proposal was focused on the construct of caring. The decision to refocus the proposal was taken in response to recurring concerns I experienced in moving closer to doing the research.
My concerns centered on the potential impact of having developed such a strong interest in caring. I reluctantly came to the conclusion that my ability to really listen to participants’ stories might be seriously compromised if I launched into the study with an established focus on caring. It seemed reasonable to assume that my continued interest and valuing of caring might influence my study. However, my goal was to be sensitized to caring rather than to be driven by it, and to cultivate and retain an attitude of openness and tentativeness in this research.

In revisiting my narratives from nursing, I discovered other themes of interest. The one that carried the most impact for me was the mother-daughter relationship. The most impactful narrative on this theme was written in response to an experience on a palliative care unit. “Nancy” was in the final stages of breast cancer. She was the mother of a young daughter, and the daughter of a woman who had herself had breast cancer and who now kept silent vigil at Nancy’s bedside. For me, the silence of Nancy’s mother, and the silent unseen presence of Nancy’s daughter in the room stayed with me as a painful reminder of unspoken questions around the legacy of breast cancer for women and their daughters.

Daughters as a silent presence in the world of breast cancer was brought to my attention in two fieldwork settings, both connected with the Life Quilt for Breast Cancer. The Life Quilt for Breast Cancer project was initiated in Vancouver by Judy Reimer, nurse and mother of two young children. Conceived as a project that would capture the voice of women touched by breast cancer in a variety of ways, the Life Quilt project
focuses on giving women visibility and voice in understanding the needs of women and in creating a healing legacy for children.

Three large painted fabric panels have been quilted at various art exhibitions and have been augmented by individually designed and quilted squares in communities across Canada. As an artistic product, the Life Quilt is a profoundly moving rendering of the pain, hopes, and dreams generated by encounters with breast cancer. Although I have had experience in working with people with cancer, my experience of the impact of the Quilt itself, and of the art and poetry displayed with it, is that artistic representations of experience have a special power “to inform, evoke, provoke, do justice, and matter “ (Sandelowski, 1994). My encounters with women around the Life Quilt project in Vancouver and in Calgary presented spoken and unspoken concerns of women for their daughters in respect of breast cancer. I will describe two such encounters.

My first encounter with the Life Quilt project was at its launch at a community centre in Vancouver. At that event I was struck by the fact that many women had brought their children. Three observations intrigued me: (a) the children were all girls in early adolescence; (b) no special arrangements appeared to have been made for these children, such as some form of activity; and (c) many of the children were looking decidedly uncomfortable or frightened. These observations left me with a curiosity about the interpersonal dynamics between mothers and daughters in the context of a form of cancer that is almost exclusively female. Sometime later in a conversation with a woman who was dealing with metastatic breast cancer, I was struck by her willingness to talk about
the impact on her older son in comparison to her silence around her daughter who was a breast fed newborn when the breast cancer was diagnosed.

A second encounter with the Life Quilt was at an installation at the Bow Museum in Calgary. There I had the opportunity of speaking with one of the guides, a woman who described herself as breast cancer survivor. For many years this woman had devoted her energies to visiting women with breast cancer, bringing information and encouragement. We talked of the experience of mothers with breast cancer and she told me that her one unspoken concern many years after treatment and reconstruction was whether she might be leaving a legacy of breast cancer to her daughters. For me, one of the most impactful paintings amongst the collage of writings, film, sculptures and paintings accompanying the Life Quilt was a painting of a mother with child. This work was done by another woman who was pregnant when diagnosed. It represented her questions and visionary hopes for the baby who had to be aborted for her mother's survival.

The survival of this study was fostered by a shift in focus over a period of reflection. For me, the impact of encountering experiences of breast cancer in settings where my role was not that of a helper with a defined role at times brought me to a point of angst and panic. In the process of crafting the proposal for this research I was distressed by a sense of personal vulnerability to breast cancer. The desire to return to a helper role, this time as a nurse and psychologist, probably fuelled the earlier focus on caring. One of the reasons I chose to focus on mothers and adolescent daughters is that I am a mother whose daughter is now grown past that stage. In focusing on the experience
of mothers and their adolescent daughters, I was afforded a measure of comfort and distance that allowed me to proceed with my study.

**Research Questions and Procedures**

This study was an exploration of the meaning and lived experience of breast cancer for mothers and daughters where the daughter was an adolescent at the time of diagnosis. An underlying assumption in this study is that individual experience is shaped in the context of relationships and impacts relationships. The study was designed to address the following questions: (a) What is the meaning and lived experience of breast cancer for mothers and their adolescent daughters? (b) What is the meaning and lived experience of breast cancer for the mother-daughter relationship?

A series of open-ended in-depth interviews was undertaken with mothers and their daughters both together and individually. A total of six interviews lasting approximately one hour each were conducted with five mother-daughter dyads. The first and last interviews were joint interviews with mothers and daughters. In between the joint interviews, mothers and daughters were interviewed twice separately. Participants were asked to describe their own experience of breast cancer and their experience of breast cancer in respect of their mother or daughter. The co-construction of findings was facilitated by a feedback process. I constructed four themes from this interpretive descriptive study (Thorne, Kirkham, & MacDonald-Emes, 1997) using the analytic procedures of portraiture (Lawrence-Lightfoot & Davis, 1997).

The design for this study was constructed from a consideration of my theoretical
and personal commitments as a researcher. Research questions were developed from a consideration of the psychosocial literature on breast cancer that relates to the experience of mothers and daughters. The purpose of my study was to produce a portrait of the lived experience and meaning of breast cancer for mothers and their daughters because the literature does not address individual and relational experience and meaning. A review of the literature follows.
CHAPTER II

LITERATURE REVIEW

This literature review was constructed to highlight selected aspects of the psychosocial literature touching on the experience of mothers and daughters and of the mother-daughter relationship in the context of breast cancer. For the most part, the experience of mothers and daughters has been studied from the perspective of individual as opposed to dyadic experience. The import of a mother’s breast cancer for adolescent daughters, and for the mother-daughter relationship has been described incidentally and more directly in various segments of the psychosocial literature on breast cancer. It is found incidentally in survivorship literature (e.g., Wyatt, Kurtz, & Liken, 1993), in studies of adult children (e.g., Chalmers & Thomson, 1996; Germino & Funk, 1993; Rees & Bath, 2000; Wellisch, Gritz, Schain, Wang, & Siau, 1991, 1992), and in family focused studies (e.g., Hilton, 1993; Lewis, Ellison, & Woods, 1985).

Relatively few studies have examined the import of breast cancer for older children and the parent-child relationship. Studies that do include children tend to rely on parents’ perceptions of children’s reactions to breast cancer (Howes, Hoke, Winterbottom & Delafield, 1994; Lewis, Hammond, & Woods, 1993; Lichtman et al., 1985; Shands, Lewis, & Zahlis; 2000), or tend to engage in limited dialogue with children (Hilton & Elfert, 1996). My review of the literature yielded four studies where children were interviewed separately from parents (Birkenbaum, Phillips, Chand, & Huster; 1999; Chalmers, Kristjanson, Taylor-Brown, Nelson, Woodgate, Dudgeon, & MacDonald,
1998; Issel, Ersek, & Lewis, 1990; Rosenfeld, Caplan, Jacobowitz, Yuval, & LeBow; 1983). Data on the experience of adolescent daughters in concert with their mothers is sparse and appears in the context of clinical work with troubled families (Wellisch, 1981; 1985).

Where families of persons with cancer have been considered, they have often been perceived as a psychosocial resource variable in terms of the support they might afford to the patient's adjustment to illness. It is only recently that families and family members have been considered as being at risk for psychosocial distress, largely in terms of adjustment problems. Adjustment difficulties in families touched by breast cancer have been described, in concert with other types of cancer in the family, in relation to several factors: illness trajectory, developmental stage of the individual and the family, and specific factors in the family's response such as needs, demands, role changes, communication, decision-making, coping, and health changes (Chalmers, Kristjanson, Taylor-Brown, Nelson, Woodgate, Dudgeon, & MacDonald, 1998; Hilton, 1993; Kristjanson & Ashcroft, 1994). With respect to children, the focus of most family studies has been to identify risk factors for children with the goal of protecting children from the negative effects of a parent's cancer (Howes, Hoke, Winterbottom, & Delafield, 1994).

Before considering data from studies that touch on family relationships, I would like to offer some personal reflections on the language of breast cancer.

My initial readings of the psychosocial literature on breast cancer left me somewhat puzzled by terminology. Many women live well beyond the time of diagnosis
and treatment and many do not, however all women tend to be described as survivors. In talking about breast cancer, there is an inherent tension around life and death that seems to shape our discourse. One of the driving forces underlying the tension is that in practical terms, from a medical point of view, women who develop metastases are considered terminally ill. From the standpoint of persons who are facing the disease there may be utility in rejecting this perspective, and it is probably rightly avoided in developing a psychological study. However, there seems to be a tendency in the professional literature to downplay the likelihood of death in the way we talk about cancer that has consequences for research design.

The issue of prognosis tends to be downplayed in many psychological studies on breast cancer. Whereas it is a common strategy in medically focused studies to document aspects of disease process such as site and stage that serve as prognostic indices, much of the psychosocial literature is either silent on the medical prognosis or treats the prognosis as simply one variable among others that may impact adjustment. Studies typically pool data where medical outlooks vary enormously. Although researchers in psychology may not have expertise in the intricacies of medical prognostics, it would seem to me important to attend to the nature of beliefs or questions about prognosis. As it stands, it is as if the biological context for psychological experience, or perhaps more accurately the psychological experience of biology is of minor import.

My sense is that this aspect of the psychosocial literature on breast cancer points to an area of sensitivity or vulnerability in conducting research in the area of cancer. It also
illustrates and honours the political nature of discourse in a serious illness but in so doing has potential to obscure psychological phenomena. On one level, grouping all women who have experienced breast cancer into a survivorship camp may serve as a shield for researchers against the angst of working with people who will succumb to a disease process yet can never or will never be acknowledged as victims of it. As subtext or in more obvious ways, metaphors of battle and war infuse both professional and public discourse on breast cancer. To avoid engaging these metaphors I have on many occasions paused to examine my thinking, by replacing words such as *invades* and *impacts* with *touches* and *imports*, to consider words that are more neutral with respect to experience without sidestepping the potential for a terminal prognosis.

On another level, describing all women as survivors honours the courage of women in their struggle with cancer where it is also politically incorrect to engage in dialogue that could become a binary discourse around living and dying, winning and losing. My concern with the picture of breast cancer in the psychosocial literature is that it replicates the overly positive picture of the illness presented in the media. Sharon Batt, a pioneer in breast-cancer activism in Canada who was diagnosed with breast cancer in 1988, has argued that it is really time to “drop the pose that we’re one happy, beautiful bunch of survivors” (Hoy, 1995, p. 54). These concerns notwithstanding, research on survivorship does have a place in developing a rendering of the experience of women and of their daughters for this study.
Survivorship

Survivorship research in breast cancer (see Irvine, 1996 for a review) has often focused on a specific aspect of psychosocial adjustment such as the type of surgery chosen by the women, exercise, sexuality, significant other, and social support. In a focus group study of breast cancer survivors, defined as women who are alive 5 or more years post diagnosis, Wyatt, Kurtz, and Liken (1993) described four themes relating to quality of life. Their study expanded the focus of other studies, which typically centre on adjustment process and outcomes, such as coping strategies, to construct a holistic portrait of quality of life. Questions were developed to probe physical, social, psychological, and spiritual aspects of experience. They reported four themes: (a) integration of the disease process into current life; (b) change in relationship with others; (c) restructuring of life perspective in social, psychological and spiritual realms; and (d) unresolved issues with health care providers. Relative to the design of this study and the focus on family relationships, aspects of the themes of ‘restructuring life perspective’ and ‘changed relationships with others’ seemed noteworthy.

The ‘restructuring of life perspective’ theme was constructed from social, psychological, and spiritual probes. Participants talked about having more appreciation for time, about paying more attention to the small things in life, and being thankful. For example, one woman talked about “not taking her family members for granted” (Wyatt, Kurtz & Liken, 1993; p. 444). The ‘changed relationship’ theme was developed from social and psychological probes, and included changes in perception of health/illness and
changes in social support. Many participants expressed a decreased tolerance for what they deemed minor complaints from others. A variety of changes in social support were noted but many participants became closer with family members, a finding echoed in a later section of this review.

Although the authors did not report on the mothering status of participants, one woman spoke about the impact on her daughter. “My daughter was deeply affected by my cancer. She still sends me [an] anniversary card every year, like ‘six down, four to go, and this type of thing’. So they [my children] still remember it.” (Wyatt, Kurtz, & Liken, 1993; p. 444). On my reading, this daughter’s celebration of her mother’s achievement in surviving for a number of years provides support for my working assumption that an encounter with breast cancer may be a pivotal event in mother-daughter relationships, one that may engender positive aspects as well as threat or challenge.

**Adult Children**

Some of the challenges for women classified as primary relatives of women with breast cancer were documented in a study that explored the meaning of risk perception (Chalmers & Thomson, 1996). A purposive sampling approach was adopted to include the risk factors of age, family history, and a continuum of experience with breast cancer from initial diagnosis, through treatment, to remission and recovery or to decline and death. In the results, no distinction was drawn in the relative’s experience based on the course of illness. Semi-structured in-depth interviews with women who had one or more primary relatives (mothers, 45%; sisters, 31%; mother and sisters, 13%; mother and other
primary relative, 11%) were used to explore women's perceptions of their risk for breast cancer and their self-care needs. Developing a personal understanding of risk evolved in three phases: (a) living the breast cancer experience of the relative, (b) developing a risk perception, and (c) putting risk in its place. Two aspects of this study that seem pertinent for my proposal touch on issues of development and legacy.

In Chalmers and Thomson's study (1996) of female family members, 'living the breast cancer experience' was influenced by the amount of sharing the cancer experience with the ill relative. Three factors affected sharing: (a) the nature of the relationship between the woman and the ill relative, (b) the developmentally determined attachment of the woman to her ill relative, and (c) other stressors competing for attention and energy. A quote from one participant illustrates the importance of shared biology and closeness to the ill relative: "I found at certain points in my sister's illness, my breasts would hurt so much... and I am sure it was all psychosomatic. I was so wrapped up in her and constantly thinking about her." (p. 267).

Given that female adolescence is in part defined by the development of breasts, one might speculate that the embodied experience of daughters of women with breast cancer may be particularly, inherently stressful for young women and by extension for their mothers as well. There would seem to be an implicit link between mothers and daughters here in terms of the potential for life and death, because of the functional and symbolic significance of the breast as a harbinger of life and as a foreshadow of death when invaded by a disease that can prove fatal.
Under ‘developing a risk perception’, Chalmers and Thomson (1996) described a three phased process where women moved away from a focus on the ill relative to themselves. A sense of personal vulnerability to breast cancer was developed by: (a) assigning significance to their own and other’s biology; (b) appraising threatening experiences with breast lumps and other body abnormalities; and (c) personalizing risk through variable, reasoned, and intuitive thought processes. Factors influencing risk perception in assigning significance to their own biology included the relative’s age at diagnosis, and perceived similarity to the relative, such as personality, lifestyle, and body type.

Perceived similarities or disparities with the ill relative served to increase or decrease a sense of risk. Although most of the women were adults at the time of their relative’s diagnosis, the authors noted profound effects on women who were adolescents. My own reaction to this finding is that it makes sense because adolescence is a time when similarity is highlighted for girls as they negotiate a physical transition to womanhood, and one of the obvious markers for transition to womanhood centres on breast development. Chalmers and Thomson’s (1996) interpretation was that ‘sharing the breast cancer experience’, one facet of the phase of living the breast cancer experience, was particularly impactful for adolescents because of their limited understanding of the illness, and the developmental challenge of gaining independence.

The initial diagnosis was horrific...I was 13...I immediately thought she was going to die...so I think there was a great fear of abandonment, and if my mother died, where would I go...When you get pissed off with your mother, you say: “Oh I wish she would get hit by a freight train”. I remember that being a real big issue for me
...'cause now she is actually going to die and I have sort of caused it. (pp. 267-268).

Conceptions of healthy development often incorporate values around independence. To a degree this perspective may be challenged as being shaped by western cultural values, predominantly oriented around gender where male development has been regarded as the norm. For example, Gilligan (1981) has articulated a different view of female development as being rooted more in a morality of connection and caring than of independence and justice. Notwithstanding this alternative conception of female development, a valuing of self sufficiency and independence has been found in cross-cultural goals that parents have for their children which move in order from: (a) survival: physical survival and health, (b) economic survival: self-maintenance in maturity, to (c) self-actualization: developing the capacity to maximize cultural values such as morality, prestige, wealth, achievement, and personal satisfaction through culturally specific norms and ideologies (Levine, 1974).

In the context of breast cancer, it seems an open question whether survival concerns of mothers for daughters regarding their reproductive capacity might be highlighted because of the role of the breast in reproductive process. However, there is data suggesting that the subject of reproduction is worth considering from the perspective of a female relative. For the women in the Chalmers and Thomson (1996) study, developing a risk perception was found to be connected to concerns about reproductive roles. Participants spoke of finding the best time to have cancer in terms of having fulfilled child-rearing goals. A middle aged woman reflected on ‘putting off’ her date
with cancer for 15 years. "I don't have to worry about him (husband) coping with a new baby or toddler; we are getting into the teen years and I have almost given myself permission to die." (p. 275)

Whether or how breast cancer experience in a mother might impact life projects envisioned by adolescent daughters with respect to mothering has yet to be explored with adolescents. One study of adult daughters of women with breast cancer suggests it might be worth exploring. Adult daughters of women who had breast cancer were interviewed to determine their level of psychological functioning on the Brief Symptom Inventory, the Derogatis Sexual Functioning Inventory, the Sexual Arousability Inventory, and the Ways of Coping Checklist, and were also questioned specifically on alteration of long-range plans and goals (Wellisch, Gritz, Schain, Wang, & Siau, 1992). In this study, developmental age at the time of their mothers' diagnosis was one variable selected to predict adjustment in light of other research (Lichtman et al, 1985; Wellisch, 1985) demonstrating greater adjustment problems for adolescent daughters.

When asked directly, daughters who were young children or adolescents at the time of their mothers' diagnosis were more likely than daughters who were adults to have a perception of breast cancer as having altered their long-range life plans and goals (Wellisch et al. 1992). An example quoted in that study speaks to marriage plans rather than mothering, but seems to me related: "one daughter... wanted to marry the type of man who would take care of her when she was diagnosed with breast cancer, which she assumed would eventually occur" (Kelly, 1990 in Wellisch et al., 1992; p. 177).
detailed account of the results of Wellisch et al.'s (1992) study is beyond the scope of this review, however with respect to alteration in long-range life plans and goals, the only variable to significantly correlate with that measure was perceived capacity to resolve feelings about the mother's illness. Daughters who were children or adolescents when their mothers became ill were less likely to experience a sense of resolution of their feelings. Those who were adolescents were generally more uncomfortable about involvement with their mother's illness, tended to have greater adjustment problems, and remembered having significantly greater feelings of discomfort about their mothers' illness. These results are perhaps more understandable when linked with data from a family oriented study that documented children's experiences with mother's early breast cancer.

Semi-structured interviews with families and children, conducted at diagnosis and again at 3, 6, 8 and 12 month intervals, revealed that the mothers' illness tended to create "an intense emotional bond between mothers and daughters, more like friends or peers than parent and child" (Hilton & Elfert, 1996; p.102). Adolescents, as opposed to younger children, tended to be very involved with their mothers in terms of personal care, such as dressing changes, attending the cancer clinic, helping with hair care, wig shopping, and shopping for a prosthesis. In their study, most of the adolescents were girls. Parental discussion with teenage daughters was more intimate, and daughters were exposed to more personal caregiving, for example, scars being seen by daughters but not sons. These results lend support to speculation by Wellisch et al. (1992) that adolescent
daughters may associate their own breast development and maturity with body-image trauma, illness, and death. One might also be curious about perceptions formed about sexuality.

Sexual functioning was examined, along with adjustment, coping, body-image, and health knowledge, in a companion arm of the Wellisch et al. study (1992) comparing 60 adult daughters of women with breast cancer with a group matched for age, educational level, and race who had no history of maternal breast cancer (Wellisch, Gritz, Schain, Wang, & Siau, 1991). Daughters of women with breast cancer reported less frequent sexual intercourse, lower levels of sexual satisfaction, and an increased sense of vulnerability to breast cancer. These results were interpreted as indicating that sexuality represented the most susceptible area in perceived vulnerability to breast cancer. One daughter's comments illustrates a legacy of anxiety around sexuality: “Why should I get attached to my body and start enjoying sex when all of that will be totally destroyed when I get breast cancer like my mother did?” (p. 334).

The preceding quote raises a question about the development of long-term health concerns for daughters of women with breast cancer. Long-term health consequences for daughters have been described more fully in lay print (Tarkan, 1999), where the fear and anxiety of daughters about one developing breast cancer is acknowledged. Adolescents in the Hilton and Elfert study (1996), most of whom were girls, seemed in the latter interviews either to have put breast cancer concerns about their mothers and themselves behind them, or to be trying to do so. A commonly expressed belief was that the crisis
was over, even for a daughter whose mother was dealing with recurrence. Most daughters acknowledged an increased risk for themselves but said that it was not an immediate concern, perhaps a reflection of the sense of invincibility carried in youth. Nonetheless, adult daughters appear to retain or to develop an exaggerated sense of vulnerability to breast cancer that is approximately double the actual risk, and to experience significantly lower levels of sexual satisfaction, that is, scores on the Derogatis Sexual Functioning inventory placing them closer to patients who had vulvar cancer that to controls (Wellisch et al., 1991).

In surveying the psychosocial literature on breast cancer through a counselling psychology lens, I have been struck by the relative lack of discussion on whether or how the functional and symbolic value of particular cancers might shape the lived experience of illness and health. For example, data touching on the experience of adult children of women with breast cancer may be found combined with that of either parent who has lung or colorectal cancer (Germino & Funk, 1993).

Families and Children

Research with families touched by breast cancer has been developed from individual and systemic perspectives. The individual perspective has tended to dominate this literature, as it does in other areas of psychological study. Studies developed from this perspective typically approach family functioning by attending to selected voices in the family, either parents (e.g., Howes, Hoke, Winterbottom & Delafield, 1994; Hymovich, 1993; Lichtman et al., 1985; Shands, Lewis & Zahlis, 2000) or children
Thus, an investigation of parent-child relationships may be structured around parents’ ratings of both their own and their children’s functioning, and of the spousal relationship, and children’s experience may be considered in isolation from the family context. Research informed by a systemic perspective follows the logic of systems theory where causality is viewed reciprocally, and the process of investigation tends to be more holistic. Studies favouring this perspective typically approach family functioning by attending to multiple voices within the family. Thus, an investigation of family functioning may include parents and children (e.g., Birkenbaum, Phillips, Chand, & Huster; 1999) and may be structured around family interviews and observations (Hilton, 1993; Hilton & Elfert, 1996).

Results from the interview-based portion of a longitudinal study of 35 families of women newly diagnosed with breast cancer described a cluster of concerns under the theme of family patterns which reflected issues and problems in functional patterns at the individual and system level (Hilton, 1993). These concerns, which to me appear to overlap, included: (a) emotional response issues, (b) family communication, (c) family support behaviours, (d) major marital discord, (e) shifting priorities, and (f) loss of control. With respect to children, parents reported being more irritable and having children who misbehaved. One mother responded to her own distress by sending her preschool daughter away from the home for a time because she was afraid of her own
angry responses. At various ages, children also appeared to wrestle with finding ways to relate to their parents or to communicate appropriately, for example, by blocking out concerns about death yet wondering if this was appropriate because it was after all mother, and by crying in private and being cheerful in mother’s presence.

Hilton (1993) suggested that difficulties in communication arose in part from discrepant expectancies among family members, for example, with what was said about the cancer and with how it was said. This suggestion received support in a recent study that was focused on the information and support needs of adolescent children of mothers after a diagnosis of breast cancer (Chalmers et al., 1998). In that study, adolescents stressed the need for privacy when being told about the cancer and the need for information givers to be sensitive to the adolescent. The following example from Hilton’s study illustrates anger and upset in one child whose parents felt they had considered all aspects of the telling process for their two teenagers.

Dad really blew it this time about telling me that mom had cancer cause I had a friend over and we were in the kitchen and I was on my way to the basketball game and dad walks by me in the kitchen and says ‘oh your mother has cancer’ and then walks out of the room and I just went ‘whoa!’ I never told you how angry I was about that Daddy... to me that was totally insensitive to say ‘oh your mother has cancer’, especially when I have a friend over. (p. 96)

The example points to a need to go beyond parents’ assessments of family communication and harmony to ask the children about their experience, and provided support for my intention of mapping individual experience in concert with relational experience. The psychosocial literature on breast cancer relating to families generally
The most common approach to measuring family functioning from a systemic perspective draws on a set of instruments developed from the Circumplex Model of Family and Marital Systems (Olson, Sprenkel & Russell, 1979). Because it is theoretically important from a systemic perspective to attend to as many voices in the family as possible in order to capture the complexity of a family system, many of these instruments have separate forms for different age groups. Two dimensions underlie the model: (a) cohesion, which is defined as “the emotional bonding that members have with one another and the degree of individual autonomy a person experiences in the family system”, and which is located on a continuum of disengagement to enmeshment, and (b) adaptability, which is defined as “the ability of a marital/family system to change its power structure, role relationships, and relational rules in response to situational and developmental stresses”, and which is located on a continuum of rigidity to chaos (L’Abate & Bagarozzi, 1993). These two dimensions are used to create a range of types where moderation is assumed to indicate healthy family functioning. Extremes in either dimension are assumed to reflect a dysfunctional system.

The three versions of the Family Adaptability and Cohesion Scales that have been developed were originally based on dissertations focused on families with troubled
adolescents (Bell, 1980; Portner, 1980). With respect to the use of these instruments in the area of psychosocial oncology, a degree of caution may be warranted on two accounts. First, the importance of attending to family values in the process of conducting family assessments has been acknowledged with regard to the Circumplex Model, but it seems to be lacking in the psychosocial oncology literature. For example, extreme types may function well given that all family members like it that way. Second, the balance between bonding and autonomy assumed to indicate healthy family functioning may be different in families dealing with an illness that produces a sense of chaos, entails prolonged uncertainty, and often develops in unpredictable stages ending in death.

The work of the family in respect of cancer has been described as negotiating life-space transitions, for which there are no ‘rites de passage’ (Lewis, 1993). This transition engages family members in a process of meaning-making that involves a re-evaluation of values, orientation, and self-formulation. On these several accounts, assumptions about normal development may be problematic in respect to the traditional view of family systems and also in respect to stage-based conceptions of development in families. Transitional stages, usually cited in connection with families with adolescents, are assumed to predispose to adjustment difficulties. These concerns notwithstanding it is useful to see how the literature deals with development.

The developmental stage of the family (Germino & Funk, 1993; Kristjanson & Ashcroft, 1994) and of children and adolescents (Chalmers et al. 1998; Hoke, 1996) has been seen as an important factor in shaping the response of family members to a cancer
experience in the family, and one that is useful for organizing data. For example, younger children are seen as being more vulnerable to concerns about their safety and the safety of the family because they are so dependent on their family (Issel, Ersek, & Lewis, 1990). For adolescents, illness demands have been seen as creating parental needs for interdependence, that is, creating increased home and caregiving demands on adolescents at a time when adolescents are concerned with the task of developing an independent identity (Lewis, Ellison, & Woods, 1985). These examples illustrate culturally based assumptions that infuse psychological theory about the value of independence, and a decreasing need in children for maintaining connections with parents as children develop into adults. Assessment of values held by individual families, offered by the individuals themselves may offer a different basis for interpretations of concerns that currently rest largely on supposition.

Overall, family focused studies in the area of breast cancer have revealed problems in the areas of emotional response, family support, family communication, marital discord, shifting priorities, and loss of control (Irvine, 1996). Because most family studies in breast cancer focus on the initial or terminal phases of illness, little is known about remission or recurrence phases, and the concept of rehabilitation from a family perspective is largely missing (Kristjanson & Ashcroft, 1994). Family adaptation to breast cancer in all phases of the illness has been described thematically in terms of powerlessness, ambivalence, role restructuring, uncertainty, interdependence, and resiliency (Lewis, Ellison, & Woods, 1985).
In a recent review, Hoke (1996) described the effects of breast cancer on parenting and adjustment in young children and adolescents produced by research and clinical experience. Mothers have concerns about the care of their children, and about what and how to tell them about the cancer as they themselves are trying to cope with their own challenges and distress. Children’s reactions to a parent’s cancer have been described in terms of: (a) mood and self-esteem changes such as anger, fearfulness, anxiety, emotional lability; (b) academic changes such as poor concentration, declining academic performance, low self-esteem; (c) somatic symptoms such as stomach aches, appetite change, difficulties with sleep; and (d) social and interpersonal changes such as withdrawal, loss of interest in extracurricular activities, denial, and acting out.

One of the first studies considering the children of parents who had cancer indicated that most parents did not seek mental health consultation for behavioral problems in their children (Buckley, 1977). Most parents tended to be inattentive to problems or responded negatively. Because adolescents of parents with cancer may express their mental health needs in a variety of indirect ways such as stealing, running away from home, a marked drop in school performance, withdrawal from family and friends, and promiscuity, parents may come to see the child as negative, non-caring, or otherwise troubled rather than as reacting out of distress (Wellisch, 1981). Wellisch (1985) has argued that covert role shifts in families are especially likely to promote acting out and decompensation in adolescents.

Based on his clinical experience with adolescents of mothers with cancer, Wellisch
(1981; 1985) hypothesized that some adolescent daughters may act out their distress in a sexual manner because their mothers are experiencing distress related to changes in their own appearance, and sexual and emotional concerns post mastectomy. For clinicians working with adolescents, Wellisch stressed the importance of adopting a systemic view of family functioning because the complex and sometimes subtle nature of family dynamics is often erroneously interpreted as a problem residing in the child. The crisis of life threatening illness should also be considered as occurring in a family context which varies in terms of well functioning, and which has the potential to produce higher functioning as well as pathology (Aponte, 1985).

Factors that appear to influence children’s adjustment to maternal breast cancer include the individual relationship with each parent, individual strengths and vulnerabilities, cognitive capacities, previous behavioral or emotional problems, financial resources or reserve, marital discord, family functioning / communication, developmental level, age, and gender (Hoke, 1996). With respect to developmental age, adolescence has been described as a period when children understand the meaning of death and loss, and are developmentally moving toward increased self-sufficiency and establishing separate identities from their parents. Conflicted feelings around the goals of independence and separate identity are therefore assumed to underlie guilt and anger which may be expressed in conflict with parents, in behavioral problems outside the home, and in academic problems.

Support for the argument of conflicted identity and independence has been
garnered in interviews with adolescents, however the picture is not solely one of conflict. On one hand, adolescents described feeling torn between the desire to be with their friends and to “do their own thing” (Hilton & Elfert, 1996). On the other hand, adolescents spoke of having a sense of maturing in the course of taking on extra responsibilities. Complaints about having more responsibilities and restrictions may also be balanced by comments on perceived benefits of the cancer diagnosis, such as bringing the family closer, or having more family time (Lewis, Ellison, & Woods, 1985). I have two reactions to these results.

First, children’s experience of other forms of illness or disability in a parent may also have some positive aspects. For example, mothers of young children who are required for medical reasons to spend a portion of the day resting and who feel their care taking functions limited may have children who appreciate increased access to their mother. With respect to breast cancer, it is important to remember that the majority of women in one study reported that relationships with their children had remained strong or had grown stronger (Lichtman et al., 1985). Second, one might understand the task of adolescence as one of moving towards mutually responsible relationships as well as moving from dependence to independence (Lewis, Ellison & Woods, 1985). In our culture, norms for independence and self-sufficiency in the period of adolescence and young adulthood may be shifting. A sensitivity to the expectations that individuals have for themselves, for similar others, and for family relationships around independence and self-sufficiency as well as interdependence seems warranted.
The experience of both adolescents and mothers has been considered in light of expectations around shifts in roles and relationships. Results from Germino and Funk’s study (1993) of adult children, who ranged in age from 18 to 59, though more focused on concerns as opposed to experience per se, were organized in this vein. Concerns were described as: (a) developing the role a support person, (b) role changes, (c) parents’ problems with their child’s changed role, and (d) difficulties in meeting their own needs. Relationship concerns were described as: (a) a desire to be closer to the ill parent, (b) confusion about how to relate, (c) unresolved relationship issues, (d) the relationship with the other parent, (e) the effect of cancer on the parent’s marriage, and (f) parents’ relationship with the extended family. In the Hilton and Elfert study (1996), adolescents experienced concerns about a blurring and shifting of roles as the illness trajectory of their mothers alternately created felt demands for more adult and more child-like roles. Anxiety, hostility, and confusion accompanied the variation in felt demands.

Changes in mother-child relationships in the context of breast cancer have been described by mothers as generally positive, that is, an increased sense of personal closeness with children, and an ability to share concerns with their children (Lichtman et al., 1985). However, for the women in this study, where a sense of increasing distance occurred, it was more likely to be felt with daughters (40%) than with sons (26%). In this study, three adolescent daughters, but no sons, moved out of the home temporarily or permanently. Mothers reported a wider variety in problems with daughters than sons, with mothers of adolescent daughters reporting the most dramatic and rejecting
responses. Their own experience was one of betrayal and injury, perhaps attributable to the level of support expected of daughters. A quote from one mother illustrates the nature and level of her distress.

My daughter went out of her way to make it hard for me - or that’s the way I saw it at the time. She would come in and make a mess in the kitchen, knowing that I couldn’t clean it up. One night she simply took off, left a note saying that she had to get out of the house. We didn’t know where she was and I was completely hysterical. Her attitude seemed to be, from my point of view, “Why did you have to get sick? (p. 14)

Fear around inheriting breast cancer was cited by several mothers as a rationale for problems with adolescent daughters. For younger daughters, fears seemed to centre on their mothers dying. A limitation of this study is that although interviews with partners essentially supported mothers’ perceptions of problems, none of the children were interviewed. In the Chalmers et al.’s (1998) study, where daughters were interviewed, they felt a sense of vulnerability to breast cancer and all of them thought that they would develop breast cancer sooner or later.

In their review of approximately 200 clinical papers, research studies, and theoretical articles published between 1970 and 1990 on the family experience of various types of cancer, Kristjanson and Ashcroft (1994) noted that changes in the health of family members has recently become an area of growing interest. The majority of studies involving spouses and family members of women with breast cancer have been quantitative studies that have looked at psychological health from the vantage point of inventories measuring a variety of behaviours and constructs, for example, health
monitoring behaviours such as mammography and pap smears, stress and coping, adjustment, anxiety, depression, marital satisfaction, and sexual satisfaction. Adjustment is a major focus in studies involving children. Research focused on lived experience is limited but complements quantitative studies that tackle the complex nature of family interactions. Two recent quantitative studies that speak to women's experience with children will be presented in some detail, and discussed in light of descriptive data.

The first study examined the relationship between medical and psychological factors in mothers with breast cancer and children's psychosocial adjustment (Howes, Hoke, Winterbottom, & Delafield, 1994). It was designed in part to speak to observations that women who have a poor prognosis or who are experiencing distress and adjustment problems in the course of treatment report more adjustment problems in their children, and more problems with daughters (Lichtman et al., 1985). The study posed the following questions: (a) Do the children of breast cancer patients experience more adjustment problems in comparison to a normative sample? (b) Do mothers' reports of children's adjustment differ by gender? (c) Is the child's age related to adjustment? (d) What is the relationship between mothers' medical status and children's adjustment? and (e) What is the association between mothers' psychosocial adjustment to illness and the children's adjustment?

Nineteen women who had children ranging from several months to 18 years (M = 12 years, SD = 4 years) completed a series of questionnaires in one interview. Their medical status ranged from Stage 1 to widely metastatic disease. Time from diagnosis
ranged from 7 to 117 months (M= 32.8 months, SD=27.8). All had undergone radiation and chemotherapy, with treatment duration ranging from 7 to 15 months. Nine women had mastectomies, and the balance had breast conserving surgery. Measures of medical status included: (a) risk status for recurrence, note: two cases which had progressed to widespread metastases were omitted from risk analysis, (b) type of surgery, described as lumpectomy or mastectomy with no information on the type or whether reconstruction was sought, (c) severity of treatment side effects; which were neither defined nor described, (d) serious complications, again not defined or described, and (e) number of distinct courses of treatment. Questionnaires included: the Child Behavior Checklist (Achenbach, 1991), which yields scores on competence, and on emotional and behavioral symptomatology; the Psychosocial Adjustment to Illness Scale-Self Report (Derogatis & Lopez, 1983); and the Family Adaptability and Cohesion Evaluation Scales III (FACES III) (Olson, Portner, & Lavee, 1985).

Results indicated no differences between boys and girls on competence or problems, no significant differences from normative samples, and no effect for age. Mothers reporting serious medical complications reported significantly fewer emotional and behaviour problems, as well as higher overall competence in their children. Mothers' overall adjustment was related to symptomatology in children but not to competence, although there was a trend for mothers' adjustment to correlate with childrens' social adjustment. No other measures of severity of illness or treatment were related to childrens' adjustment. With hierarchical regression, mothers with higher levels of
emotional distress had children with higher levels of symptomatology.

The second study illustrates one line of research pursuing explanatory models of the psychological functioning of individuals and the quality of family relationships (Lewis, Hammond, & Woods, 1993). The focus in this study was on family adjustment. A limitation, noted in the discussion, is that the model being tested was developed as a recursive model with unidirectional causality which probably represents an oversimplification of family functioning. Eighty women and their partners, who had school-aged children (aged 6 to 12 yrs.; M= 9.28 yrs; SD=1.8), completed self-administered questionnaires separately on five occasions at 4 month intervals. The majority of women (88.6%) were diagnosed with Stage 0, 1, or 2 disease, and the balance with Stage 3 or 4. Median length of time since diagnosis was 13 months. The majority of women (65.7%) had a mastectomy and the balance had breast conserving surgery. Path analysis was used to examine the role of 10 variables: (a) depression, (b) marital adjustment, (c) family functioning, (d) family introspection, (e) illness demands, (f) child-peer relations, (g) parent-child togetherness, (h) functional support, (i) socio-economic status, and (j) months since diagnosis.

Results indicated that illness demands did not directly impact family coping with the illness, but appeared to affect the couple's ability to negotiate the illness. More illness demands were associated with higher levels of depression in parents which had a negative impact on marriages. For women, social support predicted depressed mood. Less support was associated with higher levels of depression. For women, troubled marriages
had a direct and negative impact on interactions with young children. These results support earlier research documenting links between depression and impaired parenting, and between impaired parenting and lower self-esteem and social behavioral problems in children. The family as a whole benefited from reflection on family activities and flexible coping strategies.

A limitation of both these studies is that no observations or interviews were conducted with the children themselves. Because the picture is essentially a one-sided construction of relationship, these studies might best be described as family-related (Germino, 1990). Neither study considered the impact of the child’s experience of illness, nor how that experience influenced parents. The value of attending to multiple voices in a relationship may be illustrated by considering the higher competence scores of children whose mothers experienced serious complications (Howes, Hoke, Winterbottom, & Delafield, 1994). One explanation, offered by the authors, is that children may try harder to behave well and do well at school in response to illness and therefore be rated as more competent. This explanation is supported and enhanced by descriptive data generated in a study that documented the efforts children make on their own to cope with mother’s illness.

A descriptive study examined the ways children helped themselves cope and the ways families helped children cope with a mother’s breast cancer by interviewing children one year after the diagnosis (Issel, Ersek, & Lewis, 1990). Eighty-one children aged 6 to 20 years (M=12.75) were asked four, action focused questions: (a) On a day-to-
day basis, what does your family do that makes it easier for you to handle your mother’s illness? (b) What things, if any, does your family do together as a group that help you with your mother’s illness? (c) What do you do by yourself that helps you deal with your mother’s illness? and (d) Who helps you get through what you’re going through now?

Responses to questions (a) and (b) were combined for analysis because they overlapped.

Content analysis produced 17 second-level categories of activities that were subsequently organized into four domains of coping: (a) In Her Shoes was comprised of being considerate, helping out, and doing for mother; (b) Business As Usual was comprised of acting normal, doing regular things, private things, everyday talking, putting it out of my mind, not talking/thinking about it, and nothing; (c) Group Energy was comprised of spending time together, being with friends, help from others; and (d) On The Table was comprised of talking about it, thinking/talking about it, went to the treatment place. Results were grouped by age for younger (ages 6-12, M=8.9) and older (ages 13-20, M=15.75) children. My comments are directed initially to categories that seem to have relevance for data from Howes, Hoke, Winterbottom, and Delafield (1994), and from Lewis, Hammond, and Woods, (1993). Categories that reflect substantial differences in terms of the percentage of younger and older children mentioning them are highlighted, and those that seem germane to this study are then addressed.

Higher competence scores and lower scores for emotional and behavioral problems in the children of women with serious complications were hypothesized to result from one or more factors: (a) children may have been trying harder to help their mothers by
behaving well or hiding problems; (b) the relationship between competence and complications may reflect a mediating variable such as family adaptability which may have increased in response to the complications; (c) mothers may have been less able or less inclined to observe problems, or may have changed their ideas about what constituted a problem; (d) other factors not measured (Howes, Hoke, Winterbottom, & Delafield, 1994).

On my reading, the work of children in responding to a mother’s illness with consideration was revealed in the domain of In Her Shoes (Issel, Ersek, & Lewis, 1990). Younger children were twice as likely to mention ‘helping out’ as a way of coping with mother’s illness by taking care of her, helping her with chores, and making an extra effort to be nice to family members. One 9 year-old offered the following explanation.

I know she’s sick and I have to do things without her. So, let’s say my dad’s not home and my mom’s here, but she’s in bed sleeping, resting. I try not to bug her. I just try to figure it out myself, or I skip it and wait until she’s awake or someone gets home to help me. (p. 9)

This quote points to the hidden or non-obvious ways children may be helping and is augmented by the following response from a 9 year-old girl. Her response fell under the domain of Business As Usual, and was an example of ‘talking/thinking about it’. “But instead of watching TV, I went on the couch in front of the TV so she’d think that I’d been watching it, but I closed my eyes and I was thinking about her illness” (p. 9). Older children were more than twice as likely to report they coped by thinking about/talking about the illness (46 % versus 17%).

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The importance of family functioning for children’s coping was illustrated by the high percentage of both older and younger children (60%) who talked about their coping by ‘spending time together’, a category in the domain of Group Energy. A comment from this 13 year-old boy is illustrative, and also points to his care-taking of mother: “We go to church, do things together like baseball games, the fair. It makes you feel like a whole lot better, it makes her feel like she’s all right” (Issel, Ersek, & Lewis, 1990; p. 9). This response perhaps speaks to the work of children in preserving the family, and the potential impact on mothers and fathers. For mothers in Lewis, Hammond, and Woods, (1993), family functioning and marital adjustment were significantly related to depression on hierarchical regression (r = -.44, and -.42 respectively; p<.01). For fathers, family functioning and marital adjustment were also significantly related to depression (r = -.47, and r = -.59 respectively; p<.01, and p<.001). The difference was that for fathers, family coping behaviour rather than marital adjustment affected the quality of parent-child relationships, which in turn affected competence scores in children, whereas for mothers marital adjustment had a direct effect on relations with children. One comment from a 15 year-old boy, categorized as ‘putting it out of mind’ under the domain of Business As Usual, reflects family care-taking and self-care:

You have to not let it get to you. You gotta find something else to occupy your mind. Cause if you sit around all day and think [sic] that your mom’s sick, she’s gonna die, then the whole family will fall apart. (p. 9)

The question of how individual family members experience and understand the illness experience would seem to be a crucial factor in shaping their responses, but has
received scant attention. Family members may have very different ideas about what they are dealing with, in terms of prognosis, which affects experience and social discourse among family members. With respect to older adolescents and young adults, Hilton and Elfert (1996) noted parents’ information sharing about the illness tended to be more extensive than with younger children. Here is what one adolescent said.

Mom made a point of talking about everything and there were a couple of times when I really didn’t know what was going on and stuff and so I talked to her about it and she answered everything that I wanted to know. (p.100)

However, information was shared selectively in terms of prognosis. Teens who were initially well informed tended to be protected from learning about additional lumps that were found. This may in part account for the comments noted among older children by both Hilton and Elfert (1996) and Issel, Ersek, and Lewis (1990) that their mother’s illness was either no big deal or that it was over.

**Summary and Intent**

Because most studies involving adolescents have focused on coping efforts (Issel, Ersek, & Lewis, 1990), have pooled comments from parents and children (Hilton & Elfert, 1996), have relied on parents perceptions of children’s adjustment (Howes, Hoke, Winterbottom, & Delafield, 1994; Lewis, Hammond, & Woods, 1993; Lichtman, et al., 1985; Shands, Lewis & Zahlis, 2000), and have given scant attention to the place of biology and gender for adolescent daughters caught up in an illness experience, the ways in which adolescent daughters experience breast cancer in a mother remain unexplored. By the same token, studies involving the mothers of adolescent daughters have not
considered the meaning of their illness experience specifically with respect to their daughters, and the import of shared biology, gender, and relationship.

Existing studies demonstrate some intriguing discrepancies for both mothers and daughters. For adolescents, arguing, anxiety, upset, avoidance, and uncertainty about the wisdom of avoidance seem to exist alongside efforts to be considerate, to become informed, and to help mothers deal with breast cancer (Hilton & Elfert, 1996; Issel, Ersek, & Lewis, 1990). For mothers diagnosed with breast cancer, reports of support and increased closeness stand alongside reports of a wider variety of problems, distance, rejection, and hostility in daughters (Hilton & Elfert, 1996; Lichtman et al., 1985; Wellisch, 1981; Wellisch et al., 1991, 1992). For both mothers and daughters, illness experience has been documented as a phenomenon at the aggregate level as opposed to a phenomenon unfolding in the context of a social relationship that may be impacted by a variety of individual difference factors, and the ongoing mother-daughter relationship.

Because the voices of adolescent daughters themselves are rarely heard, and have not been heard in the context of their relationships with mothers touched by breast cancer, explanations for research findings are generally derived from theories that value independence and autonomy. For example, Issel, Ersek, and Lewis (1990) generated two possible explanations for the responses grouped in the domain of In Her Shoes that spoke to unmet needs or to conflict with respect to independence and to family functioning. Alternate explanations might be generated, that might reference a developmental theory based on connection and caring rather than on independence and autonomy, and might
speak to accounts of increased closeness. However, it is difficult to find support for any particular explanation in the absence of a better understanding of the experience of adolescents themselves along with that of their mothers.

Because the psychosocial literature on mothers and children tends to be problem-focused there is a natural slant to pathologize and to underappreciate the potential for growth and development that may develop in the context of a serious illness. Although there is some evidence that mothers and daughters may come to value their time together, experiencing an increase in closeness (Lichtman et al., 1985) and an intense emotional bond (Hilton & Elfert, 1996), to date there has been no in-depth study of the development of the mother-daughter relationship in the context of breast cancer.

In summary, the personal experience of breast cancer for mothers and daughters has not been studied in the context of the mother-daughter relationship, nor has the mother-daughter-relationship been examined for the import of the breast cancer experience. The voices of women with breast cancer have been heard in isolation from their adolescent daughters. Adolescent daughters are rarely interviewed, and are usually not interviewed without other family members being present. My intention in this study was twofold: (a) to create an opportunity for hearing the voices of mothers and daughters individually and jointly in the context of their particular relationship and particular illness experience, (b) to engage in a dialogue with mothers and daughters that might be more neutral as opposed to problem-focused in order to facilitate a space for the expression of diverse forms of experience, some of which might be positive.
CHAPTER III

METHOD

The design for this study flowed from the naturalistic tradition of emergent design, wherein the scope and direction of inquiry are determined by a growing understanding of the topic as the study progresses. My study is an example of a contextualist approach to research in psychology where phenomena are considered in a biological, cultural, and ecological context (Hoshmand, 1994). The study was focused on experience and meaning for participants at individual and dyadic levels, and generated a portrait of experience that is the product of my interactions with participants.

My guiding metaphor in embarking in this study was of the researcher as *bricoleur* as articulated by Denzin and Lincoln (1995). I adopted this metaphor with regard to the task of choosing the method and analytic techniques to address my research questions. The work of a bricoleur has been described as an emergent construction that results in a bricolage, a pieced together, close knit set of practices that furnish solutions to problems at hand. The work changes and takes on different forms as various tools, methods, and techniques are added to the puzzle.

The researcher as bricoleur works between and within competing and overlapping perspectives and paradigms. ...The product of the bricoleur's labour is a *bricolage*, a complex, dense, reflexive, collage like creation that represents the researcher's images, understandings, and interpretations of the world or phenomena under analysis. (pp. 2-3)

Research as bricolage is pragmatic, strategic, and self-reflexive. Because research conducted from the standpoint of a bricoleur is understood to be an "interactive process
shaped by personal history, biography, gender, social class, race and ethnicity, and those of the people in the setting” (Denzin & Lincoln, 1995, p. 3), I devote considerable space to situating myself in the research process in order to “come clean about my present orientation to the subject of inquiry” (Sandelowski, 1989, p. 78). In preceding sections, I described my orientation from three overlapping vantage points: theoretical orientation, professional interest, and personal experience.

Experienced qualitative researchers differ sharply on the question of orthodoxy and heterodoxy in the choice of method. Some regard heterodoxy as a slurring or muddling of methods (Baker, Wuest, & Stern, 1992; Stern, 1994). Others express concern about “the construction of tightly bounded typologies of research methods and their translation into prescriptive frameworks” (Atkinson, 1995, p. 119), and caution against methodolatry, a slavish attachment to form over substance fuelled by a preoccupation with selecting and defending methods (Janesick, 1994).

Discussing the theoretical traditions of anthropology, phenomenology, and grounded theory in relation to nursing, Thorne (1991) has pointed out numerous discrepancies in the process, product, and original purpose among these three fields and the aims of nursing inquiry. For example, interview and participant observation methods in grounded theory are used by sociologists to discover the forces underlying social behaviour at a macro-level of analysis, whereas in nursing the method is used at a micro-level of analysis to illuminate aspects of social behaviour that impact the practice of nursing individuals in particular contexts. This example points to the potential utility in
adopting methods from other disciplines by virtue of the fact that techniques may
usefully be employed to serve particular purposes in different contexts.

One of my purposes in conducting this research was to pursue knowledge in light
of what has proved valuable in my clinical work with respect to appreciating experience.
In working with systemic theory (Becvar & Becvar, 1988) I have developed an
appreciation for the complex and shifting nature of experience when you move between
individual and systems levels. Interviewing individuals separately and jointly is one way
to appreciate that complexity, and to uncover what Wiersma (1988) has referred to as
private versus more public or 'press release' versions of experience. My sense was not
that one was preferable to another, but that both were worthy of consideration and that it
would be exciting to consider both rather than one or the other. Experience with dyads
has taught me to attend to personal and interpersonal dynamics which may be conveyed
in a wide variety of ways, such as tone, turn taking in conversation, points of energy and
shifts in the focus of conversation, and to use these observations to advance the dialogue.

In working with cognitive constructivist theory (Mahoney, 1991), I developed a
sensitivity to metaphor, a curiosity about tacit experience, and an appreciation for the
utility in attending to the emotional landscape of experience in ways that may be
unconventional in research. For example, I came to appreciate the utility of valuing and
documenting symbolic forms of communication other than verbal dialogue for
elucidating meaning in experience, my own as well as those of clients. Symbolic forms of
communication such as how one configures personal appearance and living space that
present as givens, as well as artistic products generated in the moment such as drawings, have proven valuable in expanding the space for dialogue. Creating a space for understanding experience in symbolic forms in addition to verbal dialogue seemed a particularly important and fruitful undertaking in my study in light of the rich variety of symbols that breast cancer experience has generated, for example in quilt projects, numerous breast cancer lapel pins, and cosmetic products.

**Interpretive Description as an Inquiry Method**

This inquiry followed the logic and direction of interpretive description as method (Thorne, MacDonald-Emes & Thorne, 1997) informed by the analytic procedures of portraiture (Lawrence-Lightfoot & Davis, 1997) in data analysis, process, and product.

The method of interpretive description adopted in this study is a non-categorical method of inquiry that admits flexibility in the procedures that are used for data analysis. The method was developed to honour the nature of the project in nursing research which is to develop a form of knowledge that abstracts commonalities in order to apply them to individual cases. Because the nature of the research project in counselling psychology can be the same, and is certainly the case in this study, the method was well suited to my inquiry. A primary purpose of this study was to create a product that speaks to commonalities, because commonalities constitute the core knowledge base and language of counselling psychology as it does for nursing, and to attend to the challenge of application to individual cases in practice. Interpretive description requires that the research project be located within an existing knowledge base to provide a basis for
assessing design logic and a beginning point for a process of inductive reasoning.

Sample Selection

Interpretive description (Thorne, Kirkham & MacDonald-Emes, 1997) recommends that inquiry proceed on the basis of theoretical sampling, which strives for maximum variation on themes that develop from the analysis. Participants are sought on the basis of variations one might predict, or discover as the study proceeds. Because this study sought participants whose willingness to participate was an open question, it can be considered a small, preliminary study where the concept of theoretical sampling may be employed differently. In this study, theoretical sampling was redefined to direct inquiry questions and to articulate limitations on the meaning of findings, rather than to the selection of individuals on the basis of attributes.

Recruitment

Initial recruitment efforts sought women who had recent experience with breast cancer, approximately two years after diagnosis. Two notices placed in doctors’ offices and in various locations in the community, and a notice in the newsletter of the British Columbia and Yukon Breast Cancer Information Project are in Appendix G. The number of individuals who responded to recruitment efforts was small, and those who were interested in joining the study were found through recruitment efforts in the breast cancer community by advertisement and by word of mouth. My selection criteria for participants were altered to accommodate the few numbers of inquiries about the study. Mothers who joined the study were between two and six years from diagnosis. Initial recruitment
efforts had targeted mothers who had daughters living at home, but in one case in this study a daughter had recently moved away from home to start university. The criteria for participating in this study were that mothers had daughters who were adolescents at the time of diagnosis (between 11 and 19 years), and that participants would be willing to have a conversation about their experience. Where interested persons demonstrated a need for counselling as opposed to an interest in participating in research, interested persons were not enrolled (see screening questions in Appendix E).

Participants

The five mothers and daughters who enrolled in this study were Caucasians, lived in two parent families, and resided in urban centres. Mothers were between 40 and 50 years of age at the time of the diagnosis of breast cancer, and their daughters were between 11 and 14 years of age at the time of the diagnosis. At the time of the study mothers were between 2 to 6 years post diagnosis so I was speaking with mothers now between 44 and 57, and with daughters now between 15 and 17. The average age of mothers at the time of the study was 49 and the average age of daughters was 16. I had not experienced breast cancer, was 49, and had a daughter in her twenties – facts I was open about.

Mothers had received diagnoses of various types of breast cancer with varied propensity for spread, discovered in different stages of development. Treatment resulted in lumpectomy or mastectomy, with or without lymph node dissection. One mother had surgery and radiation, and the others had surgery accompanied by variously intensive
courses of radiation and chemotherapy. All of the mothers described themselves as healthy at the outset of the study. During the study, one learned that she had developed metastatic disease, one encountered a “real bout of depression” and began a course of antidepressants, another underwent investigation and treatment of other troubling symptoms that were not found to be related to breast cancer. All of the daughters described themselves as healthy at the outset of the study and their health status did not change during the course of the study.

Some mothers were working more or less full-time, and some were working part-time outside of their work at home. All of the mothers were active in the breast cancer community to various degrees through support groups, fundraising, awareness efforts, public speaking, and dragon boating. All had joined the study as a result of contact with other women in the breast cancer community, for example through support networks, or by learning of the study through a breast cancer information newsletter. The daughters were involved in their schoolwork and in a variety of extracurricular activities. One daughter was now in her first trimester at university.

Procedures

The following procedures recommended by interpretive description (Thorne, Kirkham, & MacDonald-Emes, 1997) were employed: (a) the use of field notes to record the context of data gathering sessions and to link context to phenomena, (b) the use of a reflective journal to guide and document the interpretive process, (c) the use of field notes and a reflective journal as a form of traceable audit, (d) repeated interviewing and
taking beginning conceptualizations back to participants for critical reflection, and (e) provision of an explicit account of personal and professional biases.

The method of interpretive description employed in this study supplements interviews with collateral data sources. Recommended sources may include lay print, case reports or clinical studies, personal communications with clinicians, and publications of health care organizations or institutions. This study utilized lay print (Caldwell, in MacPhee, 1994), a conference presentation of another teenage daughter on her experience with breast cancer (Tennant, 1999), and a publication of a health care organization (Y-Me National Breast Cancer Organization, 2000). Collateral data sources are recommended because they can provide direction for the inquiry, and can offer both confirmation and challenge to developing insights and to findings.

In-depth interviews with mother-daughter dyads and individual interviews with mothers and daughters facilitated the exploration of the individual and joint construction of the impact of breast cancer on personal experience, and on the mother-daughter relationship. Mothers and daughters were interviewed in a series of six interviews. Questions posed in the interviews are listed in Appendix F. Each individual participated in four interviews lasting approximately one hour in length. The first and last interview with each mother and daughter was a joint interview. In between the joint interviews, each mother and daughter was interviewed separately on two occasions. The choice of sequence for the individual interviews was left up to the participants. The sequence, format, and purpose of each interview are listed in Table 1.
Table 1
Interview Schedule for Each Mother-Daughter Dyad

<table>
<thead>
<tr>
<th>Sequence</th>
<th>Format</th>
<th>Purpose</th>
</tr>
</thead>
<tbody>
<tr>
<td>First</td>
<td>First Joint Interview</td>
<td>query on purpose in joining the study and desired outcomes, global questions on breast cancer experience and the mother-daughter relationship, query on family health history</td>
</tr>
<tr>
<td></td>
<td>(Mother and Daughter)</td>
<td></td>
</tr>
<tr>
<td>Second</td>
<td>First Individual Interview</td>
<td>follow up on joint interview, discussion on experience and relationship continues, invitation to create a drawing</td>
</tr>
<tr>
<td></td>
<td>(Mother or Daughter)</td>
<td></td>
</tr>
<tr>
<td>Third</td>
<td>First Individual Interview</td>
<td>follow up on joint interview, discussion on experience and relationship continues, invitation to create a drawing</td>
</tr>
<tr>
<td></td>
<td>(Mother or Daughter)</td>
<td></td>
</tr>
<tr>
<td>Fourth</td>
<td>Second Individual Interview</td>
<td>follow up on individual interview, discussion on experience and relationship continues, individual feedback letter on participation presented and discussed</td>
</tr>
<tr>
<td></td>
<td>(Mother or Daughter)</td>
<td></td>
</tr>
<tr>
<td>Fifth</td>
<td>Second Individual Interview</td>
<td>follow up on individual interview, discussion on experience and relationship continues, individual feedback letter on participation presented and discussed</td>
</tr>
<tr>
<td></td>
<td>(Mother or Daughter)</td>
<td></td>
</tr>
<tr>
<td>Sixth</td>
<td>Second Joint Interview</td>
<td>group feedback letter presented and discussed, query on participation</td>
</tr>
<tr>
<td></td>
<td>(Mother and Daughter)</td>
<td></td>
</tr>
</tbody>
</table>

The order of the interviews - joint, individual, and joint - was designed to accomplish several goals. Clarifying at the outset our respective goals in meeting served multiple purposes. At an interpersonal process level, it served as a way to attend to
factors that are important in working with any group, that is, issues of safety, belonging, and control. Concerns of mothers documented in the literature about the welfare of their children and my own preliminary fieldwork suggested that safety and control might be especially important in this study. Because my study involved children, mothers were entitled to some degree of concern about and freedom in determining how best to avoid potential harm in discussing sensitive topics. Negotiating a climate of safety and control at the outset was therefore particularly important. Issues of confidentiality were also given special attention. Because the study involved both joint and individual interviews, creating a space for discussing the sharing of information was particularly important.

Because the final product of the series of interviews was assumed to be, for all participants, inextricably related to purpose in undertaking them, the interviews began with an exploration of our joint purposes in coming together. In starting off with mother-daughter dyads, my goal was to set the tone and direction for our interviews as an exploration of relationship, a subset of experience that was critical in this study. Consent forms served as a focus to initiate a discussion related to my purpose and to the intentions of the participants at the outset of the study (see interview questions in Appendix F). Questions, concerns, and preferences about the substantive focus of the study, and about the construction, dissemination, and application of findings were encouraged. My intention was to move beyond my own need to fulfill a requirement for my degree and to consider how to serve the needs of the people who were generous enough to share their time and their stories.
In the first joint interview, a global question on the experience and meaning of breast cancer served as a starting point for the inquiry. I asked participants the following question: “Can each of you say something about the breast cancer, maybe what it was like for you and also for the other person?” A global question on mother-daughter relationships followed. I asked participants the following question: “Can each of you say something about mother-daughter relationships, maybe in general and also about your own relationship?” These two open-ended questions were designed to focus the participants’ thinking but to allow freedom of expression, therefore the substance and direction of the interview varied according to participants’ responses (Sandelowski, 1989). A question on family health history was included in this interview to provide context on the health and illness experience of each dyad.

The first individual interview began with a follow up question on the preceding joint interview. Participants were asked what the first joint interview was like for them, and whether they might like to add new thoughts. Conversations on the experience and meaning of breast cancer and on the mother-daughter relationship continued. Again, the participants set the direction and content of the interview. Near the end of this interview, participants were invited to render their experience of breast cancer in visual form. They were provided with coloured pencils and crayons and asked to spend about 10 minutes on a drawing that could be a picture or just colours and that might involve themselves alone or that might include their mother or daughter. The wording of the invitation was very general to allow participants the freedom of capturing their experience at any point since
the diagnosis. After the drawing was completed, participants were engaged in a discussion of what the drawing represented.

The second individual interview began with a question on the preceding interview. Participants were asked what the individual interview was like for them, and whether they might like to add new thoughts. Conversations on the experience and meaning of breast cancer and the mother-daughter relationship continued. A feedback letter on their participation in the study facilitated conversations. The purpose of this letter was to clarify my understanding of their experience and to prompt further discussion. Participants were aware they would be getting this letter because it was promised on the consent form. The letter was composed after I had reviewed the audiotapes of their first two interviews and had consulted my reflective field notes to capture the thrust of what they had conveyed, or rather what I had understood, and what stood out for me. The feedback letter was introduced as my own understanding of what they had shared with me so far. I invited participants to reflect on the letter, ask questions, make suggestions for improvement and offer comments. The following question “What pops out for you?” was useful in opening up a space for discussion that reduced the pressure of me asking them for corrections. This question often prompted further discussion of points of interest for the participants.

The final joint interviews were not undertaken until all mothers and daughters had completed the first five interviews in the series. One of the purposes of the final interview was to present a group feedback letter to each participant on what all the other
participants had shared (see letter in Appendix A). The purpose of this letter was to prompt further discussion and to check on the authenticity of my understandings. Participants were aware they would be getting this letter because it was promised on the consent form. The letter was composed after I had reviewed the audiotapes of all of the interviews and had consulted my reflective field notes to capture the thrust of what the group as a whole they had conveyed, or rather what I had understood, and what stood out for me. The group feedback letter was delivered with the same instructions as the individual feedback letter, with an additional query as to whether or not what the group as a whole had shared was true of their own experience. Again, a question on “What pops out for you?” facilitated discussion. The final interview gave me the opportunity to ask participants what the experience of being in the study was like, and to assess the need for referral. It also afforded an opportunity to elicit and clarify any recommendations they had concerning the product of the inquiry.

My goal in this inquiry was to construct a portrait of experience and meaning that incorporated alternative forms of communicating experience, thus expanding the dialogue beyond traditional constructivist accounts of meaning-making that focus exclusively on the analysis of verbal dialogue. For example, my data included observations on the home setting that served to illuminate the ways family members constructed a response to illness and have configured their relationships. Preliminary fieldwork drew my attention to the potential utility of this approach. The sheer amount of space devoted to nutritional supplements in the kitchen of one woman I spoke with stood
out as a highly visible symbol of an ongoing response to illness, as did a large cupboard filled with drawing materials and the drawings of her children. In this study, I made observations on the home setting, and invited participants to create drawings of their experience.

An invitation to render experience in a drawing creates an opportunity for appreciating deeply felt aspects of experience in ways that words alone may not afford or that individuals may not readily access. Research that incorporates the use of participants’ drawings is usually confined to studies conducted with young children (e.g., Allan, 1988; Williams & Bendelow, 2000), in part because researchers may assume that asking older children and adults to render their experience in visual form might be perceived as unusual and challenging for older participants. Based on my clinical work I have found that adolescents and adults are both willing and able to render experience in drawings, and to describe what their drawings represent.

The phenomenological approach to art (Betensky, 1987) employed in this study relies on techniques of observation and description, in a dialogical process that reveals both intentional and hidden aspects of experience. Discovering meaning and possibility a two-phased process of phenomenological intuiting and integrating. The first phase involves: (a) perceiving, (b) distancing to gain perspective, and (c) intentional looking. The second phase involves: (a) reflecting, with respect to intended and unintended outcomes; (b) searching for similarities and differences in art over time; and (c) searching for parallels between the art and efforts to cope with real-life experiences. In
this study, my sense was that the search for similarities and differences in art work over
time was less important then a discussion that would touch on connections between the
artistic product and coping with real-life experience.

The phenomenological approach to understanding artistic products incorporates a
significant amount of dialogue with another in perceiving, and eventually discovering
meaning in the images that are produced. It recognizes emotion as a potent organizer of
experience that directs the flow and substance of creative expression. In this study,
artistic products were solicited in a window of time that favoured a research process as
opposed to a therapeutic one. The question is one of depth. My focus in this study was on
the discovery of meaning, a process that entails growth and healing, but in a research
setting this focus needs to be managed so as not to move into therapy, thereby violating
the research contract. As researcher, I took an active role in limiting the potential impact
of conversations about the art, and conversations in general, in several ways.

In my study, I took responsibility for monitoring and setting limits on the depth of
conversations, and solicited feedback on the effects of our interviews. Because soliciting
feedback on the interview process is rarely done in qualitative research studies, aside
from follow-up interviews focused on confirmation of findings for completeness and
accuracy, this aspect of my study afforded an enlarged understanding of the risks and
benefits for participants. Discussion and documentation of the tenor of interviews and of
participant feedback on the research process with my research committee facilitated the
process of monitoring and follow up. I anticipated making referrals if needed to
therapists in the community experienced in dealing with the concerns of families visited by cancer but none were required.

Data Analysis

Data analysis in interpretive description (Thorne, Kirkham, & MacDonald-Emes, 1997) favours inductive analysis and therefore avoids techniques such as complex coding systems that inhibit inductive reasoning. Interpretive description also does not encourage the use of computer software programs because, in practice, there is a danger of programs driving the analysis. Interpretive description proceeds on a whole-to-part basis. The researcher begins by asking questions about the overall picture. General questions such as “What is happening here?” and “What am I learning about his?” are assumed to stimulate more coherent analytic frameworks than will sorting, filing, and combining vast quantities of small data units.

Strategic periods of immersion in the field alternating with immersion in the data facilitate the refinement of inquiry and the testing of developing conceptualizations. Field notes and reflective journaling provide contextual information, facilitate the process of developing conceptualizations, and challenge researcher bias. A combined view of interview dialogue, field notes, and journaling was useful in bringing professional bias to light. For example, one of the assumptions in counselling is that it is useful to talk about concerns. I noticed that in several interviews we were talking about having or not having conversations with the other half of the mother-daughter dyad. This afforded an opportunity to bring this observation forward to participants and to ask for their views on
the value of talking and not talking about personal and interpersonal concerns.

In my study I made field notes after each interview, listened to the audiotape twice, and then made transcriptions of the interview. Interview transcripts were then highlighted and marginal notes were made to capture aspects stressed by participants, conversational shifts and shifts in energy that I observed, and my own beginning conceptualizations and questions. The results of these activities were incorporated into my reflective journal, which facilitated my understanding of what I was learning in answer to my research questions, and provided direction for subsequent interviews. Conceptual mapping of my developing understandings was facilitated by the use of a white board and by making drawings of my current understandings. A consultation process with my committee members for critical feedback on my progress in making sense of the data and for assessing my biases was retained. In addition, a consultant with expertise in the use of drawings in psychological research was retained to further my understanding of visual representations of experience generated in the study. Our focus was on what the drawings conveyed in a global sense, and also what they might or might not represent in relation to what was conveyed verbally and interpersonally. In this report, drawings were presented as examples of avenues by which thematic content was developed in conversations with participants, and as illustration of thematic content.

Recommended analytic procedures capitalize on the ability of the researcher to synthesize, theorize, and recontextualize rather than to sort and code. Examples of recommended analytic procedures familiar in counselling psychology research include
the approach to phenomenological inquiry articulated by Giorgi (1985) and the
description of naturalistic inquiry offered by Guba and Lincoln (1985). The approach
advanced by Lawrence-Lightfoot and Davis (1997) in the *Art and Science of Portraiture* is
another option for data analysis, which was used in this study.

**Portraiture**

The task in portraiture, as in other qualitative research, is interpretive description.
The logic of portraiture parallels that of case study where the aim is naturalistic
generalization but it also focuses on producing themes. In portraiture, understanding is
developed along similar lines to the method of interpretive description used in this study.
The researcher asks two general questions in terms of process and product: “How does
this line of investigation inform the developing understanding?” and “How does this
mode of representation inform the developing understanding?” Portraiture has five
essential features that I used in the conduct of the study, in data analysis, and in
developing a rendering of experience: *voice, relationship, context, emergent themes*, and
*aesthetic whole*.

*Voice* reflects an explicit interest in authorship and interpretation, as is the case in
interpretive description (Thorne, Kirkham, & MacDonald-Emes, 1997). The voice of the
portraitist, myself as researcher, is to be everywhere but judiciously placed. Voice may
be illuminated and implemented by (a) witness, (b) interpretation, (c) preoccupation, (d)
autobiography, (e) discerning other voices, and (f) dialogue. Voice as witness utilizes the
outsider’s ability to view patterns and the whole. Voice as interpretation incorporates
both thin and thick description, low and high levels of inference respectively, because
details provide material the reader might use to make alternative interpretations. Voice as
preoccupation documents the lens the researcher brings in terms of theoretical
frameworks, personal and professional interests, and understanding of the literature
because these factors direct observations and shape the text. Voice as autobiography
documents a selective personal history because it alerts the reader to the researcher's
filters. Voice as discernment of other voices documents participants' voices in words,
tone, gesture, images, words often used, and silence. Voice as dialogue places the
researcher in the conversations to illustrate the co-constructive nature of dialogue.

*Relationship* reflects an acknowledgment that the encounters we have as
researchers are meaningful and significant. The task of the researcher using portraiture is
to try to make the research encounter comfortable, respectful, and benign. Relationship
focuses on building trust and rapport through empathic regard, a search for goodness, and
the development of reciprocity and boundary negotiation. Empathic regard is cultivated
because it facilitates building understanding and insight, and honours multiple
perspectives. A search for goodness facilitates a focus on functionality, strength, and
health while acknowledging problematic aspects of experience. Respecting the
boundaries of participants and developing reciprocity involves delineating the limits of
inquiry to decrease risk to participants, setting out the intents and wants of all
participants, and focusing on themes that might inform other lives.

*Context* reflects an interest in context as a resource for understanding. Context may
focus on: (a) the internal, that is, aspects of the physical environment; (b) the personal, that is, the perch and perspective of the researcher; (c) the historical, that is, the origins, evolution, and values shaping experience; (d) the aesthetic, that is, the symbols and metaphors in participants’ actions and reflections; and (e) the shaping forces, that is, the dynamics of change and constancy by which people compose and are composed by settings and circumstances.

Emergent themes reflects the researcher’s efforts to bring interpretive insight, analytic scrutiny, and aesthetic order to data collection and analysis. The search for pattern in portraiture revolves around two frameworks for organizing information and understanding: dimensions and themes. Dimensions are the initial knowledge base and areas of mattering that the researcher brings. I modified this aspect to include the initial knowledge base and areas of mattering that all participants bring. Themes are what reside in and emerge from the data and what become areas of mattering. Themes ‘emerge’ out of a process of data gathering, synthesis, generative reflection, and interpretive insight. The search for themes in this study involved: (a) searching for convergence and dissonance among the data, facilitated by the use of field notes and reflective journaling, observations and other materials, and solicited feedback; (b) listening for repetitive refrains, such as words, actions, gestures, ironies and innuendo that repeat – including personal experience not shared with particular others that shapes experience; (c) listening for metaphors that echoed across conversations, and attending to symbols both present and generated; (d) attending to social affiliations and activities.
Aesthetic whole reflects an interest in constructing a portrait of experience that is coherent, complex, lively, and storied. Form is exploited in the service of content and is developed through stories, examples, illustrations, illusions, and ironies. Detail, nuance, and emotion are used to convey movement and texture. Balance is furthered in the choice and amount of descriptive details, choices that also serve the reader in generating alternative interpretations. The researcher remains visible, although the focus is on the experience of participants. The purpose of the aesthetic whole feature in portraiture is to help the researcher create a product that informs and inspires, and that creates a “click of recognition.” The criterion for a successful product is authenticity, a recognition factor that resonates with participants, readers, and with the researcher. In portraiture, participants are also involved in approving the final product. My own view was that an authentic product had sufficient truth value if the perspectives of participants were documented where they might differ from that of myself as author.

Criteria for Judging Rigor

Multiple sources of data were employed in my study. In-depth interviews were supplemented with drawings, collateral data, observations, field notes and a reflective journal. Repeated interviews provided a means of following up on earlier conversations, expanding the dialogue, and clarifying current understandings. Drawings afforded an opportunity to appreciate aspects of experience that were not conveyed verbally. Observations provided additional information on individual and interpersonal experience. Collateral data provided contextual information. Field notes and a reflective journal
provided a vehicle for recording contextual information and developing insights.

Data analysis was facilitated by consultative process. Two feedback letters were employed, an individual letter during the study and a group letter at the conclusion of the study. Both letters provided a means of obtaining critical feedback on developing understandings. The group letter provided a credibility check on my understandings as to how they might or might not apply to all participants. A consultative process was retained with my committee in making sense of the data. Consultation with a psychologist with expertise in the use of drawings in research furthered my understanding of the drawings generated in the study. Field notes and a reflective journal provided a traceable audit for developing understandings.

Limitations of the Method

The product of this inquiry was informed by participant feedback, however it is ultimately a construction by me as author. I modified the use of portraiture by taking personal responsibility for creating the final product. The understandings generated in my study were informed by consultation with committee members on sense-making but I was the only person who read the transcripts. Neither of these two factors is precluded by the method of interpretive description employed in this study nor by portraiture, but these considerations are worth noting.

The impact of my presence in the interviews is unknown. However, by my observation there were occasions where participants seemed to seize the opportunity of my presence to clarify questions with, or to bring forward concerns to, the other half of
the mother-daughter dyad. Systemic approaches (Becvar & Becvar, 1988) would recognize the researcher as operating in concert with a natural system and impacting it. The process and product of this inquiry is thus a function of the interactions among all participants, in ways that are discernible and not discernible.

Summary

As researcher, my voice was that of a passionate participant who was actively engaged in facilitating a multi-voiced reconstruction of the constructions of all participants (Guba & Lincoln, 1995), and who was committed to ongoing reflection on my own experience of the process of inquiry. The next chapter presents my findings, findings constructed from my understanding of what participants shared and their input into that understanding.

My findings were constructed using the five features of portraiture (Lawrence-Lightfoot & Davis, 1997), voice, relationship, context, emergent themes, and aesthetic whole. I constructed themes by: (a) following an iterative process of data collection and analysis, as recommended in interpretive description (Thorne, Kirkham, & MacDonald-Emes, 1997); (b) searching for convergence and dissonance among the data, facilitated by the use of field notes and reflective journaling, observations and other materials, and solicited feedback; (c) listening for repetitive refrains, such as words, actions, gestures, ironies and innuendos that repeat – including personal experience not shared with particular others that shapes experience; (d) listening for resonant metaphors that echoed across conversations, and attending to symbols both present and generated; and (e)
attending to the social affiliations and activities of participants.
CHAPTER IV

FINDINGS

My findings are organized in three sections: Embarking on the Study, Experiencing Breast Cancer, and Being in the Study. The first section, Embarking on the Study, documents the context and the direction of the study. The second section, Experiencing Breast Cancer, documents the answers to my research questions. The third section, Being in the Study, documents the import of study participation for all participants, including the researcher. The chapter closes with Summary of Findings.

The first section, Embarking on the Study, presents the context and direction for the study for all participants, including myself. The purpose of this section is to establish the parameters of my process of interpretive inquiry. Embarking on the Study is organized into two subsections which describe: (a) Gathering Participants, and (b) Purpose and Desired Outcomes.

The second section, Experiencing Breast Cancer, documents the answers to two interlocking research questions: 1) What is the meaning and lived experience of breast cancer for mothers and their adolescent daughters? and 2) What is the meaning and lived experience of breast cancer for the mother-daughter relationship? Experiencing Breast Cancer is organized into four thematic subsections: (a) Inhabiting Another Landscape, (b) Intending and Acting, (c) Acquiring Wisdom, and (d) Enduring Mother-Daughter Relationships. Thematic subsections address both the individual and joint experience of mothers and daughters. Participants’ drawings are included to illustrate thematic content.
Descriptions of the meaning and lived experience of breast cancer include both retrospective accounts of experience, and accounts of current experience.

Within each subsection of Experiencing Breast Cancer, material gathered from the individual interviews with mothers and daughters is presented separately from that gathered from interviews with both mother and daughter. This strategy yields portraits of experience that are either shared or unshared with the other half of the mother-daughter dyad. This is important because it preserves the privacy of individuals. Material from individual interviews is identified with the labels ‘M’ and ‘D’ to preserve participant confidentiality. Material from joint interviews is identified with the first initials of mothers and daughters. Because this study was conducted with an explicit interest in authorship and voice, my own observations and reflections as a participant in this study are conveyed in the first person to emphasize my “perch and perspective” as researcher (Lawrence-Lightfoot & Davis, 1997), and to assist the reader in the evaluation and consideration of potential application of study results. My voice is identified in quotations from the interviews as ‘DM’.

The third section, Being in the Study, documents participants’ reflections and my observations on the import of being in this study for all participants. The import of being in the study is here defined as that which was experienced as meaningful and useful. This section also revisits questions of purpose and desired outcomes articulated at the outset of the study. Being in the Study is organized in two subsections: (a) Study Process and (b) Outcomes and Advice.
Embarking on the Study

This section provides the context and direction of the study in two parts. The first part, Gathering Participants, describes the process of recruitment. The second part, Purpose and Desired Outcomes, documents the starting point for my study developed from interview data on participants' purposes in joining the study and their desired outcomes for the study.

Gathering Participants

Research reports sometimes present information on recruiting participants. I decided to document the process of gathering participants for two reasons: (a) to illumine the challenges of securing participants for my study, and (b) to document the influence of this aspect of the study on my research process and on the final product. My initial strategy in recruitment was to rely mainly on referrals from health care professionals working with women with breast cancer. Initial hopes of obtaining referrals from this source waned as weeks passed and no referrals were received. Expanded recruitment efforts included: (a) expanding the criteria for enrollment; (b) changing the wording of notices, and increasing the distribution of the notices in local community centers and businesses; (c) publishing a notice in a breast cancer information newsletter that has a circulation of approximately 10,000 in British Columbia and the Yukon; (d) seeking referrals from activists in the breast cancer community; (e) distributing notices at a major breast cancer awareness event; and (f) speaking to a support group.

Almost everyone I spoke with in the course of this recruitment process assured me
I would have absolutely no difficulty in finding the small number of participants needed. But as I did experience difficulty in attracting participants I asked myself, “What was happening?” I have documented potential barriers to recruitment through reflecting on the nature of the study, the tenor of my conversations with others during recruitment, and what participants communicated in the interviews. Notes kept on the content and tone of all initial enquires also furnished some answers to my question.

The questions posed by my study seemed to present at least two potential barriers to recruitment. First, with respect to the health care professionals, some reported in follow ups that they just did not encounter the group I was seeking. I was surprised by this because breast cancer is such a common disease in women and several of these health care professionals worked in settings that were exclusively or highly focused on breast health. For example, one worked in a large hospital-based center for women’s health dealing exclusively with breast health. Another was one of Vancouver’s most widely respected and sought after breast surgeons.

What I discovered was that most of these professionals seemed to be very much focused on the individual who presented in his or her work setting. My experience in seeking referrals from health care professional was essentially the same for another researcher studying the children of mothers with breast cancer (K. Chalmers, personal communication, August 16, 2000). For a variety of reasons, contact with family members and particularly with the children of women who have breast cancer, is still uncommon. If family-oriented health care remains largely a theoretical concept in clinical settings,
much as appears to be in the psychosocial research literature on breast cancer, referrals would be unlikely. In this context, the questions I was posing may have been potentially interesting yet largely unanswerable.

Potential barriers to recruitment also emerged in conversations with women who were interested in the study. I was initially somewhat surprised by the degree of hesitancy and fear women expressed at the idea of involving daughters in the study. However, it became less striking as examples of this type of reaction occurred in numerous settings. After initially expressing an interest in breast cancer research, one woman working at a business that sponsors breast cancer research grimaced and recoiled physically. She told me she wouldn’t touch the issues with daughters with a ten-foot pole. Several women at a breast cancer awareness event paused and took a step backward after their initial smiles and interest once they learned I wanted to talk with daughters. One woman calling about the study was at pains to convey the fact that though she might be interested, her daughter wouldn’t because she wouldn’t remember anything at all. Her relief was palpable when at one point I indicated that she would know best and she quickly ended the conversation.

I found myself the subject of some careful scrutiny as mothers who did participate questioned me about the study. Some had reservations about having their daughters participate, although they said they themselves might be interested in the study. I had the sense that with respect to daughters, my interest in their experience in respect of mother’s breast cancer seemed at turns surprising, puzzling, and in some sense threatening. Some mothers warned me that their daughters probably wouldn’t be interested for a variety of
reasons. Here are some typical comments. "Breast cancer is the past for my daughter." "It was a long time ago." "She won’t remember much." "She has moved on with her life and she is just busy being a teenager." "We never talk about it much so I don’t think you’d find out much by talking with us." Mothers often told me that they would ask their daughters but to be prepared that their daughters would likely not want to participate. These mothers later told me of their surprise when their daughters did agreed to participate in the study. All mothers stressed that they did not pressure their daughters in any way to join the study. It was their choice.

My sense that there was something fearful about this study for women encouraged me to tread softly in my interviews and to watch for areas of particular sensitivity. I was alert to a concern that the interviews not "stir things up" as one woman had put it. I experienced a sense of responsibility to honor the trust these women were placing in me in allowing me to speak with their daughters. At the same time I wondered if my desire to create a safe environment for conversation might also hamper our conversations to the point where I was colluding in or creating prohibitions to dialogue. My resolution to this dilemma was to proceed with a degree of caution, treating areas of ease and of sensitivity as valuable information. I considered what I would and would not hear from participants in terms of the positive and negative spaces in a painting which together shape a picture.

From my initial conversations with the mothers, our similar age and status as mothers of daughters facilitated their decision to participate in the study. Mothers’ comments and questions indicated that they felt I was a person who might be able to
relate to them and to their daughters, and who could appreciate the complexities and challenges of the mother-daughter relationship. For example, I noticed a more relaxed tone when I shared the fact that I had raised a daughter through adolescence and I heard comments like “you know how it is.” For daughters, my being about the same age as their mothers and my having a daughter positioned me as a mother. Over the course of our interviews, this similarity in position was to facilitate and shape our conversations. For example, in discussing the turbulence and closeness in mother-daughter relationships there was an implicit understanding of how both people could ‘push each others buttons’ given the closeness and intimacy of mother-daughter relationships. I was cautioned by one daughter not to let her mother know how soft she felt toward her mother even though her mother ‘pissed her off in the way that only mothers could’. You will meet these mothers and daughters later in the next segment, which documents their answers to some initial questions on motivation or purpose in joining the study, and on desired outcomes.

**Purpose and Desired Outcomes**

The personal and interpersonal concerns of participants were placed at the forefront as the study began. At the outset, I asked participants to say something about their purposes in joining the study and what they would like to see come of it. My reasons were twofold. First, I wanted to get a sense of what each person felt was important, and to honor those interests to the extent possible. In portraiture (Lawrence-Lightfoot & Davis, 1997) the search for patterns revolves around *themes* that reside in and emerge from the data, and from *dimensions*, which are the initial knowledge base, lens, and areas
of mattering that the researcher brings. My assumption was that the agendas and assumptions of all participants shape the research process and product, an assumption most often discussed only in relation to the researcher. Therefore, my first goal in this study was to get a sense of the dimensions for the mothers and daughters.

My second goal was to document a starting point on perceptions and attitudes because it could prove valuable with respect to the effects of being in the study. My assumption was that participants' perceptions might change, much as the qualitative researcher's perceptions are expected to change in the course of a study. Summary comments offered by daughters and by mothers at the outset are followed by examples of interchanges between mothers and daughters to illustrate the contours of dialogue generated by the questions. Summary comments were composed of refrains that echoed across conversations in varying intensity.

Daughters' initial responses to the question of participation seemed more vague than those of their mothers. Their comments were also sometimes quite brief. Daughters would say they didn't know what lead them to participate, but that their mothers had asked them and they thought "why not?" One offered that she didn't think it would help adolescents but might help mothers. As counterpoint, two spoke of the value they themselves saw in talking and in attending to feelings. It was not until later interviews that I learned more about daughters' purposes and hopes, and more about the brevity or vagueness in their responses to my initial questions on purpose and desired outcome.

Mothers often described their decision to participate in terms of helping other
mothers deal with their families. They talked about a general lack of attention to families despite the voluminous materials available on their own diagnosis, treatment and recovery process. With respect to the emotional processes within the family, and especially their own emotional process, unmet needs were evident. Mothers and daughters both spoke on this aspect of their experience. Portions of a conversation with Jessica and her daughter Angela illustrate some of the benefits and drawbacks of living in a culture focused on information. They also illustrate competing hopes around dialogue. My impression of their entire conversation was that I was witnessing a considerate and carefully navigated dance. It brought to mind images of ballroom dancers gliding across the floor in soft-soled shoes, alternating between a waltz and a quickstep. We met in the family room over coffee. Words emphasized by participants, that is, words spoken with a markedly stronger voice, are in italics.

The idea of talking with your family, your children about having breast cancer, being diagnosed, how to deal with that in the family, there isn’t a lot of information. ... There always seems to be a lot of information about the physical side of cancer but not very much about the emotional side. There’s a little more than there used to be but not much. And I know there was a time even a year after my diagnosis when I was looking for that. I never even got the family relationship part. It was just me dealing with it. And it seems to be a concern of a lot of women... and I was concerned. And I was surprised when Angela agreed to participate! There’s no opportunity for families, like a mother-daughter combination, to be part of a group. I wonder if from your study there could be something like that more available. I felt very uncomfortable [with the idea] of just sending her off to a group. And a lot of it is for younger kids, and a lot with hospice.

Jessica, age 44, three years post diagnosis.

I thought this would be a different experience to sit and talk about everything. Like I find an attitude of where there are all these things that say one out of five women have a chance of being diagnosed with breast cancer. All you hear is the statistics
and you never really hear about how everyone feels. No one really knows about how it kind of affects everybody. ... I don’t know if this is realistic or not but it’d be kind of nice to have a support group thing, just for teenage kids where they can talk about it. ... If it happened again [a recurrence] I’d like to talk to people my own age who have the same kind of circumstances. I don’t know. But it didn’t seem to matter to me as much as when I was 12 or I didn’t have as much need for it.... Things written by teens would be good too.

Angela, age 15.

Mothers often referred to the difficulty they experienced in knowing what and how much to tell their daughters about breast cancer. They often expressed an interest in having some sort of guidelines to help them, or rather to help future mothers and daughters. Daughters sometimes expressed support for the idea of guidelines but not always. In the following excerpt, Heather’s request for guidelines was only grudgingly accepted by her daughter Brandy. Heather hoped for guidelines and also for better understanding of mother-daughter dynamics. Brandy stressed the individual nature of experience with breast cancer, and her resistance to the idea of learning about how others fared. The tone of their conversation was loving, but almost antagonistic at times. I had the impression that both people were straining to communicate something and at the same time restraining what they said. Brandy took some time to join us at the kitchen table, busying herself with a phone call and food preparation. Her sidelong glances at me conveyed a sense of guardedness. Mom waited, more or less patiently, for her to come to the table.

Anything to do with the whole scenario of breast cancer and your daughters and telling them and the dynamics of all that [would be good]. If anything comes of it that can guide some other woman who comes up against that wall, I think it’s well...
worth it. Guidelines for moms.... And something for the daughters if they want it. A pamphlet. Nothing too heavy.

Heather, age 44, three years post diagnosis.

She asked me if I wanted to and I said ‘whatever’... I don’t think any adolescent can learn anything from a study really. Cuz like an adolescent won’t read something. ... I don’t think it’d help anybody my age. They have to deal with it themselves because otherwise they won’t learn from it or grow from it if they just do what somebody else did. Especially what I did! That might just screw people up.... I guess something to help mothers deal with telling their daughters better [might be good].

Brandy, age 16.

Listening to mothers talk about the need for guidelines I had the impression that they were navigating a one-way street where it was their responsibility to convey information. Their comments often focused on the time around diagnosis. This interchange between Barbara and her daughter Sarah illustrates agreement on the notion of telling and on the difficulty of telling. It also illustrates something of the broader view taken by daughters on the notion of dialogue. To place her remarks in context, Sarah has been part of a support group at school for children whose parents have had or have cancer. Being part of a group has influenced her views on the value of talking with others. The tone between this mother and daughter was pleasant, albeit with subtle but definite differences of opinion. I felt I was in the presence of two very organized and focused people. We sat around the kitchen table with coffee, where mom placed an obviously heavily used daily diary and a stack of other papers she had gathered for our meeting.

I just like to encourage anyone doing research with breast cancer. It’s a passion for us in the support group and we’re often involved in studies. And I just think it’s up to us to give a little back too. ...I suppose looking down the road if it can make life
easier for mother-daughter getting through the cancer diagnosis then sure that’s what I’d like to happen. Because there are times when you’re going through it that it’s difficult. There’s no question about it - and particularly in the beginning the decision to tell your child. You need all the help you can get because you’re no expert. And it’s not an easy thing to do.

Barbara, age 57, six years post diagnosis.

For anyone affected by cancer [I’d like] just for them to be able to talk about it easier. I have a friend whose mother would never talk to her about it. She never knew for months what kind of cancer it was. She was never told because her mother couldn’t about it. ...I think the ability to talk about it helps a lot. And I don’t think people realize how easy it is once you start talking about it, keep going. How it only has positive effects on you. It’ll make you feel better getting it off your chest rather than keeping it in.... [I’d like] people to be in a more comfortable environment to talk about it.

Sarah, age 17.

The desire to be instrumental in facilitating a more open climate for dialogue, and for helping women deal with “the mental side of the disease” was a cherished hope of another mother. She too asked for guidelines and talked of the difficulty of telling. However, Cindy hoped that the open relationship she had with her daughter and the amount of talking they had done might serve as an encouragement for other women. Kate agreed that the strategy of open communication had been helpful but added a qualifier of sorts here, one she didn’t explain and her mother did not pursue. The tone between Cindy and Kate was decidedly optimistic and casual, almost collegial. I noticed how much these two were smiling.

I think anything that helps a women go through the disease physically and mentally is a good thing. ...You don’t know exactly what to do, how to approach it, how much to say and what not to say. And you don’t know if your daughters are not saying things or saying things too. And the emotions are so crazy at the time that I think it would be really useful if someone were to say here’s a good way to go
about it. ... We've always been really open with each other but I thought not every mother-daughter situation is that open. Your study is going to be really important because they are probably not going to initiate that relationship on their own ... and avoid talking about it.

Cindy, age 48, four years post diagnosis.

[What I’d like is] just if it helps ... like more and more people are getting breast cancer. A lot of people, I know. At least so girls wouldn’t have to go through the same things I did it’d make it much easier.

Kate, age 17.

Excerpts from a conversation with the last mother-daughter dyad illustrate once again the sometimes vague or abbreviated responses of some daughters as to purpose and desired outcomes. Chloe was quite soft-spoken and laid back, perhaps indifferent at times. In contrast, her mother Diane was very definite in expressing her ideas on the need for more to be done in the area of family dynamics, and on the emotional aspects of illness and recovery. She tended to take the lead in the conversation, speaking in a strong, animated voice. The tone between them was loving and supportive, with a marked contrast in the energy each brought to the room. We talked in the living room over tea and cookies.

I want people to know as much as possible about breast cancer and how it does affect the family, because we have strong communication and are very close. I want you to learn as much as possible about mothers and daughters after the mother’s diagnosis because of the high rates for daughters to have cancer. To do the whole counselling thing to help other women. To reduce fears and to acknowledge the process of diagnosis, treatment and recovery. Recovery is not when the bandages come off. It’s the emotional recovery afterward - to acknowledge how really difficult that is. In the family fears of cancer are so great, when there’s no evidence of disease - not you’re cured - everybody wants you back normal, doing everything that’s normal and the pressure that puts on you. I want the emotional stress that lives on to be acknowledged, not just buried, and that’s what a lot of people do.

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Diane, age 50, two years post diagnosis.

I just decided to do it because mom wanted to. I figured it was no big deal so I would do it. ... I don’t know what I’d like to see come from the study. I haven’t really thought about it much.

Chloe, age 15.

The repetitive refrains to questions of purpose and desired outcome coalesced in three areas of interest for mothers and daughters. The first area of interest was a desire for better and perhaps different ways of communicating about breast cancer. A second area of interest was a desire that more attention be paid to the emotional aspects of breast cancer experience. The third area of interest was a desire to help others.

Interest in fostering better and perhaps different approaches to communication around breast cancer was apparent in two ways. It was evident in the comments echoed among individuals, and in the contrast between what mothers and daughters emphasized. Mothers often spoke of the difficulty around telling their daughters about the cancer. Their comments reflected the puzzle of what and how much to say to daughters. For the most part, mothers seemed to locate communication needs largely in the past, around the time of diagnosis. They tended to talk about communication as telling. Daughters spoke about the possibility of looking at communication in a different vein. They were more likely to talk about communication as interpersonal dialogue. Two daughters spoke about the value of having a group format just for teens dealing with similar experience. Several mothers and daughters considered that some form of written materials on breast cancer experience would be helpful.
Interest in addressing the emotional aspects of breast cancer was mentioned in every mother-daughter dyad. It was mentioned sometimes by mothers, sometimes by daughters, and sometimes by both. Both mothers and daughters commented on the general neglect of emotional experience. The neglect of emotional process issues was sometimes spoken of as a matter of personal concern and or a matter of family dynamics. Sometimes it was expressed as an observation of others' situations, or as an observation of how breast cancer is dealt with in the media, for example, the factual focus of books and of newspaper articles. For the most part, emotional aspects of breast cancer were seen as very important to acknowledge and to deal with but there was little in the way of help available in this area.

Interest in helping others was evident in every mother-daughter dyad. In my preliminary conversations with mothers, it was clear to me that they were interested in helping me and breast cancer research, whether or not they benefited directly. Daughters were at minimum interested in helping their mothers by joining the study. One daughter felt that the study might benefit only adults. Other daughters seemed to view the study as potentially helpful for others, but emphasized the needs of daughters like themselves. On the whole, mothers spoke generally about helping other mothers and daughters facing a similar situation, but they emphasized the needs of mothers.

Summary

Gathering participants for this study was a challenge for two reasons. First, anticipated referrals from health care professionals intimately acquainted with treating
breast cancer did not materialize. Although contacts were interested in supporting the study, they reported that they had no contact with the group I was seeking. By my observation our health care system is set up to treat the individual and not the family, although cancer is widely acknowledged as an illness that impacts families. A second reason that gathering participants for my study was a challenge was the degree of hesitancy and fear observed around the study. Conversations with women who were interested in the study but who did not participate and conversations with mothers who did participate indicated I was on dangerous ground. Mothers warned told me that their daughters did not remember much, that they had gone on with their lives, and that they never talked about the breast cancer so I would not learn much. Mothers were protective of their daughters and questioned me closely to see who I was and to gauge whether my study might cause upset. My response was to tread softly in the interviews, watching for areas of sensitivity, regarding areas of sensitivity as valuable information, and working to create a safe environment.

Questions on purpose and desired outcome posed in the initial interviews established the context of and the direction for my inquiry. Participants’ interests coalesced in three areas: a) a desire for better or perhaps different ways of communicating about breast cancer, b) a desire that more attention be paid to the emotional aspects of breast cancer, and c) a desire to help others by producing a brochure or a set of guidelines that could prepare others facing similar experience.
Experiencing Breast Cancer

The experience of breast cancer is understood in this study as an individual experience and a joint experience. Individual experience is appreciated as being shaped in the context of the mother-daughter relationship. At the same time, individual experience also shapes the joint experience of breast cancer for mothers and daughters. Joint experience is appreciated as an aspect of breast cancer experience that is co-created, and which emerges from individual and relational experience. Individual accounts of experience and joint accounts of experience heard in the individual and joint interviews were frequently but not always interwoven. Those aspects of experience not shared with the other half of the mother-daughter dyad are therefore presented separately. Names are included with quotes only where the experience was described in the presence of the other half of the mother-daughter dyad to preserve confidentiality for all participants.

Experiencing Breast Cancer presents common patterns and individual variation in four thematic subsections: (a) Inhabiting the Landscape of Breast Cancer, (b) Intending and Acting, (c) Acquiring Wisdom, and (d) Enduring Mother-Daughter Relationships. The patterns that formed these themes were developed from a consideration of: 1) personal and social context; 2) repetitive refrains; 3) convergence and dissonance of experience; and 4) symbols both observed and generated in the study. Themes illustrate commonalities and the complexity of experience in individual lives and relationships. Descriptions and quotes provide an opportunity for the reader to consider the potential
applicability of themes to individual cases, which is the goal of interpretive descriptive inquiry (Thorne, Kirkham, & MacDonald-Emes, 1997).

Inhabiting Another Landscape

I chose the title for this theme to capture the situated and unfolding nature of breast cancer experience. Conversations with participants evoked a sense of place for breast cancer experience. “After getting cancer you are kind of in a different place.” “Nothing is ever the same again.” Encounters with breast cancer occurred in the context of ongoing and uniquely configured lives. In part because I asked about context, I heard about illness situated in the midst of moves, work and school, interpersonal relationships, and past experience with health and illness. The unfolding nature of breast cancer experience was brought home to me as participants described their experience then and now. Over the course of our conversations, descriptions of the early days of breast cancer moved to discussions of current experience, and to visions of the future. The sudden appearance of breast cancer brought one form of experience and time brought others. Subthemes on the theme of Inhabiting Another Landscape move across time from Diagnosis Experience, to Effects of Treatment, and onward to a place of Continuing Uncertainty.

Diagnosis Experience

Conversations about the experience of breast cancer diagnosis developed early on in the first joint interviews. Participants’ comments often followed naturally from my questions on purpose and desired outcome where the mothers were first to answer these questions. As most mothers referred to communication needs around the time of
diagnosis, their daughters followed suit with their own comments on that early place in
time. Mothers told stories of their encounter with breast cancer, of their struggle in
knowing what to say to their daughters and how to say it, of how they told their
daughters, and of their daughter’s reactions. Because mothers took the lead on this topic,
daughters were placed in the position of reacting to their mothers’ accounts. The
recollections of mothers and daughters on that early place in time often differed.
Compared to mothers’ accounts, daughters’ memories were abbreviated or vague on how
they first heard of the cancer. However, they often added contextual detail. Daughters
added explanations of their own reactions and reacted to mothers’ perceptions.

This conversation between Barbara and Sarah shows a contrast between what and
how this daughter was told about the cancer, and what she recalls. It also points to
assumptions about emotional reactions such as anger and offers one daughter’s
explanation for anger. Barbara refers to her diary in the opening sentences.

B: Okay. How to tell Sarah our eleven-year-old daughter. What to tell her. And we
had made the decision that she had to know. And I have written: “We tried to
explain to her over the weekend. ... And I said the cancer - I don’t think I would
have used that word if I was talking to an eleven-year-old however I’ve used it here
- and that I will have to have surgery and our lives will be disrupted for a while. I
reassure her each time and tell her I love her. She is very angry and says I should
not say I know how she feels because I couldn’t possibly understand. I realize she is
right and I tell her. Each time we talk I hug her and tell her that I love her.” That
was very difficult – especially her anger in the beginning. I didn’t expect it right
then. I knew that it could happen and it did happen down the road but it was a very
scary time for her.

S: Actually I don’t remember being told. I remember very little about that time.
I’m pretty sure I got mad. I don’t remember. It’s almost like I blocked it out.

B: Well do you remember I got books from the cancer agency “When Your Mom
Has Cancer”- there were loads of books? And we read them together. You don’t remember that. Do you remember I took you to see the nurse specialist?

S: I remember her telling me what a cancer cell is – growing out of control. I remember going with you to radiation. Sharing a taxi with somebody who was really sick. She had chemo or something and you explained the difference between chemo and radiation. … [My being angry] was compounded by your back injury the year before.

B: The year before. That’s right I had the car accident the year before.

S: I’d throw tantrums and run upstairs and want someone to run after me but no one would … I’d get upset.

In this interchange a mother described her efforts to inform and comfort her daughter. The focus on information given with forethought and care, and a tendency on the part of some mothers to respond to a daughter’s emotional reaction with attempts to normalize feelings was a repetitive refrain with other mother-daughter dyads. The value of appreciating context in apprehending another’s experience, in this case the context of health and illness in which the cancer occurred is clear in this conversation. Sarah explained her anger as part of her ongoing upset over the fact that her mother was not available to chase after her given her mother’s back injury. The fact that her mother had breast cancer was perceived as another interfering factor in their relationship. Sarah was not entirely sure she remembered being angry when she was told and when her mother told her the anger was normal. Her comments reflect the uncertainty of some daughters in recalling the specifics of how they were told about the breast cancer and how they reacted. As one daughter put it, “I’m not sure if I am remembering this or if it’s something I’ve been told happened.” As Sarah said, “It’s almost as if I blocked it out.”
In the following conversation between Heather and her daughter Brandy the issue of emotional reactions and normalcy is at issue. Brandy had a strong reaction to the idea of normalcy.

B: But how can you tell somebody it is okay to hate somebody because of...like not hate but to be pissed off at them because of something they have. How can you tell them that’s okay?

H: That’s a normal response.

B: Yes, I know. But you cannot say that that’s normal. You cannot tell somebody that’s okay and have them feel okay about it.

Later, I learned more about Brandy’s initial reaction to the news of her mother’s cancer. She talked about her need to get away from the situation, and how she would prefer to view life. Brandy left home for a week when she was told about her mother’s breast cancer. She went to stay with an aunt because “You need space to deal with stuff and you can’t have your mom in your face being like ‘How are you doing about it?’ Like - go away!” As the following excerpt begins we are on the subject of something for daughters to read about other daughters’ experience. Brandy elaborates on her continuing efforts to achieve a sense of normalcy. She describes the fear underlying her anger and her efforts to distance herself from the reality of breast cancer.

B: It’s too overpowering to have to take it in that there’s this big chance that their mother who they look up to and everything is gonna die. Not in my case though! (gales of laughter between mother and daughter for a few seconds) Just joking!

H: I know. (smiling)

B: And so like reading that there’s all these other people who are dealing with this, knowing there are other people who are just as unhappy and as scared as you are –
like me personally I'd rather believe that the world is a (small high voice now) nice happy place and everybody is happy! .... I wouldn't have wanted to go to my friends because they still function as if everything is normal, and it wasn't! ... A friend trying to empathize with you saying 'I know how you feel' - they don't. Cuz no one ever knows how someone else feels and that's one of the worst things you could ever say to anybody.

Brandy's comments portray an experience of sudden, frightening change and the fact that life was no longer normal for her. In some respects her initial reaction to the diagnosis has changed little in the years following her mother's diagnosis. Brandy's initial reaction to the diagnosis was to physically remove herself from the situation, and here she talks about her need to maintain distance by controlling her exposure to the reality and scope of breast cancer. Brandy raises the prospect of her mother dying, a possibility that was not often spoken of between mothers and daughters. Fear of dying was a subject I learned more about in private conversations with mothers and daughters.

The full scope of what is at stake for a mother, and for a daughter, when a mother is diagnosed with breast cancer is perhaps not readily shared nor appreciated interpersonally. The following conversation between Jessica and Angela illustrates the limitations on what is shared and what is understood. Like all the other mothers, Jessica considered that she had been forthright with her daughter about having cancer and that her daughter was well informed. Angela points out an important gap. Our conversation began with my asking each of them what it was like for them to be sitting with me now, talking about breast cancer. It is a novel situation, for them and for other mothers and daughters, not only because I am there.
J: I’m probably wondering what the heck she’s gonna say. Not that I’m nervous about what she’s gonna say. By no means. But it’s probably true I never hid from children what I was going in the hospital for (pause) but we didn’t sit down and talk. She knew I had cancer and needed to have treatment. On the days that I had chemo she knew what was going on basically. But I didn’t sit them down and give them the gory details. I didn’t – I probably have to admit that I didn’t ask them how they were doing.

A: It seems like it was so long ago and like everything is good now. It’s like I don’t think we ever had a big discussion about it that I can remember, like kind of how everything was going-

J: Ya you knew all the time what was going on but

A: Ya but I don’t think we actually sat down and had a talk about it. You maybe just said well now I’ve got this chemo thing coming up. And I asked about it and you explained it. But I don’t think we ever really sat down and had a conversation or whatever.

J: Right. About what?

A: Kind of like as a whole.

J: Ya, you’re probably right. Bits and pieces. You were only 12.

This interchange illustrates a somewhat factual sharing of information. It echoes the concerns of mothers about what to say to daughters considering their age. The information the daughter receives is to the point, and is given piecemeal around the specifics of diagnosis and treatment. Jessica, like several other mothers, attempts to control the impact of the news of her cancer by avoiding the “gory details.” Angela described her recollection of being told about the cancer as minimal. What stood out for her was the context of hearing about the cancer. The way she spoke about hearing the news of her mother’s cancer reminded me of how people often talk about where they were when they heard about the death of John F. Kennedy or Princess Diana. The night
of mom’s surgery she had gone out with her dad for Italian food, and she had a geography test the next day. At that dinner she asked her father what kind of cancer her mom had and he told her. She could not recall her mother having said anything about what kind of cancer it was, and had thought it was maybe skin cancer.

The question of what, when, how, and how much is conveyed to a daughter is a choice made by parents. In the previous excerpt a daughter first learned about her mother having breast cancer from her father. In general, daughters were told about the breast cancer by their mothers. The next example illustrates a mother’s careful consideration of what, when, how, and how much to tell her daughter. In this example, Diane articulates her deliberations on the timing, content, and context of informing her daughter. Prior to this excerpt Diane spoke about her determination to have all her appointments lined up and not to tell anyone before that in order not to upset the family unduly. It was upsetting enough to know that she had cancer, let alone upset the whole household. Chloe was distraught when she learned of the cancer and was initially angry at not being told earlier.

D. What I did was I got the name of the surgeon. I got told I was going to see him the next day. I came home and I called my mom and I told her. ... Chloe came home from school with my husband, all excited about something. She was in far too good a mood. And I didn’t want to (tell her then) and I didn’t know enough information because I wanted to tell her when I had information. Not just mom has breast cancer, there’s terrible news here, but give her information like this is what we’re gonna do...that there was a plan. So when she wasn’t around I told my husband. And he was all upset and I told my husband I will tell her in my time. The next morning she wasn’t in such a good mood. I told her I had a doctor’s appointment and she’d have to take the bus home. And unfortunately she said “Well what’s wrong with you? Do you have cancer or something?” I said “Yes sweetie I do.” Her face went as white as the appliances. She came and sat down beside me, held my hand and burst out crying. And we just held each other. She asked me “Who knows?” and I told her my mom did. And then she got really angry at me for telling my mom before she was told. Because we’re so close I tell her everything right away. So I explained to her I wanted to tell her after I talked to the surgeon. And then I said to her “If something happened to you, what would you have done?” “I would have talked to you.” I said “Ya well I have a mom too.” So we just held and I told her that things were gonna be okay. ...

C: I don’t remember crying when she told me. But I do remember saying “What is it, cancer or something?” It kind of disturbs me. It bugs me that I seem to know a lot of things subconsciously before they happen. At the time I was just making a
guess, but it turned out I was right. Never again! I don’t like being right about stuff like that...

Chloe did not recall her emotional reaction but remembered her thoughts and words when she learned about the cancer. Her comments bore some resemblance to those of another daughter who was initially worried about having played some part in causing her mother’s cancer. Speculations about causality are perhaps common to children and adults, but children feeling they may have caused or contributed in some way is a well recognized finding. Chloe’s deciding to exercise some control over what she thought and said perhaps provided a degree of insulation from threatening possibilities. This daughter’s level of involvement with her mother’s cancer experience was high by virtue of the fact that her mother did share a lot with her in everyday life, a pattern that extended to the cancer experience. Diane was very clear with her husband that she alone would handle things with Chloe in her own way and in her own time.

Excerpts from the next conversation with another mother and daughter repeat the pattern of a considered sharing of the news of breast cancer with a daughter. Individual variation is evident in the contrast between this example and the previous one. In the previous example, telling and hearing is a very private matter between mother and daughter. In this example, a mother tells her daughter about the cancer while her daughter’s friend is visiting. Again a daughter does not recall her emotional reaction. Kate repeats the pattern of daughters not remembering the exact details of how they were told about the breast cancer but adds some contextual detail.
C: She had a friend over that day and so I told her while her friend was there. I knew her mom and it would be okay for her daughter to know that. Everybody cried and hugged and it was kind of a whirlwind. I had surgery the same week that I found out so everything happened so fast. That’s what I remember telling you. Now you can tell me what you remember.

K: I just remember you and dad going shopping a lot. And I found it really strange because you two never go shopping together. I remember you sitting on my bed with Jackie.

C: No Amy.

K: Are you sure it was Amy? Someone was there. Maybe you told me not to worry. I don’t know where I was when you were in hospital, but I didn’t visit much.

C: I don’t think you were interested then. (Kate looks down and is quiet for a moment.)

Kate’s recollection of hearing about the cancer differed from her mother’s and seemed somewhat vague. Like other daughters, her memories added contextual detail. She noticed a change in the atmosphere between her parents, an unusual type of activity. In another portion of our conversation, Kate recalled playing with her baseball cards when she heard the news. She sat on her bed shuffling the cards and putting them in order. Like most daughters, Kate was at somewhat of a distance from her mother around the time of diagnosis and treatment. Privately, some daughters talked about somehow being unaware of the seriousness of the diagnosis. Privately, other daughters either talked about their need for distance or demonstrated it as Kate did by choosing not to visit her mother in hospital.

One daughter’s drawing illustrates a need for distance from breast cancer (see Appendix B, Figure 1). Hers was the most abstract of the daughters’ drawings and she
had few words to describe it. She drew something she referred to as doodling, the kind of
the thing she did at school. I asked her if this drawing was in any way different from what
she might do at school. She pointed out some unfamiliar elements, for example the pink
circular forms. I had the impression that she wanted to do this drawing but at the same
time didn’t want to do it. She did not hesitate to do it, and knew as the other participants
did that this was an optional activity. The drawing was done quickly, in a rather detached
manner, and she seemed uncharacteristically vague when talking to me about it. I asked
her if she could put a title to the drawing. She said “It’s a maze.” I asked her if she had a
favourite part to it and she pointed out where she had placed her initial, in the middle of
the piece. This drawing depicts a daughter in the center of a maze with neither entry nor
exit. It illuminates conflicting elements of her experience, not readily appreciable from
just talking with her. Elsewhere this daughter had told me about keeping her distance
from the breast cancer, but in rendering her experience of breast cancer in visual form it
is evident that she is nonetheless very much caught up in that experience. Her drawing
illustrates a continuing need for distance and the difficulty of achieving distance. She is
in the middle of a maze, a visual representation of entrapment in a space with no exit in
view.

The drawing of a mother illustrates the depth and importance of the emotional
aspect of her breast cancer experience to a degree not readily appreciable in talking with
her (see Appendix B, Figure 2). This mother’s self-presentation style was, for the most
part, quite matter of fact and optimistic. Hints of an emotional undercurrent were present
in our conversations, but the sadness depicted in her drawing was “an overwhelming sadness.” The drawing was done in three sections moving from left to right. On the left, large tears are falling into a pool below. In the center, a man and a woman embrace and a child reaches up to them from below. On the right, there is a large dark cloud with a silver edge, a pair of hands reaching up to the cloud. Here is what she had to say about the drawing.

On the left there are tears of sadness, of overwhelming sadness. I’m there with my husband who is very supportive and our daughter is there. She’s little and sort of pleading because she really doesn’t understand. And the cloud is dark because I went through some extremely difficult times and so that’s to represent very dark times. But I put a silver lining around it because we did work through those difficult times. The hands are friends. The support of friends is one thing I haven’t mentioned. When I was diagnosed I had some friends who I thought were very good friends that just stayed away. And that’s not uncommon. Some friends you lose because of that and so these are probably more in relation to the support group. Most of my friends were very supportive but I lost a couple of friends. After getting cancer you are kind of in a different place and you are perceived as a threat by some of your friends because it might happen to them.

This drawing affords an appreciation of the depth of emotional experience, and an explanation of the elements in that sadness. It also affords an appreciation of another aspect of experience that had not emerged in our conversations, that is, changes in friendships. Changes in friendship networks were disheartening, but new friends were gained in that “different place.” The silver lining on the cloud is actually on the outside of the cloud, in accord with the optimistic presence this mother conveys and the sadness she feels underneath.

For mothers, receiving a diagnosis of breast cancer plunged them into a fearful and
confusing place. They not only had to deal with the news themselves but also had to find a way of sharing the news with their daughters. Mothers described how difficult it was to know what, when, and how much to tell their daughters about the cancer. All said that their daughters needed to be informed, and they appeared to take the major responsibility for accomplishing this task themselves. Most mothers described the experience of telling their daughters in terms of the process and timing of giving out factual medical information. Some also described the experience of telling their daughters in terms of choosing the best time to do it. From their perspective as mothers in this study, the diagnosis experience tended to center on providing factual information to their daughters, and on preventing or dealing with emotional upset in their daughters.

Daughters talked about their surprise, confusion and upset when they learned that their mothers had breast cancer. Overall, daughter’s descriptions of the diagnosis experience were much less focused on receiving information from their mothers. Mothers were often surprised by how much information was not remembered and what their daughters did remember. Daughters’ descriptions of the diagnosis experience focused more on their feelings, on changes in family relationships, and on the personal context of hearing about the breast cancer. Some daughters commented that based on what they were told at the time, the diagnosis did not seem all that serious. Some daughters did not recall being upset, but those who did explained their upset in terms of feeling some change in their relationship with their mothers.
Effects of Treatment

The effects of treatment experience varied depending on the type of treatments chosen and the effect of those treatments. In this study, all mothers received surgery and radiation. Four of the mothers also underwent chemotherapy. This subtheme focuses on the effects of treatment for the mother-daughter relationship. Treatment experience often generated a degree of compassion in daughters for mothers, but was also a source of friction between the parties. Contrasting reactions to treatment are illustrated in the experience of two daughters whose mothers experienced painful reactions to radiation treatment. Their reactions differed in part because of their understanding of what the painful reactions were all about.

For one daughter, a mother’s painful experience after radiation was very much in evidence. This mother experienced a great deal of pain with “a really bad burn” to the point where she could not tolerate having any clothing on the chest area. The area was bright red, with open areas and a great deal of weeping. Because she was very weak from the radiation and needed help, this mother asked her daughter to break off a couple of leaves from a household aloe vera plant and apply the gel to the affected area. Her daughter was happy to help her mother and kept saying to her as she applied the gel “I’m so sorry you hurt so bad mom.” This daughter could see the problem and had an opportunity to help her mother. For another daughter, a mother’s problem with radiation was not really evident, only the effects. The different reactions these daughters had were due at least in part to the daughter’s understanding and appreciation of the problem at
I didn’t really know what was going on at the time. I didn’t really understand the whole effect of what was going on and what was involved... When you’re little you think ‘Okay. They took it out. Now it’s done’... She had to struggle with her shoulder. I remember getting angry with her. She had a frozen shoulder [from the radiation]. She couldn’t do things. And I remember getting really angry that she couldn’t do things. I thought she was just faking it or something, you know?

Where mothers had received chemotherapy, neither they nor their daughters were prepared for some of the effects that ensued. Common side effects of chemotherapy such as hair loss, feeling sick, and being tired were expected. For the most part, expected effects such as hair loss did not seem to present a problem. For example, one daughter told me how she and her mom had had fun trying out different hairstyles. Another told me about how she had accompanied her mother when her mom went to have her head shaved in preparation for the hair loss. Expected effects were, if distressing, temporary. One daughter went back to that place in time in her drawing. She said her strongest memory of her mom having cancer was when her mom had chemo.

In this drawing a daughter is visiting her mom who is now spending a lot of time in bed (see Appendix B, Figure 3). She told me that mom was quite sick from the treatment and had very little energy. The tone of this drawing is positive although it depicted a difficult time for them both, and in fact when I asked, she said it was positive. The sun is shining and the window frames a pleasant outdoor scene with healthy trees. Notice the smiles on their faces. Here is what she had to say about the drawing.

That’s me visiting mom in bed after chemo. She has just a few strands of hair left. Purple is my favourite colour not the real colour of her sheets. I’ve just come to
talk to her. It was easy to find her when she was so sick. We’re just talking. She’s really tired and has to be in bed. I wish she could get up and for things to be normal.

The desire for everything to be normal again is a common finding among children of parents who are seriously ill, as it is with the person who is ill. Elsewhere, this daughter talked about it being easy to find her mother, which was something she appreciated, again a not uncommon finding among children whose parents are not able to be up and about. However, for this daughter, the bottom line of the drawing is that she is wishing for a return to normalcy. As visible markers of disease and treatment such as hair loss and fatigue dissipated with her mother, a sense of normalcy returned. However, for this mother and for all the mothers who received chemotherapy the sense of normalcy was upset by another effect of treatment. The effect that did create some problems between mothers and daughters concerned unexpected cognitive changes.

In the following excerpt Cindy and Kate talk about changes in Cindy’s memory following chemotherapy. Mother and daughter talk about the changes in a joking matter but both found the changes frustrating and disruptive.

K: What stands out for me was when my mom went to chemo and was losing her hair and her memory. I’d tell her “Oh, I’m going here on Friday.” I’d tell her like Wednesday. And “Ya that’s okay.” So then Friday “Mom I’m going now.” She’d say “I didn’t say you could go! You have to ask me before you do things.” There’s no way I could convince her that I’d told her. That was so frustrating. I just wanted everything to be normal. I wanted her to drive me places but she couldn’t.

C: But you’d still ask! I knew she knew I couldn’t do it but she asked anyway ...The memory part of it was frustrating. I denied it when she was asking me. But my girlfriend and I would compare notes. We’d drive and not remember how to get to places. Like we knew generally but you wouldn’t be able to remember if you
turned on this street or two blocks down, and then was it left or right? We both compared notes and we really didn’t trust ourselves driving very much because we couldn’t exactly remember.

Changes in memory and cognitive functioning after chemotherapy were a repetitive refrain. The changes were sudden and unexpected, but sometimes came as gradual realizations. Some changes were long lasting. Concerns around about memory and cognitive functioning were very much joint concerns. The next excerpt is drawn from my last conversation with Jessica and Angela. I learned about changes in memory here by asking them if what others had told me about noticing changes in memory resonated with them. They burst into gales of laughter at the question. Jessica sounds frustrated and speaks animatedly in describing her problems with memory.

J: I can’t say for sure whether it’s because of the chemo. Is it because chemo threw me into menopause and menopause is contributing to the fact that I have memory loss? I don’t know. Or is it the chemotherapy, because somebody told me that “Oh ya. Don’t you know? Didn’t you know?” (in a higher tone to add even more emphasis) Nobody told me. But you know about a year ago somebody told me ‘Oh ya. Don’t you know about chemo brain?’ And I said “What are you talking about?” (again in a higher tone to add even more emphasis) Has that been documented? I don’t know I haven’t really looked into it. But so many women - either it’s from power of suggestion that they believe it, or it’s a true fact. I’m not sure but I do have a real problem with short-term memory.

A: Say on Monday I’m planning to do this on Friday night. And then when it comes – I’ve told her about this - and I just remind her I’m going out in a couple of hours. “You never told me!” “Ya, I did!”

J: See and the problem is I have to watch that she doesn’t use that (laughing)

A: No! (laughing)

J: She’d say but mom I told you. And how do I know whether in fact…But I’m a lot better. I need reminding about things. This never used to happen, I’m very good
about remembering details. I used to be extremely good... now I have to be reminded close to the time... It takes me longer to do things. Like staying focused. I oftentimes have trouble staying focused on a task so I start three or four things at one time.

In this excerpt with Jessica and Angela, and in the next two excerpts that follow, I found out about cognitive changes by following up on what I had learned about cognitive changes with other dyads. Asking successive mother-daughter dyads whether or not what others had experienced was true for them is an example of refining an ongoing inquiry through a feed forward process. The next excerpt with Heather and Brandy illustrates current memory problems and documents the severity of earlier problems. Like Jessica and Angela, Heather and Brandy are still at odds on the subject of memory. Unlike Jessica, Heather still has problems with driving.

H: My memory is terrible. You know what I did last night? I left my purse in the car - good thing the car’s in the garage.

B: She’s not smart!

H: I used to have a real good memory. I could tell you word for word what you said. Now I have to really concentrate for something to go into my memory.

B: Like I explained to her that she walked over there and chucked that bag into the garbage but she didn’t believe me! She’s like “Why did you chuck it into the garbage?” It’s like “I didn’t!” “You did!” (sounding very frustrated)

H: They call it chemo brain. I didn’t drive for a long time. Like when I was going through chemo I didn’t feel I could.

B: You did a few times to pick me up. Cuz I remember you weren’t feeling too well. I was like let’s get home before she throws up. But you never actually did.

Their disagreement lasted for a few minutes, illustrating the ongoing nature of
tensions around cognitive changes. I learn that Heather still lacks confidence in her driving and now limits her time behind the wheel to getting downtown and back. In the following excerpt I learn more about the impact of cognitive changes. Brandy tries to view it with humour but they are talking about some frightening things. I notice Brandy is quick with examples, as in fact were all the other daughters. Heather has strong words on the implications of suddenly encountering “chemo brain”.

B: I think it’s funny personally cuz she’d leave a candle on or something and leave!

H. Ya. I left a candle burning I the house and went downtown!

B: She left the stove on.

H: Ya, I left the stove on.

B: I’d come home and the stove’s all hot.

H: I left the back door wide open- not just unlocked but wide open...I told my husband if it keeps going it’s gonna get to the point where I can’t be left in the house on my own. I think it is very wrong that they don’t warn you of that. Because you think now you’ve got brain cancer! You think it’s metastasized to the brain. Cuz what you do know is that breast cancer likes to go to the lungs, the liver, the bones, and the brain. So all of a sudden you can’t remember anything. Like you become a real basket case! You can’t read because you are reading the same sentence over and over again because it’s not sinking in. And what are you gonna think? You’re gonna think you used to read all the time and now you can’t! Something’s wrong with my brain!

B: Yes. Thunder and lightening and wind.

This conversation between mother and daughter had a very rapid pace. Examples of cognitive changes and upsetting interactions came up very quickly for both parties. Brandy’s final comment evokes a sense of storm, of unsettled weather. The unsettling
nature of Diane's sudden cognitive changes is highlighted by Chloe in the next excerpt. This excerpt continues the refrain on losing memory and problems with driving. Again, the problems were sudden and unexpected. Diane's determination to create a sense of normalcy in spite of her problems is striking. Diane's problems were very evident to Chloe, and very worrying. As the excerpt begins Diane has been describing her efforts to carry on while she is having treatment.

D: The scary thing is, looking back, I never missed a day driving Chloe to school or picking her up. No matter how sick I was I wanted her to feel secure, that I was gonna be alright. And a few times she would be telling me she was a little concerned with my driving because of the effects of the drugs.

C: As she drives slowly toward the curb I get worried that the tires are gonna hit the curb and explode.

I asked Diane whether she had any memory problems, reminding her of an earlier comment she had made on having had some dementia.

D: There was none. In the beginning after the first-

C: She means there was no memory.

D: - the first dose of chemo I had not only no memory but I was putting apples into the dishwasher to wash them! I had the car parked somewhere, my dad was with me thank goodness. But he'd gone into one store and I went to the dry cleaners. I didn't know where I'd parked the car. And there was the car with my handbag, running somewhere in the parking lot - we had to go and find it. I'd be a block or two from home and not even know where I was. Like terrifying. Really really scary stuff. There's some other things I did that sort of showed I'd lost it. But because I'm so verbal thank goodness I mentioned it right away to the oncologist and right away he changed my drugs. I didn't expect any of this. I had a pill dispenser that I had a really hard time even concentrating on or reading, and putting in my pills for the week.

C: She was extremely forgetful. She was a lot more emotional about everything,
even little things. Really really frightening behind the wheel. I would be “Mom stay in the middle. Watch how you drive. You’re going into the curb

In a follow-up conversation, Diane told me a little more about the persistence of cognitive changes. For about a year after she started chemotherapy she was still disoriented with respect to her driving. She could not remember old, familiar routes. For a long period of time, Diane found herself starting a sentence and not being able to finish it. It is only within the last year that friends have begun to remark on how articulate she is now. At the time of the interview she relayed that she still has “huge problems with short-term memory.” Diane finds that she is not able to remember even important appointments, even those made for the same day. She has to write everything down.

My reaction to these accounts of various forms of cognitive change following chemotherapy was one of surprise. I carried an assumption that women receiving chemotherapy would be made fully aware of any cognitive effects that might be anticipated. More importantly, the mothers and daughters were surprised at this experience. They learned about chemo brain, a term that was also new to me, by living with it. I decided to ask about and to record the antineoplastic agents they were given because it might benefit other women and might peak research interest. Cindy was given doxirubicin and cyclophosphamide. Jessica was given methotrexate, fluourouracil, and cyclophosphamide. Heather was given doxirubicin, fluourouracil, and cyclophosphamide. Diane was given epirubicin, fluourouracil, thiotepa, and cyclophosphamide. When Diane approached her oncologist about the incident where she put apples in the dishwasher he
discontinued the cyclophosphamide.

Looking over one woman's copies of the "For Your Information" drug sheets women are given when they receive chemotherapy, I saw that no mention was made of the possibility of cognitive changes. Looking up the antineoplastic drugs these mothers had received in my own drug book for nurses (Delgin & Vallerand, 1997), I found no mention of the sorts of memory and other cognitive effects these mothers experienced. This is a book that covers drug actions, adverse reactions and side effects, and includes implications for assessment and patient and family teaching.

Like Jessica and some other mothers, I wondered whether some of their cognitive changes might be related to aging, along with the stress of having breast cancer. Perhaps they could be understood as a result of menopause. Having recently gone through menopause myself, I was sympathetic to descriptions of losses in memory and concentration and of the spillover effects with family. However, as Heather pointed out, even where symptoms might be similar they carry different meanings in different contexts. For all of these mothers, cognitive changes were sudden and disruptive for both themselves and their daughters. In some cases, the changes exert a continuing influence.

One mother's drawing captured the impact of chemo brain for her (see Appendix B, Figure 4). Before she did the drawing she told me a lot about the turbulence and fear she experienced with chemo brain. In this drawing she places herself in a reflective space, peacefully removed from some of the turbulence of an earlier time. Her drawing was done slowly, playfully, accompanied by smiles and sighs. She placed herself on one
side of the drawing reclining against a large, lush tree. Two figures on a hill occupy the far right hand side of the drawing. The contrast between the two sides of the drawing captures what she has told me about her desire for a calm and thoughtful space away from turbulence. Here is how she described the scene.

This is like the tree I used to have in my backyard when I was growing up. I loved that tree. I used go there a lot and sit and think. And there I am sitting down, leaning against the tree. Oh! I have no hair, a little pink head. But that's all right. And I'm reading a book. I can actually read again – no more chemo brain! There's my daughter way over there with a friend. She's red – that's definitely her colour - and her hair is orange, but it seems to fit. They are over there together – talking and having fun I guess.

For this mother, getting beyond her inability to concentrate and read was a major accomplishment. Chemo brain had made reading impossible, a serious disruption in her life because she was an avid reader. This mother also had an extensive library on breast cancer, a library that allowed her to feel informed and able to make informed choices. Here, occupying a calmer and more reflective space, she was at some distance from the fiery coloured teenagers - safely removed from some of the turbulence of teenage life. Like all the mothers in the study, this mother was concerned about the impact of stress. By reducing their stress levels mothers attempted to exert a degree of control over the uncertainty of breast cancer.

For mothers and daughters, effects of treatment that were not understood or not anticipated had both personal and interpersonal impact. All mothers experienced treatment effects that were long lasting and altered their ability to carry on with day-to-day activities. Those who received chemotherapy experienced a variety of cognitive
changes that affected memory, mobility, and concentration. Confusion, frustration, and anxiety about these changes diminished somewhat as friends told them about chemo brain. Daughters were frustrated and confused by treatment effects that impacted their interactions with their mothers. One daughter expressed confusion and frustration that her mother could no longer do normal things because of a frozen shoulder. Daughters whose mothers had received chemotherapy were variously frustrated and frightened by changes that limited their sense of freedom or posed a threat.

Friction between mothers and daughters occurred in respect of requests made and permissions granted for daughters to engage in activities outside the home. Most mothers denied that they were experiencing memory problems when negotiating with daughters on outside activities. Changes in a mother’s driving ability were frustrating or upsetting for daughters either because their mothers could not take them somewhere or because a mother insisted on driving when a daughter could see that her mother ought not to be driving.

Continuing Uncertainty

Both mothers and daughters described their experience of breast cancer as partly in the past but as also continuing in the present and extending into the future. Both were aware that an encounter with breast cancer meant living with a level of uncertainty. Although descriptions of continuing uncertainty occurred in the joint interviews, much of what I learned about the nature of that experience was in the individual interviews. My initial impression was that the issue of uncertainty was a sensitive area based on the
brevity of some of the comments, and how quickly participants moved away from the topic. I discovered that conversations about the uncertainty of cancer were often easier for individuals in the absence of the other half of the mother-daughter dyad because some concerns about the present and future were a private matter. In the individual interviews, detailed accounts of current concerns and of strategies for dealing with uncertainty stood in contrast to the sometimes brief, and general comments offered in the joint interviews. The uncertainty of breast cancer will be discussed in three facets: the Cultural and Biological Context of cancer experience, Reminders of Vulnerability, and Responses to Vulnerability.

**Cultural and Biological Context.**

Appreciation and support for increased awareness about breast cancer and for breast cancer support networks is currently widespread in Canadian culture as a whole. As one mother said concerning the support she finds in her group, “Having information increases your sense of power and decreases your own sense of vulnerability.” Support groups and awareness activities provide a format for women to educate themselves and to talk about the experience. The visibility of breast cancer in the media and the ability to speak openly about breast cancer in North America stands in sharp contrast to other areas in the world. Reflecting on her experience with raising awareness in a distant country, one mother offered these observations.

I guess it’s almost a little disturbing that even in this day and age you can talk more about breast cancer in North America than you can in other parts of the world. We were stunned. We didn’t realize before we went that (voice down to a whisper for emphasis) nobody talks about breast cancer! The women are almost two years
behind – not in terms of treatment but Holy cow it's just not ... We met with a support group and oh! how excited they were that we were here and could talk about it. ... Everyone was shocked that we were in the media that was the purpose, the awareness.

It is worth noting that my study was conducted in and around the month of October, which is Breast Cancer Awareness month. At this time, breast cancer has a very high profile in the local and national media and more than one daughter commented that breast cancer seems to be everywhere. Breast cancer also has a high profile in April which is 'cancer month' but October is the major time for fundraising with events such as awareness days, and runs for breast cancer. At the time this study was done some media representations around breast cancer supported daughters' involvement, and in my view highlight daughters' potential vulnerability to breast cancer.

One full-page advertisement repeated in several issues of a national newspaper caught my eye around the end of September (see Appendix C). It featured a photograph of a very young girl running with a sign on her back that read “I'm running for my mom” with a caption below that read “with your help it won't catch up to her” The first line in the accompanying text read: “When a mother succumbs to breast cancer, the chances her daughter will get the disease increase significantly”. The advertisement calls attention to the fact that breast cancer is a disease that flows in a line of women and those to become women, irrespective of the fact that only a small proportion of breast cancers have a proven heritable link. In this study, a younger daughter had recently told her mother that she wanted to run across Canada - to be the youngest person to raise money for breast
By my observation, efforts to raise awareness about the chances that any woman might encounter breast cancer at some point in her life are now beginning to be extended to include girls. For some years I have been collecting institutional and organizational materials on breast cancer prevention and treatment that are distributed to the public. Until very recently I have not found materials directed to girls. In April 2000, while attending an interdisciplinary meeting of Canadian and American health care professionals working in oncology, I found a pamphlet (Y-Me National Breast Cancer Organization, 2000) on breast health directed to teenage girls.

The pamphlet recommends monthly breast self-exams, a yearly breast examination by a physician, and mammograms after age 40. It provides instructions on how to do breast self-exams and adds a caution on using birth control pills, and on having breast implants or breast reductions. However, the primary focus of this brochure is on “...learning what your breasts look and feel like now while they are healthy” so that “Later on, if something should seem different, you’ll know how to take action immediately.” In this study, some participants spoke of their interest in raising awareness in teenage girls by placing information on prevention and early detection in the high schools. Their recommendations were based in part on perceptions that the number of young women developing breast cancer is on the increase.

Several daughters told me that since their mothers had gotten breast cancer they were much more aware of the prevalence of breast cancer because of its profile in the
media. If they came across articles on breast cancer in a newspaper or magazine they would likely read them. The daughters I spoke with all felt that they might now be more at risk for getting breast cancer, and knew that some breast cancer may be inherited. In recent years, genetic testing for breast cancer has become a possibility. Some women choose to be tested for a genetic link, and some choose to have prophylactic mastectomy. The issue of hereditary links in breast cancer was a topic of a conversation with one daughter.

The daughter in the following excerpt had recently attended a class in her school on the topic of cancer. The issue of the genetics of breast cancer came up in a film that was shown in biology class. The class discussed the option of mastectomy, referring to the choices some women made about having prophylactic mastectomies in view of their risk of developing breast cancer. One woman had mastectomies, and the other chose not to know her risk. I asked this daughter about her opinions on the film and about her feelings on the subject.

I think I can understand not wanting to be tested, because it's such grim news. But I think if I did get tested I think I'd do what she did in a second (have the mastectomies). Like breasts don't really have a function. If I had children, and done that part, she'd already had her children, it'd be less of an issue.

This daughter's comments on breasts as functional anatomy were echoed in the comments of other daughters. At the outset of the study I was curious about the import of shared biology. As girls become women they develop breasts. I wondered how daughters might talk about breasts. One said it was only in the last year that she could say the word
"breast." A couple of daughters made fleeting references to issues of femininity, or to the sensitive and personal nature of having to have surgery and perhaps other treatments that would alter body image. Two said they would not want to have that part of their body scarred, and that would be awful.

One daughter had a lot more to say about femininity and body image. She said that she felt sorry for her mom because "it wasn’t exactly her femininity but still part of it." She told me one of the most popular high school graduation gifts now for daughters in the United States was a breast enlargement. This daughter spoke about how women’s bodies are depicted in the media. She considered how tough it is on women that all this attention is paid to breasts in western culture. She thought about what women must feel like when they have to have breast surgery for cancer because these women are living a culture focused on breasts. None of the glossy fashion magazines were going to use women with one breast. She thought that it would be very hard to have to lose a breast because women’s bodies and breasts had to be perfect and that puts continuing pressure on women, and on girls. However, if she were faced with the choice between preserving her body image and having surgery, concerns about femininity and body image would take a back seat to her health.

In this study I enquired about the health and illness of families. My purpose was to develop an appreciation of the family context in which this particular illness experience had occurred. With each mother-daughter dyad I asked about current and past experience of illness in the family. My inquiry was quite general and I did not ask specifically about
the incidence of cancer or breast cancer. What stood out for me in these conversations was how often the daughters brought up members of their extended family who had died of cancer. By way of contrast one daughter knew very little about her family’s health history because she had not been told. It was her mother who later filled me in on the history of cancer in her side of the family.

My sense overall was that daughters had kept track of the incidence of cancer in the family. In three cases, daughters reminded their mothers of aunts who had either died from breast cancer or who had cystic breast disease. Several daughters grasped the opportunity provided by our discussion on the health of their families to clarify questions they had about particular family members. In the following excerpt a mother clarified that the relative was not a blood relative. Given the amount of identifying detail in family health histories, I do not mention the names of participants in this joint discussion to preserve confidentiality. The mother is referenced by ‘M’ and the daughter is referenced as ‘D’. Names of the family members mentioned have also been changed. The following excerpt touches on the incidence of cancer about midway through our discussion of health and illness in the family where this daughter raises a question.

M: There’s some cancer on my mother’s side of the family but they’re older.

D: What about Margaret?

M: She’s in her eighties. Oh, you mean.? Oh I see. One aunt by marriage who died of breast cancer after it had metastasized.

D: Oh. Was that breast cancer? (looking somewhat horrified)

M: Well she had initially, no initially breast cancer but then five years later it was
in her bones. And then it went to her lungs and she got really really sick.

D: Ya.

M: She was pretty sick.

DM: How long ago did she die?

M: She would have died shortly after … probably around 1993. My daughter would have remembered her because we saw her when she was quite ill.

D: Ya. And I remember that I didn’t want to go see her because she looked so awful.

M: Ya she did. She was pretty bad.

In this conversation I noticed the relief on the daughter’s face when she heard her mother say that this aunt was related by marriage. This mother’s response was typical of several other mothers who were quick to point out where cancer was outside the bloodline. This daughter’s relief in finding out that the relative was related only by marriage was also typical with other daughters. From my point of view, it was experience with illness per se that I was interested in but from the participants’ point of view there was an issue with bloodline and of potential heritability. In this particular example, the relative was not a blood relative but the impact on the daughter was still striking. She looked surprised and very upset at hearing that this aunt who had looked so awful had in fact died from breast cancer. I was struck by how her mother talked about breast cancer as almost separate from the metastatic disease and death, which were the ultimate results of breast cancer. Whether she was trying to reassure her daughter in some way or whether the issue was too sensitive for both of them, our discussion of this aspect of family
history closed as mother took the lead in moving the conversation to other matters.

The visibility of breast cancer in the culture at large serves as a backdrop to this study. I have included commentary on the profile of breast cancer so that readers might have some appreciation of the climate in which this study was conducted. By my observation, awareness and fundraising activities for breast cancer contribute to a climate of continuing uncertainty for all women including the mothers and daughters in this study. By my observation, the message that daughters may develop this disease is growing as evidenced in the fundraising advertisement, the brochure, and the film shown in biology class. Perceptions and questions concerning personal risk were evident in conversations mothers and daughters when we discussed the family history of health and illness. Daughters appeared to be tracking the incidence of cancer in the family and most mothers and daughters seized the opportunity of our discussion to clarify with each other where biology might or might not impact personal risk.

Reminders of Vulnerability.

Mothers spoke of a variety of ways they were reminded of vulnerability to cancer. They spoke about a rise in anxiety at certain times such as anniversary dates for diagnosis, for end of treatment and follow-up, and around follow-up appointments now. Some spoke about their changed bodies, but I heard comparatively little in respect of bodily reminders. A sense of vulnerability might also surface in feelings of sadness or fear that could pop up at unexpected times, or that existed as a backdrop to everyday life.

The drawing of one mother expressed her sense of continuing sadness that existed
along with hope and optimism (see Appendix B, Figure 5). In her drawing a large sun is shining and she is walking along a green path. Midway across the scene she seems to step up and off that path, onto a path that is now brown. I notice a tear shape on her face and that she is walking away from the green tree on the left hand side of the scene towards a heart, three tears, and the sun. A body of water stretches across the bottom of the page.

My impression is that I am looking at a picture of a solitary journey, one of tears but also of optimism. As she begins to talk about her drawing she is smiling and crying at the same time. She cries throughout the following description.

I think I just see myself walking along and still enjoying life and lots of brightness around me. Love. But I have a few tears once in a while because there’s still, there’s still a little sadness there occasionally. I mostly see things as really positive and I see myself as having a future. Ya. I think wishing that there wasn’t sadness but still ... Yes those are tears there. And I keep saying – people say “Are you really afraid?”- I say “No I think I’m at peace with all that.” I’m not afraid just... sad that it has to be. I think that’s maybe more it, just sad that it has to be. I think I’ve really gotten to enjoy the water. The water probably helps me. It’s kind of a medicine for me. ... I find it so peaceful to be by the water. It would be so nice to see a sunset over the water. I would just love to have that. It has been a big healing for me to be near the water. Being near it more often would have been an opportunity to be less troubled. The heart? It’s probably love and hope. But the tears are sort of hope too. Sometimes hope can be good and sometimes it’s there because of some sadness.

The mixture of hope and sadness she describes in this drawing illustrates the dualistic nature of life for her and for other mothers in this study. On the whole, things are positive but hope is there because of an encounter with cancer so hope also carries the sadness of cancer experience. For this mother and for others, painful emotions periodically surfaced in everyday life reminding them of the continuing uncertainty of breast cancer and of their own vulnerability. This mother, like several others in this
study, was currently struggling with a concrete reminder of the uncertainty of breast cancer. One of the major ways that the experience of breast cancer continues in the present is related to the issue of recurrence.

Breast cancer is not a curable disease in the sense that even if treatment is successful and there is no evidence of disease, there are no guarantees that the cancer will not return. Most women who are treated will not experience a return of cancer, but for those who do the outlook is not good. When cancer reoccurs in the body of a woman who has had breast cancer it often signals metastatic disease, a progression of breast cancer that for all intents and purposes means the person has become terminally ill. One of the things I noticed about the way participants talked about the uncertainty of breast cancer was that participants rarely spoke about metastases or terminal illness. Some said “recurrence.” Others said someone was “sick again.” They might mention that a friend now had cancer in what they knew to be favoured target areas for breast cancer progression, that is, bones, liver, lungs, and brain. But in general they did not speak of metastatic disease nor did they speak of someone as being terminally ill. I have written about cancer revisiting women using their term, recurrence. My impression was that this term provided some distance for participants in that it was a softer, less threatening word to use.

Recurrence as one aspect of the ongoing uncertainty of breast cancer was spoken of in terms of the statistics of breast cancer and in connection with recurrences among friends within social networks around breast cancer. One of the downsides of belonging
to a support group is that some members develop recurrences and some die. All of the mothers had friends and acquaintances who had experienced a recurrence. Three of the mothers had a very recent experience of seeing cancer recur in a friend.

In this excerpt from my last conversation with Cindy and Kate they are responding to a portion of the group letter (See Appendix A) on the uncertainties of breast cancer. The brevity of their conversation was perhaps less related to the sensitivity around recurrence than to the unique way this mother and daughter had already dealt with the issue. This mother had previously taken her daughter with her to visit a friend who was in palliative care. To place their remarks in context, Kate has just recently moved away from home to attend university. She is now physically removed from the situation of recurrence happening to a friend in her mother's social support network, and is also removed in that she was not particularly close with this person. Just prior to this excerpt, mother and daughter talked about the fact that fears around dying were present for both but were unspoken. Kate then asked me if any women in the study had experienced a recurrence or if "they are all first time through." I told her that one mother had developed a recurrence during the study.

C: Well it's always in the back of your mind. I haven't seen it but there was a movie with Meryl Streep on this. But I was thinking the other day. Say I had a recurrence what would be the best thing to do? For her to come back for a while, or to keep going if something happened to me? Have you ever thought about that? Like if I was to get sick again?

K: Not lately no.

C: I think you're settled in here now. My guess is you'd like to stay on and keep life as normal as possible.
K: I dunno. It’s hard to tell. Let’s face it, unless you’re there you don’t know.

C: One of my friends just had a recurrence and had radiation. (shifting to an upbeat note now) And all her x-rays and everything like MRIs are fine now so… she was really happy that so far she seems to have won round two.

Neither person had anything more to say on the subject of the prognosis of this mother or her friend. I noticed that their exchange here seemed uncharacteristically brief in comparison to the amount of dialogue on other topics. Cindy raised the possibility that the cancer might come back, and sought her daughter’s reaction to that possibility. This was something none of the other mothers had done. I wondered if it was easier for Cindy to talk about it because she had undergone two mastectomies, one prophylactic. She told me that having the second mastectomy made her feel less vulnerable. I suspect her daughter felt the same way, that is, that she also saw her mother as less vulnerable now. Still, as Cindy said, the possibility that she might have to face cancer again was there. For Cindy, and for the other mothers, the possibility of recurrence stayed with them. As time from diagnosis increased, mothers felt safer but the uncertainty remained. One daughter whose mother had passed the five year mark told me that reaching that point made her feel more confident her mom would be all right. However, all participants were aware that with breast cancer there are no guarantees that cancer will not return.

The effects of seeing recurrences among mothers’ friends were stronger for daughters where they were better acquainted with the person. The following excerpt provides an example of how recurrence in a close friend of the mother affected both mother and daughter. We have been talking about how they would describe their
experience of breast cancer, as in the past but also in the present. The conversation begins around one form of social network around breast cancer, dragon boating.

J: Ya, it’s kind of in the past. Although...

A: Except with the dragon boating.

J: Ya, it’s always kind of there because you see unfortunately when you’re involved in a group like that there’s women who get sick again – have recurrences. Sometimes that really bothers me. Others it doesn’t bother me as much. It depends on the circumstances. If somebody has a recurrence where you’re not surprised, for some reason it doesn’t seem to hit you as badly. But if somebody has a recurrence when you’d think they’d be the last person – you think “Shoot!” you know? I guess I’m not as safe as I think. But I don’t talk about it with her.

A: The personal side of it is kind of gone almost. The dragon boating thing – it’s always there because of that but it’s almost a common thing. People are always calling. But I know when Linda had her recurrence I got really scared there. She had been to our house like a week before and then I found out she was in the hospital. And I kind of knew her. And she was really really nice. That was kind of tough. (looking down, softer voice)

J: It’s true what she says. She sees me I guess vulnerable and she knows why.

Jessica commented that her worries about getting sick again were not shared with her daughter. She shares them here indirectly as she speaks to me. The sensitivity of the issue and Angela’s response to it was evident in pauses and body language. At one point Jessica started crying, and after Jessica’s last comment Angela left the room to get her some tissues. I told them I thought we could shift gears and turn to another topic to maintain a sense of comfort for both of them. Both looked very relieved. However, the issue of recurrence came up again later. In the next excerpt, mother and daughter have been talking about changes in the family’s diet after Jessica’s diagnosis.
A: It wasn’t such a huge deal (dietary restrictions initiated by Jessica)

J: Well then I’ll have to go back to them!

A. OoooH Yuck. Like at the time it was okay. Now that it’s over with I’m glad it’s over.

J: Well you don’t know that. (looking straight ahead, away from Angela)

A: Well it better be! (softly, head down now)

What stood out for me in this excerpt was the brevity of dialogue around the possibility that mom could have a recurrence. Angela raises the topic in an almost round about way and mom lets her know, in rather indirect manner, that cancer might return. Jessica quickly redirected the conversation back to the issue of diets after Angela’s last comment, avoiding any direct discussion of potential vulnerabilities. Nonetheless, dietary changes in the wake of cancer experience are ongoing reminders of vulnerability. Dietary changes represent an effort to reduce susceptibility to disease in the future, changes initiated by an experience of cancer. In this family, dietary changes were largely focused on eliminating junk foods and additives. In conversation with another mother I heard about her largely unsuccessful attempts to have her daughter join her in taking nutritional supplements. In that home, a portion of the kitchen counter was taken up with these supplements offering a concrete reminder of vulnerability.

Reminders of vulnerability are at the forefront in the next conversational excerpt with Diane and Chloe. Diane talks about her fears, close at hand because a dear friend in her support network has recently learned she has extensive metastases. The impact is
shared by mother and daughter. Chloe knows this woman and is fond of her. Prior to this excerpt Diane had been talking about her friend’s recurrence, and about her own distress. I turned to Chloe to see where she was in all of this, and the following dialogue between mother and daughter ensued.

C: I’ve seen her but not lately. Not since we found out she has brain cancer.

D: Chloe wanted to come over.

C: Mom looked at me and said “No no no. You’re not coming over.”

D: Well that was the day she was diagnosed and wanted to see me.

C: Well I felt really bad for her.

D: Ya. So that sort of brings home the reality…. It’s big time scary for me. That’s the scariest. Her cancer has metastasized to her bones and her lungs. And when she described to me what her bones look like, I found that pretty scary too.

C: What did they look like – Swiss cheese?

D: Ya and it’s in her head like that.

C: She’s got holes in her skull?

D: Ya.

C: Ooooooh. (head goes down) That’s gross.

D:... I realize this is something I’m living with. And the seriousness of the disease and I might be one of the very lucky women who have breast cancer – the bout of cancer that I’ve had is all the cancer that I will ever have. And there’s a possibility that I can get it again, and it can be a lot worse…. And so when you know and you’ve been touched by the lives of other people who have it it’s a double-edged sword. You feel very grateful what you’ve gone through and that you’ve got away with it and then you also realize ‘Oh my God. This can really happen with me too’.

Two things stood out for me in this excerpt. I was struck by the detail and extent of
the conversation and by Chloe’s reaction to this woman’s situation. Although Chloe had wanted to help this woman she had no opportunity to do so and was a bystander to tragedy. Diane was very open with Chloe in painting a picture of her friend’s situation – a situation she said she could find herself in one day. At one point during this exchange Chloe seemed to disconnect from the discussion. She picked up a book and flipped through it. Shortly thereafter she left the interview, a little prematurely. My impression was that it was only partly because she had a bad cold and was tired. Nonverbal language provided an indication of where Chloe was in all of this – needing some distance from it. In this, and in the previous excerpt, the fears that daughters may have are largely unspoken and are not addressed by their mothers. In the next excerpt a daughter is very open about her fears and what she can and cannot tolerate.

In this excerpt, Heather and Brandy engage in a very animated discussion about their individual responses to the possibility of death – the ultimate vulnerability. I hear about Heather’s fears, and Brandy speaks out forcefully on her ability to hear about the possibility of her mom dying. The issue is highly charged for both persons. The excerpt references an earlier conversation between Heather and Brandy, and a recent conversation Heather had with an acquaintance recently diagnosed with cancer. We have been discussing the group feedback letter where I have commented that uncertainty seems a sensitive area that seems not to be discussed.

H: You don’t know how much to talk about it, or when or how to broach the subject or..

B: Ya, because then they say stupid things like ‘I have a very bad prognosis and I
could die before you get married and I'd never see my grandchildren." (voice up in quotation marks)

DM: That's the uncertainty factor isn't it?

B: Yes. And it's also the annoying factor! (sounding very irritated and scowling)

H: ...I was talking with someone the other day... and he's kind of worried about his CAT scan so... I told him my history and that, (looking to daughter) I won't say these words, I'm still here almost four years later and I seem to be fine.

B: What words were you gonna say?

H: That they gave me a poor prognosis.

B: You didn't say that! You just don't have to say "the grandchildren might not see you.

H: Well it is a fear of mine.

B: But it's pressure on me! So stop it.

H: That's right.

B: That's my problem, because you pressure me. I don't want to know. It's fine like it is.

H: Well no you wouldn't want to.

H: ...I told him about the chemo and I said "Don’t panic if you get that kind of report. All’s not lost just because you’re told that.” Lots of people survive and I told him that.

B: Well by the same token there are people out there who are not okay.

This exchange illustrates rather forcefully that the strain and fear about the possibility of an early death is a joint experience. Brandy is unwilling to hear about her mother's fears or to hear about her mother's optimism in talking with an acquaintance.
The atmosphere between mother and daughter was tense, Brandy raising her voice to the point of shouting. Her directness and her ability to verbalize her fears is perhaps unique, but I was to hear more from another daughter on the pressures of inhabiting a landscape of continuing uncertainty.

In the following excerpt with Barbara and Sarah, the issue of recurrence serves as a reminder of the uncertainties of cancer but it is mentioned almost as a minor note in a symphony of activities around breast cancer. Like Brandy, Sarah is unable or unwilling to tolerate certain aspects of breast cancer. Her distress stems from her mother’s continuing high level of involvement with breast cancer activities. That strain is a joint experience, but in this excerpt Barbara comes to a sudden realization of the full impact of her involvement with breast cancer activities for Sarah. My voice is present here, facilitating dialogue as Barbara comes to grips with some of what she learns from Sarah. Sarah speaks with a degree of sarcasm and anger, unusual for her.

B: Unfortunately Sarah still is reminded of it constantly because I get calls from the support group-

S: It gets shoved down my throat. But that’s okay. (soft voice, sarcastic tone)

B: - through the buddy system. So there’s a lot of stuff and she keeps getting reminded about it. And I get involved with a lot of other things too. Breast cancer is still very much a part of her life whether we might like to think otherwise. As long as I stay involved with it.

S: It’d be nice to move on. But that’s okay (soft voice, sounding frustrated)

B: Well maybe as a family we need to sit down and talk about it. Because sometimes it’s a great deal of work for me.... There are times, especially the end of October. If anybody asks me to do anything with breast cancer I start to resent
it...because it’s asking me to do something. Sometime I resent that. It’s hard to say no. It does take away from – we’re a very busy family here. It’s sometimes an organizational nightmare around here. I never say it, it’s hard to say no, but there is that resentment.

S: I find that what you usually do then is talk about it with me. What happened on Friday, who had a recurrence and how they’re doing. If I asked I probably want to hear about it but when you bring it up I just don’t want to hear about it. You hear so much about breast cancer. It’s just with all the things in my life – you probably know it – I just don’t want to hear about it. I won’t listen.

B: No, I do know that.

S: I just feel kind of bored and fed up with hearing about it. It just seems like it’s the same thing happening very week...and like I know what goes on...but like there’s so many things going on in my life...Like it drives me nuts! Not drives me nuts, but I’ve heard about it for so many years.

DM: Is there any aspect of it that’s more upsetting than anything else? Probably an example comes to mind.

S: I don’t know. Unless... more than anything it’s kind of frightening to think how I just don’t want to hear about it. Because I think in the same respect I think if I don’t want to hear about it then I’ll take for granted the fact that I’ve never had it or something. Or begin to forget. Like as I’ve said before in our other meetings, just knowing that my mom has had it makes you take less for granted because you realize what can happen. And like the fact that I don’t want to hear about it – like if I don’t hear about it anymore then it’s over kind of thing. But it’s almost as if I’m kind of afraid that I will start taking things for granted again and it will happen to me kind of thing. (Barbara gazing upward, looking far away, eyes misting.)

Barbara looked shocked and overwhelmed at the point where Sarah began talking about what was most upsetting. By the end of this interchange the atmosphere between them had shifted from one of antagonism to a gentler, more reflective space of sharing. Barbara reflected on the utility of her involvement in various support networks and suggested she might stop going to the support group. Sarah looked worried and told her
that she wanted her to go. They came to an agreement that Sarah’s involvement needed
to be on her own terms. Both mother and daughter were feeling overwhelmed and
resentful about the continuing pressure of awareness activities and support networks. At
the same time they appreciated their value. Sarah appreciated that support groups helped
her mom and that her mom was helping other women. Both appreciated the important
role support groups play in proving support and encouragement, in reducing feelings of
vulnerability with information, and in raising awareness.

Reminders of vulnerability took a variety of forms. The knowledge that breast
cancer is an unpredictable disease that can reoccur was one form, and as one mother said
“It’s always in the back of your mind.” For mothers, fears about the possibility that the
cancer might return were also present in painful emotions that would periodically
surface, and in recurrences among friends and acquaintances in social networks
connected with breast cancer. Recurrences served as reminders of their own
vulnerability, reminders that were not lost on their daughters and were upsetting to
daughters. Mothers and daughters said little to each other about their awareness and
concern regarding the chances cancer would revisit their family. One daughter described,
and showed with her anger, an inability to tolerate any talk about her mother dying.
Reminders of vulnerability also had a presence in everyday life in the form of changes in
diets, and in activities connected with breast cancer. One daughter angrily described the
intrusiveness of mother’s breast cancer activities, activities that left her feeling somehow
more vulnerable herself.
Responses to Vulnerability.

For mothers, joining a support group and working to raise awareness of and funds for breast cancer are important avenues of response to vulnerability. An important function of these activities is that they provide a sense of control. As one mother put it, “Having information increases your sense of power and decreases vulnerability.” In the previous excerpt a daughter acknowledged the value of support groups. This daughter and others saw support groups as helpful for their mothers. Seeing their mothers go to support group meetings was one avenue for daughters to support their mothers, and daughters would encourage their mothers to go.

Over the course of conversations I learned that although support groups do provide emotional support, the sheer size and proactive information focus of many groups provides a limited venue for addressing emotional vulnerabilities. Only one mother had sought professional help in dealing with ongoing concerns and vulnerabilities. The upset of recurrences in friends and ongoing concerns of personal risk were managed with a variety of reasoning strategies. Most mothers dealt with emotional vulnerabilities by putting them away or reasoning around them. Concerns for daughters were managed by not talking, that is, not asking daughters about concerns they might have for mom or for themselves. As one mother said regarding the possibility that her daughter might have concerns for her own health, “... she has thought about it, I guess. Maybe momentarily. I don’t even think she thinks about it. My impression is she doesn’t think about it.” Concerns for daughters were also managed by emphasizing prevention, and by planning
for eventualities. Because I heard much more about vulnerabilities and responses to vulnerabilities in the individual interviews, comments from mothers and daughters are presented separately.

The following excerpt is an example that combines reasoning through risk and placing concerns in a contained space. This excerpt also provides an example of a common strategy among mothers upon learning of a recurrence, of looking for differences between their own situation and the situation of the woman who has had a recurrence. I hear echoes of Diane's earlier comment on "getting away with things so far." After posing a question on presence, I ask about her feelings about her friend's recurrence. Her reply is brief and she quickly returns quickly to how she reasons about the event.

M: I think for some things, probably the more negative things I want to know as much as I can but I will tend to file it away in a filing cabinet and not bring things into the open.

DM: Is that where breast cancer is for you now, is it in the cabinet somewhere?

M: Somewhere in the middle of the filing cabinet. Because a friend of mine that went through treatment with me has had a recurrence. A little bit more towards the front because we went through treatment at the same time. ... The difference that I came up with was they radiated my underarm. I don't know why they didn't with her because she had four positive nodes. But they didn't. They radiated her breast but not under her arm. And so that was enough of a difference that I felt okay.

M: If you had to put a word to how you're feeling about that could you choose one?

M: "Oh shit!" Although I guess the odds are, well you know when they give you the odds and percentages it doesn't apply to little subsets. But you do it anyway. And there were five of us who went through the treatments together. Two have died and now this one has had a recurrence. And two of us are still fine and so I think well maybe, maybe I'm in the good part of the odds for that.
Achieving a sense of distance and safety by reasoning around percentages and statistics was a strategy with other mothers. The next excerpt illustrates reasoning through the risk of recurrence by making comparisons and considering percentages in general. It includes commentary on how this mother thinks about her daughter’s risk for breast cancer, and about the limitations of follow-up and prevention in reducing the risk of breast cancer. Her tone was strong, as she spoke of her frustration and helplessness.

After all I went through my doctor said I had a sixty percent chance of surviving five years. And I remember thinking ‘Whooh! I was hoping it’d be a little better than that’. But she looked at me and said “You live your life as though you were going to be eighty.” So that’s what I took from that. Right through the whole thing my risk of dying was very high. And I used to say to people ‘Those are numbers. And what do they mean? ‘If I’m in the small percentage that makes it who cares what the numbers were! My friend has a ninety-five percent chance of making it. Now is she gonna care that she had a ninety-five percent chance if she is in the five percent who doesn’t? Stats are so weird. ...By the same token more and more and more – like I’m in a support group that now has over fifty members. And some have dropped out and some have died and we still have over fifty members. It doesn’t diminish as people don’t come. It only gets bigger. ...If it doesn’t affect you does it really matter than one in eight might get it? Maybe that’s why I haven’t really talked to my daughter that much about it. If I do, will she do breast exams? I doubt it! I forget to do those exams myself. ...It’s tough for me to do them because I don’t put a lot of faith in ever having one that’ll help me out. The only people that could feel anything were the two oncologists so if only the oncologists could feel it, am I going to? I very much doubt it! If the surgeon couldn’t feel it, if it didn’t show up on ultrasound or on the mammogram... Like it bothers me, in a lot of ways because that’s the way they follow you up...In my case it wasn’t a lump so it’s hard to pass on to my daughter that this self exam is important because it didn’t work for me. ...Diets? Linda McCartney died of it. She was a vegetarian. And I met a young young girl. She was twenty-three and she had this lump for three years before anyone would do anything about it because she was so young. ...And at twenty-three it was the size of an egg. She was a fitness instructor. So what’s gonna help?!?

The distress of this mother was obvious, the sense of vulnerability for herself and
for her daughter strong. Her observations that the number of women that get breast
cancer is increasing and that younger and younger women seem to be affected was shared
by others. The seemingly arbitrary nature of incidence and recurrence, the questionable
utility of self-monitoring, professional follow up, diet or exercise to reduce the chances
of breast cancer left her angry and vulnerable. At one point during the study she told me
that she had gotten very depressed and had had to go on antidepressants. She said she just
wasn’t coping. She found herself bursting into tears and couldn’t figure out why until
about three weeks later it dawned on her that her troubles started on the anniversary date
of her last treatment. As another mother said to me “When that last treatment day comes
it’s like ‘Poof! Off you go girl.’ And it is terrifying.” As a counsellor I was interested to
learn that the mother in this excerpt had not sought counselling for her emotional
difficulties but was only taking the antidepressants. I heard other mothers say that coping
meant not going to see a counsellor and carrying on as normal.

In the following excerpt a mother shares her views on counselling and normalcy.
We are reviewing her individual feedback letter. Previously she had told me that she
didn’t really find what she needed in the groups at the cancer agency, and in retrospect
thought she would have benefited with individual counselling. She told me that her
emotions are still just under the surface, eyes misting. In this excerpt she explains that
she had suppressed emotions around the breast cancer experience, busying herself with
being the nurturer for the family. But she offers that there is another way that the
emotional aspects of experience come to be neglected.
M: Your comment about the counselling is right. If I think about one-on-one counselling, I think that’s something I missed and should have had. I think that’s probably why I still have these feelings close to the surface. It’s getting better but I don’t think I allowed myself to - I suppose never having experienced one-on-one counselling. And I suppose getting all this care and good treatment from people that it wasn’t til later that I realized that it was probably not enough. The emotional aspect wasn’t being dealt with the way I would have liked.

DM: How long after your diagnosis did you come to that realization?

M: It’s only in recent times. It really is. I went through that whole process and while you’re going through the treatment you’re so preoccupied and there’s so much. I did go through all the programs at the cancer agency but ... perhaps things got shelved. I was on an emotional roller coaster at one point. That was when I got depressed. Of course I’d read everything in sight and knew that this was a normal thing that happened so I didn’t deal with it. This was normal, so get on with it, you know? Now I realize that that was something that should have been dealt with at the time but it never was. I’ve learned that.

DM: I get the impression sometimes in the whole area of breast cancer there’s so much emphasis on information and knowing things. I wonder where the feelings are.

M: Yes, information and knowing. Absolutely. The other thing is you become aware of your vulnerability. I know the stats on breast cancer and I know you can’t get too casual with this disease and there is no cure. It can come back when you least expect it. I know women where it’s recurred after twenty years. That’s the downside of being in a support group. Some of your friends get sick again and I’ve been to quite a few funerals. So there is that aspect of it and somehow you have you deal with it. It makes you more vulnerable – take another look at it, just put that in another compartment.

As with another mother who put her concerns in a filing cabinet, this mother tucked her feelings of vulnerability away in a compartment. The relative neglect of emotional experience mentioned in this conversation illustrates a downside to focusing on information. Emotional needs may be set aside because they are just normal and so you just get on with things. Moving on was something that mothers did strive for but they
were not always successful. The next excerpt illustrates some of the barriers to moving on. For this mother, a sense of continuing vulnerability and a fear of dying are private concerns that manifest in extended follow-up.

When I was first diagnosed my big struggle was I was worried what are they gonna do if I should die next year? I thought about it a lot. I didn’t talk to her about it though. ... I always worried that I wasn’t going to be there. I still have that problem....I don’t think about it all the time and it’s not that I’m trying to hang on to breast cancer. But having a diagnosis changes you in such a way that you don’t forget about it and put it in the past. When someone has a recurrence that really tugs on those strings, reminds you that ‘Oh man it could be me’. I don’t feel that I’m not healthy. However I still am very uncomfortable with having my checkups less than every six months. I’m not comfortable with going a full year yet... Some women can’t wait to be done with the cancer agency and be followed by their family doctor. Others can’t cope with cutting that string. Everybody is different and you have to find a doctor that will support you in this. It’s too much of an unpredictable disease. I keep saying to myself that I have to do this for me but for my daughter too because it’s not just me I have to worry about.

For this mother, more frequent checkups are one thing she can do for herself and for her daughter. Other mothers shared anxiety associated with the end of medical follow up, but as she noted responses do differ. Some women see the end of checkups as an achievement and some experience it as an abandonment of support. In one of the joint interviews, a daughter comforted her mother about her fears with an analogy. “It’s like parents holding you up when you start to walk. At some point they let you go. You have to walk.”

One woman’s struggle to carry on is captured in her drawing (see Appendix B, Figure 6). The drawing was done with great enthusiasm, energy, and enjoyment. Strong lines moving at several different angles convey a sense of an almost frenetic energy that
she exhibited in doing the drawing. My eye went first to the middle of the drawing, a space that was quieter. It was a yellow space relatively free of other colours. My initial reaction to the drawing was one of puzzlement and hers was “I have no idea what this is!” How could we discuss this work? What could we learn? I encouraged her to just sit back and relax for a bit and sort of let the drawing speak to her. As she spoke I gained an appreciation of the place she was in and the space she was reaching for. She spoke first about the colours she had used.

The yellow is two fold actually. As I was using the yellow I was thinking “Oh God yellow is the colour of cancer.” Cancer to me is yellow. But at the same time in my meditation, in my spirituality, it is a protective colour. So unfortunately it’s a dual thing. The violets are healing and so are the blues and lavender. So those are the colours I chose for the purpose. Healing colours for warmth and protectiveness, and the yellow also represents a higher power. Unfortunately yellow is the colour of daffodils and cancer. This (center) almost looks like a palm. This (left lower quadrant) looks like a person- there’s a head and two arms and a body going towards the palm, towards the trunk. Reaching towards a calm pool. And a cloud almost like a space ship (right upper quadrant) beaming down – beam me down Scottie! It’s funny cuz I never looked at these things and all of a sudden – it’s almost like an eye there (top middle). Part of my meditation is I inhale positive thought, feeling and a clearing of the mind and I exhale negativity. At the same time I visualize roots coming out of my fingers and my feet feeding it back into the earth to purify. So that’s how I sort of transcend my negativity. I have not been able to ever totally clear my mind but I so desperately want to find serenity and inner peace and inner love and all those things. And no I have not found that but it is a goal I am searching for.

In her drawing this mother portrays the process she uses to deal with vulnerability. She meditates, trying to clear her mind and body of negativity and hoping to position herself in a place of peace and inner harmony. Although she tires to create a sense of calm and freedom from negative thoughts, she has not been entirely successful. Other
mothers did not talk to me about using meditation. However they were similarly engaged in the task of putting vulnerabilities, often spoken of as negativity, in their place. Metaphors of containment were presented in two previous excerpts as mothers described putting negativity or vulnerability in a filing cabinet or in compartment. Here a mother tries to put her negativity deep underground. This drawing illustrates a response to vulnerability in attempts, variously successful, to move vulnerabilities safely away so they will not be experienced.

One final excerpt from a conversation with a mother conveys her struggle with feelings of vulnerability and her efforts to take positive action. As in a previous excerpt where a mother opts for closer follow-up, this mother is concerned to take action for herself and for her daughter. She describes her fears and the efforts she makes to deal directly with them in some detail. Feelings of vulnerability surface at work. They have a presence in reaching an anniversary date. They increase with recurrences among friends. She feels a need to plan for eventualities yet is frightened by the fact that she feels a need to plan. She talks about the catch 22 of positive thinking as she described efforts to distance herself from concerns and actions.

I have positive moments. I have very negative moments. I have extremely fearful times. I don’t believe in just keeping a positive attitude la-di-da-di-da as I go singing down the road because I don’t deny it. ...I have a huge fear of dying and it comes and goes at the most inopportune times. I’m at work and it’ll cross my mind. “Is the cancer back? Am I gonna see next year? Am I gonna be dead before retirement?” These sorts of things go through my mind. I’m having my will redone and my jewelry reevaluated. I’m so scared right now. “Am I sick again and my body is telling me to get my house in order?” I try to turn it around and think “No you are not sick. You are getting your house in order because you know how quickly things can happen.” ...But I sometimes worry about having cancer again
and like “Am I willing it on myself? Will this happen again because I’ve thought of it?” And then that can put you into a total frenzy. ... I don’t want to dwell on recurrences but I go through times when I get really scared about it. ... I just have to get through my anniversary date [diagnosis]. About dying, I’m really most afraid for my daughter - who’ll take care of her and that she have every advantage and so that’s one reason I work. I try to take care of myself too with counselling, massage, and getting out with friends.

In this excerpt a mother talks about her fears for herself and for her daughter, and the actions she takes in response. Feelings of vulnerability for her daughter were a motivating factor in working, and in setting her financial and legal affairs in order. Personal vulnerability was reduced with counselling, massage, and social times with friends, but intrusive thoughts about death persisted. This mother tries to maintain a positive outlook on her own health by reframing negative thoughts into positive ones. She worries that there is a kind of inner wisdom behind her fears, and worries about who will take care of her daughter.

Privately, daughters said little about having concerns for their mothers, spoke more about concerns for themselves, and spoke most about how they reasoned about risk. My impression was that the subtext of reasoning about risk was self-protection against fears about death and dying. One daughter explained to me how she never thought about recurrences as meaning anything more than “just that these women would just have to go through chemo again. They would all get better.” In her remarks I heard a kind of assurance of safety associated with chemotherapy. During the course of our study she had a dream about getting chemo herself. A clear fluid just kind of washed over her arm and she felt kind of calm watching it. As for her own risk, she said that by the time she was
old enough to be at risk they’d probably have a vaccination, a “boob shot”, so she wouldn’t have to worry.

Another daughter told me that she didn’t really worry because it was wrong to worry. She had decided to be calm because it was important to support her mom and this wouldn’t help her mom. Worrying was also not a good idea for her because “that would make you like totally schizophrenic.” After all, death was a natural part of life and if your mother died then you would have to grieve and get over it. At any rate her mother wasn’t in any danger because “they caught it early and if she didn’t die during the surgery then chances are she’ll be fine.” However, in another portion of our conversation she said she did worry about her mother, and recurrences were very upsetting. Privately she cried but didn’t know why. In my view, these examples of reasoning about risk and putting risk in its place have very much the flavour of ongoing experience – of experience kept at bay but nonetheless present.

With one exception, daughters said little directly about fears for themselves or for their mothers. For one daughter, worries were always in the back of her head. She worried about her mother, but perhaps more for herself and her future saying that “my risks of getting it now are really high.” Daughters spoke more about how they thought about breast cancer as a sort of distant possibility for themselves. Most were quite open in explaining to me how they thought about breast cancer. They used a variety of reasoning strategies that I would interpret as providing some needed distance from breast cancer.
Listen to how one daughter describes her situation. It is typical in that she first mentions how for her breast cancer is sort of in the past. She has mixed feelings about the possibility of breast cancer visiting her personally and her comments emphasize a degree of separation from it. I found her reasoning both surprising and intriguing, more as evidence of a need for distance.

D: Not that it’s in the past but it’s something that comes up all the time, comes up a lot. It’s something that’s not over, I don’t mean to say that but it’s not happening. Not really back to normal but...closer.

DM: I’m wondering if there are occasions when the topic of breast cancer does come up?

D: Oh it does come up. Especially like when my guy friends were like giving each other purple nurples.

DM: What is that?

D: They just like squeeze other people’s nipples. And in general the whole fact that breast cancer la-la-la-la-la. I was talking about it with my friend Mike and he said “Ya. What do I care?” And I said “Guys get it more than girls.” And he’s like ‘No they don’t! How do you know?’ And like yes. They have breasts just like girls. They don’t check for it. Women are usually more educated and they check for it. And so guys get it and they don’t even know! A bunch of my girlfriends were saying “Yes she does know!” So it comes up in that way.

DM: So, boys are more at risk than girls. (her face freezes for a moment and she goes on)

D: Cuz they do stuff that can cause it and they don’t realize that they can actually get it.

DM: Are there other things that can cause it?

D: I dunno. Like something to do with estrogen. I know what that is. My mom talks about it all the time but I don’t listen. Just not me in particular but like if you have too much estrogen and I’m like ‘No. No. Not me.’... There is other stuff that is way more common, way more severe like more people can get it. Like in school you
hear about AIDS . . . and heroin and sexually transmitted diseases and stuff. . . . [And later on] They should teach people more cuz a lot of girls my age wouldn’t know (about breast cancer). And the age is getting younger and younger. My mom knew a girl my age who had it! And I don’t really know a lot about it, just from my mom. . . . Considering the age is getting lower and lower they should gear more stuff to teenagers.

The tension between this daughter’s perception of current vulnerabilities and the desire to place these vulnerabilities elsewhere, that is, on guys was striking. At the point at which I echoed her assertion that guys can get it more than girls I had the sense that she suddenly felt vulnerable. Her expression and body language conveyed a sense of fearfulness and guardedness. Perhaps she expected me to challenge what she had just said or perhaps her comments did not ring true in her own ears. My comment had been delivered with a deliberate neutrality. I maintained an accepting stance to whatever she had to say and the moment passed quickly. However, I did feel thrown as she described how guys were more at risk and thought this a very unique way of reasoning about the risk of breast cancer.

Echoes of this sort of reasoning occurred with another daughter who was talking to me about her consideration of personal vulnerability. She said she never even thought about breast cancer in relation to herself, and added “breasts aren’t necessary to have cancer - like men can get it too.” For this daughter, the topic of personal risk only comes up now when she goes to the doctor’s office. Every time she goes there she hears that she has to be really careful now because her mother has had breast cancer. This she finds kind of scary and maybe a little frustrating because “There’s nothing I can really do about
it. So I don’t let it bother me. I’m not that worried because like I don’t think it’s hereditary. Nobody else in my mother’s side of the family has it, so...

In various ways, daughters described an awareness of being at some increased risk for breast cancer themselves. Vulnerability was rejected as an immediate issue, perhaps something to think about in their twenties. Mothers and daughters were similar in this respect. Privately, mothers spoke about the advice they would have for their daughters. Advice might include eating well, doing breast exams and having exams done by physicians, exercising caution about the use of hormones as a birth control measure, starting mammograms early. Opinions on the utility of prevention and early detection measures and on the best time to give their advice varied. Some advice had been offered because it was easier or seemed appropriate to have given it already, for example advice on healthy eating. Other advice, such as when to start mammograms, was for some unspecified time in the future in part because it was not clear to mothers just when their daughters ought to begin. The dominant feeling for both mothers and daughters was that there was a need to proceed with a degree of care and caution.

Summary of Theme

The diagnosis experience brought confusion and upset for mothers and daughters. Mothers struggled with what to say to their daughters and how to say it because there were no guidelines on how to tell their daughters about the breast cancer. Mothers opted to provide factual medical information, hoping not to unduly upset their daughters and being considerate of their daughters’ young age. Daughters recalled little factual
information and felt they did not really understand what was going on, comments that surprised mothers. Daughters were upset by the diagnosis although in retrospect said they did not really appreciate the seriousness of the situation. Feelings of upset were related to their own confusion, a perceived lack of honesty in mothers, and concerns for their mothers. Some looked back with regret on their feelings or actions at the time.

Effects of treatment that were unexpected and prolonged created confusion and upset for both mothers and daughters. These treatment effects impacted the mother-daughter relationship in a variety of ways but spelled disruption in mother-daughter relationships. Where the mother developed a frozen shoulder, a daughter became very angry that her mother could no longer do normal things. Where mothers developed changes in memory, friction arose as prior agreements on daughters' outside activities were or were not remembered. Some mothers said that they denied cognitive changes at the time, especially in the area of diminished memory, but later came to appreciate they had not been functioning normally. Mothers were in varying degrees upset that they were not forewarned of the possibility of cognitive changes.

For mothers and daughters, the experience of continuing uncertainty regarding breast cancer is supported by culture and biology, is present in a variety of reminders of vulnerability, and generates a variety of responses to vulnerabilities. As a serious health concern for large numbers of women, breast cancer now has a high profile in Canadian culture. The issue of heritability of breast cancer is a recent development which was appreciated by the mothers and daughters in this study and which was encountered by
one daughter in an educational setting.

Reminders of vulnerability as one facet of continuing uncertainty arose in several ways. For mothers, reminders of vulnerability were present in anniversary dates, in undercurrents of painful emotions that periodically surfaced or remained just under the surface, and in recurrences among friends in the social networks of breast cancer. For daughters, reminders of vulnerability were variously present in the media, in dietary changes, in the breast exam instructions mothers put in the shower, but mainly in recurrences among their mother's friends. Recurrence among friends in social networks was the most prominent reminder of vulnerability for both mothers and daughters. Recurrences had a greater impact where they had seemed unlikely or where the mother or daughter was closer to the woman.

Responses to vulnerability as another facet of continuing uncertainty were discovered in the individual interviews because this is where they were shared. Mothers were reluctant to engage daughters in conversations about vulnerabilities, either their own or that of their daughters. The same held true for daughters. Mothers talked about how they reasoned about vulnerability, setting emotions aside as best they could. Some focused on statistics, and some took comfort in making comparisons with other women to reassure themselves. They strove to maintain an optimistic attitude and presence though this was threatened by their emotions and by the knowledge that in the end they had no control over whether the cancer would return. Mothers were concerned about their daughters' risks. However, they did not know what their daughters thought,
guessing they did not think about it much if at all. Daughters talked more about their own risk and much less about concerns for their mothers. Most felt that their risk of developing cancer was now increased. Like their mothers, daughters spoke about the reasoning strategies they employed concerning their own vulnerability to breast cancer. Worries for mothers were downplayed, but might surface in an inability to tolerate any talk about prognosis, or in a belief that all women who experienced a recurrence got better.

Intending and Acting

Over the course of our conversations, participants often spoke about their intentions and presented explanations for their actions. They mused about their intentions and those of the other person. Here are some typical comments in paraphrase. This is why I did what I did. This is why I did not do, or am not doing, something else. Will my efforts pay off in the long run? In hindsight I can see this was unhelpful or this was helpful. I wonder why she said that. I wonder what she thinks. Should I have said more? Why are we still tiptoeing around here? Participants most often described intentions and actions in terms of benefiting themselves or the other person, in the process revealing their working assumptions of what was best for the other person. Examples of intentions and actions having intended and unintended results were in evidence.

Intentions were enacted in everyday life as participants strove to carry on with their lives in a normal fashion, to maintain positive attitudes, and to exercise watchfulness. Descriptions of these aspects of everyday life are presented in the subtheme Carrying On.
Another aspect of intending and acting is presented in the subtheme Contouring Conversations. Much of what I learned about intentions and actions pertained to the kinds of conversations between mothers and daughters that did or did not take place. Conversations between mothers and daughters were carefully constructed to avoid certain topics and to handle sensitive issues with care.

Carrying On

Acting on intentions, participants were caring and protective of each other and of themselves in their efforts to sustain normal family life, to maintain a positive attitude, and to exercise watchfulness. Acting on intentions, mothers did their best to continue their important functions for the family thereby strengthening themselves. Daughters were also inclined to continue with their own lives as best they could, hoping to help their mothers and perhaps also to sustain a vision of normalcy. Mothers and daughters were watchful of the other person's health. Mothers and daughters made an effort to maintain a positive attitude. Instances of the efforts expended in what I have termed "carrying on" were more or less visible to the other person. Examples of carrying on were not as prominent in the interviews as were instances of conversations carefully constructed. Perhaps this was because mothers and daughters were very focused on what was said or not said between them. But my impression is that it is also because much of the content of this subtheme is a reflection of individual, private strategizing.

Sustaining a normal family life was an important aspect of the experience of breast cancer for mothers. Some mothers, who had the help of husbands, family and friends,
were happy to temporarily relinquish certain aspects of their important work in the family. Others felt a strong imperative to maintain their activity and presence in the family as before. In the following excerpt Barbara speaks about the general importance of caring for the family.

It was important to me to meet the needs of my daughter and husband. And I think a lot of women still feel they have to stay in control, make sure everything’s fine. My husband works very hard. I didn’t want him to have to come home and make the meals and drive our daughter to wherever she had to do. So I wanted life not to be disrupted once the surgery was over.

Barbara spoke of carrying on as an issue of control. Mothers spoke more about carrying on in connection with their early experience with breast cancer, a time when they were feeling very much out of control. In the next excerpt another mother had been talking about coping at that early point in time. I asked her what she meant by coping, and learn more about how carrying on normal family life helped her too.

M: Coping? See I think there are different sides of coping, but initially coping for me was physically functioning in the family, and a little bit at work too.

DM: So you would carry on doing your tasks then.

M: Yes. I wanted life to be normal for the kids. That was coping. So coping meant getting up in the morning, doing whatever I had to do like household things. I worked a little bit. That was... I think it was almost a way of telling myself that I was going to be fine cuz I was able to do this. Even if I was dragging myself I still, I didn’t do as much as I did before but ya coping was probably not taking care of myself emotionally. I had to shove that aside because I had to function to make sure the kids were taken care of. My husband was fine. I didn’t have to worry about him. I had to put them first and that was coping for me. If I couldn’t do that I would probably worry more. If I could see myself doing things I could see beyond tomorrow. I think it was just a way for me to carry on. But I always worried that I wasn’t going to be there. I still have that problem.
Persisting worries and about dying and neglecting her emotional health were a downside to carrying on. However, the excerpt illustrates her intentions as being two-fold, partly to benefit the family and partly to benefit herself. The ability to carry on varied among mothers because they were variously affected by treatments. Some mothers did take to their beds with nausea or fatigue because as one said, “There was just no way I could get up.” With others, the determination to carry on prevailed. The next excerpt provides a striking example of the efforts of one mother to carry on when she was really very sick. She pushed herself to function in the family - to benefit the family and herself as well.

I tried to be so strong throughout the whole thing. I mean I was never pretending I was well when I wasn’t well. But I’m going to make these efforts so that I just don’t lie there in a lump and that you know that I’m fighting to get better. And because if I’m just lying in bed moaning, which I’d really like to have done most of the time, I might not have healed the same way ... and I wanted them to see I’m fighting to survive and I’m not giving up on you folks. This was me showing them I was driven. I am here and I am going to make this damn Béarnaise sauce. I’d say to my husband “Okay stir the pot I’m going upstairs to be sick” and then later “Okay, I’m coming back down again.” And he’d say “You’re nuts you’re nuts!” And I’d say “Don’t tell me I’m crazy! You married me nuts and now I have cancer but I’m not crazy!” And so I’d go and do that. And I’d go ahead and collapse afterward. I’d say to myself “Okay I’ve done this and now I’m going to collapse.” They knew that was part of my driving force to keep going.”

This excerpt makes no mention of what if any effect her actions had on her daughter. She spoke only of her husband’s reaction. I noticed that mothers did not as a rule ask their daughters about their experience with any aspect of breast cancer so I was not surprised that this mother did not speak about her daughter here.

In general, daughters made an effort to continue on with their lives as best they
could. They talked about carrying on largely as a way they could help their mothers as opposed to helping themselves. For example, one daughter told me that she just in general tried to “be less of a bad ass” and “carry on with my life” to help out. Another daughter had this to say about her efforts. Her efforts include continuing with her life, maintaining a positive attitude, and watching out for her mom – something she does now and has done for some time.

I see when she’s getting really stressed. She gets flustered and moves around a lot. I try to stop her crying before I do. And I just try to keep a low profile to make it easier for her. I try to manage my own affairs. And just carry on. I try to be a cheerful and optimistic person.

The watchfulness of another daughter was also directed to monitoring her mother’s current stress levels. If she saw her mother was overly stressed she would try to calm her mother down by talking to her in a very calm and reasonable manner. Watchfulness might also mean that a daughter would demonstrate limited enthusiasm for her mother’s participation in a fundraising run because she worried that her mother would overdo and collapse. Examples of daughters being watchful of their mothers, such as maintaining positive attitudes and looking after themselves, may not have been readily appreciated by mothers. For the most part, daughters talked about these aspects of carrying on in our individual interviews. I did not learn as much about their efforts from their mothers.

Watchfulness on the part of mothers was a topic of conversation in the joint interviews. Here watchfulness was both unrecognized and actively unappreciated. In the joint interviews some mothers mentioned that they had told their daughters’ teachers to keep an eye out for them in view of the illness. One daughter was surprised to hear of
this. Two others did know about it, and expressed their disapproval and distress about their teachers being told but I learned about their reactions in private interviews. Their concerns were about having their privacy violated. In the first excerpt, a daughter speaks about her strong reaction to the way her teacher handled the information.

D: When your mother gets breast cancer everything is totally changed. You just feel totally different from everybody else. When it was going on I didn’t want to talk to anybody about it. Cuz I was just finding a way to fit in. And my teacher one time she brought it up. I was just really bad or something one day in class and my teacher brought it up that my mom was sick in front of the whole class. And I got so mad. Like all my close friends knew but ... I lashed out at her.

DM: That was a violation of your personal-

D: Of my privacy! My mom told her. I didn’t want her to, but my mom told her just in case I was acting generally weird or whatever. And then for her to bring it up in the middle of class in front of twenty-five people – some of which I wasn’t really close to. And just to bring it up like that. And it’ll go round at lunch, that’ll be the first thing they are going to say. ‘Oh ya so-and so’s mom is sick. You know. Like…. That was not right.

DM: Why did she do that, what was the point do you think?

D: I don’t know. I think I was not doing good in something, or slacking off – cuz I didn’t care anymore. I just got to the point like ‘My mom’s sick. She might not be around. What does this stuff matter anymore?’ Like what the hell! And she said something like ‘You should be trying harder. Your mom’s sick.’ type thing.

DM: She was telling you to try harder because your mom was sick.

D: Ya. That it would upset her. That I wasn’t doing good. She said that in front of the whole class. Like I can understand her pulling me to the side if she really wanted to say it, but not in front of the class.

DM: It was a way of getting you to perform.

D: Ya and I didn’t. I just studied more. I was like ‘Screw you’. That was a violation of everything.
This daughter had some advice for teachers. She went on to add that there are
limitations to what teachers know. “There are limitations to what teachers can say to you.
Teachers should know their limitations. And if they do say anything to you, it can affect
how the student feels in their class – how comfortable they are and if they are actually
going to do anything.” This excerpt is similar to the next excerpt in that the next daughter
was also upset with her mom for telling the teacher. She too felt that her privacy had
been violated, however she eventually realized some benefit.

I don’t really think I wanted to talk about it. I remember getting mad at my mom
for telling my teacher that she had breast cancer. I just couldn’t understand why
she’d want to tell people. Like why would anyone care? That’s one thing. And why
would she want them to know? Cuz it’s kinda none of their business really. I
couldn’t understand – and it was people in my life, not necessarily hers. But I guess
I eventually realized that it wasn’t such a big deal. It wasn’t such a thing that
people would necessarily think differently of me because of it. I guess I thought if
I’d tell them my mother had breast cancer they would think I was fishing for
sympathy. They probably wouldn’t think that.

This example suggests this daughter realized a benefit, that of discovering that
people were more charitable than she had thought. By asking other people to watch over
their daughters, whether teachers or friends, mothers hoped to gauge the effects of cancer
on their daughters. Mothers were concerned that they be aware of any evidence that the
cancer distressed their daughters but, as these two examples illustrate, their actions had
negative or positive effects on their daughters. One of the reasons that mothers were
watchful of their daughters was that there was very little discussion between mother and
daughter as to how the daughter was faring. One mother described how she had on a
couple of occasions said to her daughter something like “Are you okay?” but her
daughter had very little to say in reply. Not wanting to upset their daughters, mothers waited for daughters to raise any concerns or questions and preferred to see them carry on with their teenage life.

The drawing of one daughter illustrates the difficulty mothers may have is assessing whether or not their daughters are experiencing upset (see Appendix B, Figure 7). This daughter maintained a positive, rather matter-of-fact attitude when discussing breast cancer in the joint interviews. In our private interviews I learned more about her self-presentation style. She told me how she dealt with threatening situations, how adopting an unfazed posture was a protection—"Inside I’m not like that at all." The drawing portrays elements of threat along with other pleasant aspects. A large, gray cloud stretches across the sky, partly covering the sun. Two flowers provide a bright spot, and the grass is green, but these flowers are perched on a cliff. The cliff drops off to a body of water and the peaks on the waves resemble shark fins. Like the daughter who drew the maze, this daughter had relatively little to say about her drawing. I asked her what she noticed. "Lots of different colours. Dark clouds but it’s still nice. Different colours in the birds are different changes, different thoughts. Just thoughts. Yes, that’s chop on the waves. It’s kind of peaceful though, still nice."

The reticence of this daughter in elaborating on different colours, different changes, and different thoughts mirrored a pattern in our interviews. My experience of her was that she was a rather talkative person on certain topics, such as school life. However she was somewhat reticent to talk about breast cancer, at least about her
experience. In describing the drawing, she was characteristically matter-of-fact, and emphasized that it was “still nice.” I respect her comments as an accurate reflection of efforts, variously realized, to see the positive in her situation. At the same time I also respect my own appreciation of threat in this drawing. At two earlier points in our conversations she referred to very grim situations as being dark gray. This girl’s description of her drawing and her self-presentation style are illustrative of the private aspects of daughters’ experience insofar as undercurrents of concern are not often readily apparent to others.

In summary, daughters as well as mothers chose to keep on with their lives as best they could for their own benefit and for the benefit of the other person. Mothers were intent on maintaining a relatively normal family life. Mothers were watchful of their daughters and sometimes enlisted the help of others to alert them to any indication that their daughters were not coping. Daughters were sometimes unaware of this monitoring, and in cases where they were aware they were sometimes very unhappy that their mothers had taken this action. Daughters were similarly watchful of their mothers and did what they could best to reduce their mothers’ stress by carrying on with their own affairs. Descriptions of carrying on were drawn from the individual interviews because very little was said about individual efforts in the presence of the other half of the mother-daughter dyad. With each other, attitudes of optimism helped maintain a sense of normalcy.
Contouring Conversations

Conversations between mothers and daughters on the experience of breast cancer were sparse. Those described in Diagnosis Experience tended to be brief and information focused. This subtheme begins by returning to the time of diagnosis and treatment as mothers and daughters reflect on what was said, what was not said, and why. Participants described and demonstrated in their conversations with me how conversations about the experience of breast cancer were co-constructed. Conversations were constructed to control anxieties about the diagnosis, prognosis and the possibility of death.

In a previous excerpt with Heather and Brandy, the struggle over what could be said and what could be heard revolved around fears of recurrence. It is a fear this mother carries but a fear her daughter cannot hear about because it is too much pressure for her. This excerpt with Heather and Brandy is on the issue of what can and cannot be said but from a different angle, the assumptions behind what is said or not said. We are reviewing the group feedback letter and are looking over a sentence on the limited conversation between mothers and daughters. The excerpt is fairly lengthy because it is only at the end that Brandy reveals that she has been judging and reacting to her mother’s intentions and discovers she may have been operating under some misapprehension. Brandy’s tone is quite angry until she sees her mother is close to tears. At this point she apologizes to her mother, hugs her and takes a conciliatory tone.

DM: I think if you asked mothers as a whole they would say ‘Oh yes I’ve told them everything. I decided it was important to tell them and I’ve told them. But
B: They don’t actually tell you anything.

DM: the actual content of what the telling is is a puzzle. It seems to be a puzzle to

H: Yes.

DM: Mothers are trying to do an excellent job of this, trying to balance their own fears and how they think the child can and will hear it.

B: Ya but the thing is that the parents decide what the kids can cope with and they don’t actually know.

DM: Ya. How can the parents become better informed? They can start with an assumption that it’s better to tell? That’s something you said earlier.

B. Ya pretty much. And they could just be honest because most people can handle, like if something bad happens they can handle it a lot more than they can if it’s just everyday stuff. They’re stronger than most people think they are. .... The most important thing to me is honesty. Because if you don’t have honesty you don’t have trust, and if you don’t have trust you don’t have anything.

H: …(tearing) I thought I was doing the best thing for you cuz you were only in grade seven. And why should you be worrying about something that might not even be there and more than likely wasn’t? (Brandy goes over to her mother to comfort her)

B: I know. But you told me before when I was worried about you (referring to an earlier doctor’s visit).

H: Ya but that’s when I wasn’t actually going through it. It’s one thing to go the doctor about something and think ‘Oh my God. This could be really bad.’ And then he finds something somewhere else and he’s worried about it. ....And all I was getting was reassurance that it was going to be fine.

B: Yes but what did you learn from uncle Greg? You can’t always trust doctors. ... Usually if you’re sick you would know. Don’t you feel that?

H: You don’t feel anything with cancer.

B: No. Like subconsciously or semi-subconsciously?

H: Sometimes. Not always. And you don’t know for sure until you’re told.
This conversation is a good illustration of the dilemma mothers face in knowing what to say and when to say it. It captures mothers’ concerns and hesitancy considering the young age of their daughters. It also captures a general feeling among daughters that it was best to be told everything because kids can handle more than their parents sometimes think they can. As another daughter put it, “Like even if she said that ‘Oh I didn’t want you to know. It’d get you upset.’ That’s an excuse I wouldn’t take.” Brandy’s anger with her mother seemed to be in part the result of a misapprehension about her mother’s ability to inform her. She looked quite surprised when her mother told her that you don’t feel anything and you don’t always know about the cancer. Many women do say that they somehow knew intuitively that they had cancer. Brandy may well have assumed that her mother had foreknowledge and had chosen not to share this with her.

The next excerpt with Jessica and Angela revisits the dilemma of telling or not telling. Jessica is talking about another mother’s situation and her position as a support person for someone who has just been diagnosed. She has some misgivings about how she had handled the business of telling her daughter about the diagnosis and describes the stress for herself and for other mothers at that time.

J: Sometimes it’s funny, like we were saying about how much to tell and how much not and what good will come of saying more. Sometimes that’s stressful. Stressful not to say and stressful thinking about not saying. Today one of my women called me because she was just thirty-six with two young kids. See nobody told them, the doctor or the husband, that it’s okay to feel rotten and you’re not going crazy. Her big thing is ‘What do I tell the kids?’

A: How old are her kids?
J: Nine and eleven.

A: Oh so someone almost my age then, twelve.

J: No. No. Well, a little younger. So she’s stressed. She’s stressed. She’s stressed. So is it more stressful to tell them or keep it from them? It’s so hard.

A: I say tell them!

J: Well I can’t advise her what to do. I can just tell her what I did and let her sort it through. But it always keeps reminding me maybe I should have said more. I know I’ve said this before to someone that sometimes I wish I’d said more and talked more when they’ve asked “How did you tell your daughter?” or ‘What did you tell your daughter?” But then it’s really hard to know. If you tell them a lot is that gonna scare the heck out of them? There’s no guidelines or anyone to give you any advice on it so you’re kind of at a loss. And when you’re at the oncologist you’re too busy with the medical thing. You don’t even think to ask them about that.

In this excerpt I noticed that Angela had said the children should be told. Whether she was responding to her mother’s stress or giving advice based on her own experience is not clear. I suspect it was more of the latter given her body language. I noticed that Jessica did not ask her daughter for her opinion on how it was for her, but went on to talk about the fear of scaring children by saying too much. She did not specify what the ‘too much’ entailed but I wondered if she was talking around the seriousness of the illness, an illness that is life threatening. The next excerpt deals quite directly with the subject of death.

In this conversation with Cindy and Kate, Cindy raises the issue of silence around death. Death and dying as possibilities were something I heard about mostly in private conversations so this exchange is unique. We are reviewing the group feedback letter and Cindy begins by commenting on the portion that said there seemed to have been little
conversation between mothers and daughters about the experience of breast cancer. They are talking about a shared assumption that death is a topic of conversation that is out of bounds.

C: I think it was interesting that for the most part there wasn’t a lot of conversation. They were both aware of it and protective but really didn’t get into discussing it?

DM: Ya. That’s right. And it’s going to be a bit of a challenge knowing what to make of silence. But I think the uncertainties, I’ve used a gentle term here, of losing your mom and the fear of dying are there and it’s very frightening.

C: That’s the big question. When you first find out, that’s the first thing that crosses your mind. And when you tell your family they may not say it – but it’s the first thing on their minds too.

DM: Is that true?

K: Yes. Like ‘Are you gonna die mom?’

C: And that’s your first thought too ‘Am I gonna die?’ I think probably little little kids might say it. But I think it’s the obvious thing and people tend not to ask.

Cindy’s interpretation of the word uncertainties in the letter, and her comments on why there may be little conversation between mother and daughter focused on the possibility of death. My impression is that she is correct that anxieties about death are a large part of the negative space in conversation. For the most part, mothers spoke about their fears about dying in our private conversations. And as Jessica said, “You don’t want to scare the heck out of them.” Only one other mother, Diane, checked with her daughter to see if she had thought about mom dying when we discussed the uncertainty portion of the letter. Like Kate, Chloe had little to say except “Yes.” Like Cindy, Diane did not say anything further on the subject.
It is worth noting here that Cindy and Kate had engaged in an experiential way of dealing with the possibility of death very early on. After her own treatment was completed, Cindy took Kate to visit a friend who was dying from metastatic breast cancer. She wanted her daughter to meet this friend because “she was special – very nice, an open and honest person who had the courage to die when it was her time”. Cindy thought it would help Kate to see the end was not so horrific as you might imagine. Kate would have an opportunity to meet this woman’s son, just a few years older than Kate, and see how his life would go on even though his mother’s would not. Resources were in place. Kate said that she thought that it would be scary but in fact it turned out great. She found that all of the women there visiting were so positive and that the woman herself was so friendly. Kate came away from the encounter feeling calm and more at peace with the fact that death was a part of life. Cindy considered that the situation was perhaps unique because the opportunity has just presented itself. She had this to add.

If I didn’t want to face it I certainly wouldn’t want to share it with a daughter or anybody else. If I just hadn’t come to grips with it or didn’t want to know any more myself I don’t think I’d be as likely to want to deal with it.

A brief excerpt from a conversation with Barbara and Sarah touches on the subject of things said and not said. Sarah explains how a daughter might, acting with best intentions, limit what she says. Her mother has little to add beyond agreeing with my impression that interpersonal sensitivities are a factor in silence on some issues. Again we have been reviewing the group feedback letter and have been talking about the limited conversations between mothers and daughters.
S: Well I think, regarding that general observation, that girls being more sensitive to their mothers, girls more often than not just likely to stay quiet and just kind of support their mothers and not ask too many questions. I agree with that (part of the letter). They tend to tiptoe around the subject cuz you’re afraid to upset cuz you don’t know what you can say and what you can’t say. Especially when you are so young. So you just kind of don’t say anything.

DM: Yes. I think it’s kind of an interesting situation that I’m looking at where people have things they might want to say and might want to ask and there’s a sensing going on.

S: Ya

DM: and sometimes it seems it’s almost at cross-purposes.

B: Yes.

The point Sarah raises about the silence of daughters was raised in a slightly different vein at a conference attended by another mother. At this conference a sixteen-year-old daughter spoke about her own experience when her mother developed breast cancer (Tennant, 1999). She found this daughter’s presentation very moving, as did others in the audience, in large part because it was so unusual to hear a daughter speak. It was good to hear this daughter speak from her own experience but it was also hard to hear.

M: I think it was really difficult for all these mothers in the audience to hear about this. Because probably a good number of them had daughters. And it brought it all back –and oh man, things are so similar and ‘I wonder what my daughter is feeling?’ Or, ‘We never really talked about it.’ or ‘I don’t really know what my daughter thinks about this.’ But I think it was important to know that they’re struggling too. She talked a lot about her not really having anyone that was going through the same things. How her friends avoided asking her, talking to her about it. About not really having anyone to talk to. How there was a period where she found out who her real friends were. Because I think it was an issue that kids just
didn’t know how to approach her. And then also the feeling of helplessness in terms of seeing her mom go through some of the things she did like chemo. And not knowing what to do to help her out or doing what she thought she could but kind of doing things alone a little bit as a daughter though there were other family members there. And then she did talk too about doing more in the family, a little bit like a mother.

DM: You said earlier that so many women were crying. What was that about?

M: I think all the women were crying. I don’t know what that was about. (starts to cry) I think...some of it was... again I think as a mom you’re always wanting to protect your kids. You don’t want them to be going through things that are difficult. And she spoke well, really composed and really strong, but just knowing that what she talked about was simple but knowing there’s all these other kids out there that are in the same place as she was and isn’t it awful that it has to happen in the middle of her teenage life. I can’t speak for the other women but it’s one thing they have totally no control over how this affected them. And I don’t know why it’s more so with girls than it is with boys.

DM: Is that maybe something about shared biology?

M: I don’t know. Maybe it’s about women sharing more with their daughters. ... Afterwards people crowded around her to thank her. And they talked about it a lot. So obviously there is some need there. I don’t think it was that she said anything really new or different, I think it was the fact she got up there and said it. Maybe a lot of women have never heard their daughters tell them what it’s like for them. ... When I think of it, I think I’m not saying anything to protect her and she’s probably not saying anything to protect me.

The difficulty mothers may have in talking with their daughters about breast cancer is partly a difficulty of hearing what their daughters might say. And, as this mother pointed out, the contours of silence between mothers and daughters are there for protection and are based on good intentions. In following excerpt I hear more about the negative space in conversations, the space that contains that which is not said. This mother spoke of contouring conversations with her daughter like she does with her
doctor. With her oncologist she was “on a strictly need to know basis”. He was not to tell her anything unless she absolutely had to hear it. She is reticent to talk with her daughter about risk.

DM: You made a comment about the high rates of cancer in daughters whose mothers have had breast cancer. How do you think about your daughter’s risk? Or do you think about it?

M: I am really fearful of that. ... I just never would want her to go through it. And until you have two – like you get cancer and you have a recurrence or another site or another type of cancer they won’t do genetic testing. So, not that I’d want her to be frightened her whole life, but I’d like to sort of know for her that they could really monitor her very very closely. ... You don’t want to paralyze a person with fear.

This mother worries about her daughter but hesitates to say anything lest she create some longstanding fears. In the next excerpt, another mother talks about the fear that she might die and how she has handled that with her daughter. First she tells me about the openness between them. Later she talks about how she has contoured their conversations away from the possibility of her dying. We are reviewing her individual feedback letter.

M: The first thing that popped out is how my daughter and I have been talking is probably specific to mothers and daughters who try to deal honestly. What we have to say might not work at all where the mother is trying to sugar coat everything or not to get into the depths of the disease. ..... I think you got the big question that I had “How much do I say?” ... You don’t know how much to pass on.

DM: One thing that struck me as a possibility might be to ask daughters “How much do you want to know?” Maybe in a general way and maybe also more specifically. That’s one thing I haven’t heard from women. I’ve heard a lot of puzzlement about what they might or should have said but no one seems to have raised the possibility that you could ask the other person.

M: Right. No I never thought to ask her ‘How much do you want to know about this?’
DM: How does that strike you as a strategy just off the top of your head?

M: I think it’s a really good idea. I think the daughter would have to be really mature herself to know how much she wanted to know. I think the main question the daughter would have right away is ‘Are you going to die’? And unless you’ve been diagnosed so late in the disease that you know you are going to die fairly soon it’s unanswerable.

DM: Did your daughter ever ask you if you were going to die?

M: I don’t remember … because I probably would not have given her the chance. I probably would have told her it’s going to be pretty awful for a while with the treatments but that the treatments are really good and that a lot of women do really well.

DM: It’s hard.

M: Ya cuz you know that’s the question that’s gonna pop up first.

DM: … If she did ask you, what would you say?

M: … I probably would have said that there was a possibility (now speaking in a very upbeat tone) but that I would do everything available so that it wouldn’t happen. And then when they give you your survival rates you can say ‘Ya, they’re really good!’

In this conversation I was struck with the contrast between the openness I had seen between this mother and daughter, the openness both had described, and what she was saying here about blocking questions around death. Were her daughter to ask her about the possibility of dying, this mother would acknowledge the possibility but would stress how good her chances were. With another mother, uncertainty raised by recurrence in a social network provides an example of how conversations are co-constructed to soften concerns. We have been talking about risk.

DM: Did your daughter ever ask you about the possibility of dying from this?
M: No. She was so young ... and I never seemed to stop doing everything I did. She was never aware so that question was never addressed.

DM: So she’s never really said anything.

M: Oh she has.... She knows that people can die from cancer. She hasn’t come out and said “Are you going to die?”

DM: What will she say?

M: “Do you think you’re okay mom?” And in that way I think she’s asking “Is it going to come back?”

DM: And what do you say?

M: I say “I don’t know for sure.” I can’t say anything better because I don’t know for sure. But I tell her I’m very careful with my health.

DM: I could have and maybe should have asked you not just about the possibility of dying but about the uncertainty itself.

M: I’d like to wait until she asks. I would never bring that up unless she wanted to discuss it.... In my group of friends they didn’t know how to deal with it, and it scared them. She is aware of recurrences in support groups. With one woman, I told her that this woman was at a high risk of recurrence.

This excerpt is a good illustration of how conversations may be contoured for mutual comfort. The daughter is said to have asked her mother about the risk of dying in an indirect way. The mother is honest with her daughter, but at the same time she plans to keep quiet until she is asked. As she notes, the uncertainty of breast cancer is a scary subject and she does her best to soften the impact of recurrences her daughter knows about.

I will close this subtheme with three excerpts from a conversation with a daughter to illustrate the contouring of conversation from a daughter’s point of view. The first
excerpt speaks to the value she found in the way her mother spoke to her about
uncertainty. She passes on some of what she found was helpful.

It seems like parents usually say it's gonna be okay. But with my mom, she didn't
necessarily say it's going to be okay. She said 'It's probably gonna be okay but
there's no guarantees'. And so she really prepared me for if it wasn't gonna be
okay. Which I think is good because if your mom says 'I'm gonna be okay' and
then she isn't it's so much harder. Like why did you tell me it was gonna be okay? I
can see some parents not knowing how to tell their kids, especially when they are
as young as I was. They don't want to say 'I'm not gonna be okay.' They just want
their kids to be feeling good about it, so "Oh don't worry I'm gonna be okay."

In the next excerpt I had asked her if there were things she did not talk about with
her mother.

I didn't ask my mom that many questions cuz she told me a lot. And I didn't even
know what to ask. I didn't understand much about it. I didn't ask her certain things,
not the general things, but things specific to my family. Like I thought about them.
What are my risks now? How much have they gone up? But I didn't ask her
anything like that. I'd ask her about her surgery. Just like little things that don't
matter at the time. Like they do matter but ... it's hard to explain.

Later in the conversation I asked her if she had ever spoken with health care
professionals when her mother was sick. I wondered if, given there were some questions
she would not raise with her mother, she might have spoken with knowledgeable others.
She tells me no and she tells me why.

No I really didn't have that much contact with the nurses at the hospital. I wouldn't
talk with nurses and people at the hospital cuz I'm not the one who's sick. The
nurses are so busy. It might be good to have someone in the community, a
volunteer who would come to the hospital. But it didn't bother me. They talked to
my dad. Doctors don't want to waste their time. And it's hard for them to talk to
kids because like they think we wouldn't understand. And I understood that.

In these several examples I learned that participants were contouring conversations
probably most often in response to the uncertainties of breast cancer. Sidestepping the possibility of death, conversations might be cut short or be directed towards the possibility of positive outcomes. Participants considered the ability of the other to talk or listen, and spoke or did not speak for the comfort of the other person. Their own ability and sense of freedom to engage with the other person on a sensitive topic also influenced if and how a conversation would happen. Mutual sensitivity and an unspoken understanding of what was and what was not to be discussed influenced the shape of conversations about breast cancer. My impression was that the shape of conversations, including silence, constructed from personal and mutual considerations was not always obvious to the other half of the mother-daughter dyad. What stood out for me was that conversations were constructed with a great deal of care.

Summary of Theme

Participants often spoke about their intentions and actions in response to breast cancer. By carrying on and by contouring their conversations, mothers and daughters attempted to lessen the impact of breast cancer for themselves and for the other person. By carrying on with their work in the family as best they could, mothers could feel comforted that the family would still function and could be encouraged that they themselves would survive their encounter with cancer. By carrying on with school and their own activities, daughters hoped to reduce the stress on their mothers and could be encouraged that things would be normal for them. Mothers and daughters were caring, protective, and watchful of the other person. Both tried to maintain positive, optimistic
attitudes for personal and mutual benefit.

Conversations were contoured in response to the uncertainties of breast cancer, most often to avoid the subjects of risk and death. Uncertainty and mutual sensitivities facilitated an unspoken agreement on the negative space in conversations. Daughters held the opinion that more could be said to children but that adults make assumptions about what children can and cannot hear. Mothers talked about the difficulty in speaking about certain issues. Their ability to hear their daughters also limited conversations. Neither person wanted to upset the other and did not know if, when, or how anything more could be said.

Acquiring Wisdom

One useful definition of wisdom is that wisdom is experience plus reflection. Reflecting on their experience, both inside and outside of this study, participants shared what they had learned as a result of their encounters with breast cancer. In many respects, participants realized what they had gone through and what their experience meant only with time. Realizations acquired over time are presented in the subtheme, Gradual Realizations. A second subtheme, Changed Perspectives, documents the shift in the way participants viewed themselves, others, and life in general as a result of their experience with breast cancer. Material for these two sections was drawn from individual interviews, a space more conducive to sharing personal insights. A third subtheme, Lessons in Living, addresses the question of the teaching and learning of wisdom.
Gradual Realizations

Mothers spoke about gradual realizations in terms of what they had gone through, and the choices they had made which affected both themselves and their daughters. Choices made in the early days of breast cancer were made in a state of emotional chaos. Caught up in the whirlwind of diagnosis and treatment, mothers were overwhelmed by the demands of making decisions about medical treatment and coming to grips with the knowledge that they had cancer. Sharing the news of breast cancer with their daughters was a difficult task, accomplished without any clear set of guidelines or advice on how best to go about it.

In hindsight, some mothers had moments of second-guessing themselves and their doctors on the treatment they had chosen or been offered. For example, in comparing themselves to others who had had different treatments and had different outcomes they might wonder what choices were best. However, the basic uncertainties of a disease like breast cancer brought home a realization that no medical decision could ensure a cure. Receiving a diagnosis of breast cancer meant entering a landscape of continuing uncertainty. Years after diagnosis and treatment mothers realized the emotional burden of that uncertainty and that they really didn’t take care of themselves emotionally. As one mother put it, “I didn’t anticipate how I would feel. How I would be doing. I thought as soon as the treatment was finished that I’d be fine.”

With respect to how they had handled the experience of breast cancer with their daughters, some mothers wondered whether they might have done things differently.
Mothers felt that they had done their best given the circumstances, but also realized they perhaps could have done some things differently. Concerning the amount of information that she shared with her daughter and the nature of her daughter's experience this mother reflected on her daughter's position. She compared her needs and the needs of her daughter.

Not knowing all the possibilities, good or bad, is worse. And why shouldn't that be the same thing for the kids? As mothers you always want to protect, therefore – does that mean not telling, not saying, not discussing, not talking? I think for me I always thought so. ... I didn’t realize that she had needed - I thought she understood the basics of what was going on. She said not initially, that only as time went on . . . She had no one to talk to. She really didn’t. Nobody talked to her about “How are you doing?” or “Ya, I went through the same thing.” because she was a teenager. I don’t think any of her friends talked to her.

This mother had come to a realization that her own needs and the needs of her daughter may have been more similar than she had initially thought. She recognized that knowing all there was to know, good or bad, and having a support network where she could share her feelings was important to her and would probably have been helpful for her daughter as well. Another mother had a similar insight into what and what had not happened between her and her daughter. She recognized now that although she had been very open in sharing her feelings with her daughter, she really had not heard how her daughter was feeling. This insight came as a result of our study together.

I’m thinking just what came out of our discussions, some of the things you asked me. Like how she felt about me having breast cancer. That question really really shocked me. I never even asked her! Like how do you feel? ... I was thinking like about the chance of recurrence. When she gets older she’ll have to have mammograms because it could be hereditary if I get cancer again and then she’d have to get gene tested and all that sort of thing. But I never really asked, “How do
you feel about me having breast cancer?” I guess it was intuitive, like just the way she looked at me. But that was just what I interpreted. I never really sat down and considered her feelings on it. ... I think too that’s part of our survival, that we’re taking care of ourselves. So we want to be in control and get information and pass on information as opposed to worry about how you’re feeling. Because I’m having a hard enough time dealing with what I’m feeling. So it’s a survival technique, I’d say.

In this example, a mother came to a realization that she was focusing more on the medical implications of her cancer and had not fully explored the emotional implications for her daughter. Considering her daughter’s feelings, aside from asking her about them, would be too much. Fighting for survival, needing to focus on information, and dealing with her own feelings was about all that she could manage. After this excerpt she said that she was grateful for the insight because “I don’t feel that I wasn’t doing a good job. I just feel that that was a big piece I left out, that I could cover.” Overall, mothers had some regrets about how they had dealt with their cancer either personally or with their daughters. Daughters also spoke about regret.

In the following conversation a daughter talks about coming to a gradual realization of the seriousness of her mother’s illness. Part of her realization concerns the potential for regret.

D: I’m a lot more aware of breast cancer now, the dangers, and like my risks. It was good though because it opened my eyes. You know how teenagers think they’re invincible. Well I thought that way about my whole family. We were always healthy. My parents don’t smoke, don’t drink a lot, and try to eat well. So like I don’t have to worry about that. When my mom got cancer it was like wow I guess I do have to worry about that. Like what was I thinking? I think I’m lucky that my mom made it. If she didn’t make it I’d have so many regrets.

DM: Like what would you regret?
D: Just like not spending much time with her. Almost taking her for granted.

This daughter had, like some other daughters, initially kept her distance from her mother's experience. For her, the potential for regret was something encountered much later. Daughters had learned of their mothers' illness in varying degrees of detail, and were variously prepared to hear about or to become involved in their mothers' experience. Daughters often said they had not really realized what the illness was all about, but only over time came to understand more about it. They spoke of their limited understanding, and of their reactions based on what they were told and what they gathered over time. Years after their mothers' diagnosis and treatment, most daughters looked back on their behavior with a degree of self-criticism or guilt, partly because they had not realized what was really at stake for their mothers and for themselves. In this excerpt a daughter reflects on her understanding then and now. Over time she has gained an awareness of the seriousness of the illness.

D: I remember that after we dropped my mom off at the hospital I asked my dad. I knew that she was going in for cancer but I didn’t even know what kind of cancer. I asked him if it was skin cancer and he said no it was breast cancer. ... I almost ignored it. I remember at school I was kind of thinking she was going in for surgery at this point, but kind of the whole time I just assumed it would be okay. And I didn’t think there would be a problem. I don’t know, because if there had been I wouldn’t have been ready for it at all. But I just kind of assumed that it wasn’t a big deal. That she would just get the little tumour removed and then she would be okay. I don’t know why but it never dawned on me to be worried about it. This is just simple. She’ll just get this done. She might be sick with the chemo but then it’s done.

DM: I think I heard you say that you wished you had known more. Is that right?

D: Ya. Maybe it was good that I wasn’t worrying too much about it, but I didn’t
really understand how serious it was. I just assumed that nothing would happen to my mom and everything would be fine. I think I would have liked to know more exactly what was happening with my mom. Kind of exactly what was going on. Why she was going for chemo and what the chemo was doing. I didn’t really understand. Maybe before the surgery too, cuz I knew like nothing before the surgery.

DM: So it sort of kind of came out of the blue. And then she had the surgery and you thought that was the end of it and then stuff came later.... And you’re thinking now it might have been nicer to know a little bit more about it - though knowing more about it might have made you aware that it was more serious than you thought then?

D: Ya. Looking back I almost feel kind of guilty for not being worried. I was more self-centered, worrying about school. I didn’t realize how serious it was.

This daughter’s comments echo the sense of guilt some daughters felt looking back on their reactions to their mothers getting breast cancer. One daughter spoke of feeling guilty for being mad. Her anger she said was due in part to a feeling of being caught off guard by her mother’s illness and, as with this daughter, not really understanding what was going on. She described her experience then as a feeling of being “pretty much in the dark.” In the previous excerpt, a daughter has been looking back. She has been thinking about what she knew, and about how she reacted based on the knowledge she had then. I was interested to learn what if any curiosities or needs she had now.

DM: You’ve told me about what it was like when your mom diagnosed, and then how she went for treatments. And that you really didn’t understand what was going on. Do you have any curiosities or needs now?

D: Maybe just kind of to know what or how everything was from her perspective at the time. And how much I actually was told, and how much I really like registered. And maybe the principles. Why was I told something and wasn’t told something.

DM: So another perspective on what was said and what wasn’t said and why.
D: Ya.

DM: Why do you think that might be helpful to you?

D: I don’t know. I think I’d like to know, like it’s kind of in the past, but I’d like to kind of know everything and put it in the past.

This excerpt illustrates a need for better understanding of past events and the value of that understanding for the present. For this daughter, it would be valuable now to understand her mother’s perspective on past events, because a better understanding would provide a degree of closure. During the course of this study, another daughter was able to achieve a better understanding of her mother’s experience because she was able to read her mother’s diary. In years past, her mother had shared some of what she had written, but for this daughter it was still valuable to revisit the early days of experience with breast cancer through her mother’s eyes. Reading her mother’s diary now gave a better appreciation for what her mother had gone through, which she said was helpful.

Reflecting now on what she knew in the early days of her mother’s cancer experience, she also realized how it was she came to be angry then. Like other daughters, her understanding of the scope of the cancer experience was very limited. From her perspective, there was no rhyme or reason to her situation because she expected the cancer to be over and done with after the surgery. Years later she realized why the attention she was used to getting did not return. Years later she also recognized that “mom’s emotional scars took a lot longer to heal.”

The drawing of one daughter presents a symbolic representation of the long-term
presence of breast cancer in her life, one that she describes as representing a gradually acquired appreciation of her mother’s experience (see Appendix B, Figure 8). She drew a daffodil. I asked her to say something about her drawing, maybe including the feeling she got from it.

I don’t know when I got started drawing daffodils. It’s the breast cancer flower. I always seem to draw them – not just for cancer, for anything. I’ve done art projects with them as well over the years. Whether it was related to breast cancer or not, I don’t know. In the center that’s pink because that’s the breast cancer colour. The feeling? Not really sad but just kind of sorry for my mom and what she went through. Realizing how hard it must have been. I guess about the yellow, she did become a stronger person because of it but I’m mostly sad that it had to happen.

Elsewhere in our conversations this daughter had described how her feelings of empathy for her mom had grown. It took time for her to appreciate the seriousness of her mother’s illness, an appreciation gained in part by seeing how many women die from the disease. As she matured she was better able to appreciate her mother’s position and her own as a young girl.

Together the voices of daughters provide one answer to the dilemma mothers face in knowing how much to say. From the perspective of these daughters, it might be helpful to know more. More might mean more details on treatments and the sequelae of those treatments. More might mean having a better understanding of the nature of change encountered, that is, that this was not perhaps a short-term, limited encounter with illness. More might mean having a better understanding of a mother’s experience from a mother’s perspective.

Over time, mothers and daughters came to realize that breast cancer would have a
long-term impact on their lives. Looking back on their experience, both expressed the view that they perhaps had a rather simplistic notion of what breast cancer would mean. Information given and received was perhaps not adequate. Treatment did not necessarily mean that the breast cancer was over and could be forgotten. The emotional aspects of breast cancer experience were far reaching. Not fully realizing the stress and chronicity of breast cancer, most mothers now recognized with some regret that they had given scant attention to their emotional experience. Some mothers also reflected that they had not appreciated how their daughters might have felt, recognizing now that there had been no venue for daughters to talk about what the experience was like for them. Daughters’ needs may have been more similar to their own then they had realized. Not fully realizing the seriousness and chronicity of the illness, or in one case not being able to handle the news, most daughters now recognized that they had understood little and looked back on their actions with some degree of self-criticism, guilt, or regret. A better understanding would have been helpful then, and could be helpful years after breast cancer first touched their lives.

Changed Perspectives

Both mothers and daughters talked about how their perspectives on life had changed as a consequence of the breast cancer experience. Mothers and daughters now saw what was important in life and what was not. Changed perspectives influenced attitudes, actions, and relationships.

In the following excerpt a mother talks about the change in her perspective in all
three areas.

About my controlling nature - I’m better than I used to be. And I think it’s because of the fact that I was diagnosed with breast cancer and I started realizing that - it sounds really typical of what somebody would say, but it puts things in perspective. And so I think I started realizing - I did spend a lot of time with my kids before I was diagnosed. It wasn’t as if I didn’t. But then I think I started realizing that here were certain things that were really important to me, more so than I thought. So in the last few years I have been trying a lot more not to let little things get in the way of our relationship. ... I don’t work more than I want to. And I don’t feel pressure to. And I think that’s another thing that’s probably changed with me is I don’t feel guilty about saying no. I don’t feel guilty as much anymore about not having a full time career.

This mother emphasized the importance of family and the relative unimportance now of work outside the home. For her, a change in perspective provided a newfound sense of freedom from what had seemed important responsibilities. Since having breast cancer her sense of career had shifted more towards family and away from work outside the home. The next mother also talks about a change in perspective about her role in the family, and her sense of self. Again there is a sense of freedom as she abandons the role of fixer and stops trying to change herself to please other people.

Lots of things changed for me. All of a sudden things fell into place - what’s important and what’s not important. I have a perspective on my husband now and I don’t always try to fix things. All the time we were married I was the one who tried to keep things in balance. Now I don’t see that as part of my job description. There are things I can do but I shouldn’t have to change myself. When you have breast cancer you never know how much longer you have. Like you can live until you are ninety. But it’s much nicer to be who you are. And people usually like that, and if they don’t it’s not your role to change for people.

The drawing of one mother illustrated her changed perspective on life (see Appendix B, Figure 9). The drawing portrays an experience of transformation that begins
in the left upper corner, and moves in a curving path to the right lower corner. The drawing illustrates a personal journey with twists and turns. It is a journey that includes her whole family and that centers on a change in how she sees herself, how she views the family and her role in the family, and her new perspective on life. Here is what she had to say about the drawing.

This is the family like before. I was usually the one who was most involved with the kids and he would supervise. And then when I got sick. They are all kind of standing back but they are making a circle around me to kind of protect me. And then afterwards, there’s my one breast. Things go back to normal, just about as quickly as possible I think in any household. And then that’s everything – all the books I read and the tapes and everything else. And life is good. And then there’s me and the kids basically on one level, and dad jumping in or out. Now this is how I feel. Because the kids are older I don’t worry about what would happen if I’m not around. Like they’re all really .. I feel like they’re over the hump. So I’ve taught them most of what they need to know. Like their character. I know they’ll be okay. I don’t get sucked in any more if like their grades are not perfect. Before it was like it was my fault. I don’t do that any more. And then there’s the chance of walking out on your last appointment day and getting hit by a bus (laughing)! You can’t worry about dying cuz even if you’re sick you’ve got way longer than somebody who gets hit by a bus. And so I think you do focus on that for a while. You kind of have to face that first - my friends and I talked a lot about it. And then once you accept it, everything’s okay cuz it’s not as scary.

Prior to this excerpt, this mother talked about how cancer brings you face to face with the reality that this is your life now. “You have to deal with whatever is now. This is your life now.” Living now, and not years down the road according to some plan, was a point raised by the next mother. Like the first mother, she felt that having gone through breast cancer had effected a positive change in her temperament. She also talked about the good she has found in new relationships.

Well it makes you take stock of your life. Hey this is for living. I don’t look down
the road ten years anymore and plan, although that can be done. But I don’t look for that. Now I think I’m much more relaxed. I don’t take things as personally. Going through cancer and getting on with a relatively normal life and coming out the other side, aside from the emotional aspect, that has been a wonderful experience. And I’ve met a lot of great people since the cancer experience.

A changed sense of self, changed perspectives on the value of long range planning, and a new joy in relationships were some of the good things that happened for the next mother. However, there was a sense of separateness too that came with a new friendship network.

The good things. I was very conscious about my hair, so egotistical about my hair. I loved myself bald. And now I keep my hair really really short. And my hair was bone straight and really thin and it came out really nice and thick. ... My husband and I are a lot closer. My mother-in-law and I became really quite close. She did a lot for me and so did my cousin. And I got all these cards from friends and family and people I didn’t even know knew I existed. And in my church they did a lot of praying for me. I have never felt so loved in all my life. ... But with the positive comes I have to live for today. That’s where I find it really hard with other people because my way of thinking is so different now. I don’t have a five-year plan. I don’t. I get up every morning happy that I’m getting up and doing something. I can’t plan the way other people plan. Things that are so important to other people are not important to me. Now I find that I’m starting to relate more to people that have had cancer than to people who haven’t. There’s that intuitiveness that starts to happen. You hardly have to say something and they understand it.

The sense of connection with people who have had encountered breast cancer and the disconnection from people who have not encountered cancer was echoed in many daughters’ comments. Daughters experienced a sense of separateness from friends who, though perhaps willing to listen to them, could not really understand what it meant to have a mother who had breast cancer. Years later, daughters were interested in meeting with other daughters who had had a similar experience. One spoke about wanting to
know if what she went through was normal. Others thought they would be interested in meeting other girls who were going through what they had gone through because they thought maybe they could offer some perspective and advice.

This is how one daughter described her need for connection with similar others.

Her mother’s breast cancer had set her apart from friends and changed her perspective on what was important.

It is just as hard for us as it is for them. We have to see you go through it. And we don’t know what to do. We can’t make you better. We can’t help you. And we are going through a lot of the same feelings – maybe not as deep as you are, but we are going through a lot of the same things. ...Like for daughters, there’s really nothing for us. Like we have parents but we are more inclined to stick to our group. And you can talk to your friends about it but they don’t know what is going on. I think if there was a support group (for daughters) I think people would be inclined to go and talk to one another. It’d be good to talk to other people. Some people wouldn’t want to at first, but when they – like now that I’m older I wouldn’t mind talking to people about it, how I dealt with it and what I was feeling... You have to grow up pretty fast when you find out something like this. I mean you do – it’s automatic. You look at people your own age and you’re like ‘you guys are really immature’. You look at ‘Oooh, what are we doing this weekend?’ and for you it’s not like that any more. It’s changed.

For this daughter, the experience of breast cancer was a maturing influence in the sense that typical teenage concerns seemed now rather trivial. For another daughter, breast cancer experience was a maturing influence in the sense that she felt ready to take on more responsibilities if it became necessary. This daughter had a younger sibling. Both her parents developed cancer around the same time. If her parents died, she had worked out a plan whereby she would delay going to university and would take care of her younger sibling until that person graduated from high school. They would pursue
higher education together. I asked her if that was a shift for her, all that responsibility.  

"Well it wasn't a big jump. Just a natural development. I thought 'I could do that'. It's strange to think it might happen, but if it does I can take care of things."

Another daughter had this to offer on the subject of perspective, what she would be able to share with other teens now and one positive effect of her experience.

D: As I got older I think I understood it more, like I had matured physically and emotionally. I understand more the pain of going through that now. As I said it's like losing part of your self. I just didn't understand it before. I think it's helpful to show other people that you do get through it and you get stronger because of it. It'll change you but it won't be bad. The period in your life when they are going through treatment, it'll pass. It seems like it is never ending but it passes.

DM: Do you feel stronger for having been in this situation do you think?

D: I think a little bit. Like taking things for granted. It'll always be in my mind. I can be a little bit more comfortable knowing that I won't take as many things for granted. I can think of that and realize that we're not invincible. Things can happen. It makes me more secure feeling that things will maybe take me less off guard. You can deal with it better.

DM: Ya. That's something I heard from another daughter. Losing that sense of personal invincibility that's typically associated with adolescents. And she mentioned that for her it was extended to the family as well. And that her sense of invincibility was gone but it wasn't necessarily bad. It sounds as if you had some kind of similar experience as well.

D: Mm Hm. Just knowing that things can happen...you can deal with it better. ... It has given me perspective on life. Losing my sense of immortality early is probably not a bad thing, but it is sad to have to through it so young.

Several daughters talked about the experience of breast cancer as giving them a degree of perspective on life and on daily problems. As one daughter put it, "When I get into like stupid little arguments with my friends I think 'Na, it's not worth it.' Because if
something happens to them I’m just taking it for granted that things are gonna be okay.”

Some daughters described themselves as a kind of helper or counsellor for their peers at school. Their experience with breast cancer had as one daughter put it, helped her to see ‘what was important and what wasn’t.’ Here is how another daughter described it.

D: I try to be positive about everything. I’m kind of, everyone knows me as a kind of cheery, happy, friendly person. And everyone tells me their problems and I kind of deal with it. Kind of because I think I can handle it - like I never real have any problems or crises and all my little problems seem kind of trivial. Because of that, I don’t get worked up over little things. I kind of just let everything slide. It’s really not a big deal in the end. It’s easier for me to step back and take a look at all my little daily problems as something that isn’t really a big deal.

DM: It gives you some perspective?

D: Ya. It allows me to kind of step back and realize all my little problems aren’t really that important.

DM: So that’s maybe one change.

D: Ya. And I think it’s for the better. And then I help everyone put their problems in perspective – like it’s not such a big deal.

As I listened to daughters talk about having a changed perspective on life I was struck by the number of times daughters told me about their inclination to help friends by taking on the role of advisor or helper. It seemed as if having a changed perspective on what was important in life not only removed them from some of the day-to-day concerns of teenage life but might also have encouraged them to be caring of others.

All of the mothers in this study were members of support groups and as such have demonstrated a commitment not only to find support for themselves, but to be supportive to others. Beyond group meetings there is often a buddy system in support groups.
Sometimes friendships develop naturally. Sometimes new women are matched with a woman who is dealing with similar circumstances, such as being a mother of young children. This aspect of mothers' experience speaks of the value of connection and caring in their careers, careers defined as that which we find meaningful and that in which we choose to invest our time and talents. I was surprised to find that all of the daughters are currently considering or pursuing a career in the health care professions.

The health care career choices these daughters spoke about would be novel in three cases in the sense that nobody in their families was connected with health care. For the other two daughters who did have family members in the health care professions, their choices were in different fields of study. Whether or not having a mother who has had been diagnosed with breast cancer has anything to do with an interest in the health care professions is an open question, not answerable in this study. However, one conversation with a daughter who wants very much to be a doctor suggests that it might.

DM: If you visualize yourself in the future as a doctor what are you doing? What kind of practice?

D: I wouldn't do just general practice .. not dealing with head colds and stuff. I would like to work in third world countries for a couple of years just to see what tough times really are like – so I wouldn't take things so much for granted. And I know I do. You just do. I’d like to do hospital work with children.

DM: You’re talking to me about wanting to take a different perspective on life. About the values that you have.

D: Yes.

DM: Is there any kind of history to that, to your thinking now?
DM: I dunno. Like I see people on the street and I think about how much we take for granted. There’s so many things we take for granted.

DM: Like what’s in that bag of ‘things’?

D: I guess like material things. It seems silly, but it’s true like we get attached to a pair of shoes or something. But mostly I think about mom and things. Like I’ve had friends who have lost a parent to cancer and I can imagine they must be thinking ‘Oh I can’t believe I yelled about that one thing. I don’t even know why we had that big fight over it’.

DM: Mmm Hmm. Regret.

D. Ya.

The connection this daughter made in respect of her career was between taking a mother for granted and taking our comfortable lives and our health for granted. In other portions of our conversation, this daughter explained to me how poor people have to struggle for their health whereas we in the West take chances with our health and don’t appreciate how lucky we are.

The fact that all daughters were currently considering career choices in the health care field was one of the items on the group feedback letter that intrigued both mothers and daughters. Daughters looked generally surprised and pleased, perhaps because they had learned of having something in common with other daughters. Mothers were also surprised by this result but their comments sometimes reflected a sense of hesitancy about there being any connection with breast cancer experience. My interpretation of their reactions was that hearing about a commonality among daughters of women who had experienced breast cancer might challenge a mother’s sense having protected her daughter from any long-term implications. We talked about the impossibility of
establishing any causal connections, something this study was not designed to do, but I
sometimes found that daughters saw more of a connection than did their mothers.

Changed perspectives were common with both mothers and daughters in terms of
attitudes, actions, and relationships. Participants spoke of gaining the ability to sort out
what was important in life. Having a new perspective involved a separation from friends
as participants came to recognize the trivial nature of most day-to-day concerns and
interactions and rise above them. Mothers talked about finding new friends, realizing the
goodness in others, and gaining a sense of freedom and self-confidence. Daughters talked
about acting as an adviser or counsellor to current friends and gaining maturity, and
wanting to meet other girls who had gone through a similar experience. Mothers talked
about living for today and about adjusting their priorities regarding work and family life.
Daughters described their plans to build careers in the health care professions. Whether
their experience with breast cancer influenced their plan is uncertain but one daughter
did make a link between her choice and her experience with breast cancer.

Lessons in Living

I wondered what was being taught and what was being learned in the course of
experience with breast cancer? I wondered what was being shared openly, and what
might be learned from observation? To answer these questions I looked first to the joint
interviews to consider what mothers were teaching and what daughters might be learning.
In this excerpt, Cindy and Kate are talking about looking at cancer with a degree of
humour.
C: She (Kate) was sitting at the kitchen counter one day and we all were talking about something - kind of joking about some health thing, and she put her head down on the counter. And radiation causes a lot of discomfort, and I had the heavy prosthesis then, so I had taken it out and just set it on the counter. And she put her head down and said to her dad ‘There’s her breast’. And she said ‘My parents are so sick!’ [Gales of laughter from mother and daughter.]

K: Ya. I dunno. Not that the whole thing was a joke but it kind of was. We could laugh about it really easily. Like make jokes about it – her breasts, her hair falling out. Cuz there’s always laughs.

C: There is cancer humour. When women get together and they all have family stories to tell. Different things. It can be very funny. There was just an article in the paper about a girl who had lost her leg. She was young. She had Ewing’s sarcoma. They were telling some of her jokes. Like how she had one foot in the grave cuz she had a ceremony and buried her leg. And they were shopping and a lady says “Can I give you girls a hand?” And she says “No but I could use a leg [Kate laughs] So there is humour.

DM: There is humour in the group of people who’ve had cancer. And I don’t know how much humour there is in family situations.

K: There is. It made it easier.

My reaction to their conversation was that it reflected lessons taught and learned on handling serious illness with fortitude. In this family, living with breast cancer with a degree of humour made it easier for the daughter and, I gather, for the whole family. From our first meeting I was struck by the qualities of optimism, humour, and strength that this mother and daughter brought to our discussions. Whether or not these qualities were characteristic of family dynamics around problems or challenges in living before the encounter with breast cancer I cannot say with any certainty. However, based on what Cindy shared with me elsewhere my sense is that relying on optimism and humour was part of her personal growth initiated by breast cancer. The next excerpt speaks of
personal growth in a mother characterized by a new attitude towards others and towards herself.

In the following conversation, Sarah listens as Barbara talks about her reactions to the negativity of others now, and of her new self-confidence since developing breast cancer. We have been reviewing the group feedback letter, discussing the separating aspect of breast cancer experience for mothers and for daughters with friends who just don’t understand.

DM: It seems to me it’s almost like entering a similar landscape.

B: Yes.

DM: You hear that once you’ve had breast cancer then things are never really quite the same.

B: No that’s right.

DM: And you feel a very different connection with people. And so in some sense there are ripples of that for the daughters.

B: Yes. I think also I was less tolerant of some of my friends who don’t understand. Once you’ve had cancer I think you are less tolerant of people when they are being snarky, snide, or negative. You think ‘Oh forget that!’ And I’m more likely to speak up in groups etcetera whereas I might not before. Somehow I feel more qualified, or I don’t care about the repercussions perhaps. We went on a holiday to Hawaii. And they had parasailing, and I did it! My family said “You don’t want to do this.” And I said, “I do. I really want to do this!” And of course I’m scared of water. I looked down, couldn’t see my feet and I thought ‘My life is in His hands’. But at the end of it I was glad I did it. And I know I did it because I’d had cancer. And I said to myself “Once you’ve had cancer you can do anything. What’s wrong with that?” And I know that was the motivating factor.

For this mother, the experience of breast cancer freed her from attending to some of the unpleasantries of day-to-day conversations with friends. It gave her the ability to
voice her opinions, and a new sense of confidence. She took a risk with the parasailing, redefining who she was and what she could do. Sarah said nothing, but as a listener was in a position to learn something about what was important in life and what was not, and about the uses of adversity. My impression was that listening to her mother describe how she had found her voice encouraged Sarah to speak up on an issue that was important to her. Recall an earlier excerpt where Sarah told her mother about being overwhelmed with support network activities. She no longer wanted to attend to these things. That excerpt followed the one above. My reaction to these conversations with Cindy and Kate, and with Barbara and Sarah was that these daughters were privy to lessons on fortitude, priorities, and growth in difficult circumstances.

Lessons on balance in life and taking care of oneself were present to some degree in all the mother-daughter dyads after the flurry of carrying on in the early days of diagnosis and treatment. Learning about balance was the subject of a portion of an individual conversation with one mother. Recall the voice of one mother who talked about changing her priorities more to family and away from work outside the home. Here is another excerpt from our conversation that speaks to what this mother hopes to convey to her daughter. She is talking about the importance of balance in life in connection with her daughter’s career choices.

M: It’s not at the top of my priority list, my work. It’s gone down the ladder a little bit. And I don’t feel guilty about that. Whereas I used to feel guilty if I wasn’t taking every course and working full time.

DM: That’s one positive thing that’s come out of this whole experience for you.

M: Yes it has.
DM: That's the balance you were talking about earlier.

M: Yes absolutely. And I think she [her daughter] sees it too. I want her to see that. That it is important for her to find something she loves to do, but. And I've told her about this. ... At the end of the day it's really important that you like what you do and that it's not just drudgery for you. That you enjoy what you're doing, and have some other things that you like to do, not just one thing in your life.

This mother's comments echo an earlier conversation between Cindy and Kate. Cindy was quite open with her daughter Kate on the importance of not getting too focused on school but of having fun as well. Both mothers were trying to teach their daughters something about having a balanced life.

The actions of two other mothers provided lessons by example on speaking out on issues that were important to them, issues connected with breast cancer experience. In the first example, a mother spoke out about an article in a newspaper. The article portrayed the heroic efforts of a woman who was diagnosed with breast cancer who proceeded to carry on with a grinding work schedule throughout her treatment. This mother’s reaction was that it was a horrific article to publish and many other women in her support network had the same reaction. She decided to speak out publicly for the benefit of the many women who could never have done what the woman in the article had done, herself included. This mother was taking action for the benefit of the breast cancer community, and she was also modeling social action for her daughter. Her daughter was aware of mother’s public stance on the issue. Regretfully I cannot provide the text of what she said because that would identify the mother and her daughter. Her
commentary on her actions will illustrate the flavour of what she said.

I’m sorry but I there’s no way I could do what that woman did. And I didn’t want other women to feel they had to get back to work quickly, that there was something wrong with them because – Look! There’s this woman out there who can just carry on like nothing happened! All kinds of people, including people in the workplace could read that article and think about a woman like ‘Well why isn’t she back at work?

What her daughter took from this mother’s action in speaking out on an important issue I do not know. The point of this example is that this mother offers an example of using her voice to speak out on an important issue, an issue that affected large numbers of women. Speaking out like this was a novel experience for this mother, and evidence of an ability gained through her experience of breast cancer. In a second example of social action, a mother talked about becoming involved in a letter writing campaign in the presence of her daughter. Barbara has just explained to me that the current government has just voted down a move to increase funding for breast cancer. Women across Canada are going to embark on a letter writing campaign speaking out against the government’s decision and she will be a part of that. Sarah shares her mother’s enthusiasm for this effort and provides a suggestion.

B: Because I have contacts in the breast cancer communities in different areas I feel it’s important to be part of the letter writing campaign to turn this around. It was voted down in the caucus because it’s male dominated.

S: How do their wives and daughters feel about his?

B: Well they may not know about it.

S: You should write to the wives. I think it’d be a good idea – wives, mothers, and
daughters too. Somebody would be sleeping on the couch.

B: Yes you’re right. And to all the opposition female MPs.

Lessons on taking action to benefit a community of people might, as the two previous examples illustrate, be done where the person taking action might not know the recipients of that action personally. Actions that benefited others closer to home were prevalent in how the mothers in this study contributed to local breast cancer community networks. As members of support networks, mothers were involved in helping other women as well as gaining support for themselves. In these situations, mothers provided object lessons on courage and compassion by offering support to their contemporaries. Recall the voice of Jessica who struggled to extend herself to a newly diagnosed woman whose children were about the same as her daughter was when Jessica was diagnosed. With women who experienced recurrence, mothers might offer a different kind of support. It is support courageously offered in a situation that, by a twist of fate, they themselves might be facing one day. The following example of one mother’s attempts to provide support to a friend who had a recurrence took a practical turn. Her daughter is out of the picture in the sense that her mother limited contact with the woman, but she is involved in the sense of wanting to lend her own support and comfort in a difficult time.

She wants my cancer away and gone and not to have to think about it and I think my friend scared her. ... She says she’s not scared of me getting cancer and maybe on a conscious level she – it’s not like she thinks about it every day – but I think when we’re discussing it and when she sees that my friend has it, it’s like all of a sudden it’s like ‘Well this can’t happen to mom too and I won’t think about it, and this can’t happen to mom’. ... So I got her [my friend] the name of a psychologist right away. And her children are starting to see the psychologist. And I gave her a
copy of my, it's not called the living will but that's what everyone calls it.
Instructions. We talked about her will and I told her stuff that I had in my will.
...So she's got all her affairs in order so now I said everybody can stop talking
about you dying and start working on how this treatment is going to be able to help
you.

For this daughter, there is an object lesson here on the value of connection and
compassion in the face of personal fears. This daughter is well aware of her mother's
sadness and distress concerning her friend, and of the fact that her mother is doing what
she can to help her friend. As a daughter she herself has no venue for taking helpful
actions. My impression is that other daughters occupy the same space of feeling an
inclination to be helpful. Recall the voice of Angela who offered some advice to her
mother on the importance of telling children about cancer, advice that she could not act
on herself. Recall the hopes of some daughters that there might be a group for daughters
where they might offer support and advice. Recall the desired outcomes for some
daughters at the outset of the study were that this study would be helpful to other girls
dealing with breast cancer. Perhaps, only perhaps, one venue for taking helpful actions is
in the health care professions.

Lessons in living were garnered by mothers and made available to daughters both
as advice and by example. Handling illness with humour, finding a new sense of self and
voice, taking social action, achieving a balance in life, and extending oneself to others –
sometimes despite personal fears - were lessons offered.

Summary of Theme

The experience of breast cancer involved acquiring wisdom. With the passage of
time participants came to certain realizations, developed new perspectives, and created or encountered opportunities for teaching and learning. Descriptions of gradual realizations and changed perspectives were given to me in the individual interviews, a space more conducive to sharing private reflections. Material for lessons in living was developed from both individuals and joint interviews.

Participants described a number of realizations about their experience that came with the passage of time. Looking back, they described having had a limited appreciation of the seriousness and chronicity of breast cancer and of the emotional impact of the illness. Mothers spoke most about the neglect of emotional experience, mainly their own but in some cases their daughters’ as well. Some mothers now considered that their own needs for information and support might have been more similar to their daughters’ needs than they had realized at the time. Attending to the emotional aspects of breast cancer experience was difficult given the chaos and the medical demands of breast cancer. Daughters spoke most about not understanding what was going on and how a better understanding then might have saved them from guilt, self-criticism, and regret. Broadening their perspective on the experience years after the diagnosis could also be helpful.

Mothers and daughters both spoke about having changed perspectives on life as a result of their experience with breast cancer. They gained an ability to sort out what was important in life. The trivialities of everyday life and the fractious interactions of others were no longer important and they were not drawn into them. Mothers developed new
and important friendships with others who had similar perspectives on life, became aware of the goodness in others, and gained self-confidence. They adjusted priorities to suit their inclinations. Daughters experienced a gap between themselves and their friends who had not had a mother who developed breast cancer. Unlike their mothers, they did not develop new friendships because there was no contact with similar others. They were interested in meeting similar others. Daughters often described being in the position of counsellor or advisor to their friends. All daughters spoke about plans to enter the health care professions and one made a link between her decision and her experience with breast cancer.

Lesson in living were garnered in the wake of experience with breast cancer. Lessons were made available to daughters in a number of areas. Mothers conveyed these lessons both by giving advice and by modeling. Two mothers spoke about teaching their daughters the importance of finding and maintaining a balance in life, and modeled balance in changed priorities. Humour was used to meet the difficulty of serious illness in one dyad. Mothers modeled a new self-confidence in taking on new challenges. Mothers used their voices to speak out on important issues for women with breast cancer, modeling social action. All mothers modeled compassion and courage in providing support for women in the social networks of breast cancer and in other related activities. For example, they chose to participate in this research and invited their daughters to join them. All were active in raising awareness and most had participated in fundraising. Daughters were privy to a variety of lessons in living and there was evidence that they
had absorbed them.

Enduring Mother-Daughter Relationships

The word enduring can be used as an adjective and as a verb. As an adjective, enduring describes something that is long lasting, something that has a quality of permanence. As a verb, enduring signifies an act of lasting, of sustaining with patience. The title for this subsection was chosen to reflect both the quality of mother-daughter relationships described and observed in this study, and the efforts of mother and daughters in sustaining their relationships. The joint interviews provided an opportunity to observe mother-daughter relationships in action and to listen to how mothers and daughters described their relationships. Individual interviews provided an opportunity to hear about mother-daughter relationships from the perspective of one half of the mother-daughter dyad.

In talking with mothers and daughters I was stuck by the closeness they described and exhibited. Adolescence was also seen and experienced as a turbulent time by both parties, and this too was evident in moments of friction between mothers and daughters in the joint interviews. The perception that there are difficulties in mother-daughter relationships during adolescence is a commonly held view, acknowledging the fact that each person is renegotiating longstanding roles as daughters move into womanhood. In this study, the experience of breast cancer was an additional factor affecting the quality of mother-daughter relationships. Words and emotions were occasionally very strong, yet the love and closeness between mother and daughter shone. Descriptions of the
turbulence and closeness of these mother-daughter relationships are presented in the subtheme Close and Tumultuous by Nature. The fact of breast cancer experience adds an additional element to mother-daughter relationships. Descriptions of parenting an adolescent daughter after breast cancer and being parented by a mother who has had an encounter with this illness are presented in a second subtheme, Import of Breast Cancer Experience.

Close and Tumultuous by Nature

Participants were asked to say something about their relationship in the first interview along the lines of: “Can you say something about your relationship?” “How would you describe your relationship?” In our initial interviews mothers were usually the first to answer any questions or to offer comments, with the exception of that particular question. All the mothers deferred to their daughters on the question of relationship. My sense was that they were often unsure of what their daughters might say. It seemed a delicate question, more so than others that dealt directly with the experience of breast cancer. Mothers seemed to be a little on edge, a little worried about how daughters would respond. Most were pleasantly surprised at what their daughters said. All the daughters described their relationships as close, though their relationships were not without conflict.

In this conversation with Barbara and Sarah, Barbara listened as Sarah described their relationship. Sarah talked about the teen years as difficult time, and how their similar natures created difficulties. On the whole, she viewed their relationship as getting
better.

DM: I guess I have a general question about your relationship with each other. What's it like at this time of life?

S: It's been worse and it's been better. We're still close but I think - we have some big fights now and then and I think it's just the things we have in common. Stubbornness and we cut each other off. Push each other's buttons. We have our own strong point of view and we're both right all the time. It's kind of hard when you disagree and have two right answers. I'm not sure what our relationship was like during the cancer but I think it's getting better now. We have more of an understanding of where we are individually and together. And we're kind of growing back. Definitely the teenage years you do go your own separate way and then you eventually come back. I'm not through the teen years yet but I'm on my way back.

In this excerpt, Sarah offered her views on the roller coaster nature of mother-daughter relationships during the teen years. She talked about her need to find her own way as a teenager but painted a picture of two strong-willed people who are close but growing closer now. After this excerpt, Barbara went back to the time when she diagnosed. She talked about her daughter's anger back then and how hard it was to cope with that. Sarah's voice on the subject of their relationship emerged again in the second joint interview. Mother and daughter are responding to the section on the close and tumultuous nature of mother-daughter relationships. Both seem reassured that their relationship seems normal.

B: There's nothing here you would disagree with Sarah or ..?

S: Well I definitely agree with the tumultuous times in the teens! (laughing)

B: Ya I do too (laughing). Well recognizing it too. I mean it is a -

S: and recognizing all the other people are going through the same thing.
B: That's right!

S: So I'm not that bad!

B: I think you're pretty good!

In this excerpt a daughter received some reassurance from her mother that she was "pretty good." She looked pleased and a little relieved. Privately, most mothers commented on how nice it was to hear from their daughters that their relationship was good and perhaps better than most mother-daughter relationships. Discord resulting from what were perceived to be similar natures was echoed in more than one mother-daughter dyad. Progress from earlier years was another. Listen to how Cindy and Kate responded to a question on relationship.

DM: I have a question about mother-daughter relationships. What would you say about your own relationship? And also what would you say about other mother-daughter relationships say among friends?

K: Probably closer than most.

DM: Just sitting here, things seem very cordial and very smooth. Has it always been that way between you two?

C: Grade seven or eight! (mother and daughter burst into laughter)

K: Ya. There was a period.

C: We're both very stubborn and she and I are really good fighters. We'll argue and it'll get loud and then it's over and done. I've always maintained that if she can convince me my position is wrong, then fine – go for it! Her dad doesn't like to her us fighting and so when you are trying to not let him know you're arguing that would be frustrating. I remember I brought her toast in a Tupperware thing, and she was being really awful. Well the toast flew off and like the Tupperware plate hit her on the stomach. She was going to phone social services to get her out of the house (both laughing again)!
K: Those were my grade seven and eight days though.

C: Ya those were the only ... well she wanted to be stubborn and independent. But I think the older she gets the closer we get. Cuz I'm not having to be responsible for her (daughter nods agreement). Instead of coming at each other it's more going that way together.

DM: Would you say you're quite independent as well, and you're a stubborn person?

K: Ya (laughs). All my friends say I'm exactly like my mom – all of them. (both laughing)

DM: Is that what you want to hear?

K: Oh I don’t mind it (smiling at her mom).

Cindy ended this exchange with an explanation of her approach to mothering. Because she was open to whatever her daughter wanted to say to her, she felt they have maintained their relationship better than other mothers and daughters. Kate agreed with her mother on this point, but said that she did not like being told what to do. “Sometimes that’s what we fight about. Often.” Cindy described her responsibilities as a mother winding down, describing herself as more like a safety net now.

The developmental challenge articulated by mothers and daughters in this study centered on struggles for control as daughters moved through adolescence. The following excerpt with Jessica and Angela picks up on this refrain and ends on the closeness they have despite some tumultuous moments.

DM: How would you describe your relationship?

J: A battle of control. I have a real battle with control – more so with her than anyone else. But I think most of the time we get along. We talk. But I know that
there are times. I don’t really have any friends with teenage daughters to compare.

A: We get along generally. Sometimes we get on each other’s nerves and stuff. Especially on certain issues we don’t agree on but I think generally it’s good. We’re doing better than others. I would say we’re in the top whatever.

Judging by her expression, hearing her daughter describe their relationship as comparatively very good was a surprise and relief for Jessica. All of the daughters in this study described their relationships with their mothers as being good and above average despite moments of conflict. The following exchange between Diane and Chloe again illustrates the closeness of a mother and daughter, and their struggle with the developmental challenge of adolescence for mother and daughter. Both describe their relationship as unique. Chloe provides some examples of how their relationship is better than most, in contrast with most teens she knows. Diane articulates her struggle in letting her daughter go as she matures.

C: We have a unique relationship. We’re pretty much like best friends. I am one of the few people who can talk to their mom and have confidence in them. I don’t talk about everything – nobody does. ... The reason I say that my mom’s relationship with me is unique is the fact that I don’t know very many other children who have a relationship with their parents like I have with mom. I mean you’re getting into the teens and so many teens are rebellious and they want to go out and party all the time and they don’t give a hoot what their parents think. So many kids will abuse the fact that they are children. They all feel ‘Well you guys should pamper me and respect me and all this stuff and I don’t have to give you anything in return because I’m a kid, what do you expect?’ You know? And that’s what they do. They take and they take and they take from their parents and they don’t give anything back.

DM: And you’re not in that place.

C: No. I never ask my parents for money if I don’t have it. Like if I don’t have the money in the bank to pay them back I don’t borrow it. I figure if I have no money I’ll wait til I do have it. Stuff like that.
DM: Ya. So the relationship you have with your parents, with your mom is, it sounds to me - if I could put a word to it and you can correct me on this – is more mature than with other kids.

C: Ya.

D: From my experience, I have a lot of friends with daughters. I keep knocking on wood that it’ll never end. I have never loved anyone as much as I love her. I have learned so much from her. She’s so unique, my little miracle, a gift, so intelligent, such a sense of humour – she makes me laugh. We travel together, go to fine musicals, have wonderful dinners, go to the hairdresser together. Just a lot of together stuff. When I wasn’t working we’d go out to lunch together once a week. She’s never been embarrassed of me. She hugs me in public. She tells me she admires me. When something is bothering her I give her three conditions. Do you want me to listen, to give you advice, or do you want me to make you laugh?

C: Actually there’s four. Do you want me to leave you alone?

D: Oh, ya. Sorry. That’s the hardest. That’s what I find the hardest now when she says leave me alone mom. Cuz sometimes she’s very upset and up until about two months ago I’ve always been able to take her in my arms and make it all better. And now she’s learning to deal with certain things. And I have to let her go and do that. That’s really difficult but I know I have to do it. We have long discussions. I can talk to her! Sometimes she’s upset or I’m upset but we have to grow away from each other so she can become herself but we can do it by talking and not by rebellion and negative ways. I will let her go, but she has to take it easy on me because I love her so much.

All of the mothers and daughters spoke about the love and closeness they felt for each other. One of the ways mothers and daughters frequently described their being close was in terms of how much they talked and how much they shared. Their comments here may provide an explanation for upset around the time of diagnosis and treatment because that was a time when daughters felt their mothers had not been as honest with them as they might have been. It was a time when mothers were pointedly not sharing in an effort
to cushion their daughters, and perhaps also themselves, from upsetting realizations.

One of my curiosities at the outset of the study was whether there might be an element of closeness based on shared biology. In this study I tried to stay as close as possible to what participants wanted to talk about and found few opportunities to ask any direct questions on the subject of shared biology. I heard comparatively little from mothers and daughters on the subject of shared biology aside from comments that daughters were now seen and saw themselves to be at some increased risk for developing breast cancer themselves.

What I discovered was that, where daughters spoke about the notion of shared biology, it was as a sort of given that provided a shared appreciation of the other. As one daughter said to me, with a knowing look, “Usually mothers and daughters are really close. She’s like my best friend.” Another daughter spoke about being able to understand her mother because as women they would come across fashion magazines that demand perfect bodies and exert pressure on all women, including her and her mother. Another daughter said, “She can relate to me better because she’s a woman. Like if you think about having a baby, there’s a basic connection with the labour and delivery.”

Here is an excerpt from a conversation with one daughter who had the most to say about the notion of shared biology. This excerpt acknowledges that the question around shared biology is something I brought into the study. Because I wanted to find out if the notion of shared biology was something I was imposing or if it had relevance, I asked her to consider that question as well. She explains that her mother having had breast cancer...
has resulted in a bond between them, a bond of understanding based on shared biology.

DM: When you said that probably your understanding grew as you got older, I wondered if a shared biology increases an understanding, or empathy, or something between mothers and daughters. Do you have any thoughts on that?

D: What do you mean by shared biology?

DM: Shared, by the fact that as women we develop breasts at some point, sooner or later, and that we have female bodies.

D: Ya I guess. I guess so just because it’s like you’re both women and it could happen. I guess you could relate on that level, and you can imagine what it would be like to have a new self. It was just something biological in a female body that happened. I can relate to it a lot more cuz I can think about ‘What if that happened to me?’

DM: You can imagine a little bit better. I don’t know if that’s kind of a novel thought that I’ve introduced, or like a novel idea. It may be. And I’m aware that I’ve come to this study with my own curiosities and that’s one of them. So maybe that was a novel thought.

D: I think so, though I think it’s connected in that way because it’s more of my understanding. Like I think that is why we will always have that bond between me and mom is because we don’t understand each other on any other level. Like we have completely different opinions about everything. She grew up completely opposite to how I grew up. And the one thing that I can always understand about her is what that must have been like. Because I can – it can happen to me. We live completely different lives and different things are important as a result, but health is one of those things that is kind of the same. We can always relate on that. And both of us being female. Like if I was a boy it wouldn’t be the same. I can understand just because I’m a girl some of the feelings that you’d go through with breast cancer because it’s a part of your femininity. I guess guys can understand that it’s a big thing and that it’s an emotional thing to go through, but they can’t really empathize because they don’t know.

By virtue of a shared biology, daughters were perhaps more sensitive to mothers and better able to understand something of what their mothers had gone through. In this...
excerpt a daughter talked about a bond she shared with her mother. For her, the experience provided a ground of understanding between them. She did not speak about her relationship with her mother as such, but of her personal feeling of connection and understanding.

In summary, mothers and daughters described themselves as enjoying close relationships despite the difficulties for both in the teenage years. Mothers appeared somewhat ill at ease when I asked each dyad to say something about their relationship. All chose to let their daughters answer first and were pleased if not relieved to hear their daughter describe their relationships in positive terms. Overall, mothers and daughters described their relationships as being very close in comparison with others. Closeness was often gauged by the amount of talking they did. Some daughters spoke about having a sort of built in understanding or appreciation because they were both female. Difficulties in their relationships were often described as a being a natural consequence of them having similar natures, for example being stubborn or having strong opinions. The struggle for control, for having their opinions respected, and for meeting needs for a daughter's independence also contributed to friction. Ways in which breast cancer experience shaped mother-daughter relationship is the subject of the next heading.

Import of Breast Cancer Experience

Some of the import of breast cancer experience for mother-daughter relationships has already been illustrated in previous sections. For example, acting on their intentions, mothers and daughters were caring and protective of each other and contoured their

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conversations accordingly. The caring and protectiveness of mothers and daughters was an aspect of mother-daughter relationships that was privately and jointly constructed, something the other person might not be aware of because intentions were not always discussed with the other person. One result of contouring conversations was that daughters were often slow to recognize the seriousness of the illness and had feelings of self-criticism or guilt for not fully appreciating the situation or appreciating their mother as much as they could have in earlier days.

For mothers, breast cancer experience brought a degree of anxiety about their ability to fulfill the tasks of mothering. Facing an uncertain future they wondered if they would be around for their daughters. Would they see them at next year's recital? Would they be there to see their daughter graduate? Would they get to see their grandchildren? Mothers reached or did not reach a resolution of these anxieties but referred to their efforts to ensure a measure of safety and self-sufficiency for their daughters. Safety and self-sufficiency included actions and planned actions to ensure their daughters took care of themselves physically, made good life choices, and were prepared to take care of themselves if it happened that mother could no longer be with them.

The actions mothers took or contemplated in respect of their daughters' physical well being focused mainly on directing their daughters to healthy eating, and in a general way advising them of the need to be vigilant about their own breast health. Talking about healthy eating was a comparatively easy matter, something mothers could recommend and model. With respect to teaching their daughters about being vigilant about their own
breast health, what to offer in the way of advice and when to offer that advice was unclear. Depending on their own confidence in the efficacy of early detection measures, such as breast self-examination and mammograms, mothers were more or less enthusiastic about encouraging their daughters on these matters but felt some obligation to do so.

Knowing when and how to raise the topic of early detection measures was difficult because most mothers tended to see their daughters as not yet ready for these kinds of conversations and were themselves reluctant to get into these kinds of discussions. To their knowledge, none of the mothers in this study had a heritable form of breast cancer but the fact that they had experienced cancer was felt to put their daughters at some increased risk. Given the uncertainty, the degree of urgency to embrace methods of early detection was unclear. Without any guidelines on exactly when their daughters might best start doing self-examinations and having mammograms, mothers were left with the feeling that their daughters ought to be monitored early and closely but exactly when to start that process and how to follow through was unclear. Some mothers had hung the kind of waterproof directions for breast self-examination that you hang in the shower but did not know whether their daughters had ever used them. In this excerpt a mother describes what she would see as good breast health practice in the future and describes her uncertainty about what measures are being put into practice now.

M: That was one of the first questions I did ask my oncologist – about my daughter’s risk. He said she should start having regular mammograms at age forty. He said that with my kind of cancer she’s not at greater risk than the average woman. However I have different ideas. I would have her going for mammograms at a young age.
DM: What age would you want her to start having mammograms and is there anything else you’d recommend?

M: I certainly think not in her teens, but probably in her twenties is a good age to start. I’ve hung those little things in the bathroom many times. I don’t know whether she does or not. Maybe she does and doesn’t tell me. We have the same GP. I don’t know what happens when she visits the GP but I’m hoping he will encourage her.

Talking about breast health practices with their daughters seemed to be difficult for mothers. It was an awkward subject, difficult to raise in the course of everyday life, perceived as disruptive to daughters, and perhaps unnecessary for now. This mother planned to talk to her daughter about mammograms sometime after she was out of high school. Based on her own experience, she had decided that her daughter was safer starting mammograms much earlier than what her oncologist had recommended.

Feeling that their daughters were equipped to act responsibly in life and make good decisions seemed to be very important to the mothers in this study. Although mothers could and did describe their daughters as being intelligent or as having a variety of talents, the ability to act responsibly and choose wisely seemed to be very encouraging and comforting for mothers. Mothers would tell me about how levelheaded their daughters were, often describing their own efforts in developing that quality in their daughters. For example, one mother referred to having put effort into making sure her daughter had a good set of values and knew how to make good choices in life. Feeling that her daughter had the ability to make good decisions for herself provided a sense of having accomplished an important task. If it turned out that she could not be there for her
daughter at least her daughter would be prepared to manage her affairs. Another mother told me how important it was to her keep her job outside the home because she wanted to make sure that her daughter would be able to take care of herself. Accumulating the funds to put her daughter through university would ensure that she would have a good education and earn a decent living.

Daughters did not have as much to say about the possible impact of breast cancer experience on the way they interacted with their mothers. When I asked daughters quite directly to consider if they thought their mother having had cancer changed their relationship with their mothers in any way, I heard a variety of responses. Some said they were closer, and some were more tentative in their replies. For example, “I couldn’t love her any more than I already do. But it has brought me closer because I realize she’s not going to be around forever.” Daughters who were more tentative also spoke of having more understanding of their mothers or being more admiring of their mothers. “Maybe we’re a little closer. It’s hard to say because so many things affect a relationship and relationships are always changing. We may have a better understanding of each other though.” In the following excerpt a daughter recounts how watching her mother go through breast cancer had produced a positive effect on their relationship because she admired the way her mother had handled her illness.

D: I’ll always have this respect for her that she went through this. And she didn’t just go through the treatment and say ‘Well I’m done with it.” She went out and she started support groups. She was looking at the system and she decided it wasn’t where it should be. Even though she was okay and she probably wouldn’t have a recurrence, other people were going through the same thing. They needed help and might not have the courage to say what she said and to ask all the questions and to
pursue and keep going. And she joined other breast cancer activities too.

DM: So it's a story in some way of having a bad experience but then turning it into something positive with community action.

D: Yes. I'll always look up to her for that I guess - that she did that.

Over the course of our conversations, I learned that some daughters had been encouraged by a teacher or by a father to be understanding and considerate of mom by being good and not making her life more difficult. Some were considerate of their own accord. Recall the voice of one daughter who said she just tried to carry on, lay low, and manage her own affairs. Another daughter said that she tired to be more accepting of her mother’s moods and inability to do things because “I was understanding of that and not feeling like she’s making me do everything cuz she’s lazy or something. I understood that she had gone through this and needed rest and everything and so I was a bit more tolerant.”

Being considerate of mom took effort. As one daughter put it. “It’s hard to be considerate one hundred percent of the time.” For this daughter, years after her mother’s diagnosis her father would still tell her to take it easy on her mother if they were having a disagreement. Her interpretation was that her mother still deserved special consideration, which was a source of irritation for the daughter. One mother described how her daughter had been and still was extremely supportive and considerate. Her daughter calmed her down by walking her through some anxieties about medical procedures, reminding her that some things were expected and so she should not get upset. When her mother was
having a lot of difficulty with a friend’s recurrence, this daughter also brought home resources on grief and loss from her career and life-planning course to help her mother prepare for the possibility that her friend would die.

Whether the experience of breast cancer had had an impact on the mother-daughter relationship from a mother’s perspective was a more difficult question to answer in this study. Sometimes mothers talked about challenges and changes as a result of breast cancer, but the tenor of my conversations with mothers emphasized normalcy. I found it more difficult to ask mothers questions about changed relationships with their daughters as a result of breast cancer because it felt like I would be challenging how well they had achieved a goal of maintaining the status quo. It felt comfortable asking a question about the import of breast cancer for the mother-daughter relationship with two particular mothers. They talked the most about their mothering.

The first excerpt illustrates one mother’s efforts to change the way she interacted with her daughter. This mother saw the friction between her and her daughter as a threat to her own survival. We have been talking about her relationship with her daughter and the way she mothers her. She has strong feelings about the amount of support she gets with housework and the implications of getting into conflicts with her daughter.

M: It’s just so much easier not to have a fight. Now, especially since I was diagnosed with the cancer I just don’t want big fights. Any time now if I get mad at her and start yelling at her— I have a sore throat for days afterwards. It’s just not worth it.

DM: It’s dangerous for your health to be getting into those things?

M: Ya. So she’s not gonna make me sick. It’s like— forget it!
DM: I think you mentioned last time that you have had moments when you were very frustrated that you weren’t getting enough help at home. And there wasn’t any thought given to what you were going through. Maybe that’s connected to what you are saying?

M: Yes. I think it’s all interconnected. I thought that being close, I thought she would help out more than she does. She’s too busy with her friends and everything, which is normal for her age, but there’s gotta be some kind of balance. … When I got breast cancer and nothing seemed to be that important any more I thought ‘If her room’s dirty, who cares?’ That was a major shift where I just thought ‘It’s not worth the fight’. It’s just gonna make me sick. And one of these days she’s gonna leave and what’s gonna happen? I’ll be sick. Like forget it. Or it may cut my life short. Forget it! It’s not worth it!

This mother struggled with the dilemma of either insisting her daughter take on more adult responsibilities in the home, that is, her share of the household work, or preserving her own health. She is also under some pressure from family members to get her daughter to help out more but feels it is not worth the effort. She sounded resentful during this conversation but also looked very hurt that her daughter seemed to have no consideration for her health. When I arrived for this interview she had been working hard to get the house ready for company and was looking very tired from the effort. Her daughter was aware of the extra work needed but had not volunteered to help her mother and her mother had not asked for help. As a mother I recognized the struggle around duties as typical of mother-daughter relationships in adolescence but also reflected on how breast cancer added another dimension to parenting and being parented. For her daughter, unwilling or unable to accept the fact that her mother’s health was not what it once was, offering help might entail acknowledging that her mother was not entirely well.
Stressing the need for her daughter to separate from her and “become her own person”, another mother struggled with another widely accepted task of parenting an adolescent. For this mother, the task was difficult because her ability to carry on as nurturer and mother was an important part of how she survived the encounter with cancer. Prior to this excerpt she has told me that living for her daughter gave her strength and purpose. “That was key. Part of my survival has been I have to live for her. That’s given me strength. I tried to be so strong. And without that I might not have healed the same way.” In this excerpt we have been reviewing her individual feedback letter.

DM: In the last paragraph I wrote ‘You feel very close to her, but are currently navigating the task of separating from her because you feel it’s important for her to be independent.’ And the task of separation is seen as very important in our culture.

M: Yes.

DM: And I’m thinking as I’m writing this, it must be very difficult given your situation with breast cancer and how important she’s been to you in your sense of survival.

M: Yes.

DM: At the same time, that need to deal with separation I would think would be very difficult.

M: Oh I find it extremely difficult. And a prime example, I have a need or a routine in the morning. I drive her to school and tell her how much I love her, and no matter what she wants to do in life she has the ability to do it but she’ll have to work very hard. I say every morning that I love her and I tell her this other bit maybe three times a week. It’s also helpful to motivate her in school. And so this morning she told me she wished I would stop this preaching to her every morning. I don’t need to tell her any more. ... And that brought tears to my eyes because on the one hand okay that’s enough, and on the other hand you know if I didn’t say it, how many kids never get to hear that from their parents? ... So that’s part of the separation. But I know if I wasn’t here, if I was dead, she would miss that so desperately. You know?
What this mother sees as an integral part of parenting an adolescent is more difficult for her because she has experienced breast cancer. She struggles with reducing overt displays of affection, recognizing that her daughter didn’t want to keep hearing “I love you” every morning. She also considers how much her daughter would miss hearing these words of love and encouragement were her mother to die. Given the degree of closeness they shared, negotiating a level of separation was probably hard for both of them. Afterwards, this mother told me how when she did stop telling her daughter “I love you” her daughter would seek her out in a bit of a panic and ask her if she did still love her. Her daughter had told me that having a mother who got breast cancer made her mother more precious. I suspect that she too struggled with the need to grow apart but this was difficult given the circumstances.

The drawing of one daughter says something about the closeness between mothers and daughters and the significance of breast cancer (see Appendix B, Figure 10). It is a drawing of a mother and a daughter. Overall, the tone of this drawing is positive and optimistic. Mother, one-breasted though she had only a small wedge resection, and daughter are smiling and holding hands. A large sun is shining and the grass is green. Her comments about the drawing were brief, and emphasized a positive outlook. “It’s kind of behind us, and life is good now. We have a pretty good relationship. We’re smiling and we’re holding hands.”

For this daughter, as for all the other daughters, the turmoil of diagnosis and...
treatment was behind her and she described things as being relatively good now. As far as this daughter knew, and as far as the other daughters knew, their mothers were pretty healthy. For this daughter, and for other daughters, worries were present but not in an overtly obvious way. The optimistic tone of this daughter’s drawing and her description of it belie the worries that she said were always there in the back of her head even though she maintained an optimistic attitude and presence. For this daughter, the worries were for her mom but also for herself and for her own risk of getting breast cancer some day. For all daughters worries were not overwhelming, not discussed with anyone, but present nonetheless because daughters inhabited a landscape touched by breast cancer alongside their mothers.

For mothers, having breast cancer entailed worry about their daughters’ health. Worries for daughters were variously translated into efforts to improve their diet, to teach their daughters how to make good life choices, and to work hard to ensure a daughter would be well educated and financially secure. All mothers described their daughter as being pretty levelheaded which was a source of satisfaction. Mothers worried that their daughters were more at risk for breast cancer but were at somewhat of a loss to know what they could do about it. Some had provided guides to breast self-exam but had no idea if their daughters were doing exams. One mother told me that she had cautioned her daughter about using birth control pills. Mothers hoped that their daughters would be closely checked, but when that should start and when and how they might raise the matter with their daughters was uncertain.
In general, mothers chose not to talk with their daughters about risk or about breast health, fearing they would upset their daughters. In two cases, a mother’s hopes for survival were threatened or enhanced by their relationships with the daughter and both situations created challenges in parenting and being parented. Some daughters had been encouraged to be understanding and considerate of their mothers, or were understanding considerate of their own accord. They did their best, but this was sometimes difficult to do. Daughters had comparatively little to say about the import of breast cancer for their relationship with their mothers but the experience brought them closer.

Summary of Theme

Mother-daughter relationships were described as close and tumultuous by nature. Mothers and daughters spoke about the closeness they shared despite the fact that both saw and experienced the teenage years as sometimes difficult. Mothers seemed to be nervous about how their daughters would describe their relationship and were relieved to hear positive descriptions. The degree of closeness between mothers and daughters seemed to be measured largely in the amount of talking they did. The talk might be positive or fractious, but they shared a lot and this was important. Difficulties in relationships arose as mothers and daughters struggled for control, and strove to have their voices heard and their opinions respected. The friction between mothers and daughters was often described as being the result of the fact that mother and daughter were so similar in nature.

Mother-daughter relationships were affected by the experience of breast cancer in a
variety of ways. Mothers worried that their daughters were now at risk for getting breast cancer themselves. They struggled with what to do about it, but largely avoided talking about it with their daughters. Mothers did not want to upset their daughters unduly and were unsure of what to say to them and when to say it. Those who had provided their daughters with instructions breast self-exam instructions had no idea what their daughters thought about them or if they used them. Advice on diet was easier to give, but was it helpful? Mothers made plans to say something more to their daughters at some point in the future but they were not certain when the right time might come.

Two mothers provided examples of the difficulty of parenting after breast cancer. One mother tried to avoid any conflict with her daughter and abandoned efforts to get her daughter to take on more responsibilities in the home. Normal parenting responsibilities were set aside to preserve her own health, but this was painful. Another mother described the struggle she had in helping her daughter become more independent. Because her daughter had been key to her survival separating from her daughter was extremely difficult.

Daughters were closer with their mothers as a result of the breast cancer experience. Daughters tried to be understanding and considerate of their mothers, but this was not always easy. My impression was that the efforts of daughters in being considerate of their mothers was not readily apparent to mothers. For example, recall in an earlier section some daughters described being optimistic and trying to manage their own affairs to relieve the stress on their mothers. Daughters might be assumed to be indifferent or
preoccupied with their own interests. Daughters, like mothers, were reluctant to say too much to their mothers on the topic of breast cancer lest that upset the other person. For both parties, consideration brought an element of tentativeness and an area of silence into the relationship.

Being in the Study

Research reports rarely document the effects of being in a study. This section documents the import of study participation for all participants, and revisits purposes and desired outcomes articulated at the outset of the study. Material for this section has been drawn from participants' comments, from my own observations, and from questions asked about the effects of being in the study. In the final mother-daughter interviews, I asked participants to say something about what it was like for them to be in this study. I have included my experience of being in the study as a participant-researcher. This section has three segments. The first segment, Study Process, documents reactions to the design and subject matter of the study. The second segment, Outcomes and Advice, documents some expected and unexpected results of participation, revisits the questions of purpose and outcome raised at the outset of the study, and documents the advice of participants for similar others and professionals.

Study Process

The design of this study was emergent in terms of the questions that were asked and the subjects that emerged as important to participants. In the process of developing conversations with participants, questions and curiosities I had at the outset of the study
were set aside, altered, or pursued depending on the areas of mattering and sensitivity that emerged for mothers and daughters. My experience of sometimes having to let go of preconceived ideas of how the study might proceed and what it might encompass was both anxiety producing and liberating. I felt anxious about missing opportunities to discover something of value by being overly concerned about what I perceived to be sensitive areas and moving away from them too quickly. I learned to have confidence in the ability of participants to direct or redirect conversations as needed, in the process gaining a more than theoretical notion of research as a co-construction. I also learned the value of my education in counselling psychology. By fostering a climate of openness with participants and attending to the process of conversations as well as the content of conversations, much could still be learned about an area of interest. To illustrate, an example of an initial curiosity follows.

My initial curiosity about the import of biology for mothers and daughters in respect of breast cancer experience was tempered as I encountered few natural openings in our conversations for this sort of question. As the interviews progressed it became evident that sensitivities around vulnerability, for example in the risks of a daughter developing breast cancer, were for the most part privately held and seemed not an easy subject of discussion for mothers and daughters. Honoring the boundaries that participants had in this areas afforded an opportunity to discover the negative space in conversation. Recognizing that that which was not said could encompass areas of irrelevance as well as sensitivity, my work as a researcher turned more to observation.
Observing the process of how mothers and daughters relayed the health and illness experience in their families was informative with respect to the import of shared biology. Daughters were generally the first to bring up the incidence of cancer in the family, and mothers responded by quickly pointing out where they were not blood relatives. Here the import of shared biology for mothers and daughters surfaced as an issue of heritability, a topic that most had not discussed judging by the surprised reactions of daughters.

Adopting a respectful stance and taking a relatively unstructured approach to the interviews allowed conversations to develop naturally and to move forward with minimal intrusiveness. At the end of the study some participants reflected on a degree of hesitancy or anxiety they had in entering the study and on how it had turned out to be easier and more enjoyable than they expected. Here is what one mother had to say about her experience of being in the study. We are winding down our last conversation, and she brings up the topic herself.

M: I found that this whole procedure – it could have been a real emotionally traumatic experience. And I found it very - alleviating and very easy to talk too, you know?

DM: Hm. That was one of the things I wanted to ask you tonight. What has been the effect of being in this study, and of me popping into your life? Because researchers don’t often ask that. They often just sort of pop in and out.

M: Ya. No it was wonderful. I’m really glad we did the study. ...I find you very easy to talk to and as I say you allow that openness to happen. I didn’t feel at any point in time you were trying to angle me or coerce me in any way to say something that wasn’t even close to my mind. I like the way you phrase what I have just said to make sure you understood what I said. And then to have this write-up to look over, and the way you encapsulate everything it’s done really well.

DM: We can be encouraged then that we were able to communicate and that we’ve got some understanding going.
M: Oh totally…. This could have been *so dry* and so technical. And I didn’t realize I could just sit in my room where I wanted to with my candles and go blah-blah-blah-blah-blah. (laughs)

Meeting at times most convenient for participants and meeting in rooms of their choosing helped build comfort levels. Having a relatively unstructured approach to our conversations fostered a feeling of openness. Using active listening skills such as paraphrasing developed my understanding and the participant’s sense of being understood. Another aspect that was valued in developing a sense of understanding and being understood was the feedback letters.

The individual feedback letter and our discussion of it provided an opportunity to assess and build understanding between participant and participant-researcher. The group feedback letter and our discussion of it did that as well, but it also provided a sense of connection and commonality among participants. I noticed with the group feedback letter that participants appeared to be both pleased and comforted by recognizing how similar their experiences were to that of others. Even if they felt somewhat at odds with elements of the letter, or came to new realizations as a result of it, the sense of connection with others predominated. This interchange between Jessica and Angela was fairly typical of the reactions of most mother-daughter dyads.

J: It’s funny how it’s just very similar to what we talked about. A lot of the stuff. So it’s the same things that are coming out. At the beginning you did say that there were diverse conversations so that you did find some things that were different from conversation to conversation. Still.

DM: Anything that doesn’t fit for you Angela?
A: No. I agree with it. I’m reading it thinking ‘Ya, I said that. I remember saying that.’

J: Maybe she took your whole conversation and didn’t listen to anybody else! (both laughing) Well no, but – that’s how similar your conversations must have been. Isn’t that interesting!

Some perceptions of similarity were especially welcomed. For example, mothers and daughters seemed especially pleased to learn that, for all the mothers and daughters, adolescence was seen and experienced as a tumultuous time. Recall the voices of Barbara and Sarah in an earlier section where they read the portion of the letter that referred to tumultuous times and closeness. It was reassuring to hear that everyone else was going through a difficult period but that the closeness between mother and daughter was still evident. My impression was that this portion of the letter was especially reassuring for mothers because they were unsure of what their daughters would say about the relationship. Two other portions of the letter were received particularly well.

One part of the group letter that was well received dealt with the possibility of strength and resiliency, such as gaining a new perspective on life. The idea that something positive might come out of experience with breast cancer seemed both intriguing and comforting. My impression was that most mothers were surprised that, like themselves, their daughters had a changed perspective on life. One mother was especially pleased to learn that daughters did benefit in some way, for example in gaining perspective, because she had wondered about that from the outset. Other mothers and daughters said that it really applied to them. Another section of the group letter, one of
the most interesting aspects for both mothers and daughters, dealt with the career aspirations of daughters. This was a part probably most often selected in answer to my question, “What pops out for you?” Daughters seemed particularly delighted by this finding. Mothers were intrigued and asked for details on the commonality.

The places where participants sometimes wanted to emphasize a difference were the lines that read “As a general observation, there seemed to have been very limited conversation between mothers and daughters on the experience of breast cancer” and “Mothers tended to adopt a watchful attitude, and what might be described as a policy of “don’t ask don’t tell because it’s important not to scare them.” One mother and daughter dyad felt strongly that the portion of the letter on limited conversation and the phrase ‘don’t ask, don’t tell, because it’s important not to scare them’ did not apply. By my observation they were quite open with each other, and were the ones who had dealt most openly and directly with the possibility of death. However, as with all the other mother-daughter dyads, they had individually told me about the unspoken aspects of breast cancer experience that were the basis for the portion of the letter that they said did not fit for them. My reaction to their comments, and to those in the next excerpt, was that this might be an example of differing perceptions where both had truth-value. Here is what another mother had to say about that portion of the letter. Her daughter was silent during this exchange.

M: The one aspect in there I think that didn’t fit was regarding the “don’t ask, don’t tell, don’t scare them.” I don’t remember feeling that. My concern was, and I suppose it depends on how old the child is, my feeling was I wanted her to know as much, not the whole thing, but that it was fairly serious. I felt it was better to be
open and up-front. I was very aware that children do hear things and get misinformation.

DM: Okay. And that was around the time you were diagnosed.

M: Yes the weekend.

DM: So that’s the time frame you’re referring to.

M: Yes. And I don’t think the ‘dealing with uncertainty’ fits.

My reaction to her comments was that as a mother she might have felt challenged that she might not have done what she had set out to do, that is, have her daughter fully informed. My understanding of breast cancer experience for mothers and daughters was that it was an ongoing experience. The study had shown me the import of breast cancer for both mother and daughter years after diagnosis. What this mother focused on here was the early days of diagnosis. I found her comments representative of how other mothers described their actions or lack of actions in that comments were often focused on the early days of telling or not telling. I recognized that my words in that letter might generate feelings of being criticized, and accepted her remarks without further comment. I appreciated her comments as an expression of what was true for her in reading the letter. However, I reflected on what both she and her daughter had shared privately. Privately, their experience seemed to be more in line with what was stated in the letter.

Over the course of this study I discovered that, on the whole, mother and daughters were more relaxed in their individual interviews. They seemed to feel much freer to talk.
I was curious as to what if any dialogue about breast cancer experience there might have been between mothers and daughter outside the interviews. When I asked, I learned that mothers and daughters rarely spoke about what had transpired in the joint interviews or in their individual interviews. I had expected the study might generate some dialogue between mothers and daughters but discovered that our conversations were neatly packaged in space and time. As one mother whispered to me when we had a private moment "It was good. It was good. It was interesting! It was kind of weird though, you know? Like you feel still, still like I said, you're tiptoeing, tiptoeing. Why is that?" The relative lack of conversation on the experience of breast cancer between mothers and daughters that was documented in the group feedback letter was still present for this mother and daughter, and for the others.

The design of this study afforded an opportunity for participants to talk about their experience, feel their experience was heard and understood, and get some sense of where their experience was shared by others in the study. My initial anxiety about having an open-ended interview format, relying more on my counselling skills to facilitate communication, slowly diminished as I came to see commonalities among participants. Having feedback letters provided a vehicle for developing shared understandings and new insights as we discussed the letters. Participants were pleased to learn how similar their experiences were to others, and were pleased to find out that something positive might come of an experience with breast cancer. I had envisioned the possibility that the study might generate dialogue between mothers and daughters outside the interviews but
when I asked, I was told this did not happen.

**Outcomes and Advice**

One of the outcomes of this study was that being in the study generated new learnings. By entering a space for dialogue, mothers and daughters each were privy to some of what the other person had not previously shared. Some surprises were welcomed, for example finding out a relationship was better than they might have thought or finding out that a relative who had cancer was not a blood relative. Other surprises were, even if beneficial, difficult to come upon. For example, recall the conversation between Barbara and Sarah on the subject of breast cancer activities. They eventually came to an agreement on the matter but it was a highly charged conversation.

In the following excerpt, Barbara and Sarah offer their reflections on being in the study. Prior to this excerpt they had both told me how much they enjoyed being in the study. Here they talk about the value of having an opportunity to reflect and to gain a new perspective on their experience. They also talk about dealing with aspects of their experience that had not been dealt with previously in other venues. Barbara, like all the other mothers, was a member of a support group. Sarah also had experience in a support group at school. Here is what they had to say about being in this study in comparison to being in a support group. The excerpt includes my answer to Sarah’s question on how it was for me to be in the study. It is an illustration of the comfortable feeling of being on an equal footing with each other.

S: I liked being able to talk about these things with somebody who didn’t necessarily know me. Someone who didn’t really know about me and my life, just
hearing about it from me first. And I liked being able to think back. ... like talking about it and kind of being able to think about it again years later. The support group at school was good but we never really did anything like that. I don’t know what we did. It was kind of an excuse to go out to lunch together sometimes. It was more for people who were going through tough times just to have the group. ... Nobody had to say anything there. It was just there. And I think it’s good several years after the fact to be able to go back and think about things that happened. Not necessarily the way I felt, but find out how I think about it.

B: My turn? When I thought about doing this I really wanted to do it because it was something Sarah and I could do together. I thought that that could only be beneficial for us to talk about this. But I was nervous. I was nervous about someone I didn’t know coming and asking me personal questions. But what I did get out of it – particularly the one-on-one sessions – I found that that was, once I got going, I was able to talk about my emotions quite easily. And I found it quite beneficial, quite therapeutic. In fact it was like a cleansing. It was something I hadn’t been able to do in a long time. And as I say, I brought it up at the group to say that I wasn’t really a group person. I found that in the end I was really a one-on-one person. They had a hard time believing that, but I am. I find these conversations quite beneficial because I was able to talk about my feelings.

DM: Mm. Right. Well I’m glad it turned out well for you and I can appreciate that, you know, it takes a certain amount of courage to say ‘Yes okay you can come over and talk to me.’ and you don’t know who that person really is.

S: How’d you like it? (Laughs)

DM: I enjoyed it immensely. But that was good –

S: Turn the tables!

DM: Ya! I went into this study with some general curiosities and some nervousness about a decision I had taken to let our conversations develop. And to have it really very unstructured. But I decided it was probably a gentler way of doing it. It’s also the way I do counselling so it fits for me. And it was really good too to discover that ya, you still do come out with commonalities and you can appreciate the unique aspects of people’s lives. And I feel that for each person I’ve met in this study it’s been a privilege and a pleasure for me. And I’m very appreciative.

In this excerpt a mother told me about the benefits of being able to talk about her
emotions, and discovers that she was really more of a one-on-one person rather than a group person. A daughter told me about the benefits of being able to think about her experience, and appreciates the opportunity to share her experience in a one-on-one setting.

Daughters thought it would be nice to meet the other daughters if that were possible. The inclination to meet with other girls was present for one daughter at the beginning of the study, but by the end of the study all of the daughters were interested. My observation was that as daughters spoke about their experience, they both acknowledged some unmet needs and came to the realization that they had something to offer to other girls. Mothers were not as enthusiastic about having their daughters meet with other daughters, but they did not object to the idea. My sense was that the idea was something they had not considered. For example, in reviewing the portion of the feedback letter that raised the issue Diane said that Chloe did not want to talk with other girls. Chloe corrected her mother saying “I never said that.” and her mother simply acknowledged it with “Okay.” and moved on. My interpretation of Diane’s reaction, and that of some other mothers, was that it was perhaps disturbing for mothers to ponder a daughter’s inclination to meet with other girls. This would perhaps require a shift in their thinking, that is, from everything is back to normal and breast cancer is not an issue to maybe there would be a benefit for my daughter.

My conversation with Jessica is a good illustration of a mother coming to a new realization in the study. The example is lengthy because it illustrates a process. It
illustrates what it was like for this mother to develop another perspective on the position of daughters with respect to breast cancer. She questions me closely. We are beginning our discussion of the group feedback letter.

M: A couple of things I thought were interesting. The first one where you say “little conversation between mothers and daughters.” And the second part there on the “parallel for daughters in that they tended also to be watchful and caring of their mothers and might well defer some curiosities in an effort to protect their moms.” So you’re saying that generally speaking a lot of daughters were just not asking questions?

DM: Yes. There were areas that were sensitive, that were held in abeyance, maybe for a proper time or whatever. It was kind of funny that symmetry between mothers and daughters.

M: But yet the daughters didn’t have another venue to ask those questions, whereas the mothers would have a support group to say you know ‘How are you dealing with talking with your children?’ whereas the daughters didn’t have that.

DM: That’s right. It’s interesting isn’t it? And when I spoke with the daughters about who they might have conversations with, they might say ‘Not my mom, for sure.” That might be out of bounds. And with their peer group they could have conversations about everything else but this was a little different because their friends wouldn’t understand. They didn’t have the experience of going through something similar so – just a different kind of wavelength they’d be on. So they thought it would be useful to talk to other girls. And for the most part the girls said to me they might not need it for themselves but they were interested in helping other girls.

Our conversation moved on to other areas but a short while later this mother came back to the topic of conversations and of daughters’ needs. She had a few more questions. Her comments here seemed to be carefully worded. She was talking at a slower pace, and her facial expression was focused and slightly guarded.

M: Did you find that in speaking with daughters that …like you did say there wasn’t a conversation, or that the girls weren’t interested or they didn’t want to talk
about it or deal with it? Do you know what I mean?

DM: Yes. Both I think. Certainly the idea of wanting to live a normal teenage life... but also there’s a certain element of what I’m calling protectiveness there. Like one daughter told me if she had felt scared she wouldn’t say that to her mom because then her mom would be worried about her and that would not help mom. So it’s a consideration and it’s a desire to get on with things. The whole issue of silence intrigues me and it is very complex.

M: Ya. But it comes back again to whereas for daughters even if she wanted to ask questions there’s nowhere to go.

This conversation took place in our last joint interview. Her daughter is silent in this excerpt but her mother did check with her elsewhere as to whether she would be interested in going to a group for daughters. Angela showed enthusiasm for the idea. Her mother said that it would be interesting to connect with the others in the study. She imagined that the girls might even form the first support group for daughters in North America - in fact in the world. Mother and daughter both said that that would be neat.

In the previous excerpt a mother was responding to the possibility that daughters might have found some type of support group useful in earlier days, and that they might still find it useful now. In the following excerpt a mother and daughter reflect on having some unmet needs in earlier times. Cindy and her Kate both agree that being in the study made them realize that they both could have used more help in the early days of breast cancer, thoughts voiced by other mothers and daughters. This realization did not alter the fact that, for Cindy, it was nice to revisit a special time.

C: Although we talked a lot, it still would have been helpful in retrospect to have met with someone along the lines of what we have been talking about.

K: Ya.
C: To kind of assist us in how it's likely to be, or these are just some of the things that mothers and daughters have told me. Be prepared for whatever – the emotions or the physicalness. How we can work through this together. I think that would have helped.

K: Ya it would have helped.

C: It has been nice to go back and think in retrospect. In a way it was a special time. When you go through a crisis it ends up being really special.

This mother and daughter, as did others, endorsed the idea of being able to talk with a psychologist, or rather a person like me, early on, both individually and jointly. Having a better idea about what to expect, and how to work through the experience of breast cancer together would have been useful.

Some participants told me that before joining this study, they would have been very reluctant to consider meeting with “someone like me” because they did not realize how easy and beneficial it was to talk about their experience. Were they interested in seeing someone like me on a professional basis they would not know how to go about it.

Counselling services provided by cancer agencies are mainly focused on group counselling, something mothers viewed as beneficial but limited. Individual counselling and counselling that is family focused were services that mothers thought would be very beneficial. Although cancer agencies do offer individual counselling, and children may on rare occasions join their mothers in individual counselling sessions, the focus of counselling services is on groups. A group format is not something that all mothers found useful, and mothers were reluctant to send their daughters to groups where their daughters would be among dissimilar others. Were family counselling available, mothers
would be inclined to take advantage of it. Were groups for teenage daughters of mothers who had breast cancer available, daughters would be interested in meeting with their peers.

Being in the study offered participants an opportunity to pass on some advice based on their experience. Some advice was offered spontaneously. Some was offered in response to the question “What would you like professionals in health care and counselling psychology to understand?” In our last meetings we also revisited the idea of a book or a brochure for mothers and daughters, which some participants had thought at the outset would be a desirable outcome for the study. By the end of the study all participants endorsed the idea. Having examples of how ordinary people like themselves dealt with the breast cancer experience would be helpful, as would any guidelines that might come from the study.

Daughters had some advice for mothers in dealing with their daughters. They stressed how important it was that daughters be made as fully aware as possible about their mother’s illness, even if knowing more might be upsetting. That was important for two reasons. First, there was an issue of honesty and trustworthiness in their relationships with their mothers. Second, there was an issue of being prepared if their mothers did not recover from the illness. Mothers were not unsatisfied with the way they had handled the news with their daughters, but might have done some things differently if they had known how to go about it. Having a handbook or pamphlet would be very helpful for both mothers and daughters because it could provide information, support and direction
at the outset of a difficult time.

Mothers and daughters had advice for educators and health care professionals. They spoke about the need for more education in the schools, and for an improvement in the skills and attentiveness of some physicians. More than one mother thought that health classes in schools should include a component on breast cancer that would educate girls on the importance and practicalities of attending to breast health. Daughters were skeptical about how realizable that idea would be but did see a benefit. Mothers talked about the level of skills in physicians doing breast exams. Most felt that physicians, on the whole, were either not adequately trained to do breast exams or were not prepared to spend the time necessary for doing a thorough breast examination. One mother, who had been left with limited mobility in her shoulder years after treatment, stressed that physicians ought to be providing referrals to physiotherapy.

Several mothers recommended that psychological services in a one-on-one and in a family setting be made more available. With respect to group formats, some mothers said that they would be more comfortable with services for daughters if they knew the facilitator, knew what the group would entail, and could be assured that daughters would be handled with care. Some daughters recommended that groups for daughters include other activities aside from just focusing on the cancer. They had some reservations about not knowing the other girls and unless that were dealt with, it would be awkward to meet. What I learned I learned from this study was that mothers and daughters each had areas of experience that were not shared, and might or might not want to be shared, with the
other person. One mother recommended that it might be good to have counselling for mothers and daughters where these groups could alternately meet together and privately. This may be one viable solution to designing services for mothers and daughters.

One of my last questions to participants was whether they might be interested in some form of follow-up to this research. I asked them, "If the opportunity arose to participate in a conference or to attend a conference would that be of any interest to you?" All agreed they would like to be given the opportunity to participate, say for example with some of the other participants on a panel, and would most likely attend a public presentation. I also asked them, "If the opportunity arose, would you be interested in participating in any follow-up research to this study?" All but one mother-daughter dyad, Barbara and Sarah, indicated they would indeed be very interested in being contacted about any future study. In view of our recent conversation about how breast cancer activities can become overwhelming, I was not surprised at their response. Barbara asked me check to with her maybe in six months or a year’s time. At the close of the study I felt encouraged that overall participants found they had enjoyed being in this study. They were interested in what opportunities might be crafted to move what we had discovered together into professional and public spheres. Many encouraged me to continue my work through research, writing, public speaking, and counselling practice.

**Summary**

Participants said that the process of being in the study was easier and more enjoyable than they might have expected. Participants could feel understood and
appreciated by virtue of the open discussions and feedback letters. Having the group feedback letter promoted a sense of normalcy about their experience and offered a sense of connection with others. They were pleased to have the opportunity to reflect on their experience, perhaps especially in the individual sessions but also with their mother or daughter.

The process of being in the study generated new learnings, and these were welcomed whether positive or whether difficult to come upon. For some, the study offered an opportunity to develop perspective on their experience. For others, the study offered an opportunity to address the emotional aspects of breast cancer. The study offered an opportunity to discuss unmet needs, and they might have an opportunity to deal with them. All of the daughters thought they would like to meet similar others, perhaps others in the study. All participants were pleased with the opportunity to have some input into the products of this study.

Participants were asked what advice they might have for similar others and for health care professionals both during the study and in the final joint interviews. Daughters advised that it was important that mothers be open with their daughters about the illness. Honesty was important in and of itself but would be more important if a mother was in the end not going to be okay. Mothers thought there was a need for some guidelines for mothers so they would know how to deal with the cancer with their daughters. Daughters endorsed the idea of having something they could read as well. Some dyads thought that bringing breast health education into the schools would be
valuable. Mothers had some advice for physicians. They should be more thorough with breast exams examinations and should provide more referrals to physiotherapy.

Participants saw a need for improvement in the provision of counselling services. One-on-one counselling should be more available and groups for families and for teenage daughters in similar situations would be valuable.

Summary of Findings

The first section, Embarking on the Study, described the context and direction of this study. This section documented the process of gathering participants and the direction of the inquiry. Gathering participants was hindered by two factors. Expected referrals from health care professionals did not materialize and I discovered that family focused care in the area of breast cancer is largely yet to be realized. I redirected recruitment efforts towards mothers involved in breast cancer information and support networks and discovered that some mothers were interested, if guarded. Mothers were protective of their daughters and had some anxiety about what would come of the study. Daughters surprised their mothers by indicating their interest and by joining the study.

The inquiry began with an initial query about why participants had joined the study and what they hoped might come of it. This question was posed to facilitate an inquiry that would respect the concerns of participants and that might meet their needs as well as my own curiosities and academic needs. Participants' comments coalesced in three areas of interest and concern: (1) improving communication about breast cancer between mothers and daughters; (2) giving more attention to the emotional aspects of breast
cancer; and (3) producing something that would help others in similar situations, such as stories of ordinary people like themselves or perhaps guidelines or a brochure. Asking a question on purpose and outcome at the outset was also designed to facilitate an appreciation of where all participants, myself included, were at the outset of the study and where they might be at the end of the study. Because I was conducting an inquiry of a sensitive nature I felt an ethical obligation to consider and document the impact of this research.

The next section, Breast Cancer Experience, presented the answers to my research questions: 1) What is the meaning and lived experience of breast cancer for mothers and their adolescent daughters? and 2) What is the meaning and lived experience of breast cancer for the mother-daughter relationship? Descriptions of meaning and lived experience were presented in four themes. Themes were developed from a critical consideration of participants' descriptions and my own observations and reflections. Participants were invited to critique and reflect on developing insights both during the study and at the close of the study. Themes are often described as emergent and sometimes taken to have a reality of their own but it useful to state that the themes presented in this study are ultimately a construction of the author. This inquiry proceeded as an interpretive process and its product is my interpretation of the meaning and lived experience of breast cancer.

The first theme, Inhabiting Another Landscape, provided descriptions of experience from diagnosis, through treatment, and on into the present and possible
futures. Participants described feeling that they were now in another place, and that life was no longer the same. The landscape of breast cancer involved medical jargon, fears, and uncertainties and it was a landscape they would never entirely escape. Mothers and daughters described the diagnosis experience differently. For mothers, receiving a diagnosis of breast cancer entailed strong emotions and a felt obligation to inform their daughters. The task of telling their daughters when they were caught up in a whirlwind of emotion and medical decision-making was both difficult and stressful. Mothers were very unsure of what they should say to their daughters and how they should say it. There was nothing to guide them in this process and so they opted to provide factual medical information on diagnosis and treatment. Their strong inclination was to protect their daughters from undue upset but this was very difficult because cancer is by nature a scary disease. Most daughters did get upset, but at the same time most said they really did not understand what was happening.

Daughters’ descriptions of the time of diagnosis were sprinkled with contextual information, both personal and interpersonal. They told me of their activities at the time and of noticing puzzling changes in relationships. Some daughters became very angry around the time of diagnosis and their anger was related to perceptions of change in their relationships with their mothers. Most remembered little factual information. Like their mothers, daughters had expectations that the cancer would soon be over and done with. Most daughters looked back on the early days of breast cancer with a degree of self-criticism, guilt and regret because they had not appreciated the seriousness of the
Some effects of treatment were unexpected and long lasting. These effects brought changes in the mother-daughter relationship. For one daughter, a mother was no longer able to do things with her because she had a frozen shoulder. For the other daughters whose mothers had received chemotherapy, cognitive changes produced confusion and friction in the relationship because mothers could no longer remember things or had difficulty with driving. Mothers denied cognitive changes at the time and felt that their daughters were tricking them by saying that there had been agreements on outside activities. One mother insisted on driving though in retrospect thought it was a very scary thing that she did continue to drive.

In retrospect, mothers did appreciate that they were not functioning normally and some were still not back to normal. Some still had problems with memory and concentration, and one mother still limited her driving because she had lost her confidence behind the wheel. Mothers learned about chemo brain by living through it and by hearing about the phenomenon in support networks. It was upsetting to have been given no forewarning. One mother was particularly angry that she had no foreknowledge because she had thought the cognitive changes signaled metastatic disease in her brain.

The continuing uncertainty of breast cancer is supported by culture and biology, is present in reminders of vulnerability, and generates a variety of responses to vulnerability. In recent years breast cancer has gained a high profile in Canadian culture. Awareness and fundraising efforts have produced huge dividends in the fact that more
attention is paid to prevention, early detection, support, and efforts to improve treatment. However, in the process, media representations of breast cancer have highlighted the vulnerability of all women and by extension the vulnerability of daughters who are to become women. The heritability of some breast cancers is a widely known recent development in breast cancer research and has given rise to genetic testing and counselling.

In this study, participants paid close attention to media representations of breast cancer and breast cancer research. Heritability was appreciated by both mothers and daughters though none of the mothers had to their knowledge a heritable form of breast cancer. One daughter spoke about seeing a film in her biology class on heritability and the choices women might now make about testing and prophylactic mastectomy. Mothers worried about their daughters getting breast cancer and daughters worried about getting it. With respect to biology and cancer, daughters seemed to be tracking the incidence of cancer in their families.

Reminders of vulnerability were present in for mothers in anniversary dates, in efforts to remain optimistic despite recurrent fears, in painful emotions that would sometimes surface or were just under the surface, and in recurrences among friends and acquaintances in the social networks of breast cancer. Reminders of vulnerability were present for daughters in media representations of breast cancer, in changes in family routines after the diagnosis, in the breast self-exam instructions some mothers had provided, and in recurrences among their mothers’ friends. The strongest reminder for
both was recurrences in social networks. Recurrence brought home that fact that cancer was an unpredictable disease that could come back years later, and if it did it might well be fatal. Recurrence was more difficult where the mother or daughter was better acquainted with the woman.

Responses to vulnerability were conveyed in the individual interviews. Mothers and daughters said little about their sense of vulnerability to the other person and so the response to vulnerability was something privately held. Mothers’ responses included seeking information and support, going to their support groups and to other activities associated with breast cancer, being vigilant about their health, and reasoning strategies. Using reasoning processes mothers attempted to quell their fears and put their painful emotions in a place where they could be contained. Some talked about not paying attention to statistics or by reasoning their chances were better than others because of differences in type of cancer, early detection, or treatment. Mothers strove to maintain an optimistic attitude and presence but this was threatened by their feelings and the knowledge of the unpredictability of breast cancer. Mothers did not ask if their daughters felt vulnerable or what their daughters were doing about feelings of vulnerability if they had them. Most opted to wait for their daughters to say anything and as far as they could tell daughters were not concerned about them or about themselves.

Daughters’ response to vulnerabilities was to keep their concerns to themselves, and like their mothers they spoke about how they reasoned about risk. They hoped or believed that their mothers would be okay although they knew some women developed
recurrences and succumbed to the disease. They talked more about their own risk, putting concerns for sometime in the distant future, imagining a vaccination might prevent it, and displacing concerns about breast cancer onto boys. Some daughters made comparisons to other risks like sexually transmitted diseases, reasoning that the chances of getting AIDS would be higher.

A second theme, Intending and Acting, presented descriptions of the intentions and actions of participants in respect of breast cancer. Participants spoke at length about their intentions and actions. Intentions and actions were both self-protective and protective of the other person. Mother and daughters both talked about carrying on with life. Mothers spoke about the importance of maintaining a normal family life for the benefit of their daughters but also for their own benefit. Carrying on with life meant that they were not succumbing to the illness and would get better. Daughters spoke about carrying on with their schoolwork and activities mostly as a way to reduce stress on their mothers. Mothers and daughters both tried to maintain a positive attitude and presence, and were watchful and caring of the other person. Caring and protective intentions and actions were not always obvious to the other person, and had both positive and negative effects. One example of a positive and negative effect concerned they way they talked or rather did not talk with each other.

Conversations were contoured to protect themselves and the other person from the darker realities of breast cancer. Neither person wanted to upset the other and so conversations were steered away from talk about vulnerabilities and the possibility of
dying from breast cancer. The effect of this unspoken agreement was that conversations were held on tiptoe and concerns were privately held. Mothers had some opportunity to talk about fears with friends but daughters had no such outlet. Mothers’ ability to deal with their own fears, to speak about them with their daughters, and to hear what daughters might say was a limiting factor in conversations. On the whole, daughters followed their mothers’ lead in what was discussed and what was not. In one case a daughter was very vocal about what she could and could not hear, and told her mother very directly that she could not tolerate the idea that her mother might die. With respect to the early days of breast cancer experience, daughters felt that more could have been said to them and that mothers did not appreciate the fact that daughters could handle it.

A third theme, Acquiring Wisdom, presented data on the process and product of learning and personal change that developed over time. Descriptions of two facets of acquiring wisdom, gradual realizations and changed perspectives, were shared in the individual interviews. Lessons in living garnered by mothers, that were either shared or modeled, were drawn from both individual and joint interviews.

With the passage of time participants came to realizations about what breast cancer really meant and about what they had gone through. Most mothers described not fully appreciating the emotional burden of the illness and felt they had not paid enough attention to their feelings. They had also perhaps not really appreciated their daughters’ feelings. Some mothers now considered that their daughters might have had similar needs for information and emotional support. Attending to the emotional aspects of breast
cancer in the early days was difficult because they were then caught up in a whirlwind of
diagnosis and treatment. Most daughters said that in retrospect they had not really
understood what was going on even though their mothers had given them information.
Most daughters looked back on the early days of breast cancer with some self-criticism,
guilt, or regret for their actions or lack of actions. It would have been helpful then to
know more and it would still be helpful to have a better understanding of what they and
their mothers had been through.

Both mothers and daughters talked about having changed perspectives on life in the
wake of breast cancer. One immediate change was in their sense of mortality. Life could
end much sooner than they expected. Both experienced a sense of separation from
friends, partly because they now had a different sense of what was important in life and
what was not. Mothers lost some friends but made new friends in social networks.
Daughters no opportunity to make new friends with similar outlooks on life but were
interested in meeting other girls who had gone through the same experience. For both
mothers and daughter, experience with breast cancer meant that everyday interests and
certain interactions were no longer as interesting or were seen as trivial if not irritating.
Mothers and daughters described rising above the trivialities and avoiding irritating
interactions. Most daughters described being in the role of advisor or counsellor to
friends because they were known to be quite levelheaded about problems. They were also
often sought out because they were sort of a cheerful, helpful person.

All the daughters talked about making careers in the health care professions. Most
mentioned how much they liked the idea of being able to help other people. Daughters were variously interested in physiotherapy, in medicine, and in psychology. One daughter made a link between her experience with breast cancer and her decision to become a doctor. Mothers talked about shifting the priorities in their lives and in their careers. Some focused more on themselves and their needs and some focused more on improving their family relationships. Some also described an increase in self-confidence, and a willingness and ability to speak out about women and breast cancer.

Lesson in living were garnered by mothers and presented to daughters directly in what mothers taught them and indirectly in what they modeled. Lessons were presented on: a) achieving a balance in life; b) handling illness with humour; c) taking a risk in life; d) initiating social action; and e) acting with compassion and courage to benefit others. Two mothers told me that they had talked to their daughters about the importance of finding a balance in life between work and enjoyment. Both of these mothers also demonstrated balance by the changes they had made in their own lives. One mother and daughter talked about how they used humour to deal with the cancer and demonstrated their humour in our interview. Two mothers spoke about taking a risk in life by deciding to redefine their sense of what they could do and who they were. Two mothers talked about taking action in the community to benefit women with breast cancer. In one case a daughter joined her mother in strategizing on a course of action. All of the mothers in this study were active in the breast cancer community and were members of support networks. They devoted time and energy to furthering awareness, fundraising, and
research. They also offered their support to others, sometimes in very difficult circumstances. In one example given, a mother modeled courage and compassion by the support she gave to a friend despite her own considerable fears. Lessons in living were probably taken in by daughters in varying degrees but all were given learning opportunities.

A fourth theme, Enduring Mother-Daughter Relationships, presented data on mother-daughter relationships and on the import of breast cancer for those relationships. Participants were asked to say something about their relationships in the first interview. They described the teenage years as difficult at times for both parties but also the closeness they shared. Closeness was often described in the amount of sharing and talking between them. They talked about how open they were about their lives with each other. They talked about exchanging opinions and feelings. They talked about sharing a similar nature. These relationships were sometimes challenging because opinions sometimes differed and each was able to irritate the other, partly because they were similarly stubborn or opinionated. However, both described their relationships as close. Daughters often said that their relationships with their mothers were better than others, a surprising and pleasing revelation to their mothers.

Mother-daughter relationships were affected by the experience with breast cancer in a variety of ways. One of the most important changes was that they were cautious in what they said to each other about the breast cancer. Both wanted to avoid upsetting the other person by raising any potential upsetting topics, which introduced an element of not
sharing. For example, mothers worried about their daughters' risk but said nothing about it, preferring to wait until their daughters asked them. Out of consideration, daughters would not ask their mothers about their own risk.

The closeness between mothers and daughters sometimes made parenting and being parented more difficult. In one example, a mother found that the normal parenting responsibilities of helping a daughter take on more adult responsibilities produced friction that threatened her own health. Her daughter avoided work in the home partly because that is normal for a teenager but also because she wanted to believe that her mother was capable of doing it herself. In another example, a mother and daughter struggled with the challenge of negotiating the daughter’s separation. It was difficult for this mother because living for her daughter had been key to her sense of survival, and it was difficult for the daughter because she realized that her mother was not going to around forever. Most mothers had little to say about the effect of breast cancer on their relationships, perhaps a reflection of their felt responsibility to have a normal family life. Most daughters felt that they were probably closer to their mothers because of the breast cancer.

The final section, Being in the Study, presented reflections on what it was like to be in the study, the outcomes of the study and participants’ recommendations. Being in the study offered participants the opportunity to reflect on their experience and deal with emotions. The study created a space conducive to discovering what the experience of breast cancer had meant to them and had meant to their mother or daughter. The open-
ended format and feedback letters offered a way of expressing themselves freely, generated feelings of being understood, and offered an avenue for their input. The group feedback letter afforded an opportunity to feel connected with similar others. Being in the study was more enjoyable and easier than they had anticipated.

Being in the study produced new learnings about their own experience and the experience of the other person. There were some surprises, and some were puzzling or difficult to come upon, but the learnings they discovered were welcomed. Participants recognized and shared some unmet needs, needs that could now be addressed. Participants had some advice for similar others and professionals. Mothers should be more open with their daughters. Some form of guidelines or a brochure on the experience of breast cancer would be valuable for both mothers and daughters. Education on breast health might be made available in the schools. Counselling services should be more available for individuals, for families, and a group for daughters or for mothers and daughters was a good idea.
CHAPTER V

DISCUSSION

This interpretive descriptive study explored the meaning and lived experience of breast cancer for five mothers and their five adolescent daughters. Meaning and lived experience were considered in relation to two research questions: 1) What is the meaning and lived experience of breast cancer for mothers and their adolescent daughters? and 2) What is the meaning and lived experience of breast cancer experience for the mother-daughter relationship? My understanding of the meaning and lived experience of breast cancer was presented in four themes: (a) Inhabiting Another Landscape, (b) Intending and Acting, (c) Acquiring Wisdom, and (d) Enduring Mother-Daughter Relationships.

The discussion in this chapter is structured from a consideration of my findings, what the existing literature implies, and how this study supports and challenges some of the state of the art ideas in this field. The discussion takes a step back from the themes generated in this study, although it references them, and considers the larger picture of the findings. Subsequent to the discussion of findings, the strengths and limitations of this inquiry as a qualitative research study are discussed. Finally, implications are drawn for research and counselling practice.

Discussion of Findings

My discussion of findings is organized in three sections: (a) Trajectory of Experience, (b) Strategic Responses to Threat, and (c) Growth and Relationship. In the first section, Trajectory of Experience, my discussion is focused on the emotional impact
of the breast cancer, ongoing communication issues, and perceptions of vulnerability. This section draws on findings described under the theme of Inhabiting Another Landscape. In the second section, Strategic Responses to Threat, my discussion is focused on the self and other protective intentions and actions of participants. This section draws on findings described under the theme of Inhabiting Another Landscape in the subtheme of Responses to Vulnerability, and findings described under the theme of Intending and Acting. In the third section, Growth and Relationship, my discussion is focused on the acquisition of perspective and the quality of mother-daughter relationships. This section draws on findings presented under the themes of Acquiring Wisdom and Enduring Mother-Daughter Relationships.

**Trajectory of Experience**

One aspect of the meaning and lived experience of breast cancer apprehended in this study unfolded in a trajectory from diagnosis to the present, and on into imagined futures. A trajectory of experience was evident in the emotional impact of the disease, ongoing communication issues, the effects of treatment, and perceptions of vulnerability. These findings were presented under the theme of Inhabiting Another Landscape. They are important because they provide information on what is often referred to as the ‘watchful waiting’ stage of breast cancer, and the progression of experience.

**Emotional Impact**

Mothers and daughters both spoke about the need for more attention to the emotional aspects of breast cancer from the time of diagnosis to the present. The
emotional adjustment in families to breast cancer has been described as very difficult. In her study of issues, problems, and challenges for families coping with breast cancer, Hilton (1993) reported major concerns for some families in emotional responses. In my study, most mothers recognized at the time of the study that they had not appreciated the emotional impact of breast cancer themselves and were perhaps ill equipped to explore the emotional impact on their daughters. Daughters also felt that the emotional aspects of breast cancer were not fully appreciated. Feeling overwhelmed and frightened by the cancer, mothers’ first priority was on acquiring and sharing information. The task of dealing with their emotions and the emotions of daughters understandably taxed their resources. Some made attempts to normalize their own feelings and those of their daughters, which in retrospect yielded unsatisfactory results for all concerned.

One of the barriers to dealing with the emotional aspects of breast cancer experience stems from the difficulty mothers have in hearing about the experience of daughters. As reported in Shands, Lewis, and Zahlis (2000), and as found in this study, mothers may be neither prepared nor inclined to fully address the emotional aspects of cancer experience, either their own or that of their daughters. Mothers and daughters in this study both commented on the relative lack of attention given to the emotional aspects of breast cancer, which underscores the need for emotional support for both mothers and daughters. The need for more support for adolescents was also documented in another study that focused on the information and support needs of adolescent children of women after a diagnosis of breast cancer (Chalmers et al., 1998).
With respect to adolescents, reports of adjustment difficulties with a parent’s cancer tend to emphasize conflict with parents, emotional reactions such as guilt and anger, or preoccupation with personal interests (Hilton, & Elfert, 1996; Lewis, Ellison, and Woods, 1985; Lichtman et al., 1985; Wellisch, 1985). Conflict, strong emotions, and preoccupation with personal interests are often interpreted in light of developmental challenges for adolescents in developing a sense of identity and separating from parents. In my study I heard about guilt and anger in daughters, some conflict between mothers and daughters, and only one instance of what was considered by one mother to be problematic busyness with friends. The explanations offered by participants for anger and guilt, conflict, and busyness with outside interests were different from those found in the literature.

Studies considering adolescent children of parents with cancer often report reactions of guilt and anger, or conflictual relations with parents in connection with a pull felt by adolescents between needs at home and the need to be with friends (Clarke, 1985; Hilton & Elfert, 1996; Lewis, Ellison, & Woods, 1985; Lichtman et al., 1985; Wellisch, 1981). In this study I heard about anger in some daughters, and about guilt and closely related feelings in most daughters, but the explanations offered by mothers and daughters for these reactions were related to a perceived rift in communication, or the potential for a permanent rift because of the mothers’ health. Mothers and daughters reported that daughters’ anger stemmed from feelings they had not been properly informed about the cancer, and from their mothers’ apparent inability to appreciate their
feelings. Daughters reported that feelings of guilt, self-criticism, or regret stemmed from their limited understanding of the cancer experience in the beginning and a gradual realization that they could in fact have lost their mothers to the disease. One of the recommendations of daughters was that it was important for them to be fully informed from the outset, even if the information they received might be upsetting. In the present study, none of the mothers had asked their daughters how much they wanted to be told. Their inclination to protect their daughters as much as possible was presented under the theme of Intending and Acting. The protectiveness of mothers towards daughters and their gate keeping function in respect of what information is passed on to daughters was noted in a study of adult daughters that considered the flow of information between mothers and daughters (Rees & Bath, 2000).

Ongoing Communication Issues

From the perspective of daughters in the present study, the information they received and their communication with their mothers about the experience of breast cancer could have been and could be improved. Mothers found little or no information on how to communicate with their daughters about the breast cancer. At the time of diagnosis, mothers were stressed by a felt obligation to inform their daughters about the breast cancer, and at the time of this study had concerns about their daughter’s risks and how to speak with them about these risks. In both situations, mothers were somewhat at a loss on how to accomplish these tasks because they felt there was a paucity of guidance available to them on how best to proceed. They hoped that this study could provide
mothers with some answers or ideas in the form of guidelines or a brochure.

Mothers in a recent study that considered mother and child interactions about breast cancer (Shands, Lewis, & Zahlis, 2000), and the mothers in this study assumed a teacher/educator role with their children. In both studies, mothers tended to provide factual medical information about the breast cancer. They tried to present a fair but optimistic explanation of the situation but did not engage in conversations of the feelings involved. Mothers in both studies showed little evidence of checking on children’s understanding, and in this study they emphasized the fact that their daughters had been told everything about the breast cancer. As Shands and colleagues noted, “Telling is not explaining; talking to children is not the same as talking with children” (p. 84). In both studies, mothers were focused on the informational needs of children and waited for children to ask questions. In my study, mothers tended to assume that no questions meant there were no problems or concerns. On the whole, their relationships with their daughters were good and there seemed little evidence that daughters had any problems in adjustment.

The present study revealed that daughters’ concerns were privately held, concerns both for their mothers and for themselves. As far as mothers could see, their daughters were doing okay because they rarely brought up the subject of cancer, were doing well in school, and were leading busy lives like their peers. A number of studies that have considered children’s experience have considered it from the perspective of parents. In a recent study of school aged and adolescent children of parents who developed cancer,
Birenbaum, Yancey, Phillips, and Davis (1999) concluded that problems may be underestimated by parents because internalizing problems require personal knowledge of the children's thoughts or private behavior. Because most family focused studies have not involved the participation of children, incorporate children in a limited way, and may rely only on parents' perceptions of children's reactions to breast cancer (Howes, Hoke, Winterbottom & Delafield, 1994; Lewis, Hammond & Woods, 1993; Lichtman et al., 1985; Shands, Lewis, & Zahlis, 2000), the literature is rather one-sided.

Unlike other studies that have reported problems with adolescents (Adams-Greenly, Beldoch, & Moynihan, 1986; Hilton & Elfert, 1996; Lewis, Ellison, & Woods, 1985; Lichtman et al., 1985; Wellisch, 1985), these adolescent daughters did not talk about feeling a burden of increased responsibilities in the home that conflicted with a pull to outside interests. Only one example of conflict over responsibilities at home surfaced. This mother saw her daughter as rejecting but from the daughters' point of view she was helping her mother stay active and it helped her to see her mother manage the house on her own. Although this is only one example, it points out the value of hearing an adolescent's reasoning about conflicts over responsibilities in the home. Speaking with daughters may reveal another side to what can easily be seen as a hostile or rejecting response in a daughter (Lichtman et al., 1985). In this study, conflict between mothers and daughters was most apparent in unexpected and continuing effects of treatment and was described in the theme of Inhabiting Another Landscape under the subtheme of Effects of Treatment.
Effects of Treatment

Prolonged effects of treatment, whether a result of radiation or chemotherapy produced confusion and concern for individuals, and friction in mother-daughter relationships. Descriptions of friction touched on developmental issues for daughters insofar as normal activities with their mothers and with their peers were disrupted. However, the issue at hand was that mothers’ limited ability to interact with a daughter, to drive, and to remember agreed upon outings for daughters was related to puzzling treatment effects rather than to perceived demands at home that reduced the freedom of daughters. The cognitive changes in mothers were most surprising to mothers, to daughters, and to this researcher. They suggest unmet needs for information and support that extend past the time of diagnosis and treatment.

Cognitive changes were unexpected and disturbing for both mothers and daughters. Further research is needed to explore the nature and extent of the phenomenon, however, this study indicates that cognitive changes may be a hidden factor in the adjustment of mothers and children. In my review of the psychosocial literature on breast cancer, review of information on the side effects of chemotherapy provided to one mother, review of my own nursing information on the side effects of chemotherapy (Deglin & Vallerand, 1997), and discussion with mothers, the possibility of the type and extent of cognitive changes mothers reported in this study were not mentioned. The types of cognitive changes mothers reported and their insistence that they had not been forewarned were puzzling since much effort is put into informing women about their
treatment and possible side effects. It would therefore be fruitful to investigate what information is provided and also how that information is processed.

Concerns about the possibility of long-term cognitive changes in women undergoing chemotherapy are a fairly recent development and an area of growing interest in the medical oncology literature. In one of the earliest studies, Wienke and Dienst (1995) reported significant cognitive impairment in women who received chemotherapy on tests of verbal and visual memory, attention and concentration, mental flexibility and speed of processing, visuospatial ability and motor function. A subsequent study that compared women who had received chemotherapy with a control group who received only surgery (Schagen, van Dam, Muller, Boogerd, Lindeboom, & Bruning; 1999) found significant cognitive impairment approximately 2 years post treatment for women who received chemotherapy. As Brezden (2000) noted in a recent study that again revealed significant cognitive impairment in women two years after completing chemotherapy in comparison to a control group, changes which were unrelated to mood, these results have implications for informed consent, counselling, and psychosocial support.

My study indicates that it is easy to underestimate the continuing impact of the physical and psychological effects of breast cancer. For example, because this study involved several interviews with participants, the problem of cognitive changes found in one mother-daughter dyad was uncovered in all mother-daughter dyads where the mother received chemotherapy. I learned about cognitive changes in the final interviews by asking a question about there having been any changes in cognition in those dyads where
it had not been mentioned. With their daughters, mothers tended to deny they had problems which suggests that studies that focus on the developmental challenges of adolescence as an explanation for conflict and studies that rely only on mothers’ perceptions of problems with children may be short-sighted. As noted by Schagen et al. (1999), discrepancies between measures of cognitive impairment and women’s self-reported cognitive changes may be partially explained by the difficulty that women experiencing cognitive deficits may have in assessing cognitive changes.

As Hilton and Elfert (1996) suggested, and as the present study indicates, research where family members are interviewed together and separately is needed. In this study I discovered that daughters had their own health concerns that were privately held and not shared with their mothers. Hilton and Elfert also suggested that adolescents might be willing to discuss their concerns with someone outside the family or with peers in a similar situation. This study indicates that both suggestions have merit. Daughters in this study commented on how good it was to talk with someone else or how talking with peers would be valuable. Because daughters’ concerns were privately held and because the exchanges between mothers and daughters in this study were focused on information as opposed to experience, potential needs in daughters for information and emotional support were not apparent to mothers.

Perceptions of Vulnerability

In my study I discovered that mothers were as anxious at the time of this study as they were around the time of diagnosis to avoid burdening their daughters with concerns
about cancer. These concerns included any worries they might have for themselves and apprehensions that their daughters were now more at risk for breast cancer. In a study of parents' perceptions of changes in their relationships with children after breast cancer (Lichtman et al., 1985), spouses saw more adjustment problems for children than did mothers. One possible explanation for that finding suggested by the present study relates to the intent of mothers to protect their daughters from any ill effects of the cancer. To the extent that mothers are motivated to protect their children, they may be more inclined to report that their children are doing well. Nonetheless, in the Lichtman et al. study, mothers suspected that greater difficulties with daughters were to due to daughters' fears of inheriting breast cancer.

In the Chalmers et al. study (1998) and in the present study, daughters had concerns about whether their mothers were going to be okay. Daughters in that study and in the present study also worried about their own risks of developing breast cancer. Daughters' perceptions of personal risk in both studies were influenced by media information, in particular on the genetics of breast cancer. In the Chalmers et al. study, all daughters felt they would develop breast cancer themselves at some point in the future. In the present study, daughters had concerns about developing breast cancer but did not speak about their risks in terms of inevitably.

My study suggests a caution for researchers who continue to investigate the effects of cancer on the family without differentiating between the types of cancer and the sex of the child. Most studies involving mothers who have received a diagnosis of breast cancer
and their children have not explored the meaning of breast cancer experience in relation to the sex of the child. Studies involving children are few in number, typically group boys and girls together (Birenbaum, Yancey, Phillips, Chand, & Huster, 1999; Germino, 1990; Lewis, Ellis, & Woods, 1985), or are focused on the family as a whole (Hilton & Elfert, 1996). Breast cancer is a unique form of cancer because it is a disease that only rarely touches men. To date most psychosocial studies of breast cancer that involve daughters do not address the sex specific fact of breast cancer.

With breast cancer as with some other types of cancer such as ovarian, cervical and endometrial cancer, where there is an obvious or perceived sex link, it might be reasonable to assume that there might be different vulnerabilities for the children of affected parents. Mothers and daughters worried not only about the future health of mothers but also about the future health of daughters. Concerns were privately held and little was said between mothers and daughters on the subject of daughters’ risks. Mothers felt an obligation to protect their daughters but had little guidance on what could or should be said, a continuation of the problem they faced with their daughters at the outset around the time of diagnosis. Mothers were still in the position of teacher/educator but had little information to go on and had no support in addressing the difficult issue of vulnerability for their daughters.

Breast cancer is a complicating factor in mother-daughter relationships given that mothers are especially caring and protective of their daughters with respect to the health of their daughters well into the future. Daughters carry the burden of being at some
increased risk for developing breast cancer themselves because their mothers developed breast cancer. Estimates of the risk for daughters varies according to several factors including whether the number of close relatives who developed breast cancer, the extent of the cancer, the age of the mother at diagnosis, and whether the mother was premenopausal at diagnosis. A history of breast cancer in a premenopausal close female relative, that is mother, daughter or sister, breast cancer in more than one close relative, or cancer in both breasts of a close relative may increase the risk for daughters by up to four to six times (Olivotto, Gelmon, & Kuusk, 1995). Women with a first degree relative, that is mother or sister, are known to be two to three times more likely to develop the disease than women with no such history (Slattery & Kercher, 1993).

In a study of adult women who were primary relatives of a woman with breast cancer, developing a personal sense of risk was influenced by the perception of shared similarity with the woman (Chalmers & Thomson, 1996). A shared biology, closeness, and the developmental stage of the relative were three factors that increased the sense of personal risk, and all three factors were considerations for daughters in this study. In the Chalmers and Thomson study, a shared biology described assigning significance to their own and to the other’s biology through selective appraisal of biological data. The daughters in this study approached appraisal differently but they did appear to be tracking the incidence of cancer in the family and seemed most interested in cancer occurring in blood relatives. These daughters described very close relationships with their mothers, and were adolescents, at an age when breast cancer in a female relative appears to have a
particularly strong impact (Wellisch, Hoffman, & Gritz, 1996). They all considered they were at some increased risk for breast cancer and some considered their risk to be high.

In this study, all of the daughters were concerned about getting breast cancer one day but described putting off concerns to some time in adulthood. None of the mothers in this study considered that they had a heritable form of the disease, and their daughters held the same view. Nonetheless, the fact that breast cancer is a disease almost exclusively confined to one half of the human race means that women and daughters are both vulnerable and this fact was not lost to the mothers and daughters in this study. It was a realization that resulted in various levels of continuing anxiety for both mother and daughter.

Years after diagnosis and treatment, some mothers continued to experience periodic emotional upset themselves and were careful to avoid an open discussion about the uncertainties of breast cancer either for themselves or for their daughters. Some reminders of the uncertainty of breast cancer and personal vulnerabilities reported in other studies were present for these mothers and daughters, for example reminders on TV and in magazines (Hilton, 1993). In my study, one of the strongest reminders of vulnerability for both mothers and daughters stemmed from recurrences in women in the social networks related to breast cancer. This finding, described under the subtheme of Reminders of Vulnerability, provides one answer to the question of how people judge whether an outcome is potentially controllable (Thompson & Spacapan, 1991).

Although support networks were valued by both mothers and daughters and were a
part of everyday life, recurrences brought home the fact that breast cancer is a disease that can be treated but may prove fatal even in those who have survived for many years. It is well recognized in the breast cancer community that women sometimes drop out of support networks because of the stress of seeing friends develop a recurrence and succumb to the disease, but the impact of recurrence on daughters has not been documented. Mothers have the option to withdraw from support networks if the experience proves too stressful but daughters do not have the same option to disconnect because it is their mothers' group not their group. Daughters are brought into an awareness of vulnerability by their mothers' memberships in groups but have no avenue for seeking or providing the support women can receive in their groups or the support they could offer to a friend when a recurrence happens.

Strategic Responses to Threat

One aspect of the meaning and lived experience of breast cancer was that intentions and actions were focused on assuaging the ongoing threat posed by the uncertain nature of breast cancer. Responses to uncertainty were described in the theme of Inhabiting Another Landscape, under the subtheme of Responses to Vulnerability. Intentions and actions to diminish the impact of breast cancer were described under the theme of Intending and Acting. The intentions and actions of mothers and daughters are important because they speak to the question of how family members deal with the threat of the initial diagnosis and ongoing uncertainty.
Handling Uncertainty

Mothers and daughters handled the chance that cancer might recur in mothers and the chance that daughters might one day develop cancer in both similar and different ways. Coping theory provides a framework for considering the different responses to the stress of continuing uncertainty described in this study. Coping theorists have emphasized two ways of dealing with stress: problem-focused coping and emotion-focused coping (Lazarus & Folkman, 1984). In problem-focused coping, direct actions are taken in the environment or with the self to remove or change circumstances that are appraised as threatening. In emotion-focused coping, actions or thoughts are altered to control the distress of threatening influences.

Around the time of diagnosis, there were immediate actions to be taken in respect of treatment. Daughters were outside of the medical decision-making loop, but actions such as managing their own affairs to reduce the stress on their mothers were possible. Around the time of diagnosis, most mothers and daughters assumed that actions would take care of the cancer and that it would soon be thing of the past. With passage of time, mothers and daughters recognized that a diagnosis of breast cancer entails prolonged uncertainty. With respect to actions that could be taken to ensure the future health of mothers and daughters, conflicting information and a recognition of the limitations of medical knowledge contributed to a sense of confusion for mothers and daughters about what actions would be appropriate. For example, mothers were careful of their own health and also encouraged their daughters to be careful but it was unclear how to be
careful and how effective being careful might be. Daughters recognized some need to be
careful about their health but there seemed little to be done at present.

In this study, the use of emotion-focused coping was evident in the descriptions
mothers and daughters gave of their responses to perceived vulnerabilities at the time of
the study. Feelings and worries were put away. Troubling statistics on breast cancer were
downplayed. Their own situations were defined optimistically, and in some cases
redefined almost beyond reason. For example, daughters might reference the equal or
greater vulnerability of boys to breast cancer or explain how all women who experienced
recurrences just got better. Comparisons were also made with women who had
recurrences or with the chances of other life threatening possibilities to increase feelings
of safety.

Mothers often engaged in a process of social comparison, reasoning that their
chances were better than a woman who had a recurrence by virtue of differences in the
type of cancer they had and the treatments they received. A recent experimental study on
social comparison and adjustment to breast cancer (Stanton, Danoff-Burg, Cameron,
Snider, & Kirk, 1999) revealed that women utilized downward social comparison in self-
evaluation. The reasoning of mothers in my study speaks to the question of whether or
not social comparisons are made spontaneously about personal risk and what form of
comparisons might be made, that is upward or downward comparisons (Klein &
Weinstein, 1997). Mothers in this study most often engaged in downward social
comparisons, and some spoke to their daughters about their risk as being much less than
those of other women. With respect to their daughters’ concerns for them, mothers tried
to present a truthful but optimistic front. However, the basic unpredictability of breast
cancer, whether or not it might revisit mothers in the future and whether it might happen
to daughters one day was a fact of life.

Carrying On

Restoring and maintaining a sense of normalcy was a goal shared by mothers and
daughters from the time of diagnosis. Mothers were intent on keeping family life as
normal as possible and tried to carry on as normal, both for their own benefit and for the
benefit of their daughters. Daughters tried to carry on with the normal activities of work
and play, both for their own benefit and for the benefit of their mothers. Attempts to
return to a normal life after a diagnosis of breast cancer have been documented in
mothers who try to act normal and not do anything differently (Shands, Lewis, & Zahlis,
2000) and in children, more often older children, who try to act normal (Issel, Ersek &

In this study, daughters’ attempts to act normal seemed to be interpreted by
mothers as indications that things were in fact pretty normal for their daughters, which is
perhaps not surprising. Daughters often adopted a cheerful and optimistic attitude and
presence and kept their concerns to themselves. In another study (Issel, Ersek & Lewis,
1990), one young daughter described how she would pretend to watch TV and how her
mom would think she was watching TV. In fact she was thinking about the illness and
wanted to conceal this from her mother. The mothers in this study did not seem to fully
appreciate the efforts of their daughters, perhaps because they were attempting to control 
the impact of the cancer and were in a protector role. Daughters were similarly protective 
towards their mothers and intent on shielding their mothers from the realization that they 
did have worries. The mutuality of protective intentions in mothers and daughters created 
a sense of normalcy but it is an adaptation to illness that may produce unwanted 
consequences.

Parents are often concerned that talking about their experience will only heighten 
the anxiety of a child and if they are experiencing emotional distress themselves, so it is 
in the best interests of the child to not share their experience (Hoke, 1996). The daughters 
in this study voiced their opinion that on the whole it was better to talk about everything 
even if it might be upsetting. Hoke observed that children follow their parents cues in not 
talking but when parents are more open they are reassured even if parents are distressed. 
By participating in this study, mothers and daughters had some opportunity to air their 
concerns and share their feelings and this contributed to their positive reactions to being 
in the study.

The watchfulness and caring described and shown between mothers and daughters 
were touching. Mothers were generally not very aware of the efforts of their daughters. 
The portion of the group letter that dealt with comments on the watchfulness and caring 
of daughters seemed to come as a surprise to most mothers. Efforts of children to help 
their parents are sometimes reported but they usually cite very obvious signs of helping 
behavior such as household help or intimate assistance with caregiving (Hilton & Elfert,
1996). In this study I learned about the less obvious ways children tried to help their mothers, such as maintaining positive attitudes and looking after their own affairs, through my private conversations with daughters.

In one of the few studies that focused solely on the children of mothers diagnosed with breast cancer (Issel, Erek & Lewis, 1990), the questions posed by the researchers were all focused on what families did to help children cope and what the children did for themselves that helped them cope. It would be interesting to know what might be learned if researchers were to ask a question on what children do to help their mothers. This study was not focused on that question and thus can provide only a limited answer, but the daughters in this study were more inclined to help their mothers than most mothers realized. In my study, and in the presentation by the 16 year-old daughter (Tennant, 1999), I noticed that one of the frustrations for daughters was that there seemed to be little they could do to help their mothers. One of the ways that children could be supported might be to provide concrete opportunities for children to do something for their mothers, and to receive recognition of their efforts.

**Contouring Conversations**

In my study, mothers and daughters were careful to avoid discussing the darker realities of breast cancer. Whether in the joint interviews or the individual interviews, mothers and daughters both talked about and demonstrated an avoidance in discussing the uncertainties of breast cancer and the threat of death. A study that was designed to explore the role of communication in family coping and assess the impact of an
intervention to enhance communication reported similar avoidance of any talk about death (Walsh-Burke, 1992). In that study, families' self-ratings of communication were generally good or excellent. However, there seemed to be one area that was not spoken about. There was very little or no communication between partners or between parents and children about prognosis and the possibility of death. Participants talked about the importance of maintaining a positive attitude and the author suggested that perhaps these families did not see a lack of communication in this one area as problematic. This study suggests that the lack of communication about possible futures is problematic.

Conversations between mothers and daughters about prognosis and death were difficult and anxiety producing, and by and large were avoided. By turns, mothers and daughters showed their discomfort with the topic and showed this is a variety of ways. If the topic was raised by a daughter, for example a question about her mother’s prognosis or a question about cancer in the family, mothers were inclined to answer very briefly, shift the conversation to another topic, or counter the “negativity” with positive comments. This was something observed in the interviews and something mothers told me they did with their daughters, when we were speaking privately. In only one case did I see the tables turned. One daughter was very vocal with her mother about the fact that she could not handle any negative talk about her mother’s prognosis. Again, for the most part, Hoke’s (1996) comment that children take their cues from parents in respect of what can be discussed applies.

Advice that daughters offered mothers on the importance of including daughters in
their experience by fully informing them produced mixed responses in mothers. In one
interview a daughter offered a comment that was quickly dismissed. Some mothers
dismissed the portion of the group letter that read “don’t ask, don’t tell, because it’s
important not to scare them.” Most daughters listened quietly to what their mothers had
to say and voiced no objections of their own. However, in private both mothers and
daughters had told me that there were limits to what was said and heard and what could
be said and heard. The contrast between what was said and not said in these interactions,
and what was said in the individual interviews can be viewed as an example of the public
and private versions of experience which are more and less readily articulated (Wiersma,
1988). Mothers and daughters each had a private version of experience and each had a
shared version of experience. Private and shared versions of experience appear to be
defined by mutual sensitivities, mutual protectiveness, and anxiety about death.

The joint construction of experience and meaning was evident in the intentions and
efforts of mothers and daughters to restore and maintain a sense of normalcy, and to
avoid the darker realities of breast cancer. The design of this study afforded a unique
opportunity to consider how experience and meaning might be jointly shaped in a natural
system. Most studies consider the responses of individuals either in isolation or as a
family unit and that provides limited possibilities to document the mutuality of
experience.

Growth and Relationship

One aspect of the meaning and lived experience of breast cancer apprehended in
this study was that participants described personal growth as a result of their experience with breast cancer. For both mothers and daughters, time brought an opportunity to acquire new realizations, some of which were positive, and to consider the importance of the experience for themselves and for the mother-daughter relationship. These findings were described under the themes of Acquiring Wisdom and Enduring Mother-Daughter Relationships. They are important because they point to the potential for personal growth that can be accrued for both persons and they illustrate the strength of mother-daughter relationships in the face of serious illness.

Personal Growth

Women who have been diagnosed with breast cancer often say that the experience although frightening and difficult had its benefits. In breast cancer support groups, two statements are consistently heard, “Breast cancer is the worst thing that’s ever happened to me” and “Breast cancer is the best thing that’s ever happened to me” (Caldwell, in MacPhee, 1994, p. 274). However, however the possibility of good things happening for children has received little attention. Most studies that speak to children’s experience are focused on apprehending and preventing adjustment problems in children. Some benefits have been reported but these are often in relation to the quality of family life rather than personal benefit.

In their interviews with adolescents of mothers who had non-metastatic breast cancer, Lewis, Ellison, and Woods (1985) found that adolescents did see some good effects such as bringing the family closer or spending more time in family activities.
Mother’s reports of having a closer relationship with their children after breast cancer (Lichtman et al., 1985) could also be interpreted as a beneficial effect for children. In this study, daughters rather than mothers reported that their relationships had grown close as a result of the breast cancer. However, the benefits daughters described in this study were more like those their mother described.

Mothers and daughters both described changes in attitudes, actions, and relationships that were documented in the theme of Acquiring Wisdom. Both described seeing now what was important and what was not, having a decreased tolerance for the negativities of others, changed ways of interacting with others, not taking things for granted, and becoming a resource person for others. The changes reported by daughters are a new finding, and may be considered in relation to the lacunae adolescents encounter as they struggle with deciding on the question of what is important in life (Violato & Travis, 1997). An encounter with breast cancer provides daughters with an avenue of focus for answering that question. The descriptions of these mothers and daughters of having changed perspectives are remarkably similar to those in a focus group study of older adult survivors of breast cancer (Wyatt, Kurtz & Liken, 1993) that explored quality of life issues with women who had survived breast cancer for over five years.

Lewis (1993) described the changes brought about by cancer as constituting a change in the life-space where family members “must re-evaluate their values, orientation, and self-formulation” (p.127). Her observation that families become actively involved in generating meaning as they reflect on their experience seems an appropriate
way to describe my understanding that mothers and daughters acquired wisdom in their experience with breast cancer. For example, the diagnosis of breast cancer brought an immediate realization of mortality for both mothers and daughters but in time it also brought a greater appreciation for life and the importance of family relationships.

In his descriptions of human change processes, Mahoney (1991) argued for the value of periods of emotional disorganization in affording an opportunity for change and personal development. An event as powerful as a diagnosis of breast cancer could easily serve as a stimulus to a reconstruction of personal realities, such as those reported by mothers and daughters under the theme of Acquiring Wisdom. A diagnosis of breast cancer entails fear, anxiety, and uncertainty and challenges some basic assumptions about life (Lewis, 1993). In this study, the question mothers asked themselves was “Am I going to die?” and the unspoken question that daughters did not ask their mothers was “Are you going to die?” In this study, mothers and daughters talked about the fear of death as something privately held and not discussed with the other person. For the most part, I learned about participants’ concerns about mortality in the individual interviews. If Mahoney is correct that personal growth processes are often initiated by overwhelming events and emotions, then the transformations participants described might be expected.

The work of Mahoney (1991) and the findings in this study suggest that it would be valuable for researchers and practitioners to pay more attention to the uses of adversity for both mothers and daughters. Because one of the anxieties that mothers have is that their breast cancer can produce only negative effects on children, the stress on mothers
may be reduced if they are aware of possible benefits both for themselves and for their children. Lessons in living described in this study point out that mothers, in the process of dealing with their cancer, are realizing the role of teacher/educator in an experiential sense. Their experience may have far reaching effects for their daughters, not all of which are negative.

The personal growth demonstrated by mothers as a result of their experience with breast cancer is perhaps one answer to the question of the uses of adversity. This study shows that mothers were providing important lessons in living to their daughters either directly through instruction or by modeling behaviors and attitudes. Living for today, appreciating relationships, supporting others, and achieving a balance in life were some of the values mothers passed on to their daughters. As mothers articulated and demonstrated what they believed and valued, the possibility of personal growth in response to a devastating illness was shown to daughters. This finding is important because it offers women the hope that their encounter with illness can provide more for their children than just worry and threat. Mothers worry a great deal about the negative impact of their illness on their children (Hoke, 1996) and this places additional stress on mothers.

**Implications for Caring and Relationship**

Caring for others may order and give meaning to life (Mayeroff, 1971). One of the changes that mothers described and demonstrated as a result of their encounter with breast cancer was their caring of others in similar situations. Mothers described having a
different sense of themselves, which involved a shift in their career priorities that included the time and effort they devoted to friends in their breast cancer support networks. The daughters in this study were all at an age where they were considering career choices and had taken courses on career development and planning. The fact that all of the daughters in this study were considering careers in the health care professions could be viewed as coincidental or it could be viewed as a having some connection with the experience of breast cancer. The comments of one daughter suggested a connection between her experience with breast cancer and her choice of career.

In a study that looked at the impact on daughters who were adolescents when their mothers were diagnosed with breast cancer, Clarke (1995) found that career choice was one of the five major issues raised by daughters. Several women reported that one of the chief results of their mothers’ having breast cancer was on their choice of career. They chose to become nurses, perhaps because, as one said, she related to people and the experience had made her a real caregiver. The fact that all daughters in the present study were considering careers in the health care professions, when considered in light of Clarke’s (1985) report of career choices made by daughters suggests that it would be interesting to explore career implications for daughters.

The helping actions of mothers in support groups and the hopeful intentions of all participants speak of a valuing of connection and caring. In my study most daughters described themselves as someone others would go to for help and advice, and they saw value in helping other persons. Collateral data obtained from another teenage daughter
suggests that transformation to a more helpful and caring stance can result from experience with a mother's breast cancer (Tennant, 1999). Again, this study does not lead to the conclusion that daughters planning careers in the health care professions were doing so as a direct result of their experience with breast cancer. The finding that daughters were all considering careers in the health care profession was somewhat incidental and was not explored in any detail. Future research might address the question of the impact of breast cancer on the career aspirations of daughters in more detail. However, the results of Clarke's (1995) study, the collateral data provided by another adolescent daughter, and the career interests of daughters in the present study raise a question about the uses of adversity.

In this study, daughters were all privy to seeing their mothers respond to illness by not only seeking help from others but also providing help to others. The value of helping others was also articulated by both mothers and daughters. Mothers and daughters hoped that the results of this study would provide assistance to other mothers and daughters who were dealing with, or who would one day have to deal with breast cancer. These findings can be viewed in relation to theories of moral development. A social learning approach (Hoffman, 1981) and a feminist approach that speaks specifically to the moral development of girls (Gilligan, 1982) seem most relevant.

In his study of moral development in adolescence, Hoffman (1981) reported that mothers were the most influential person in determining internalized moral standards. Hoffman's approach to moral development is based on a joint consideration of cognitive
abilities and social learning. The ability of adolescents to empathize with others and to engage in abstract reasoning processes combined with an exposure to the pain of mothers and other women dealing with breast cancer would afford an opportunity for moral development. The work of Gilligan (1982) suggests that most females see moral behavior as efforts that involve some degree of sacrifice and attempts to lessen the pain of others. Adolescent daughters’ experience with breast cancer may thus offer an opportunity for moral development. By participating in this study and offering their time and their views on their own experience, adolescent daughters hoped to lessen the pain of other daughters in similar circumstances.

In the present study, mothers and daughters did not report that their relationships were marked by an overabundance of conflict. They considered that their relationships were good. Daughters described their relationships with their mothers as close, and closer than most, and mothers had few complaints about daughters. My study supports a view of relationships between parents and adolescents as being relatively peaceful and harmonious as opposed to being inevitably conflictual (Violato & Travis, 1987) even in the wake of serious illness. My study also supports the findings of Lichtman et al. (1985) that changes in mother-child relationships after a diagnosis of breast cancer were more likely to involve an improvement rather than a deterioration, and the findings of Hilton and Elfert (1996) of an intense emotional bond between mothers and daughters.

In the Lichtman et al. study (1985), mothers reported that the positive changes in their relationships with their children stemmed from an increased ability to share
personal concerns and the fact of the breast cancer having providing a bond and more understanding. In the present study, daughters described the closeness they felt with their mothers largely in terms of their ability to talk with each other and considered that their relationships with their mothers were probably closer as a result of the breast cancer. One limitation to this finding is that other mothers and daughters might not have volunteered for his study because they were experiencing intense conflict.

Some challenges for mothers and daughters in achieving developmental goals as a result of their experience with breast cancer were noted in this study. To the extent that mothers and daughters are focused on a view of daughters’ maturation as involving separation and individuation, the closeness between mothers and daughters probably adds to the difficulty for both. In this study mothers ascribed to a view of maturity as involving separation, particularly in respect of daughters achieving a goal of economic self-sufficiency (LeVine, 1974). An alternative view of maturation based on the values of connection and caring (Gilligan, 1982) might better serve mothers and daughters in similar situations. The mutual caring between mothers and daughters and their closeness might be interpreted as an enhancement to personal growth rather than an impediment.

Strengths and Limitations of this Study

Interpretive description (Thorne, Kirkham, & MacDonald-Emes, 1997) is oriented by a critical analysis of existing knowledge. A critical examination of the psychosocial literature on breast cancer revealed that as yet we have limited understanding of the import of breast cancer for mothers of teenage daughters, for teenage daughters, and for
the mother-daughter relationship. This gap in the literature was the basis for my decision to do a study with mothers and teenage daughters. Existing research on the children of mothers who have received a diagnosis of breast cancer demonstrates a bias towards uncovering problems with children. My bias in this study was that it would be valuable to consider the experience of daughters more broadly. My assumption at the outset of this study was that a diagnosis of breast cancer affords women an opportunity for personal growth. Attuned to the possibility of positive outcomes arising from an encounter with a serious illness, I looked to the good that might be articulated by participants.

The method of interpretive description employed in this study promotes the idea of purposive sampling, aiming for maximum variation on the themes that emerge in the inductive analysis. I discovered barriers to recruitment, which forced me to rely on the few individuals who responded to extensive recruitment efforts. Recruitment was facilitated by an appeal to the breast cancer community. A limitation of this study is that the findings were developed from a group of participants who were connected with breast cancer support networks. A second limitation is that the findings are derived from a sample of white, two-parent families, all of whom lived in urban settings. Thus, caution is warranted in considering how the findings in this study might illumine the experience of other mothers and daughters not connected with support networks. This study provides in-depth information on a small number of participants who are a subgroup of mothers and daughters who have experience with breast cancer. A strength of this study is that the themes that were generated are in several respects related to the existing literature.
Interpretive description advocates using a variety of data sources which this study did use. Verbal descriptions of experience were supplemented by visual descriptions of experience. Individual and joint interviews incorporated feedback letters. Collateral data in the form of media information, organizational print, and the presentation of another teenage daughter was referenced. Interpretive description favours an inductive analysis, and this study employed the inductive approach to analysis articulated by Lawrence-Lightfoot and Davis (1997). Strategic periods of immersion in the field and in the data facilitated the process of synthesizing and recontextualizing as recommended in interpretive description. Recommendations for rigor in interpretive descriptive study were followed. Field notes and reflective journaling provided a basis for following the logic of developing conceptualizations. Repeated interviewing and a feedback process offered the opportunity to refine developing conceptualizations. Credibility was addressed by taking understandings back to the participants at different times during the study for critical reflection, questions, and suggestions as to how current understandings could be improved or expanded.

Two further limitations to this study deserve mention. First, much of the data in this study is retrospective in nature, and it references interactions between mothers and daughters to which the researcher is not privy. An alternative approach to inquiry might utilize a strategy where the mothers and daughters would be invited to have conversations about their experience in the absence of the researcher which could be tape recorded and reviewed with participants (Young, Lynam, Valach, Novak, Brierton & Christopher; in
This strategy would provide an opportunity to analyze conversations and probe for recalled thoughts and feelings when reviewing the tape in the here and now. Second, the difficulty I experienced in recruitment begs the question of who did not chose to participate and why. I have documented my own observations and reflections on this question but my ability to fully appreciate who did and who did not participate remains an open question.

Implications for Research

The present study suggests a need to consider the emotional aspects of breast cancer experience for both mothers and daughters. Mothers and daughters both commented on the paucity of information available to them on the emotional aspects of breast cancer, and considered that their needs for emotional support had not been addressed satisfactorily. The point they were making was that experience as a whole is not considered, and that the available information for mothers and daughters is focused on the medical aspects of breast cancer. Studies focused on the emotional experience would make a valuable contribution to mothers and daughters, and to the literature, because they might generate a more holistic account of what the experience of breast cancer entails.

My study suggests that research on the psychosocial aspects of breast cancer experience in the family may be well served by interviewing family members both together and separately. Studies that rely on either but not both approaches to inquiry are valuable but are ill equipped to appreciate the private and shared aspects of experience.
The present study afforded a view of the relational aspects of breast cancer experience. To date, the literature is largely focused on individual experience, with the exception of studies that consider the experience of women and their partners. This study makes a contribution to our understanding of mother-daughter relationship issues, an area of study that deserves further research.

Because breast cancer is almost exclusively a disease that affects women, and is in a small number of cases heritable, the impact on daughters becoming women deserves more attention. My study indicates that teenage daughters worry about getting breast cancer and their mothers worry about their daughters regardless of the fact that none of the mothers and daughters knew of a heritable component of the mother’s illness. The high profile of breast cancer in the media contributes to the anxiety of mothers and daughters, but to date the literature focuses on the concerns of adult daughters of mothers diagnosed with breast cancer. The mothers and daughters in this study had concerns about taking preventive actions but had no guidelines on what would be helpful and when. A study that would address current medical advice in concert with the concerns of mothers and teenage daughters would be useful.

In this study, coping efforts to deal with the threat of uncertainty in breast cancer were by in large emotion-focused. These responses might be considered adaptive because the degree of controllability of the threat of breast cancer was perceived as low. The question of adaptability however turns on whether or not efforts can affect change in a threat aside from cognitive strategies to ameliorate the sense of threat. For example, is it
the case that particular preventive actions can be taken and is there a best time to take those actions? Research that would address the understandings of mothers and daughters about the type, effectiveness, and timing of preventative health efforts could illumine ways to decrease anxiety and increase effective preventive health efforts.

The transforming aspect of experience with breast cancer documented for mothers and daughters deserves further study. Gradual realizations of the meaning of breast cancer, perspectives gained, and lessons in living garnered from an experience with breast cancer speak to what becomes valued in life. To date, the literature does not consider any possible benefits of experience for daughters although benefits for mothers have been described. The present study suggests that benefits may accrue for both persons and research that would consider the long-term implications for mothers and daughters would be valuable. A longitudinal study, or a follow up study on these mothers and daughters would be two avenues to further inquiry.

Future studies with mothers and daughters might profit from an active consideration of the benefits that can accrue from serious illness for both persons. The problem focused approach in studies considering the experience of children is valuable but is also rather one-sided. The finding that daughters described some beneficial outcomes of their experience with breast cancer was unexpected and suggests a need for further study. The finding that daughters were all considering careers in the health professions was also surprising and deserves further study. The area of career is complex and this study can only offer a suggestion that career choices of daughters may be
influenced by their experience with breast cancer.

Studies on the rehabilitation and recovery phase of breast cancer are sorely needed. This phase of breast cancer experience has been neglected, perhaps because contact with health care professionals who are often the most interested in conducting studies of breast cancer is concentrated in the early and terminal phases of illness. Based on my experience with this study I have a better appreciation for the ongoing effects of treatment and the recovery process. An unexpected finding in this study was the ongoing effects of treatment on mothers and on the mother-daughter relationship. Additional research that could explore the extent and nature of cognitive changes reported in this study would be of value to mothers, family members, and health care professionals. In my view, researchers, physicians and other health care professionals, as well as women and family members may underappreciate the possibility of cognitive changes resulting from chemotherapy.

Focus group studies with mothers and with daughters, conducted separately, would be a useful way to build on this study. Mothers and daughters both experience a sense of isolation in dealing with their experience and a group format would probably be an appealing avenue for discovery for both. One of the most pleasing aspects for participants in this study was the opportunity to hear the experiences of similar others through the group feedback letter. Daughters have a particular interest in making contact with other girls and mothers are keen to learn about the experiences of other mothers who have teenage daughters. The vulnerability of daughters is a sensitive issue, and mothers would
most likely be interested in the opportunity to talk with other mothers who struggle with this issue.

The present study has shown me that repeated interviewing affords an opportunity to access private meanings not shared in the initial stages of the interview process. Incorporating a feedback process was valuable not only in checking on developing understandings and refining conceptualizations but valuable in that it facilitated trust and promoted a free exchange of ideas with participants. Working in an area as sensitive as breast cancer requires a level of trust, and the mothers in this study were from the start guarding the interests of daughters. By starting with a joint interview, the sensitivities of mothers in respect of their daughters could be appreciated and mothers would have the opportunity to judge the tenor of the inquiry. Adopting a respectful, open stance would allow conversations to develop naturally and reduce the stress of an inquiry on personal and sensitive matters.

Implications for Counselling Practice

Counselling psychology has recently developed an interest in the application of counselling psychology to health issues. In 1992, the American Association for Counseling and Development adopted a resolution on counseling psychology as advocates for optimum health and wellness (Myers, 1992). The remedial, preventative and wellness focus is of value for the numbers of counselling psychologists that come into contact with women and families touched by breast cancer. The present study offers a number of possibilities for assisting the women and daughters with issues raised in the
study. The findings in this study do not suggest that breast cancer is a problem that indicates a need for all mothers and daughters to seek counselling. However, the following suggestions would be of value to those counsellors who do encounter women with teenage daughters and who should be prepared to appreciate individual and relational processes.

Counsellors should be prepared to deal with personal and interpersonal processes for women and families touched by breast cancer. Where a counsellor is aware that women have adolescent daughters she or he could begin by exploring the concerns that women may have in respect to their daughters’ own health, and their relationship with their daughters in respect of the cancer. This study has shown that women take responsibility for dealing with their daughters without adequate information or support and this is a major source of stress, particularly in the early days of breast cancer. Counsellors should also be aware of the concerns a woman may have about the implications of her diagnosis for her daughter. All of the mothers in this study were concerned about the risk their daughters now faced but were uncertain how they ought to be dealing with this issue. School counsellors should be aware of daughters’ anxieties.

A family counselling format or counselling interventions designed to address individual and family dynamics would be of interest and benefit to mothers and daughters. To the extent that counselling services focus on women exclusively, they are disadvantaged in addressing concerns in an illness that impacts a family system. This study has shown that mothers are protective of daughters and would be disinclined to
send their daughters off to groups for children of varied composition, for example where children have a parent who is in the terminal stages of illness. Daughters in this study were interested in meeting with other teenage daughters in a similar situation. Most counselling programs for children include children of varying age and who have parents with a variety of cancers in a variety of stages of their illness.

It would be appropriate to consider offering groups for mothers and daughters where mothers and daughters would meet together and separately. Mothers are hesitant to speak about some concerns in the presence of their daughters. Daughters are similarly hesitant to speak about some concerns in the presence of their mothers. A counselling design that would begin and end with mothers and daughters together, and incorporate separate meeting times for mothers and for daughters is one possibility. A group design that would allow the private concerns of mothers and daughters to be shared anonymously in a group of mothers and daughters would open up the possibility of more open communication between mothers and daughters.

Counsellors should be aware that mothers and daughters take care to avoid discussing worrisome issues of prognosis and the possibility of death. Mutual sensitivities and personal fears limit conversations between mothers and daughters on this important aspect of breast cancer experience. Finding ways to facilitate a comfortable way for both parties to discuss their concerns would be helpful. Caution is warranted in pursuing open communication about prognosis and death as a goal of counselling without ascertaining the readiness of both parties to tolerate open discussion on the darker realities of breast
cancer. In this study, concerns about breast cancer were managed with a variety of
cognitive strategies that should be ascertained and respected. Finding alternative avenues
to support individuals in their own resolution of concerns would also be helpful aside
from focusing on communication between mothers and daughters.

Conclusion

This study provides information on the question of the meaning and lived
experience of breast cancer for mothers and their adolescent daughters, and for the
mother-daughter relationship. At present, the paucity of research on mothers and
adolescent daughters is striking and my hope would be that this study might peak the
interest of other researchers and clinicians in a group that deserves much more attention.
Although the findings generated in this study were developed from a small number of
participants and represent the understandings of one researcher, albeit with the
collaboration of participants, this study makes a unique contribution to the literature.

The strength of this study is that it employed individual and joint interviews to
appreciate the individual and relational aspects of breast cancer experience. The design
of this study allowed the voices of mothers and daughters to emerge individually and in
concert, revealing aspects of experience that were either shared or not shared with the
other half of the mother-daughter dyad. The trajectory of illness experience, responses to
it, and the opportunity for growth in the wake of illness make a valuable contribution to a
literature that remains largely problem-focused and targets early or late stage illness.
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GROUP FEEDBACK LETTER

As promised, here is a summary of what mothers and daughters as a group have shared with me in this study. The purpose of the summary is to again invite you to reflect, to ask questions, to make suggestions and offer comments. What follows is my initial attempt to develop answers to the research questions posed in this study, and to make sense of what emerged in the course of some very interesting and diverse conversations. Because each individual and each individual mother-daughter situation is unique, the summary is necessarily selective. A more complete summary of study findings will be provided sometime in the first half of the New Year.

An initial question in this study had to do with our collective purposes in coming together. Some participants expressed a general interest in supporting research on breast cancer, some hoped for specific answers to unmet needs. Mothers were inclined to emphasize a general need for help in dealing with daughters, for example in what and how to tell children about breast cancer. Daughters were inclined to participate because their mothers had asked them and they wanted to help their mothers. They also spoke of a need for knowing how to deal with their mother's breast cancer, for example in dealing with the emotional side of that experience, and of the value in talking with other girls with similar experience.

As a general observation, there seemed to have been and to be very little conversation between mothers and daughters on the experience of breast cancer. Mothers were curious about what their daughters were thinking and feeling, and were caring of them. However, mothers tended to adopt a watchful attitude, and what might be described as a policy of "don't ask, don't tell, because it's important not to scare them". There seemed to be a parallel
for daughters in that they tended also to be watchful and caring of their mothers, and might well defer some curiosities in an effort to protect their moms. For both groups, the caring and protectiveness extended to the other was perhaps not obvious to the other person. To some extent, mothers and daughters both attempted to adopt a positive and optimistic attitude to the experience of breast cancer, perhaps to enhance their own sense of safety and comfort but also to benefit the other person.

All the mothers and daughters described their relationships as being very close – despite the fact that the teen years are often seen and experienced by both parties as a tumultuous time. All the mothers belonged to support groups, which were and very helpful, but which also highlight elements of vulnerability and uncertainty for both parties. For example, mothers and daughters are both aware of women coming into the groups, and of the fact that cancer sometimes recurs. Dealing with the uncertainties associated with breast cancer appeared to be an issue with both mothers and daughters, but an area that was quite sensitive and tended to be dealt with briefly if at all.

With respect to the possibility of strength and resiliency developing in the face of an illness, it appears as if both having breast cancer and having a mother experience breast cancer provides an opportunity of epiphany with regard to values. Both mothers and daughters spoke of having a different perspective on life as a result of their experience. Losing a sense of personal safety or invincibility, although a sad experience, provided an opportunity to put life in perspective, to sort out the important from the unimportant, and to cherish relationships. A sense of wanting to contribute to others, seen in mothers is perhaps also present for daughters. For example, all of the daughters in this study are currently considering entering various health care professions.
Figure 1.
Figure 5.
family - connected - each person is who he is - I don't need to "fix" everything to suit. A B in English. a male - her activities are is ok, her activities are ok ok. I am ok
Whatever happens is OK in some way - Everybody's lives will go on, and anyone can get hit by a bus.
Figure 10.
APPENDIX C

NEWSPAPER ADVERTISEMENT
I understand that my participation in this study and that of my mother are voluntary and may be terminated at any time. Should I have any questions about the procedures, I may ask them at any time. If I have any concerns about my rights or treatment as a research participant, I may contact Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration, at 822-8598. There are no known risks to participants. I have read this form, have been given the opportunity to ask questions about the form and the study, and have had my questions answered to my satisfaction. I acknowledge receipt of a copy of this consent form.

Date:    Signed    Witness

As          's mother I do / do not consent to her participation in this study.

Date    Signed    Witness

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two exceptions: 1) report of sexual or physical abuse of children; and 2) threat of harm to self or others. These would be reported to the appropriate authorities.

I understand that my participation in this study and that of my daughter is voluntary and may be terminated at any time. Should I have any questions about the procedures, I may ask them at any time. If I have any concerns about my rights or treatment as a research participant, I may contact Dr. Richard Spratley, Director of the UBC Office of Research Services and Administration, at 822-8598. There are no known risks to participants. I have read this form, have been given the opportunity to ask questions about the form and about the study, and have had my questions answered to my satisfaction. I acknowledge receipt of a copy of this consent form.

Date: ________  Signed: __________________________  Witness: __________________________
APPENDIX E

SCREENING QUESTIONS
SCREENING QUESTIONS

Potential study participants contacted the researcher by phone. Recruitment efforts were directed to mothers. Participants were screened for: 1) study requirements, that is, the mothers’ health status and the family relationship targeted in this study; 2) availability, that is, approximately four hours of home-based interviews for each participant; 3) current health status of both mother and daughter concerning any condition, such as ongoing therapy, that could foreseeably complicate the study or their lives; and 4) motivation for entering the study, where participants seeking counselling services as opposed to wanting to participate in a study were not enrolled. The following questions were raised.

This study is focused on women who had adolescent daughters at the time of diagnosis, who are approximately three years post diagnosis of breast cancer, and who are not dealing with recurrence or metastatic disease. Would you meet the requirements for this study? Can you tell me when you received your diagnosis, and when your medical treatments finished?

This interview based study is being conducted in participants’ homes. Each participant would be expected to commit approximately 4 to 5 hours of their time. Could you and your daughter both meet these study requirements?

Can you think of anything about your health and your daughter’s health that might foreseeably complicate this study, or that might complicate your lives? For example, people who are currently involved in therapy might not be well served by participating in this type of study at this point.

Can you tell me something about your interest in the study, and also about your daughter’s interest in the study? Can you tell me something about what you would envision as a good outcome, if you and your daughter decide you’d like to participate in the study? If your daughter would like to talk to me about this study and ask any questions, would you let her know that I would be interested in hearing from her directly and would be happy to talk with her.
APPENDIX F

INTERVIEW QUESTIONS
INTERVIEW QUESTIONS

First Interview (Mothers and Daughters together)

1. Can each of you tell me something about why you chose to participate in this study? Can each of you tell me what you would like to see happen as a result of this study?

2. Can each of you say something about the breast cancer, maybe what it was like for you and also for the other person?

3. Can each of you say something about mother-daughter relationships, maybe in general and also about your own relationship?

4. What could you say about health and illness in your family? I’d be interested in hearing about your immediate and extended family.

Second, and Third Interviews (First Individual Interviews)

1. Before we move on, I’d be interested to know something about how our last meeting was for you. What was it like? Is there anything you’d like to add or change?

2. Can you tell me something about how breast cancer (or your mother’s breast cancer) has affected you personally? Has the experience changed your life in any way?

3. Can you tell me something about how breast cancer (or your mother’s breast cancer) has affected your relationship with your daughter (or your relationship with your mother)?

4. I’d be interested in knowing if you would consider putting down something of your experience in visual form. A drawing is something most people enjoy doing once they get going, and it would only take about ten minutes. It could be a picture or just colours, and you might be in it or you might not, and your mother (or daughter) might be in it or she might not. It’s really up to you. I have no way of knowing what a drawing represents without talking the person who did it so afterwards we could talk a bit. Would you be interested in having a go?

Fourth and Fifth Interviews (Second Individual Interviews)

1. Before we move on, I’d be interested to know something about how our last meeting was for you. What was it like? Is there anything you’d like to add or change?
2. As promised, I brought along a summary of your participation in the study so far, my understanding of what you have shared. I thought we could start here today. The purpose of this summary is to help ensure that I am understanding what you have shared, and to give you an opportunity to reflect, to ask questions, to make suggestions and to offer comments. So I'd like you to feel free to say whatever. Could you have a read and let me know how it strikes you, and maybe also what pops out for you?

3. Based on your experience, what would you like health care professionals or other people in your position to understand?

Sixth Interview  (Mothers and Daughters together)

1. As promised, I brought along a summary of what mothers and daughters as a group have shared with me in this study. The purpose of the summary is again to invite you to reflect, to ask questions, to make suggestions and to offer comments. This is my first attempt to make sense of what emerged in the different conversations. So could each of you have a read and let me know how it strikes you and what pops out for you? If your experience is the same or if it is different, I'd be interested in knowing. Feel free to say whatever.

2. If you think about what it has been like for you personally to participate in this study, what would you like to say? If you think about your participation in terms of your relationship with your mother (or your daughter), what would you like to say?

3. Thinking back to what we discussed at the outset of the study in terms of what might come of this study, do you have any further thoughts?

4. If there were an opportunity to attend a conference or a presentation on this study, would you like to be notified? Might you be interested in attending?

5. If an opportunity arose to participate in a follow up study along the lines of this one, or maybe something related, would you be interested in being invited to participate? Might you be interested in participating?
APPENDIX G

RECRUITMENT NOTICES