

Decision-making in the Cancer Trajectory: Mothers with Cancer

By

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Abstract

Mothers with cancer are required to make medical and social decisions while attempting to balance their own physical, psychological and social needs with the many needs of their children. The decisions made during this time of complexity can affect their quality of life as well as that of the family system. To explore the decision-making process among this highly vulnerable group, in-depth semi-structured interviews were conducted with 7 mothers with a cancer diagnosis and children aged birth to 6 years. They were asked to describe: 1) the types of decisions they had made; 2) the process they used to make the decisions; 3) the conditions that shaped their decision-making; 4) the meanings they assigned to their decisions. The grounded theory method of qualitative inquiry was used to develop a framework for understanding the decision-making process of mothers with cancer. The driving force behind these mothers' decision-making was their overriding desire to maintain their bonds with their children. The conditions that shaped their decisions within this context were: 1) the inseparability of the medical and social aspects of their decisions; 2) the overwhelming fear they were feeling; 3) the nature of their relationships with sisters and maternal figures; and 4) the challenge of fulfilling their maternal responsibilities. Their approaches to making decisions that would maintain their relationships with their children under these conditions involved constantly managing: 1) their physical and psychological distance from their children; 2) their physical changes; 3) the information they shared with their children; and 4) the ongoing chain of interdependent decisions. The findings have implications for improving the quality and usefulness of psychosocial supports for mothers with cancer and their families.

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Dedication

This study was inspired by the women in my family who have mothered with cancer and the children who have been affected by that experience.

This work is dedicated to my family.

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CHAPTER 1

Introduction to the Study and Literature Review

Introduction to the Study

In Canada, approximately 10,000 cancers are diagnosed in young adults aged 20 to 44 every year (Cancer Care Ontario, 2006). Two-thirds of these diagnoses are among women, with the higher incidence rate largely being attributed to the sex-specific cancers of the breast, cervix, uterus and the ovaries. Among young adult women aged 15 to 29 years, thyroid cancer is the most common followed by Hodgkin lymphoma and melanoma (CCS, 2009). Research is showing that cancer incidence is rising in young women in Canada aged 20 to 39 although the cause is not fully understood (CCS, 2009).

The increasing rate of diagnosis in this reproductive age group has far-reaching implications. At a societal level, the cost of cancer is high in terms of the potential years of life lost (CCS, 2009). At an individual level, a cancer diagnosis has a powerful impact on women's decisions about employment, education, relationships and family (CCS, 2009).

This increasing incidence of cancer within the reproductive age group suggests that there is an increased incidence of cancer among women parenting young children. The roles of mothers in this age group includes the fostering of attachment with her child (Tacon, 2002), facilitating the healthy cognitive, emotional, social and physical development of her child (Berk, 2005; Ferrell et al., 2003), and protecting her child from harm (Elmberger et al., 2008). If the mother has cancer, she is also required to make medical and social decisions while attempting to balance her own physical, psychological and social needs with the many needs of her children (Billhult & Segesten, 2003). The decisions made during this time of complexity can affect the

quality of life of the mother with cancer as well as the quality of life of her family system (Mellon et al., 2006).

The number of women mothering young children in the context of cancer is largely unknown, to the point that even the number of women with children who are affected has not been identified. The purpose of this study is to explore the decision-making process for women with cancer when the women are mothers with young children.

Review of Literature

This literature review explores published literature that may contribute to a greater understanding of the background to the present study. The review discusses literature regarding mothering, the impact of cancer on individuals as well as the family, and decision-making in the context of a life-threatening illness.

Mothering

Mothering is typically viewed as a biological and moral activity of caring (Elmberger et al., 2005) that is particularly significant because it is among the child's first significant relationships. Caring is about fostering growth and protecting and preserving life according to the values of the social group (Elmberger et al., 2005). But mothering is more than this from a western cultural perspective: it is a relationship that has been institutionalized by society (Green, 2004) and laden with social and moral connotations of responsibility, sacrifice, wisdom and "goodness" (Green, F., 2004; Horwitz & Long, 2001; Liamputtong, 2006).

Each mother has an ideal of what a "good" mother is, created by her own life history and the world around her (Elmberger et al., 2005; Horwitz & Long, 2001). Living with the self-concept of motherhood can be a source of strength while it can also be a burden (Elmberger et

al., 2005). Although mothering is a part of a larger and more complicated identity, motherhood becomes a defining role for the woman and a fundamental part of her identity (Kinser, 2008).

Mothering in normal times. In this review “normal times” refers to the times of life in which the experience of motherhood encompasses the typical stresses of daily life. These normal stresses are varied depending on each family’s particular situations but here these stresses are termed “normal” because they are experiences common throughout the course of motherhood. Because these stresses are common experiences, most mothers can readily find social support networks (McBride, 2008) to help them during normal times.

But mothering young children, even in “normal times” has unique challenges. Young children have intense needs (Berk, 2005) for daily physical, emotional, and social closeness to parents; safety; nutrition; and intellectual stimulation. These needs are most salient to parents during this time when it is normal to be lacking sleep (Geramo et al., 2009) while pursuing paid work and/or further education (McBride, 2008) and trying to reconcile multiple identities and roles imposed on the mother by self and society (Kinser, 2008). In this way, the experience of motherhood is filled with the messiness of blurred identity boundaries (Kinser, 2008). The cumulative effect of feeling the immense responsibility of providing for their children’s well being (Horwitz & Long, 2001) while experiencing the tensions of multiple roles (Kinser, 2008) is a stressful, yet common, existence for mothers of young children (Horwitz & Long, 2001).

Mothering in times of crisis. For the purpose of this review, “times of crisis” refers to the stresses that are not the common experiences of everyday life. These stresses may be expected (e.g., moving) or unexpected (e.g., injury, sudden illness or death of family member).

The realities of mothering during a time of crisis are exemplified in the situation of parenting a child with cancer. This situation represents a significant crisis for families and it

defines/redefines the roles of mothers (Young et al., 2002). Mothers of children with cancer experience the consequence of chronic illness as role strain that reduces the quality of their lives. Young et al. (2002) found that mothers of children with cancer: 1) redefine their self-identity as a mother and grieve for their life prior to the child's diagnosis; 2) feel obligations around protection and responsibility during illness, particularly comforting the child and keeping vigilant watch which may compromise other responsibilities and relationships; 3) experience an intense emotional interdependence with their ill child.

Typically, parent-child relationships are constituted by the interactions of the pair over time (Collins & Madsen, 2003; Evans & de Souza, 2008; Holden & Hawk, 2003; Kuczynski, 2003). That is, each member of the parent-child dyad contributes to the dynamic relationship which changes in several ways over the course of time. Parents adjust their behavior to suit a change in context (Holden & Hawk, 2003) and they will also modify their parenting practices over time as they assess what is happening in their lives (Holden & Hawk, 2003). Both child and parent are active agents (Kuczynski, 2003) who will change in their interactions and modify their thoughts and actions as needed (Collins & Madsen, 2003; Holden & Hawk, 2003). The "closeness" between the parent and child is dependent on the degree of interdependence between members of the pair (Collins & Madsen, 2003). The actions of both parent and child are driven by strong developmental forces (Collins & Madsen, 2003) as well as the conditions in the environment (Collins & Madsen, 2003; Holden & Hawk, 2003). These actions, as well as the capacity for the members to make sense of their experiences (Kuczynski, 2003), contribute to this interdependence in the relationship in times of crisis (Collins & Madsen, 2003).

Among mothers of children with cancer, there is an increase in the degree of emotional interdependence between mother and child (Young et al., 2002), signaling a deepening closeness between the pair.

Mothering in times of illness. When a mother is ill herself it is a crisis of a different sort for the mother. Whether an illness is perceived as life-threatening or not, the mother makes adjustments to facilitate what she perceives to be her motherhood role (Evans et al., 2006).

When a mother faces an illness that is not perceived as life-threatening, such as chronic pain, she tends to work toward balancing caring for herself and caring for others (Evans & de Souza, 2008). She may feel deprived of social and career options, and may find it difficult to carry out tasks due to pain (Evans & de Souza, 2008). Frustration is a commonly felt emotion (Evans & de Souza, 2008).

When a mother faces a life-threatening illness, fear is a more common emotion than frustration – fear of leaving her children without a mother (Billhult & Segesten, 2003). When her children’s continuity of care is affected by the illness the mother’s fear is accompanied by the feeling of burdening her family (Ferrell et al., 2003).

In the case of life-threatening illness, mothers experience a transition in self-identity (Elmberger et al., 2008; Ferrell et al., 2003), but being a “good” mother remains the goal (Elmberger et al., 2005, 2008) while balancing daily life, treatments and side-effects of medical interventions (Billhult & Segesten, 2003; Elmberger et al., 2008). In particular, mothers of toddlers and preschool children attempt to fulfill their ideal of being a “good” mother (Elmberger et al., 2005) by discounting their illness in an effort to normalize life (Billhult & Segesten, 2003), at least until the children would be at the age when the mothers felt that the children were more independent (Elmberger et al., 2005).

The Impact of a Cancer Diagnosis

While a cancer diagnosis could be considered to be the experience of the individual diagnosed, each individual lives within a social environment. A diagnosis of cancer has effects on the entire family system.

The impact of a cancer diagnosis on the mother. The term ‘existential plight’ was coined by Weisman and Worden in 1976 (Lee, 2008) to describe the thoughts one will typically have about the purpose of one’s existence and the potential for nonexistence in a time of crisis. The contemplation of one’s existence after a cancer diagnosis is seemingly inevitable, although the degree to which individuals experience this stress is wide-ranging. The causes of this variation include the severity of the psychological strain, as well as the age of the individual receiving the diagnosis (Blinderman & Cherny, 2005). Regardless of this variation, it is common that a person’s life purpose is called into question at the point of a cancer diagnosis as the belief system that previously offered a person some semblance of normalcy and security has been forever shaken by the arrival of cancer in his or her life (Elmberger et al., 2008; Lee, 2008; Rancour, 2008).

As referred to earlier, when a mother is diagnosed with cancer her self-concept can be affected (Blachman, 2006; Elmberger et al., 2008; Lethborg et al., 2008). Her life changes abruptly and she can no longer rely on her previous understanding about the way life is and her previous promises to provide security for her children (Billhult & Segesten, 2003). Cancer interrupts the continuity of care these mothers can provide for their children and they may struggle with not being able to live up to their own mothering ideals or those of the wider society (Elmberger et al., 2005). Mothers with an illness may feel that they do not fit the societal idea of

the experience of mothering (Blachman, 2006). Their lives can become reoriented in such a way that they must readjust their individual concepts of what being a “good” mother is (Elmberger et al., 2008). Mothers in this situation must work toward balancing being needed by their children and allowing themselves to be ill (Billhult & Segesten, 2003; Elmberger et al., 2005; McCue, 1994; Shands et al., 2006). Perhaps most profoundly, they must go on living in a way that they hope helps their children feel secure while their own security is being threatened (Blachman, 2006).

The impact of a mother’s diagnosis on her children. A mother’s cancer diagnosis impacts a young child in a variety of ways. The stress of the event may impair parenting and the mother’s ability to cope, as manifested in, for example, less psychological availability, less communication, a lack of consistency in discipline and supervision, or increased hostility and irritability (Faulkner & Davey, 2002; Haber, 1994). The family stress resulting from cancer can be manifested as marital tension, which also affects the child (Faulkner & Davey, 2002; Haber 1994).

These changes in parents’ behavior and family functioning are linked to an increased tendency toward behavioral, social and emotional problems in the child (Faulkner & Davey, 2002; Haber, 1994; Hamilton, 2007; Lau, 2002; McCue, 1994). Little research has been conducted regarding the impact of parental cancer on young children from birth to 6 years of age. But the findings available suggest that young children are deeply affected by changes in their perceived security, as well as in changes in their daily routines (Haber, 1994; McCue, 1994).

Typically, young children are in a developmental stage in which they gain their sense of safety and security from their parents. Separation can produce fear and anxiety (Blair, 2001;

Haber, 1994; Hamilton, 2007; Lau, 2002). They also often are egocentric in their thinking; they tend to take responsibility for events and have difficulty understanding the perspectives and needs of others (Hamilton, 2007; Lau, 2002). Toddlers and preschool aged children generally experience the upheaval following a mother's cancer diagnosis as a change in *their* lives rather than the mother's (Hamilton, 2007). They may respond with anxiety and depression due to separations (Blair, 2001; Haber, 1994; Hamilton, 2007), regression in their communication and physical skills (Hamilton, 2007), sleep and eating disturbances (McCue, 1994), worry about causing the mother's illness (Beale et al., 2004; Haber, 1994; Hamilton, 2007), anger toward or rejection of family members (Haber, 1994; Hamilton, 2007), or attaching to another significant adult in lieu of the mother (Haber, 1994; Hamilton, 2007).

A child's difficulties in coping with a mother's illness may become more severe when compounded by multiple stressors such as past or current trauma or abuse, or family dysfunction not attributable to the mother's illness (Beale et al., 2004; Lau, 2002). A child who experiences chronic adversity is more likely to be affected negatively in the long-term than a child who experiences discrete events of a challenging nature (Lau, 2002).

Another factor that compounds the risk that parental cancer poses to children's well-being is how parents communicate with the child about the diagnosis and the illness. Children who are adequately informed cope better with the stress of the situation and show less maladaptive behaviour than children without sufficient information (Forrest et al., 2006; Hamilton, 2007; McCue, 1994). In the latter case, parents might assume that children are naturally resilient and adaptive, that they can survive difficult circumstances on their own with little assistance (Beale et al., 2004). Or they might believe that young children are incapable of understanding the significance of cancer and decide that they children do not need be part of the

communication about family illness (Beale et al., 2004; Forrest et al., 2006). The decision about what and how to tell their children is just one of many decisions that mothers facing cancer must make.

The impact of a mother's cancer diagnosis on the family system. "Cancer" is a word that commonly evokes powerful images of pain, suffering and death (Lee, 2008). Despite advances in care and improved survival rates, cancer continues to carry a societal stigma because the disease is so intensely feared (Lee, 2008). As a result, persons with cancer are affected by their disease not only physically, but psychologically and socially as well (Zittel et al., 2002). This impact is felt by the individuals within a family system (Baider et al., 2008; Faulkner & Davey, 2002; Grinyer, 2006; Lau, 2002; Shands et al., 2006; Waldrop et al., 2005) that includes all significant emotional relationships for that individual. Perhaps the most significant of these are the individual's relationships with his or her children and spouse (Ferrell et al., 2003).

When a mother is diagnosed with cancer, this event changes her life and the lives of those in her family system (Faulkner & Davey, 2002; Haber, 1994; Waldrop et al., 2005). Cancer upsets the family's normal balance of daily existence (Billhult & Segesten, 2003) and necessitates a shift in roles or identities among family members, while burdening them with new limitations and new fears (Elmberger et al., 2005; Ferrell et al., 2003; Grinyer, 2006). The stress of this adjustment to life with cancer may be felt throughout the family system (Baider et al., 2008; Faulkner & Davey, 2002; Grinyer, 2006; Lau, 2002; Shands et al., 2006; Waldrop et al., 2005).

A family experiences cancer as a unit comprised of individuals with various personalities, needs and goals (Waldrop et al., 2005). Cancer disturbs the family balance at several turning points along the cancer trajectory. Waldrop et al. (2005) describe these turning points as caused

by “trigger” or memorable events. Trigger events include: 1) functional changes for a person with cancer, cognitively, socially and/or physically; 2) crisis events such as dramatic symptomatic changes or hospitalization and; 3) the dissemination of new information by a health care provider (Waldrop et al., 2005). These events are turning points for a family because positive or negative family dynamics tend to come to the forefront at these times (Waldrop et al., 2005). These turning points occur following an initial cancer diagnosis and their effects are heightened with recurring diagnoses (Northouse et al., 2005).

Caregivers of persons with cancer are at-risk for negative health outcomes associated with stress, such as depression and anxiety (Baider et al., 2008; Grinyer, 2006; Sherwood et al., 2008). In the case of a young woman diagnosed with cancer, the caregivers might include her spouse or partner, as well as her aging parents. The impact of caregiving stress is affected by several variables including the characteristics of the disease and the caregiver’s personal characteristics, psycho-behavioral responses, biological responses, and overall physical health (Sherwood et al., 2008).

Couples experience stress together when one member of the couple is diagnosed with cancer (Haber, 1994; Shands et al., 2006). This family stress is revealed through decreases in marital satisfaction and family functioning, and increases in communication problems (Ferrell et al., 2003; Haber, 1994; Shands et al., 2006). Family stress often is exacerbated by the guilt experienced by the individual with cancer due to the role-shift required when his or her spouse is a caregiver (Ferrell et al., 2003). Also contributing to the family’s stress are the decisions that must be made regarding time away from work and pressure to return to work as a result of the economic needs of the family (Ferrell et al., 2003).

When a woman with cancer is young, cancer may profoundly affect her parents as well (Baider et al., 2008; Grinyer, 2006; Haber, 1994). For example, mothers of women with cancer may participate in the caregiving of their adult daughters and tend to experience distress similar to their daughter's distress (Baider et al., 2008). As well, the devastating nature of the potential loss of an adult child is associated with emotional and physical ill health of parent caregivers (Grinyer, 2006). Compounding the devastation further is the cultural expectation that children are to outlive their parents (Haber, 1994). Mothers of women with cancer may also experience guilt if they feel responsible for the illness because of their genetic make-up or their own high-risk behaviors (Haber, 1994). If the mother masks her emotions to protect her daughter, this can further complicate their relationship (Haber, 1994).

Decision-making in the Context of a Life-threatening Illness

The cancer trajectory may begin slowly as a mother notices the onset of cancer symptoms or it can begin with a sudden, unexpected cancer diagnosis (Nussbaum et al., 2003). The trajectory can be either a decline in health that leads to death or continued improved health and years of survivorship. Between the onset and conclusion of this trajectory, persons with cancer make many decisions that involve the wide-ranging and overlapping spheres of medical and social decision-making. Decisions must be made continually throughout the cancer trajectory and, while these decisions may have some similar characteristics, each is unique in terms of the time, place, emotions and persons involved. To date, there is an absence of research on the cumulative effect on families of mothers' medical and social decision-making throughout the cancer trajectory.

Medical decisions in the context of cancer vary among individuals depending on the type and stage of the cancer. Upon a cancer diagnosis, a woman may need to make rapid decisions

regarding physician choice, surgical options, and treatment choices. A woman may also be considering genetic testing when family history warrants it (Arden-Jones et al., 2005; O'Neill et al., 2006). These decisions can be influenced by the way that information is presented (Fallowfield, 2008; Halpern, 2008; McDermott, 2008; Schwab, 2008) by oncologists and surgeons and their medical teams, patient counseling services, public access medical sources and online fora (Kenen et al., 2007).

Social decisions to be made throughout the cancer trajectory also vary among individuals. In general, constrained by a lack of knowledge and feeling the effects of time (Baider, 2008) a newly diagnosed woman must make decisions regarding the communication of her health status to the significant people in her life. When this woman is a mother to young children, she faces the additional task of making decisions about communicating her illness with her children (Baider, 2008; Beale et al., 2005; Hamilton, 2007; McCue, 1994). The need for constant updates of information continues beyond the initial communication (Baider, 2008). These ongoing communication decisions may seem endless and ever-changing (Hamilton, 2007; McCue, 1994).

A woman with cancer also must make decisions regarding her level of participation in the social milieu (Ferrell et al., 2003; Lethborg et al., 2008). When she is undergoing surgery and treatment, her schedule and energy levels are affected and it is likely that her priorities will shift to a new way of participating in the social world around her (Billhult & Segesten, 2003). She must make decisions regarding her priorities, as well as how to go about implementing new priorities when they involve people she cares about and activities that she may have previously enjoyed. In particular, mothers of young children may feel that there is a challenge in finding a balance between conserving her energy during treatment and meeting her children's needs (Billhult & Segesten, 2003; Elmberger et al., 2005; McCue, 1994; Shands et al., 2006).

From the literature reviewed it can be expected that mothers with cancer must make medical and social decisions quickly. Each decision may carry a tremendous weight, as it can affect not only her own survival, but her quality of life and the well-being of her children and other family members. How do mothers in such stressful situations make these important decisions? This is the question to be addressed in the present study.

Theoretical Starting Points

This study is a qualitative study. I did not test theories or hypotheses, but explored mothers' decision-making processes in the context of cancer. The theories presented here guided methodological approach taken to gaining an understanding of these processes.

Decision-making Theory

Decision-making theory is widely used in the conceptualization of models and frameworks in economic environments, as well as in the development of decision-making aids used in a variety of contexts (LeBoeuf & Shafir, 2005; Sanfey & Chang, 2008). Classical decision-making theory and multiple-process decision-making theory are explored here in an effort to develop an approach to understanding the decision-making process.

Classical decision-making theory. The classical treatment of decision-making theory is referred to as the rational model, or "rational theory of choice". This model has provided the traditional normative standard in regard to understanding decision-making (LeBoeuf & Shafir, 2005). The rational model uses the concept of "greatest expected utility", meaning that a person assigns a value to each possible outcome. It assumes that people have orderly preferences which may involve a measure of intuition but when faced with a choice, the individual will sum the alternatives and make a decision based on the greatest expected utility (LeBoeuf & Shafir, 2005).

The rational model suggests that decisions are made in this way despite levels of uncertainty (LeBoeuf & Shafir, 2005).

The rational model is useful in making predictions in disciplines that focus on economics and mathematics, as these disciplines employ utility models when understanding decision-making under risk as well as decision-making with consequences spread over time (Sanfey & Chang, 2008). However, the rational model does not fully describe human behavior and the complexities involved in the cognitive process of decision-making (LeBoeuf & Shafir, 2005; Sanfey & Chang, 2008). In fact the decisions that humans make often violate the principles of early rational models. Therefore, the principles of rationality alone cannot fully describe the human decision-making process (Sanfey & Chang, 2008).

Multiple-process decision-making theories. Multidisciplinary research indicates that human decision-making behavior is not a product of one process, as suggested by the rational model, but by the interaction of multiple systems or processes (Evans, 2008; Kahneman & Fredrick, 2005; LeBoeuf & Shafir, 2005; Reyna, 2008; Sanfey & Chang, 2008). Evidence of the multi-system process originates with the recognition that many human decisions fail to obey the normative standards of the rational model due to the subtleties of decisions' contexts (LeBoeuf & Shafir, 2005; Safey & Chang, 2008). These theories suggest that it is the interaction among complex subsystems, or processes, that determine human decision-making behavior rather than one single process (Evans, 2008; LeBoeuf & Shafir, 2005; Sanfey & Chang, 2008). It should be noted that while these theories may describe multiple-processes in decision-making, the majority of these theories are descriptors of two interacting processes and thus they are referred to as "dual-process theories".

Many disciplines draw on the concepts of dual-process theory to explain decision-making in their particular contexts. Research in this area has demonstrated that a generic dual-process theory cannot capture the decision-making process across disciplines, as it becomes oversimplified (Evans, 2008). As a result, a number of dual-processing theories have been put forward to explain decision-making in a variety of contexts.

Each dual-process theory assumes that different modes, or systems, of processing are involved in decision-making (Evans, 2008; Kahneman & Fredrick, 2005; LeBoeuf & Shafir, 2005; Reyna, 2008; Sanfey & Chang, 2008). It is the interaction of these underlying systems, whether synergistic or competitive, that enables an individual to form a decision (Sanfey & Chang, 2008). All dual-process theories are structurally similar in that each theory focuses on two processes, but each theory has unique nuances depending on the domain being described (Evans, 2008; Sanfey & Chang, 2008).

Despite the variations among them, all dual-process theories distinguish between cognitive operations that are fast and intuitive from others that are slow and rule-based (Evans, 2008; Kahneman & Fredrick, 2005; LeBoeuf & Shafir, 2005; Sanfey & Chang, 2008). Dual-process models propose that there are two distinct cognitive processes at work within the decision-making context, most commonly labeled System 1 and System 2 (Evans, 2008; Kahneman & Frederick, 2005). In the most general sense, System 1 processes are unconscious, rapid, and automatic while System 2 processes are conscious, slow and deliberate (Evans, 2008). Intuitive decisions appear to have System 1 characteristics while analytic decision-making is more of a System 2 process (Evans, 2008).

Making decisions is inherently a demanding process. The process usually becomes automated in the case of high-frequency decisions that are not perceived as having an impact on

the long-term future of the individual, family or community (LeBoeuf & Shafir, 2005).

However, throughout the lifespan there are decisions that an individual is required to make that do not have a foundation of prior experience to build upon. It is in these situations when the difficulty inherent in decision-making is particularly evident (LeBoeuf & Shafir, 2005).

A dual-process theory of decision-making describes the psychological struggle between an individual's unconscious intuition and conscious reasoning when making a novel decision (Evans, 2008). This psychological struggle is difficult to resolve, particularly when the individual feels that the decision outcome carries a great amount of risk and the outcome is uncertain (LeBoeuf & Shafir, 2005; McDermott, 2008). To compound the difficulty, it is not only the interplay between processing systems that is involved: social influences such as distress (Halpern, 2008) can complicate decision-making as can the individual's personal characteristics, such as personal beliefs (Halpern, 2008), mood, intelligence, impulsiveness, prior experience, emotion, motivation, and the time available to make the decision (Evans, 2008; Kahneman & Frederick, 2005; LeBoeuf & Shafir, 2005; McDermott, 2008; Sanfey & Chang, 2008).

Difficulty in making a decision can lead to several outcomes. First, the individual might make a decision that reinforces the status quo, which can appear to be a non-decision (LeBoeuf & Shafir, 2005). Second, the individual might postpone the decision or select a "default" alternative (LeBoeuf & Shafir, 2005). Third, the individual might take a myopic or "focal" approach to the decision, treating it as an isolated event and focusing on its immediate consequences rather than considering its long-term consequences (Halpern, 2008; LeBoeuf & Shafir, 2005; Schwab, 2008). As a result, the decision might bring comfort in the short-term but may not be the best one for the more distant future (Halpern, 2008; LeBoeuf & Shafir, 2005).

Individuals have preferences in their decision-making but these are malleable and affected by a host of factors (LeBoeuf & Shafir, 2005). Individuals generally strive to make the "right" choice, but the reasons on which they base their decisions may be fleeting, heavily influenced by the momentary context and available resources (LeBoeuf & Shafir, 2005).

Dual-process theories of decision-making are important when considering the process of decision-making for mothers in the cancer trajectory. These theories draw attention to the complexities involved when an individual experiences conflict between the unconscious and conscious processes of decision-making, particularly when a decision may affect the long-term wellbeing of the mother.

Family Systems Theory

According to family systems theory, family members operate as a set of interdependent units and each family member influences the other (Faulkner & Davey, 2002). This theory emphasizes the intense emotional connectedness of family members (Chibucos & Leite, 2005) which makes the functioning of all family members interdependent to some degree. There is reciprocity involved in these relationships (Kuczynski, 2003). As a result, each interaction, individual need, or change in a family is followed by reciprocal changes in the functioning of other family members (Chibucos & Leite, 2005; Faulkner & Davey, 2002; Kuczynski, 2003).

Throughout the cancer trajectory each family member, including the child, responds to a trigger event or turning point in a personalized way depending on their personality and history (Waldrop et al., 2005). However, these individual family member responses act as a part of a family system and ultimately become a collective family experience. This family experience is expressed in a collective family response which may be changeable but also shows patterns (Waldrop et al., 2005). In the end, a parent's illness as a result of cancer will affect the balance

of the entire family system (Faulkner & Davey, 2002) and the quality of life of all family members is at risk (Mellon et al., 2006).

Family systems theory is useful when considering decision-making in the context of cancer because it reveals the contribution of multiple individuals to a family unit. This theory provides a basis for understanding decision-making that is not done by an individual alone, but that is strongly influenced by a wider system of significant family and friends.

Transition Theory

In 1981 Nancy K. Schlossberg developed transition theory to explain how adults cope with changes in their individual lives, changes in relationships as well as work transitions (Goodman et al., 2006). This theory was connected to the sphere of health care when Meleis et al. (2000) used the concept of transition in nursing, stating that persons in transition tend to be more vulnerable to health risks.

In the context of illness, transition theory would posit that confronting a life-threatening illness is an identity-transforming phenomenon (Rancour, 2008). As established earlier, the event of a cancer diagnosis is justifiably perceived as life-threatening for mothers and can lead to existential plight. Transition theory describes this experience as a sudden and harsh transition from a perceived “normal” pre-cancer existence to an existential crisis and optimally to self-actualization (Elmberger et al., 2008; Rancour, 2008).

The property of time is required for a person to process any change in life, albeit that each individual processes transitions at different rates (Bridges, 2004). Three main stages comprise the transition theory framework. These predictable stages are: endings, the neutral zone, and new beginnings (Rancour, 2008). In the context of cancer the “endings” stage describes the letting go of the existence prior to the cancer diagnosis. Endings are typified by the

resistance to transition to the new role of patient or person with an illness (Elmberger et al., 2008; Rancour, 2008). The “neutral zone” is characterized by anxiety and confusion. As applied to a mother of young children, a mother may feel that her life lacks its previous structure in the neutral zone and she may experience a sense of chaos because of the identity crisis involved in transitioning to a new role (Elmberger et al., 2008; Rancour, 2008). Finally, the “new beginning” stage can be reached after an individual has navigated the first two stages (Rancour, 2008). New beginnings refer to the woman with cancer finding meaning and opportunity in her life as a result of the life journey that included cancer (Elmberger et al., 2008; Rancour, 2008). “New beginnings” is typically associated with survivorship in the literature (Elmberger et al., 2008), so it may appear to restrict meaning-making to those experiencing cancer survivorship. But this stage may also be useful to describe the self-actualization that can come in the event of a life-limiting disease and the eventual decline of health.

Transition theory reflects on the journey through crisis for an individual rather than an individual within the family unit. While no research has been found about how a family may help or hinder a person through these transition stages, the theory provides a language and a guide to understanding the life-threatening experience of cancer and its impact on decision-making.

The Purpose

The overall purpose of this study was to arrive at a detailed understanding of the decision-making process for women in the cancer trajectory when the women were mothers with young children. The specific objectives of this study were to identify: 1) the types of decisions made; 2) the process used to make the decisions; 3) conditions that shape decision-making; 4) meanings assigned to the decisions; 5) recommendations that help to facilitate decision-making.

Assumptions

This study was guided by a social constructivist perspective which emphasizes the process that humans use to make meaning of their contexts, formed by their interactions with others (Creswell, 2007). This study assumed that mothers are experts in describing their own experiences and identifying issues of importance to them. This study also assumed that the role of motherhood is influential on the meanings that mothers assign to events in her life as well as to the actions they take in response to those events.

The Significance

The findings are useful to health practitioners and health promoters such as physicians, oncologists, surgeons, nurses and professionals working in psychosocial oncology as they provide support to women navigating complex decisions that affect their personal wellbeing and that of their families. The findings are also helpful to mothers with cancer and their families, as a greater understanding of the decisions they face, and how they approach them, have been obtained.

CHAPTER 2

The Grounded Theory Method

This chapter introduces the history and philosophy of grounded theory as well as the specific use of grounded theory in the present study. This includes the study design, participant recruitment, data collection, and data analysis.

Study Design

A grounded theory approach to data collection and analysis was used in this study. Unlike other research methodologies, grounded theory is both a method of inquiry and a product of inquiry (Charmaz, 2005, 2006). It provides a flexible system of guidelines and tools that allow researchers to synthesize data, analyze contradictions, interpret data and show relationships within a process (Charmaz, 2005).

Grounded theory was established by Glaser and Strauss, sociologists who argued that theory should be grounded in data (Charmaz, 2005, 2006; Creswell, 2007; Glaser & Strauss, 1967), especially theory explaining human actions, interactions or social process (Creswell, 2007). Later, Strauss and Corbin introduced technical procedures for verification of data analysis using the grounded theory approach (Charmaz, 2005).

Classical grounded theory is founded in positivism (Charmaz, 2005, 2006) with an emphasis on logic, analytic procedures, unbiased observers and discovered theory (Charmaz, 2005). All data are seen as being separate from the researcher and “rendered objective” by data collection from many cases. As a result, the grounded theory methodology described by Glaser and Strauss is known by contemporary theorists as “objectivist” grounded theory (Charmaz, 2005, 2006). As a new generation of researchers began to use grounded theory, this positivist

approach was criticized for its lack of interpretation of the data. As a result, a “constructivist” grounded theory was developed (Charmaz, 2005).

Constructivist grounded theory challenged the objectivists’ assumptions about objectivity, the relationship between the researcher and participants, and how a researcher represents the participants (Charmaz, 2005, 2006; Creswell, 2007). This approach emphasizes researchers’ interpretive frame of reference (Charmaz, 2005, 2006; Creswell, 2007) rather than assuming that they are unbiased observers. According to this approach, during data analysis conceptual categories *derive from* the data because the researcher interprets the data by interacting with the data, as opposed to the objectivist notion of categories *emanating from* the data without interpretation (Charmaz, 2005). There is no neutral analysis. Indeed, the researcher’s knowledge may shape the data analysis, although it does not determine what is found in the data (Charmaz, 2005).

Constructivist grounded theory guidelines are flexible, analytic and allow the researcher to simultaneously collect and analyze data and build inductive theories (Charmaz, 2005, 2006, Creswell, 2007). Each part of the process informs and further focuses the others throughout the entire research process (Charmaz, 2005, 2006). Theories emerge as the researcher collects and analyzes data, makes comparisons, develops categories, and conducts an integrative analysis (Charmaz, 2005, 2006; Creswell, 2007; Glaser & Strauss, 1967). Throughout this process, the researcher’s past experiences interact with his or her emerging ideas (Charmaz, 2005, 2006; Creswell, 2007).

Grounded theory is a research methodology concerned with generating or discovering a theory about an abstract process (Creswell, 2007). Grounded theory provides the tools to compare what people say with what they do and to help researchers identify and analyze

contradictions revealed in the data (Charmaz, 2005). In this way, researchers can go deeply into the experiences of individuals while accounting for the specific social location of the experience (Charmaz, 2009). Among the purposes of this study was to identify a decision-making process as well as meanings assigned to the decision by individuals in a complicated social context of motherhood and the cancer experience. Constructivist grounded theory provides focused tools, a systematic process and analytic guidelines for a rigorous study while allowing for the flexibility needed to understand a process in this complicated social situation.

Sampling

In the grounded theory approach, participants are recruited through purposive sampling, a sampling procedure in which the researcher selects participants for the study because they can purposefully bring knowledge of the central idea being explored (Creswell, 2007). Ideally in a grounded theory study the purposive sampling begins as “initial sampling” and gradually changes to “theoretical sampling” as the study proceeds (Charmaz, 2005, 2006). Initial sampling is based on predetermined inclusion and exclusion criteria aimed at recruiting a diverse sample of participants (Charmaz, 2005, 2006; Creswell, 2007; Glaser & Strauss, 1967). As data collection progresses, the researcher begins to develop preliminary theoretical concepts and categories and then theoretical sampling is used (Charmaz, 2005, 2006; Creswell, 2007; Glaser & Strauss, 1967). This is a strategic and systematic procedure for selecting participants that will most likely help to obtain rich data to refine, fill-out and check those emerging categories (Charmaz, 2005, 2006). Data collection ends when theoretical saturation is reached, which means that new data no longer contribute to new theoretical insights nor reveal new properties of the core theoretical categories (Charmaz, 2006).

Data Collection and Analysis

Fundamental to grounded theory is the simultaneity of data collection and analysis. Analysis begins very early in the process as all data are transcribed, read and re-read. It is through this process that constant comparisons are made and connections are explored. Constant comparison analysis is a method of comparing data with data, categories, and concepts throughout the research process (Charmaz, 2005, 2006). This is an inductive method used to generate abstract concepts and theoretical ideas (Charmaz, 2005, 2006). This process prompts the researcher to pursue ideas that might have otherwise been ignored (Charmaz, 2005, 2006). As the researcher gains insight into the meanings, actions and worlds of the participants, he or she seeks specific data to refine, fill-out and check the emerging conceptual categories (Charmaz, 2005, 2006). Therefore, the researcher continually seeks empirical answers to emerging theoretical questions (Charmaz, 2005, 2006; Creswell, 2007; Glaser & Strauss, 1967). The final result of the simultaneous collection and analysis of data is the development of conceptual categories and an analytic interpretation of the participants' worlds and of the processes that construct these worlds (Charmaz, 2005, 2006). The constructivist grounded theory approach guided the methodology of this study because it has the flexibility required for discovering emergent ideas while offering focused tools and a systematic process to provide scientific rigor.

Coding

Coding began soon after the data collection began (Charmaz, 2005, 2006; Creswell, 2007; Glaser & Strauss, 1967). Coding is the process of taking the data apart and naming each piece in concise terms. It allows the linking of data and the generation of theoretical concepts.

In this study, I developed “active” codes (Charmaz, 2005, 2006; Creswell, 2007) as I interacted with the data, rather than imposing pre-existing categories onto the data (Charmaz, 2006).

Coding was carried out in several steps. In the first step, “initial” or “open” coding labeled participants’ statements line-by-line or incident-by-incident (Charmaz, 2006). Special attention was given to “in vivo codes”. These are specific terms used by participants that carry special significance or unique meaning for them (Charmaz, 2006; Creswell, 2007). Judith Green (2004) gives the example of medical staff categorizing patients as ‘good patients’ and ‘interesting patients’. These terms were explored further in the analysis, unpacking the meanings of these categories and connecting them to normative ideas in the health field. During the initial coding process, I paid particular attention to these “in vivo codes” and took category labels from the words of the participants.

In the second step, “focused” or “axial” coding involved making comparisons across interviews, relating and reassembling the data, and developing higher-level categories (Charmaz, 2006). In this step, I used “memoing”, which is spontaneous writing that helps develop focused codes by connecting concepts and clarifying ideas. Memoing provides an opportunity to look for processes in the data, to describe what is being revealed, and to discover gaps (Charmaz, 2006). As the study proceeded, these memos were sorted and integrated to facilitate comparisons among categories and support the logical analysis of the data. Diagramming was used to provide visual representations of the categories and their relationships to each other (Charmaz, 2006).

Generating Theory

As the study proceeded and constant comparisons were made, a cyclical process of induction, deduction and verification evolved which, according to the tenets of grounded theory,

would assist in balancing my assumptions against the data. The processes of thematic description and induction allows the generation of a preliminary theory.

Throughout this process, hypotheses were formulated through logical inference. These hypotheses were verified continually by constantly comparing the data and creating codes and categories until core concepts emerged that described participants' decision-making. Ultimately, a preliminary theory was constructed to describe the process of participants' decision-making.

Methods and Procedures

Pilot Study

The present study was based on the outcome of a pilot study that I conducted in spring of 2008. The pilot study followed a fully developed research protocol and received ethical approval by the Education/Nursing Research Ethics Board at the University of Manitoba as well as CancerCare Manitoba's Research Resource Impact Committee. Its purpose was to provide insight into mothering with breast cancer and identify the needs of mothers and children in this situation. I interviewed 3 women with primary breast cancer who were mothers of children aged 5 and younger. My interview guide was exploratory, asking general questions about the mother's life before cancer, her experience of being diagnosed with cancer, what it was like to be a mother with breast cancer, what she believed her children understood about her illness, and what she felt were the most pressing concerns for mothers with breast cancer. The interviews elicited responses that were categorized into themes: 1) fear as the primary emotion following diagnosis; 2) mothers' desire to normalize life for their children; 3) mothers' perceptions of their children's knowledge of cancer and its impact on the children; 4) children as support systems; and 5) making meaning of cancer as a mother. All of these themes were involved in these women's struggles surrounding the disclosure of information to their children. Even when they

had sought advice from professionals and understood their recommendations, they continued to have great difficulty in deciding what and when and why to disclose to their children. On the basis of these findings, I chose to focus the present study on issues surrounding decision-making. Therefore, the present study was based upon the pilot data, but those data are not included in the present study, as the pilot study was formulative and based on a different interview protocol.

Study Setting

Each individual interview took place at a time and place of the participant's choosing. As a result, the interview settings were varied. Six of the 7 interviews took place in the homes of the participants. One interview took place at a participant's private office space in her place of employment.

All participants were associated with CancerCare Manitoba (CCMB) as a part of their ongoing medical care. Most of the women were diagnosed by CCMB physicians after being referred by their family doctors. All of the women were in the process of treatment or had received their cancer treatments at a CCMB facility in the care of CCMB oncologists, surgeons, nurses, and social workers. The majority of these women used CCMB's psychosocial support services, such as patient and family counseling, group therapy, accessing the patient resource centre, and other wellness activities.

CCMB is an organization with two large site locations in Winnipeg and 16 Community Cancer Programs in rural Manitoba. CCMB is "charged by an act of the legislature of Manitoba with responsibility for cancer prevention, detection, care, research and education for the people of Manitoba. CancerCare Manitoba is dedicated to enhancing the quality of life for those living with cancer and blood disorders, and improving control of cancer for all Manitobans"

(www.cancercare.mb.ca/home/health_care_professionals/information_for_health_care_professionals/ccmb_and_you, accessed May 18, 2010).

Sample Recruitment

Purposive sampling was implemented according to the inclusion criteria outlined below. Saturation of the data was reached without the need for theoretical sampling. This may have been possible because the inclusion criteria were specified clearly and all women fitting the inclusion criteria were able to contribute to the findings.

To be included, a woman must have been: 1) diagnosed within the past 5 years with cancer of any type and stage, and 2) a mother of one or more children under the age of 7 at the time of diagnosis. Mothers of children older than 11 years at the time of diagnosis were excluded on the basis of the independence typically achieved by children of this age, and the increasing likelihood that they will be helping to care for younger children in the home.

Participants were recruited through CCMB via approved posters (Appendix A) placed by CCMB's Communications Department in public spaces in the CCMB buildings. My name and contact information were available on these posters for participants to contact me directly by telephone or email. Recruitment was assisted by Ms. Jill Taylor-Brown, who is the Director of Patient and Family Support Services at CCMB. Ms. Taylor-Brown and her staff handed out invitation letters (Appendix B) to women who met the study's inclusion criteria. The women were invited to contact me directly about their interest in the study. As well, the Patient and Family Support Services staff, under the direction of Ms. Taylor-Brown, contacted potential participants to notify them about the study. When a woman indicated an interest in participating, her contact information was provided to me with her permission. I would then contact the mother by telephone to provide further information about the study and answer her questions. If

she showed continued interest in the study, I would arrange to meet her at a time and place of her choosing and obtain her signed consent to participate in the study (Appendix C).

Participants

The data of 7 participants are presented in this study. Each participant was interviewed once with a total of 7 interviews. After the fifth interview, participant responses were repetitive and did not add to the developed categories, leading me to determine that saturation was reached. However, 2 more interviews were conducted to ensure that the data were robust.

The sample's demographic characteristics are presented in Table 1. The average age of the participants at diagnosis was 35.7 years. Five of the mothers were diagnosed with breast cancer, one with brain cancer, one with leukemia. One mother had two types of primary cancer, breast and uterine. One mother had a cancer recurrence. Together, these 7 women had 15 children. At the time of their mothers' diagnoses, 4 children were aged birth to 3 years, 10 children were aged 4 to 6 years, and one child was aged 7 to 10.

Data Collection

The data were collected via three methods: 1) a demographic questionnaire; 2) a semi-structured interview; and 3) field notes. The demographic questionnaire (Appendix D) was completed by each participant prior to the interview. This questionnaire was designed specifically for this study with the aim of obtaining descriptive information about participants and their families. The semi-structured interviews (Appendices E, F, G, H, I) ranged in length from 36.95 minutes to 66.53 minutes, with an average length of 51.77 minutes. I transcribed each interview verbatim. The purpose of the interview was to explore each mother's decision-making process by drawing out her interpretation of her experience (Charmaz, 2006). I asked each participant to describe and reflect upon her cancer experience and encouraged her to

Table 1

Demographic Profile of Participants

Age*	Cancer	Marital status	Employment status	Number of child(ren)		
				Aged: 0-3	4-6	7-10
42	breast	married	fulltime**	1	1	
33	breast	married	part-time**	1	1	1
33	leukemia	single	fulltime**		1	
35	brain	married	fulltime**	1	1	
39	breast	married	part-time**		2	
40	breast***	married	part-time		2	
28	breast	married	unpaid	1	2	

Note:

* at diagnosis, in years

** indicates Leave Of Absence at time of interview

***participant had a prior diagnosis of a gynecological cancer, in this study she refers to her cancer as her breast cancer

explore her experience of decision-making as a mother of a young child. To facilitate the establishment of trust, I guaranteed each participant confidentiality, listened to her attentively and encouraged her to articulate her intentions and meanings by requesting clarifying details where needed (Charmaz, 2006).

Building on the foundation of the pilot study, the present study interview guide aimed at contextualizing each woman's experience in relation to decision making. The guide was revised to elicit details as needed throughout the course of the study yet the foundation remained the same. Participants were asked to describe their experience with cancer, from the time when they first suspected they had cancer up to the present. This question was guided by transition theory, which would predict that an understanding of the participant's diagnosis experience will be important to understanding her journey along the decision-making trajectory.

The second question asked participants whether family life has changed since the cancer diagnosis and, if so, how it has changed. This question was guided by family systems theory, which would predict that an understanding of the participant's family relationships will be important to understanding her approach to decision-making. As the study progressed this question was changed to ask if mothering had changed since diagnosis because participants were describing the changes in their family lives while answering the first question.

The third question asked participants to describe a significant decision-making experience since diagnosis. Responses were probed as needed in order to reveal which decisions were perceived as significant, the nature of those decisions, the meaning given to them, and the conditions that affected participants' decision-making, including the motherhood role. I also probed for information about what it was like for participants to put their decisions into action and what the results of their decisions were. To understand participants' decision-making more

deeply, at times I asked participants to describe their decision-making prior to diagnosis, as well as how they felt about their significant post-diagnosis decisions in hind-sight.

Finally, I asked participants to reflect on any decisions that they were currently contemplating in order to reveal changes in the decision-making process as a result of their reflection on previous decisions or due to changes in their life contexts. I ended the interviews by asking participants to describe what decision-making supports would be most helpful for mothers with cancer.

Field notes were taken during and after the interviews. These notes described the setting and recorded participants' non-verbal expressions, as well as my thoughts. The field notes were incorporated into memos and attached to the interview transcripts.

Data Management

Signed consent forms were kept in a locked, secure location at my office. All interviews were digitally audio recorded. Each audio file was stored on a computer hard-drive and titled with a letter and numeric code, and transcribed. Each audio file was deleted from the digital recorder within one week of the interview, after its transcription was complete. An electronic copy of each transcript was stored on a memory stick and was also sent electronically to my thesis supervisor. The typed transcripts did not contain any information that would identify the participant, her family, or any medical professionals. The specific locations of the interviews were excluded from the transcriptions. A hard copy of each transcript was used for coding. These working copies were filed in binders and kept in a locked, secure location at my office.

Data Analysis

Line-by-line coding was carried out after each transcript was complete and prior to the next interview. Question guides were revised as category development occurred as reflected in

the appendices. After the third interview, focused coding began. All interviews were compared and codes were reassembled into interrelated groupings. The fifth interview then took place and the developing categories were saturated: no new information regarding the categories was forthcoming. Two more interviews followed and, although they did not contribute to creating new categories, these interviews enabled me to explore the breadth and depth of the categories for these participants.

Ethical Considerations

This study received ethical approval from the Joint-Faculty Research Ethics Board at the University of Manitoba (Appendix J) as well as approval from CCMB's Research Resource Impact Committee (Appendix K). Written consent was obtained prior to each interview. Participation was voluntary and participants could withdraw at any time.

The privacy of each individual was and, continues to be, respected as well as that of her family members and any other individual of whom she spoke of during the data collection process. To protect identities, each participant, and anyone she named, was given a code. Only codes appear on recordings, notes and transcriptions. No individual received financial gain from participating in this study. Compensation was offered to mothers for parking and/or babysitting but no such costs were incurred, as mothers asked to be interviewed when their children were at school or sleeping. A small gift was mailed to each family after the data collection was complete as a token of appreciation.

The interview process had the potential to involve emotional stress for the participants, but it also provided an opportunity for them to share their stories and contribute their personal experiences to the development of a preliminary theory to help explain their situations to others. Care was taken to respect the feelings of each participant; I let them tell their stories without

intrusive questions and I was prepared to end the interview if the participant became emotionally distressed. All participants were provided the contact information of Patient and Family Support Services at CCMB, as well as information about resources that can be obtained at no cost through that department.

CHAPTER 3

Findings

This chapter describes the meaning mothers assigned to their decisions in the context of cancer, the conditions affecting their decision-making, and the decision-making strategies they used.

The Core Category: Maintaining the Mother-Child Bond

The core category that emerged from the data analysis was that mothers with cancer make every decision in an effort to maintain the mother-child bond. Mothers assigned meaning to their decisions. This meaning is the assumption that every decision they made would affect their children. As a result, mothers considered their children at every point of their decision-making. “I feel like I’m not making a decision just for myself. It’s involving a whole family unit now. How is it going to affect the future of not only myself but my husband and the children as well” (Interview 4)? As one mother said:

“I mean every decision. I don’t think there’s a single decision that was made through the entire process that did not revolve around them. It wasn’t based really on what I could tolerate physically or emotionally or mentally... or what my husband could tolerate... it was, what impact was this going to have on them?” (Interview 7)

Every decision made by mothers with cancer was made considering the decision’s potential impact on the children. This meaning assigned to the decision stems from the conditions that shape decision-making and results in the development of a variety of strategies by mothers as they strive to maintain the mother-child bond.

The Conditions that Shape Decision-making

Mothers made decisions under conditions that were varied yet several dimensions of the decision-making context were universally identified as shown in Figure 1: 1) the inseparable nature of the decisions that had to be made; 2) the presence of fear; 3) mothers' relationships with female family members; and 4) mothers' maternal responsibilities.

Inseparable Decisions: "They kind of all blend together"

Mothers felt that there were no decisions to be made while, at the same time, they felt that there was a myriad of decisions to be made. One mother described the individual decisions she faced as "not feeling very significant [because] they all kind of blend together" (Interview 3). Another said, "It's kind of funny because there really is no decision to make. There is, but there isn't really" (Interview 7). What underlies this apparent contradiction?

From their descriptions of their experiences from when they first suspected they had cancer or were first diagnosed until the present time, it was evident that each woman's narrative was unique, including her cancer type and stage, her medical care, her family dynamics, and the manner in which she navigated the months or years since diagnosis. However, despite the differences in the way they were diagnosed and in the types of cancer they had, the mothers were quick to acknowledge that many decisions are expected, or obvious, in the context of cancer. For example, they faced decisions conventionally viewed as medical treatment decisions. But they also acknowledged that all of these decisions had nuances and could be quite complicated. For example, the choice to have chemotherapy contains a second layer of choices as there may be two, three, or even more chemotherapy options. One mother described making a treatment choice and then finding that "there's a million other decisions to follow" (Interview 7). The first decisions to which mothers referred can be found in Table 2.

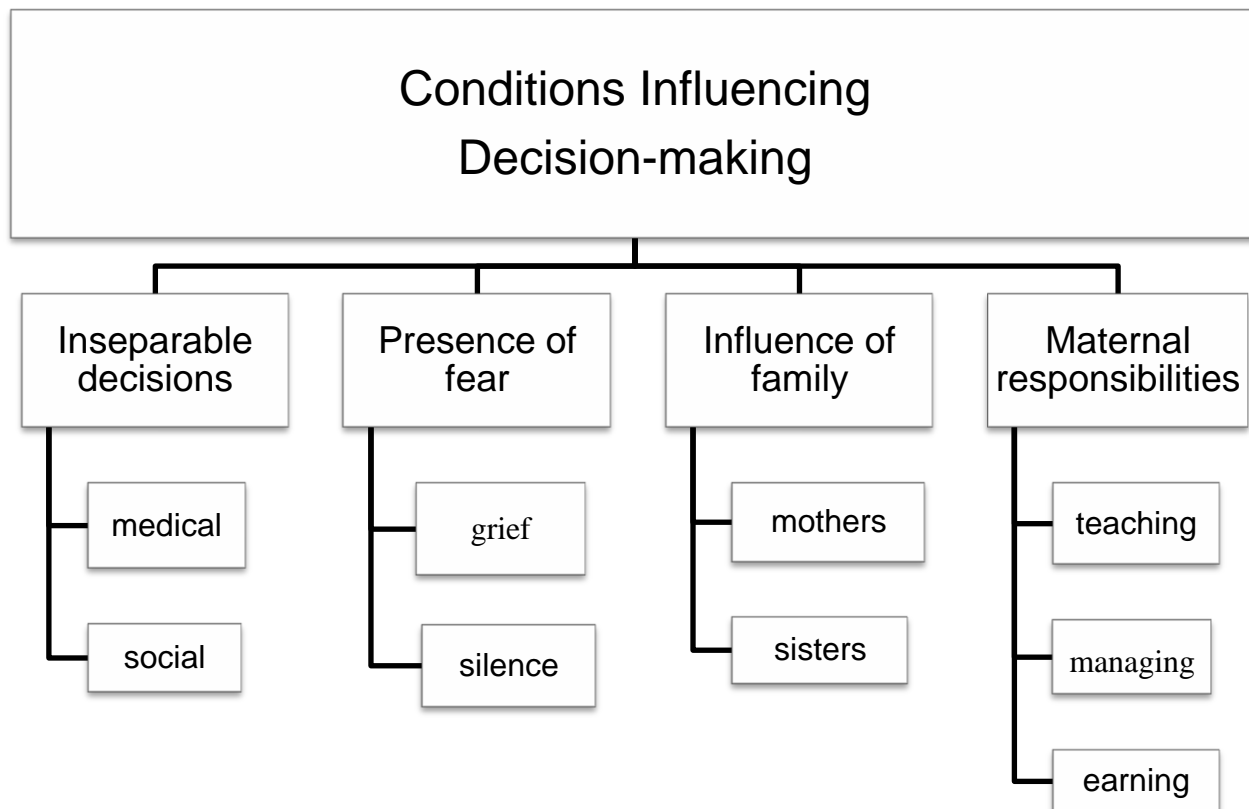


Figure 1. Conditions influencing decision-making among mothers with cancer.

Table 2

Conventional Categories of Decisions in the Cancer Trajectory

Category	Examples as listed by mothers
Medical Decision	Chemotherapy Clinical trial Diagnostic tests Genetic testing Medications Physician choice Radiation Surgery Transplant
Social Decision	Asserting self to pursue diagnosis and/or treatment Childcare Child's participation in extracurricular activities Cutting back on paid work/school (self or partner) Disclosing cancer information Finances Finding time to be alone when needed Future pregnancies Menu planning Receiving counseling or other emotion support Receiving help with basic household duties Selecting supports in the event of critical illness or death Wearing a wig in public

When asked which decisions they would like to describe, most mothers focused on what would be conventionally termed “social” decisions regarding their families. Disclosure about their diagnoses to their family members was of primary importance. They described their struggles with “decisions about who to tell and when to tell and how to tell” (Interview 7). Other common social decisions involved managing their workplace relationships and their home environments, including finances, childcare, and household chores. But what became apparent was that medical and social decisions in this context are interconnected. When a participant discussed a medical choice, she would reference how she perceived the present or future impact of her choice on her family. Medical choices and social choices blend together in the daily lives of mothers with cancer. In some instances a medical factor propelled a social decision and in others a social factor influenced a medical decision:

“You make your medical decisions based on medical information and you make your... you know social decisions all have to do with what happens after that. Or what happens as a result of that. I mean I certainly looked at... they were intertwined for me to a large degree because of the kids. You think about what are they going to be able to tolerate? I think those decisions are intertwined and connected because one effects the other. So the medical decisions you make affect the other stuff. Like coming to work- I mean working through the whole thing. Do I wear a wig to work? Do I not wear a wig to work? What do I do about that? Do I wear a wig when I take the kids to school or not? All of that kind of stuff. That all comes- stems from- the medical decisions that you make. I had to deal with the fact that my hair fell out, socially, so how was I going to do that?”

(Interview 4)

Another mother, describing her treatment decision said: “I made it on the basis of time with my daughter. I didn’t really make it on basis of my medical prognosis” (Interview 1). This mother’s “medical” choice was led by her social need to be near her child as much as possible. Those decisions that mothers identified as important were not described as either exclusively medical or social; each decision wove together aspects of both the social and medical worlds.

The Presence of Fear: “I was terrified”

Fear was a pervasive and influential factor in mothers’ lives, enveloping every decision they made. This finding was physically apparent in the raw data. At one stage of the data analysis each decision point was highlighted in red while words referring to fear were highlighted in green. A substantial number of red-highlighted decision points were surrounded by green-highlighted words referring to fear.

Mothers consistently reported that their first and primary emotional response at the time of diagnosis was “fear” or “worry” due to the possibility of a shortened life. One mother described her emotional state at the moment of diagnosis:

“I think you’re instantly afraid of the worst. I don’t think anyone diagnosed with cancer doesn’t instantly fear that they are going to die. I first got diagnosed, I was terrified.

And when I found out I was stage 3, I was terrified all over again because that’s not good.

And it’s the fear. I never thought, ‘O God, I’m terrified to die.’ I thought, ‘I don’t want my kids to be the kids who lost their mom when they were little.’ I don’t want that to be

the legacy that they have for the rest of their lives. I thought, ‘Who am I going to get?

Who am I going to make in charge of making them ok?’” (Interview 7)

With the fear came grief, as mothers contemplated their children’s futures. While all of the mothers spoke of feeling optimistic that they might live a long time, as one mother said:

“There are still those feelings like maybe my life is shortened a little bit” (Interview 5). Mothers anticipating a shortened life also carried anticipatory grief related to the real possibility of dying prematurely. The relationship between fear and grief was explained:

“The grief piece is more about what you might miss. You grieve over things like, ‘What if I never see them graduate? What if I never see them get married and have kids and all of that?’ I think everyone has a point that they want to get to, and it’s different for everyone. A timeline. I want to get to at least this... if I can just get to the point that they’re this age, I’m ok if the worst happens after that... and for me, because they were so young, I had a time in my head that I just want them to be where they have memories of me. And it’s all connected to your fear because you’re afraid of when you’re going to die. So, when are you going to die? So what am I going to miss if I die? I never once was afraid, I don’t think, the impact on me. I don’t really think I even thought about that.” (Interview 7)

A factor affecting the mothers’ fear was the speed with which they received diagnostic information, whether it was swift or involved a long wait for confirmation of test results. When diagnosis was unexpected and swift, the shock of that life-altering moment transported mothers into intense fear. One mother who experienced a recurrence of cancer described the news of her recurrence:

“It was probably more intense the first time although again, like I said, I thought it was cancer all along so it doesn’t matter. It doesn’t matter if you think that. When you hear it, it’s still a really big shock. It’s the finality kind of thing. It’s the confirmation of your worst fear.” (Interview 5)

At the same time, when diagnostic information came slowly, tension and fear escalated. One mother described the waiting time to see a surgeon to have a lump investigated. As the time passed, her stress level increased as well:

“I remember becoming more and more concerned about it as that time wore on. And being at the walk [fundraiser for cancer], I had the appointment shortly after the walk. I remember being very stressed out and terrified at the walk. And I actually remember the most salient thing for me about that was a woman who was walking with her husband and her two kids. And she had on her, you know, “I’m Running For” thing [sign] and she had ‘myself and my daughter so my daughter doesn’t have to deal with this.’ And her husband had, ‘my wife and my daughter.’ And the kids had, ‘my mom’. And I remember walking behind them and being fairly moved by that and also thinking this could be us next year. Which it was.” (Interview 7)

Whether information comes rapidly or slowly, fear and worry are intense. But this fear is often unspoken, even when decisions are being made. One mother explained that her closest family and friends did not want to hear her thoughts of a potentially shortened life, and that silencing carried over into her decision making:

“Because you make your decisions with that at the back of your mind but you don’t talk about the fact that that’s why you’re making your decision. Because nobody wants to hear that’s why you’re making that decision. I made a million decisions with my kids in mind without saying I’m worrying about the long-term impact on them... even my husband - I didn’t talk to him about those fears.” (Interview 7)

Throughout the interviews mothers did not describe telling friends or families about their fear. Only one mother mentioned speaking to a counselor about her fears. As another stated:

“Nobody wants to talk about that. Nobody. Even still [years later]... nobody wants to talk about that... even still people don't want to talk about that. It's because the people that are closest to me who are the most - who were the most supportive through the whole thing - my close girlfriends and that... it scares them. And they have the gut reaction to say, 'That's not going to happen, you're going to be fine.' So it is hard because there isn't anybody who you can talk to about those really deep, dark thoughts that you have. And there are lots of them. That's one of the hardest things, that you don't have that - the people that you can talk to about anything in the world, you can't talk to about that because they can't hear it. And they can't hear it because of their own fears, which is fine. But at the same time you need to talk about it or think about it or process it or do something with it.” (Interview 7)

How do mothers cope with the constant presence of fear in their lives? Some mothers employed strategies to cope with their fear so that they could make decisions. One mother described her way of coping with the fear and grief that she called “the black cloud”:

“I'm an all-star compartmentalizer I think. That's how I got through the whole thing. That's how I managed to come to work every day... So I have my moments of being extremely low and scared and sad. And those times would usually be in the car by myself. So I'd have a little cry in the car by myself driving home from work. And when I'm at home, I'm at home and I'm focused on at home. So those transition times are when I could focus on cancer. I do the same thing with the black cloud. I allow myself to think about that at times but it doesn't overtake me. It doesn't become what I'm about. I make plans for the future but I still always have that, 'We'll do this... if everything is ok.' It's kind of always in the back of my mind. 'Ok, if nothing bad happens then this is

what we'll do.' It's not as fore-front as what it was. I mean I didn't want to plan... I didn't want to buy a winter coat because it might be wasted money. Now I'll buy a winter coat... I think about it but it doesn't overpower me. It doesn't terrify me to the point where I don't do anything. It doesn't make my whole life about cancer. I mean it's a small piece of my life, it's a small piece of my identity but I have a full life outside of that. And I think you have to or it will consume you." (Interview 7)

Another mother described how her religious faith helped her cope with her fear of leaving her children without a mother:

But my initial thought was for my kids and how they would cope and what would happen to them and how would things work for them. And then I really had to work through the... like I'm a Christian so I believe that as much as I love them, that God loves them even more. So if this is what is going to happen, he is somehow working to the good of us because he loves us even more than even more than I do. So somehow he's going to work it to good, no matter how it turns out. So once I came to that, I was ok with that and then it was more just, "Ok, how are we going to get through this?" (Interview 6)

For some mothers, the presence of a trusted listening person helped them cope. Mothers who perceived their oncologists to be listening to their concerns felt that they were able to make more satisfying medical decisions than mothers who did not feel listened to by their physicians. One mother said:

"He [oncologist] said to me, 'You don't walk out of here with any questions left unanswered.' We never felt rushed, we never felt like we were asking a stupid question or that we were taking up time. None of that. That was massive. That gives you the confidence that you are making the decision that is best for you." (Interview 7)

Other mothers, however, felt that their doctors provided information but did not provide an opportunity for the mother to ask questions or talk about her concerns. One mother described her experience with a pathologist who, in her opinion, provided her with misinformation: “I tend to think these doctors are all demigod in a way. Like, if they tell you, you believe them. And I don’t talk to a pathologist so these are doctors I’ll never see” (Interview 1). This mother, and others, did not feel she could communicate with the doctor who confirmed her initial diagnosis. The weeks to follow were very stressful for her: “The appointment’s never right away, it’s like a week or so. A week, a week and a half I think it was? Yeah, I don’t think I slept very much in those two weeks. I was in a lot of tears too, eh? I was pretty emotional” (Interview 1).

The diagnosis of cancer resulted in the presence of fear of a shortened life for mothers with cancer. This vulnerable state-of-being led mothers to live in silence about their fears. Although unspoken, these fears are very much present in the context of the decision-making experience.

Maternal Figures and Sisters: “Every time I make a decision, it’s affecting her decision”

The presence of maternal figures and sisters in the lives of participants contributed to their decision-making. These women provide advice, protection, and help with daily tasks. In some cases, they acted as an extension of the mother by taking the children to activities and helping the mother with her mothering role. They often provided support in quiet ways by being physically present as a source of comfort. One mother, experiencing a sudden cancer diagnosis and lengthy hospital stay said of her maternal figure: “She just makes it more positive and things like that. Defending me and, you know, she’s being way more overprotective. To prevent anything else from making me upset and things like that. And taking care of taxes on the car, insurance... just being more there” (Interview 3).

In some cases, mothers' relationships with their maternal figures and sisters had a direct impact on their decision making. For example, several of the mothers in this study had inherited a genetic mutation assumed to be involved in the diagnoses of their cancers, and their families had multiple female members who had been diagnosed with cancer. In one case, a mother needed to make a surgical decision while her sister was making a similar decision. She described this situation by saying, "It makes her have to work through her decision again, right? Every time I make a decision, it's affecting her decision as well. Like, even when I'm deciding things I'm thinking about what she's decided as well and how she came to decide" (Interview 6). In these situations, the opinions of sisters and maternal figures had considerable weight in mothers' decisions. It was not clear whether this situation made mothers' decision-making easier or more difficult but it certainly made it more complicated. Those with female family members eager to be involved in decision making, found this involvement helpful in most cases.

Mothers identified the need to select help carefully and setting boundaries. For example, in some cases, maternal figures or sisters became more involved in daily family life than previously. In these situations, mothers accepted help tentatively:

"When [husband] is working usually my mom is here for the whole week to help at night with the kids and during the day with meals and things like that. This week my friend is here but they're not connected yet [friend and children] for helping go to bed and things like that. So it's a little rough but I do enjoy the help... But you just got to accept that you need help and go from there." (Interview 4)

Another mother explained: "You have to make all these decisions about your boundaries and what you need and don't need and what you can accept and what you can't accept and what's out of your control and what you can keep control of" (Interview 6). Mothers spoke about involving

their maternal figures and sisters in roles that were an extension of their mothering, but they felt the need to manage those roles carefully.

The absence of maternal figures and sisters had an impact as well. One mother spoke of the loneliness she had experienced since her diagnosis: “People that are my family and close, close friends... they let us go. They don’t call. They don’t write. They don’t email. They don’t drop by... they treat me like I’m dead already” (Interview 1). This mother had a maternal figure and other family members close in proximity but they were absent from her life, accentuating the loneliness that came along with the diagnosis. Mothers who did not have maternal figures or sisters to provide care, comfort or instrumental assistance, found comfort in a supportive listening professional as well as connectedness to women of their own generation. A listening professional was most often a counselor but some mothers referred to other health professionals who played the role of listener, creating a sense of comfort. For example, one mother experiencing loneliness spoke about a health practitioner with whom she could discuss her physical pain and its emotional impact: “We’ve kind of become really good friends - she’s kind of someone I really look forward to seeing” (Interview 1). This practitioner was able to provide comfort and calm when the mother was making complicated medical and social decisions.

Connecting with organized support groups also ameliorated the effects of absent maternal figures and/or sisters. When speaking about the absence of family and friends in her life since her diagnosis, one mother said, “I was really upset about it for a while but... it’s part of why I joined a support group. I figure that you can cry all you want; it’s just a lot of tears you’re wasting. We’re all at different stages... it’s kind of nice. Maybe I’ll make a few more friends” (Interview 1).

The presence and absence of significant maternal figures and sisters in the lives of mothers with cancer often had an effect on decision-making. These family members were, at times, an extension of the mother to her children which was often appreciated by mothers with cancer. Maternal figures and sisters provided advice, protection and a measure of comfort during times of decision-making.

Maternal Responsibilities: “I was still being as much as a mother as I could be”

Mothers described many facets of the maternal role. Activities of caring such as teaching, managing and earning were mentioned repeatedly by mothers as they worked to maintain their bonds with their children during the cancer experience.

Mothers were continually teaching their children, with respect to the cancer diagnosis specifically, and to the skills and attitudes the mother feels are important for their children to learn. They taught their children about the physical changes that their children could see, such as alopecia (hair loss), peripherally inserted central catheter (PICC) lines, and portacaths (ports). Some mothers brought their children to their chemotherapy treatments so they could learn from the experience.

Mothers continued to assess their children’s needs and tried to be present as much as possible in their lives, even during treatment. One mother who experienced an extended hospital stay remained her child’s teacher despite the distance: “I like to be on the ball. To teach him ‘be on time’, ‘be a good kid’ and things like that... I’m supposed to be recovering, getting healthy and I’ve got to stress about things like that” (Interview 3). This mother used text messaging to monitor the activities of her child’s other caregivers so that she felt she stayed in control of what they were teaching him. She laughed, “Right now his dad’s mostly in charge except for I text

him my commands” (Interview 3). Even from a distance, she positioned herself as a teacher to her child.

Mothers were not as concerned about domestic tasks as they would have been in times of health, but they were concerned with the tasks that directly affected their children. The mothers preferred to be the ones who directly supported the needs of their children – whether the needs were physical, social or emotional. Mothers accepted help from others with such tasks as meal-making and house-cleaning so that they would have the energy to be present for their children: “My focus was how is this affecting my kids and trying to keep everything as normal as it could be for them and to be able to do as much as I could. And accepting as much help as I could so that I could be with them... I was still being as much of a mom as I could be” (Interview 6).

Being physically present was important to these mothers, as it allowed them to monitor their children and anticipate their needs. One mother stated:

“I feel like a lot of those mundane decisions are like a mom’s decision, like it’s more of a female decision than a male decision... where will, like all the winter clothes, they got to go [to be] put away somewhere. Does this fit somebody? Does this not fit somebody? Does this have to go in this pile, that pile... it’s not a horrible task or anything but it’s something that needs to be done... I’m the only one who really knows where everything goes.” (Interview 5)

Even in the face of exhaustion or pain, these mothers wanted to fulfill their maternal role as much as possible. When they could not physically manage to meet their children’s basic needs, the mothers were the managers who delegated those tasks to others:

“I knew he [son] would be taken care of that way... I need to know that... I had to make sure that he was taken care of and I had to make sure that everyone knew where

everything was. Make sure, you know? Somewhere to stay, someone to take care of him, he's got food, he's got clothes." (Interview 3)

Most mothers contributed financially to their households through paid work. Of these, most were on leave from their paid employment as they were undergoing treatment. Concerns over financial matters were a common theme, often repeated in the interviews. One mother described her experience of handling the finances in the home while being on a leave of absence from her paid employment:

"As a mother I had been the main decision-maker in the house. And, like the finances - everything from budgeting to deciding how much we're paying, saving, how much is going on the mortgage and things like that. It's all been on my shoulders... I don't know how long I'm going to be around. And, like normally, a year ago I was planning for the long-term... it's more short-term now unfortunately. It was a main concern. Staying awake at night wondering, how are we going to manage?" (Interview 4)

Mothers expressed ambivalence about their work lives. Several longed to participate in the work force after treatment and yet wanted to balance that time with time spent with their children. Some felt conflicted: "Since I've had cancer, I've been thinking that even going back to work... maybe I just won't. Like climbing the corporate ladder isn't such a big thing for me anymore. You know, like family is more important to me" (Interview 1). Later in the same interview, this mother said:

"I'm wondering if I should just go back for a couple of hours to see if I could get there... so I'm struggling with that decision... I think it's good for me mentally. I mean, I'm home all day... I think it would be good... if you don't use your brain you kind of lose it... I don't think you should live your life thinking, 'I've got to go back to work because

I need the money.’ I think you should think of it in terms of, ‘If it benefits you, you should go back.’ If I think of the money aspect then for sure I’d be back tomorrow because my sick time will run out and long-term disability doesn’t pay that much.”

(Interview 1)

Mothers’ desire to fulfill their maternal responsibilities led to feelings of guilt about how their children’s lives were affected by cancer. They felt guilty for not being able to participate in life as they had prior to the cancer diagnosis and they also felt guilty about imposing responsibilities on others. One mother said:

“While you’re going through treatments, you don’t have the energy or the time or the wellness to do all the things that I used to do, which I had a lot of guilt for during that time. I remember feeling really guilty bringing them places [to be without me], which they loved actually, and feeling terrible about - like my husband would take them and doing stuff with them and I’d feel really guilty that I couldn’t be doing that. It’s kind of silly to be guilty about that but it’s... sometimes jealous and envy that I couldn’t be out there too. Just sometimes [it was] the guilt that I couldn’t be there for them to do those things.” (Interview 6)

Some mothers also felt guilty about the responsibilities that were imposed on others as a result of their illness. One mother said: “I feel like I’m not a good mother right now because I’m... well, I used to think I was ‘the bomb.’ Like I said, take care of everything that he needed and I would be the one. And now I feel like pushing motherly responsibilities onto other people and not being able to do them myself” (Interview 3).

Throughout the interviews, there was no evidence that mothers were finding ways of relieving their guilt. They did not speak of sharing their feelings of guilt with others. However,

after describing their feelings of guilt, some spoke about their hopes for a good future and their anticipation of the fun activities they were planning for their children following their recovery. Their expressions of hope changed the tone of the interview, suggesting that it might have a moderating effect on mothers' guilt.

Mothers with cancer continued to work toward fulfilling the motherhood role as they perceived it. These mothers performed acts of teaching, managing and earning while they navigated their many decisions. Mothers with cancer experienced feelings of guilt for not fulfilling their motherhood role as they hoped during this time.

Decision-Making Strategies to Maintain the Mother-Child Bond

Mothers use a variety of strategies as a result of their need to maintain the mother-child bond as shown in Figure 2. Some of these actions were behavioural, such as being both near and far from children, maintaining their bodies, and struggling with disclosing cancer information. Other actions were at the level of their thought processes as they made decisions.

Strategy: Managing Distance

Mothers described their need to be both near to and far from their children, physically and emotionally as a strategy to maintain the mother-child bond. They described pushing their children away and pulling them close. This theme was present, and frequently apparent, in every interview. One mother explained:

“I think you want them close because that’s what you’re clinging on to. You want them... I mean for me, you want them there because that’s why you’re doing all this... So I think I wanted them close because they provided me comfort. I mean they did, they really truly did and they still do... That’s who you are doing this for and there they are and they love you... But sometimes you don’t want them to see you the way that you are.

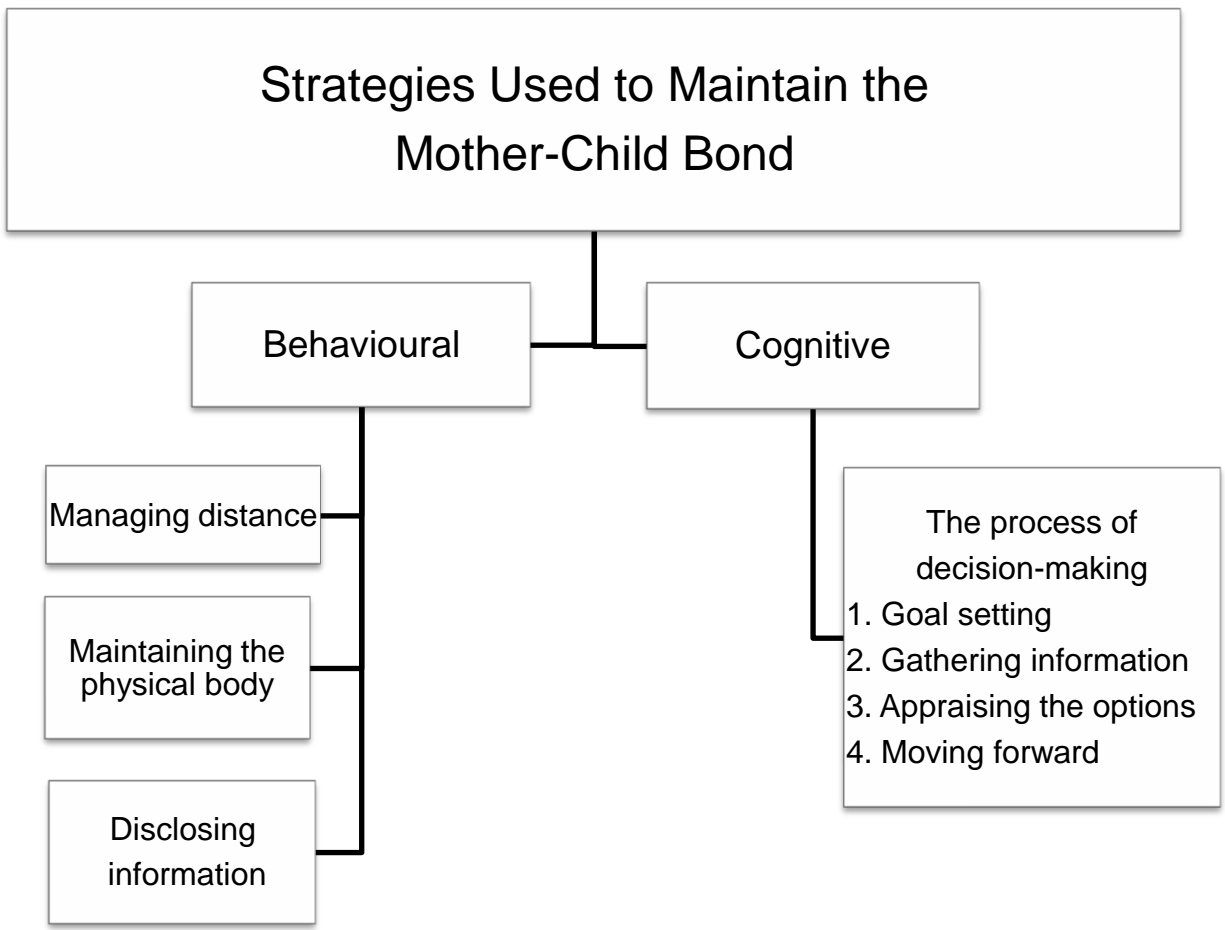


Figure 2. Strategies used by mothers with cancer to maintain the mother-child bond.

You don't want them to be asking you for things... Sometimes you just want them to go away because they are demanding so much of you and sometimes you just need to curl up into a ball by yourself and feel like crap and allow yourself to feel like crap. And you can't do that when they are there... Yes, you want them to go away...." (Interview 7)

Another said,

"Even if I got very sick, I wanted the kids to be here as much as possible because I didn't want them to not understand that this isn't just, 'Oh, mommy has a cold'. And I didn't want to be without them." (Interview 2)

Mothers needed their children to witness the illness but, at the same time, they did not want the illness to interfere in their children's lives. One mother described her struggle to decide whether her daughter should attend her last chemotherapy treatment. She said:

"And I didn't really want her with me then either. At the end I thought, 'I don't really want to take her there, that's no fun for her. She'll have way more fun playing at her friends'. Like, it takes 3 hours, you know? She's just going to sit there beside me, I guess we could watch TV, whatever... but for 3 hours she'll get way more out of being with her friends, playing with her friends. She shouldn't come with me.' Even at the last minute she was asking how it's all going to work so, well she can come with me for the last one. So she came with me and I wish that I had taken her to every one! She was so sweet and we... the chairs are fairly wide and she could sit beside me 'cause I'm small enough and she's small enough. She sat beside me and we got this nice, warm heated blanket and we had a colouring book and we turned on the TV and all the nurses were like, 'Oh!' because there's a cute little girl. It was kind of distracting everybody and she was totally loving it- lapping up all the attention so it was really sweet for her... But she

really liked being able to see how it [PICC line] came out and how that all worked. So that was really good for her I think. And then afterwards we went to the coffee shop and so she remembers that now. ‘The really special day we had together mom.’ We should have done it every time because it was so nice for me to have her there. But I didn’t want her.” (Interview 6)

Being near. Mothers described their desires and efforts to be near to their children during their illness. They wanted to create memories for their children, to strengthen the family unit, and to carry out their maternal duties. They also wanted to be near to their children to have their comfort and to feel a sense of purpose as they endured their treatments.

Participants also described their fear that their children would be too young to have memories of them if they died. One mother said:

“I needed to be there for them- which is what I needed to be- then that was the most important thing to me. I was just very focused on being there just as much as I could. I think at the back of your mind at the time too is you don’t know what they’re going to remember of you either, right? So you really want to have that... especially because they were so young? You don’t know how it’s going to turn out. You’re hopeful and I think deep down I never really believed that I was going to die right away. But you know, you don’t know how much time you have so every moment is more precious, right? So you have to... I said, you make your choices that way, right?” (Interview 6)

Some mothers made an effort to create memories by being with their children during important events, such as holidays. One mother received a cancer diagnosis a few weeks before Christmas and was told by her doctors that she needed to be admitted to the hospital the same

day as the diagnosis, but they could not tell her when she would return home. This mother described the hours between her diagnosis and being admitted to the hospital:

“But we ended up coming back here [home] and it was Christmas. So Santa came early and we did all the presents and everything and that doctor’s office was calling me and then [the ward] was calling me to arrange for me to come in so we ended up going to my parents’ house and I left my son there with my dad and my mom and we threw some stuff in a bag. I don’t even know what was in there at this point - nothing that I needed. So I ended up getting admitted.” (Interview 3)

Participants described a variety of ways of creating memories for their children. One mother, several years after her diagnosis, reflected on her need to create memories for her children and how that has changed with time:

“I think, through the process, I’ve realized that it’s all big. The little things are big things and the fact that one of the things you think a lot about I think, especially when they’re younger, is what memories are they going to have? And so you try to create these big ones. You try to give them everything they want for Christmas or for their birthday because that’s what they’re going to remember, right? But that’s not it. It’s the fact that when I tuck [my daughter] in every night I’d give her a kiss and she would wipe off the kiss and I’d pretend to be really hurt and we’d go through this thing every night. And I would go to tuck [my son] in and he would hide and I’d go, ‘Where’s [my son]?’ Those are the things they’re going to remember. Those are the silly little things that someday they’ll tell their kids about.” (Interview 7)

The desire to be near to their children was the overwhelming motivation for the decisions that were made by some mothers. As one mother explained, “I didn’t even care about the side-

effects [of treatment]. I just wanted to have the shortest amount of time [spent in treatment] because I wanted... my daughter is really attached to me” (Interview 1). This mother went on to explain, “For me quality of life is what I wanted and I didn’t want to spend that away from her. Yeah, if she was like eight or nine, I probably wouldn’t have. But she was like three at the time I was diagnosed so I really... everything I did was like, you know, had to be what’s the shortest thing” (Interview 1).

Mothers also had the desire to be near to their children for the mothers’ own comfort. They were comforted by their children’s touch, conversation and happy presence, as illustrated by the story of the child who accompanied her mother to her last chemotherapy treatment. This nearness distracted participants from their illness for short periods of time, helping them to forget their fears and worries or lessening their physical pain. One mother said,

“When I felt bad physically they made me feel better. Just being with them, listening to their day, just having cuddles on the couch just made me feel better. But I don’t think they know... I mean, my daughter - my daughter came with me for my big hair-cut before chemo and if she hadn’t been there I would have been, probably, a puddle on the floor but we made it this big girls’ event. And she had no idea that that got me through that hair-cut appointment. Just the fact that she was there and sipping her hot chocolate and being so cute.” (Interview 7)

Mothers also experienced their children’s presence as a source of strength, giving them the determination and sense of purpose they needed to endure the illness and treatments. Mothers repeatedly described the hope and determination that they drew from their children’s presence, regardless of the type or stage of their cancer: “They have no idea the fact that if it wasn’t for them I’m not sure if I wouldn’t have just curled up in a ball and stayed in my room

and cried 24 hours a day. I didn't because of them" (Interview 7). Another mother said, "They just... hearing them and seeing them and seeing them smile and dance and laugh and things like that, just gives me the determination I need... So, they've definitely have given me that - what I need" (Interview 4).

The presence of children affected the very meaning participants found in their diagnosis. While recognizing the extreme challenges of raising children in this situation, mothers were also grateful for the purpose the children gave to their lives.

Being far. While being close to their children gave participants comfort, distraction and purpose, it also could be the source of great emotional struggle. While all of these mothers wanted to have their children near, they simultaneously found themselves needing distance from their children, for their own sakes as well as their children's. For example, one mother described her struggle over not wanting to be near her son during an extended hospitalization. She desperately wanted the comfort of his presence, but she knew that it was not possible to be with him long enough to satisfy her need, and his departure would accentuate her loneliness. She explained:

"He wanted to come see me more but it's like... oh... when he left it's like... too hard."

Interviewer: What did you think about when he left the most? "What did I think about the most? Just not being with him. Because he's a snuggle bug so there wouldn't be a night, well most nights, where I couldn't sleep the whole night without having him crawling in my bed and kicking me and tossing-turning and doing his little things. Now he's always sitting right beside me. And that's hard because you're like in a hospital, this crappy hospital bed... Not hearing his voice everyday or playing and things like that so... it's the little things... I know his dad had texted me and said that [my son] wanted to see me in

the hospital... I had only seen him 4 times cause it was hard.” *Interviewer: Hard for you or him? What do you mean?* “No, for me. To see him leave and not take care of him...

So that was hard to say, ‘Hey, don’t come see me.’” (Interview 3)

Feelings of guilt, mixed with the grief of anticipating time apart led this mother to create distance between herself and her child.

Mothers also expressed a need for distance from their children in order to create a physical and emotional space to heal. They also recognized that they lacked the energy to participate in the daily lives of their children during periods of recovery from the diagnosis, surgery or treatment. Mothers consistently justified their need to have space from their children to heal:

“Well I think that I have a life-threatening illness. I mean, I could die from this, you know. And it’s hard, like even doing everyday stuff. Like keeping my son’s schedule, because he has swimming, piano, basketball tournaments... he’s also a bit behind in reading so...you know, I’m... I can’t do those things now but when I get better... all I think about is I want to do what I did before which is to take him to those things, those activities, and see that game, you know? But I can’t because I’m too tired... I just couldn’t... I couldn’t do it. I can’t do it. I’m just so tired. My head buzzes. I have to take that nap.” (Interview 1)

In some cases, the mothers of young children needed physical space between them and their children while they were managing the side effects of their treatments. One mother explained that her youngest child went to stay with relatives while she recovered from her treatment:

“Yesterday I just couldn’t... I was almost crawling just to get to the bathroom, it was just awful. The T3s just weren’t cutting it and I’m feeling a bit better this afternoon. And

they say it only lasts a couple of days so we'll see... I'm almost better then maybe he'll come back. But the older children can care for themselves. Like, they can put themselves to bed. They may not like to but they can. And they may not want to eat a peanut butter sandwich but they can. But with the youngest one, I can't... if I can't get up to make sure where he is and if I can't get up to get him something to eat or change a diaper or whatever... like he needs to have that done. It's not... it's not an option... What's different with the youngest than the older children is that he needs care. And how do I make decisions about his care when I can't even lift my head of the couch?"

(Interview 2)

Mothers of young children were attempting to create some of the space they needed by promoting their children's independence. One mother said:

"I'm just trying to get my daughter to be a little more independent. I'm just finding that... like my oldest is not one to go to bed on her own and it often takes half an hour to put her to bed and half an hour to put my youngest to bed. So it's just a matter of trying to make, obviously my youngest can't go to bed alone, but just getting them to be just a little more independent so that I don't have as much to do. Cause like once seven or eight [o'clock] hits at night I'm pretty wiped." (Interview 4)

Mothers also recognized that their children need time and space away from the illness, and they described the importance of others' support at those times:

"He [brother] took our older two and went sledding. And that was really good for me because I was feeling bad that it was so nice out and I couldn't go out and I couldn't do anything... You feel guilty. And you feel that you're letting them down... you still want them to have fun and you still want them to go and do stuff." (Interview 2)

Mothers' creation of space between themselves and their children was also motivated by the desire to protect their children from the intensity of their emotions. In describing her need for distance in order to hide her distress from her children, one mother said:

“You physically want them close and you emotionally want them close and at the same time you want... I didn't want them to know the emotional... my kids were not old enough to impose that emotional reality on them... the fear... they don't need that fear. They don't need to know that I'm afraid I'm going to die and move them on. They have their own fears... I wanted them to understand it and I wanted them to see it was happening and know it was serious. But not be terrified of it. And if they saw me terrified . . . It was one thing for them to see me physically in pain because that they can understand. But they don't need to know that I'm afraid that I'm going to leave them. That's not something they need to know. And I think as a mother, you can't let them know. Yeah, their job is not to help me to feel better.” (Interview 7)

Mothers wanted not only to protect their children from seeing their fear, but also to protect the normality of childhood. While they did speak often about their children's happy times during this period of illness, they saw their illness as an intrusion into the idyllic lives they wanted for their children. By keeping childhood a time of happiness and fun, and shielding their children from their fear and distress, these mothers attempted to normalize their children's lives.

Mothers with cancer utilized their ability to manage distance to maintain the mother-child bond. At times mothers pushed their children away and then pulled them close. Although these mothers relished being near their children, they also had reasons to be far as they sought to protect their children and themselves in a time of change and heightened emotion.

Strategy: Maintaining the Body

Mothers with cancer maintained their bodies when possible in an effort to maintain the mother-child bond. Mothers described their sense of having lost control of their bodies, and as a result many had a negative change in their body images. One mother, explaining the changes in her arms because of lymphedema said: “I remember thinking I’m never going to physically be normal again. And I still feel like that. So I kind of grieve that, physically [my arms] are not like they were... how do I integrate that into the identity of who I am now” (Interview 7)?

Mothers revealed the emotions they experienced regarding the sudden changes to their bodies as a result of surgeries and treatment. These included both visible physical changes and changes to their levels of energy and strength. Women who had undergone mastectomies or lumpectomies had to make adjustments to their self-images as women. About her mastectomy and breast reconstruction one mother said:

“I thought I could handle breast cancer, I thought I could handle chemo, I thought I could handle radiation or whatever they decided... but to not have no breasts and to have just two scars... I thought emotionally that would be the worst for me. Just because I’m this age. And to say, ‘Ok, you’re this age and you don’t get to have breasts anymore.’ That was... it was one of those things where, ‘No, I am. I’m going to... I’m not ready to get rid of them yet.’” (Interview 2)

While some of their feelings were connected to womanhood in general, others were directly related to motherhood. The part of the female body that is visibly, symbolically and emotionally connected to womanhood and motherhood is the breasts. This was clear in participants’ descriptions of their decision-making regarding breast reconstruction following a mastectomy, which is a more difficult surgery requiring a substantially longer recovery time

compared to a mastectomy alone. Therefore, the decision about whether to have breast reconstruction was a difficult one for participants who had been diagnosed with breast cancer. But they chose to undergo this surgery in an effort to regain their sense of wholeness. One mother explained she was reluctant to have this surgery because the recovery time added distance from her children:

“To have this reconstruction it would also increase my recovery time which was a huge factor for me. Because I look after my kids and I have to pick up my son and, you know, he was still a baby. And, you know, I’m a huge cuddler and all those kind of things, right? So that was a really hard struggle for me [to have reconstruction]. For me it was, ‘Do I get reconstruction or not?’ My husband told me, ‘You’ll hate it if you don’t.’ And he was right. I woke up from my surgery and saw that there was something there [reconstructed breasts] and I was so thankful. It would have been so much harder to deal with if there was nothing there. You know, at least I still kind of look normal.”

(Interview 6)

But the breasts are symbolic representations of motherhood as well. The breasts represent a mother’s ability to provide sustenance for her child and they also are a source of physical and emotional comfort for her child. This symbolic meaning of the breasts played an important role in mothers’ decision-making regarding breast reconstruction:

“The surgery, actually almost as a mother I made the decision because when you’re reading stories to your kids they are sitting on your lap and they are leaning against your chest. I thought for them to lean against a chest that didn’t have anything and have stories - how traumatic that would be for them... I think [reconstruction] would make things more normal because you’re not different. I think not choosing to do

reconstruction would have a bigger impact on my children than being bald for 6 months or a year or however long it takes.” (Interview 2)

Some mothers viewed maintaining their breasts as a way to support their children as they grow older by being “normal” for them:

“I wanted to be normal for my kids... For cuddling them, like they’re going to lean against you and just to have it be normal. You know, and just feel the same to hug them. You want to be the same. For when your kids are growing up I didn’t want them to be totally embarrassed... and just to look as close to normal as I could for them, and to feel as normal as I could for them... To be me and that’s it.” (Interview 6)

Therefore, mothers’ beliefs about how a mother’s body feels and how a mother’s body looks was important to how they made treatment decisions. This also was true in the case of a participant who had female family members who did not have breast reconstruction after mastectomies. This participant did not consider her breasts to be necessary to her identity as a mother, but she chose to have reconstructive surgery nonetheless. However, when describing her decision in further detail the mother reflected on how the surgery affected her mothering experience:

“I wasn’t thinking about them [my children] when I was making my decision for reconstructive or not reconstructive. Like I wasn’t thinking, ‘Oh look I don’t have breasts, my girls will think I’m not normal.’ Because... my sister doesn’t have any breasts and they don’t notice it at all... That wasn’t really part of my decision. Although it’s funny, they treat them like they’re normal. Like, if they’re snuggling and pretending to nurse or something, that they still think there’d be milk coming out of them.”

(Interview 5)

Mothers who had undergone other body-altering treatments also wanted to appear “normal” because they observed that their physical changes were distressing to their children. In particular, temporary physical changes such as hair loss, surgical wounds, general malaise and weakness were symbols of the mother’s illness in the eyes of their children. Hair loss was perhaps the physical change that was most salient, and one that mothers attempted to manage in a way that would minimize their children’s emotional distress. As one mother explained:

“When my hair started growing back and I kind of had a buzz cut kind of a look and it was just coming in, I hated wearing my wig and so one day I was like, ‘Whatever, I’m fine. I’ve got hair now.’... I just wore it to church like that and my young daughter was so upset with me. She cried at church, she was so mad that I did that. I’m not totally sure if she was just embarrassed that I would go out like that and not looking all pretty like a princess or exactly what it was. And then next Sunday I did it again and she was a little bit better. And then after that my hair was growing too. My hair was probably about up to my chin and I had dyed it darker... and that really upset her because she remembered me being blonde. So she really wanted me to be blonde, so I dyed my hair blonde. And then it was up to my chin and she said, “Mom, when is your hair ever going to be long like before?” And I think she really associated me having long hair with being healthy. And because as soon as my hair reached long enough she was like... you could see, you could almost feel her relax.” (Interview 6)

At times mothers explained that they made decisions about wearing wigs because they considered their children’s emotional needs. One mother said, “Sometimes I’ll ask them, ‘Well, should mommy wear a wig to this or not?’ Like I’ll just sort of see where they are at. ‘Cause I don’t like wearing it all the time” (Interview 5). The mothers in this study wanted to appear

“normal” in an effort to avoid making her children the focus of unwanted attention or embarrassment.

Mothers with cancer considered their children when decisions were to be made regarding their bodies. Mothers undergoing mastectomies considered breast reconstruction surgery, not only because they were women who protected their femininity but also because they recognized that maintaining their bodies normalized their physical relationship with their young children. Mothers were keenly aware of how their physical changes may impact their children in the short-term as well as the long-term and they made decisions to maintain the mother-child bond when possible.

Strategy: Disclosing Difficult News

Mothers’ beliefs about the impact of their decisions on their children were evident in their actions surrounding disclosure of the diagnosis to their parents, friends and children. They did not want their pre-cancer existence to change; they wanted to maintain the mother-child bond. Mothers described decisions surrounding disclosure as exceedingly difficult. As one mother said, “The hardest thing to think about was... how am I going to tell everybody else” (Interview 6)?

Mothers particularly struggled with when, where, what and how to tell their children because they felt responsible for ensuring a happy childhood for their children. Even mothers of the youngest children expressed their need to be honest, but they faced an internal struggle between their need to protect and their need to inform their children. One mother described the challenge this way:

“I was worried about telling them. Even though they were really small, I didn’t want to not say anything because they could sense it. And they knew there was busyness

happening around the house - flowers and baking and more visitors than usual and that sort of stuff. And so you kind of want to protect them and not tell them too much because they are too young to understand it anyway. But you kind of want to include them in things.” (Interview 5)

Mothers’ beliefs about the value of trust and honesty in their relationships with their children and the solidification of the family unit guided them as they carefully weighed their decisions about disclosure. These themes had several dimensions. First, mothers felt the need to be honest with their children on principle: “I didn’t want them to hear it from someone else or have someone else tell them, ‘Oh, your mom has cancer.’... or to feel lied to... I guess they are part of this family and they are a part of this team that is fighting this” (Interview 2).

Second, mothers acted out of respect for the family as a unit and for their children as full members of the family: “Honesty and some trust with them as to what the family was going through cause it’s not just me. Everybody else is kind of connected to it” (Interview 5).

Third, they wanted to ensure that their children did not hear about their illness from someone else. One mother monitored what her extended family was telling their children:

“I just wanted to make sure they knew, and from me... My sister, I had to double-check what she’s telling her kids because she has older kids than mine. And I didn’t want them to be saying something to my daughter at school or when they were together or something that we didn’t tell them. Or in a way that we didn’t tell them, right? So I know a couple of times I just double-checked with her, ‘What are you telling your kids?’ just so I know so that we’re covering all the bases over here. I don’t want any shocks or surprises or those kinds of things.” (Interview 6)

Fourth, mothers disclose to their children because it is a hardship for her to carry cancer as a secret. A mother explains,

“I didn’t want to have any secrets because it was hard on me because I couldn’t talk about it with friends on the phone without having to run and hide off to another room and I felt like I was holding this big secret. And I didn’t like that at all... I just wanted everything to sort of be in the open, not super detailed but as much of the plan as to what was going to happen so that they would not be upset with more visitors or on me crying... just trying to be honest with them and to reassure them that mommy and daddy are here and the plan of their day is not going to change because of all this.” (Interview 5)

The disclosure process unfolded over stages. First, participants waited for the confirmation of the diagnosis. One mother described this stage in the following way:

“I really wanted to wait until we had a full confirmation even though I knew... I knew that I had cancer just from the way the doctors were acting... but we waited for full confirmation from biopsy and mammogram and everything altogether and until we knew what we were going to do about it. I didn’t just want to go to the kids and say, “I have cancer and I don’t know anything else to tell you.” (Interview 2)

The second stage was an adjustment period during which mothers came to terms with the diagnosis, worked to manage their emotions and formulated their treatment plans within the context of their families’ needs. One mother said: “I didn’t tell anybody that I had a lump because I thought, well, no use saying something if it’s nothing. We’ll find out and then once I’ve dealt with it then I can tell people” (Interview 6).

In the third stage, mothers, often accompanied by a spouse, began teaching their children about their illness gradually, concealing information they deemed unnecessary or inappropriate

for their children to know at that time. The ways in which mothers gave information to their children varied, as they struggled to decide how to explain the disease and its treatment. One mother said, “Surgery is easy for them to understand. You’ll be sick. They can see the scars, see the band aids and know that you’re going to be sick. But with chemo I find it trickier” (Interview 2). Another mother decided to demystify her chemotherapy treatment: “One time they [children] did come and they just came for a bit... so that they could see that it wasn’t horrible... And so they did come and see that I’m just sitting in a chair. There’s nothing horrible, they aren’t doing something awful to me” (Interview 7). Regardless of what they specifically chose to tell or show their children, participants generally viewed themselves as teachers to their children, explaining and helping them to understand, preparing them for uncertainty and reassuring them that they are being cared for. One mother described her approach in this way:

“My son would visit me in the hospital and I showed him my picc line. I showed him where I was getting my medicine. I was teaching him things. I told him, ‘Mom was going to lose her hair, she was going to be bald.’ And when I was bald I showed it to him. He said, ‘Mommy you’re still pretty’ so he was fine with it. And when I’m wearing a shirt you can’t see my picc line, he goes, ‘Is it still there?’ and I go, ‘Yup’ and I show it to him. And he asks if it hurt, and it doesn’t, so like I’ll explain it to him. Even when I was diagnosed I told him that ‘Mommy was going to have to be in the hospital for a long time, you can visit me in the hospital but I’m not going to be with you. Grandma and Grandpa will take care of you, you’re going to be with your dad.’” (Interview 3)

The disclosure process, however, was not only about deciding to share information; it also involved deciding to withhold information. Mothers’ drive to protect their children from

emotional distress, and their desire to normalize their children's childhoods, required careful and balanced decision-making. They generally undertook a period of planning during the second stage of the disclosure process to prepare a strategy that would balance their children's needs for information and honesty against their needs for protection and security. As one mother explained:

“I didn't want to tell them until we knew exactly what the first step was going to be. So I didn't want to say, ‘I have cancer but we don't know what's going to happen.’ So that we could say, ‘I'm going to have an operation and this is what it's going to be like’ and then told them each step along the way. But I didn't want to tell them until there was something concrete that they could understand in terms of what was going to happen.”

(Interview 7)

In making their decisions about when, what and how to disclose their illness to their children, mothers also considered their own emotional health. Mothers who were experiencing anticipatory grief tended to avoid talking with their children about their illness in order to preserve their own emotional stability: “We made a lot of things fun or tried to make things fun and then I just dealt with everything else with a social worker or my sister or friends and things like that” (Interview 5).

Disclosure decisions were not limited to the initial planning stage following diagnosis. Rather, mothers continued to face these decisions throughout the course of the illness and its treatment, as the impact of surgery and chemotherapy's side effects unfolded. The process of adjustment, planning and deciding to disclose occurred repeatedly as mothers progressed along their individual trajectories.

Just as a period of adjustment preceded the disclosure the diagnosis, it also preceded the disclosure of changes to their bodies. Following this period of adjustment, mothers were able to re-assume the teaching role, sharing information honestly and providing reassurance to their children that they all could cope with the challenges posed by cancer:

“Now I’m totally comfortable with my own self so... it’s easier for me to talk to them about it...Because before I was still trying to deal with my own changes in my body so I think I was calm enough and very straight-forward... but inside it was different for me to tell them now. And with me accepting it, I think it’s easier for them to accept it. [I was] trying to find a swimming suit and they were with me and I’m like, ‘Ok, I can’t wear this kind... mom’s body is different now.’ And they’re like, ‘Ok, that’s true. Yeah that one looks way better mom’... They just go with it... I don’t want to look too far ahead but if they ever have to deal with [cancer] they kind of know, right? What it’s all about.”

(Interview 6)

Mothers attempted to maintain the mother-child bond by disclosing cancer information because they valued honesty and trust in their relationships with their children. Children were respected as members of the family and mothers wanted to tell children the necessary information themselves and often did so using a strategic process.

Strategy: The Decision-making Process

During the course of this study mothers revealed both their perceptions and the reality of their decision-making processes. On the surface, mothers making decisions in the context of cancer found it difficult to describe the process of their decision-making. At times mothers described how they would typically make a decision and then reflect the detailed accounts of making specific decisions in the context of cancer. There was inconsistency between what some

mothers perceived their decision-making process to be and what they did in actuality. To illustrate, one mother described how she feels she makes decisions but her description of her decision-making strategy did not match her behavior in the context of cancer. She said,

“I’ve always probably thought too much into my decisions in the first place. But it’s definitely more so than it was before and less of a spur-of-the-moment kind of thing. You’ve got to really think about it. Probably weigh several options and decide which would be best-suited for the family.” (Interview 4)

She then went on to describe how she made two decisions in the context of cancer, speaking to her children about cancer and attempting to come home earlier than would be typical after surgery. In both of these situations the mother described the goal relating to the mother-child bond and that she was looking for an opportunity that would lead her to that goal. She did not weigh other options.

Many mothers recognized themselves as novices in a complicated situation. Mothers with cancer found that they were in a new decision-making situation after being diagnosed with cancer. The conditions surrounding their diagnoses led to the mothers feeling that they were beginners at decision-making. Now when making a decision, their old ways of thinking did not easily match their new existence.

Despite the confusion about how mothers perceived they should make a decision in a new context, they were able to describe much of their actual process: the condition of their lives at the time, their decision-making goals, options, how they gathered information, why they chose a specific option and eventually the consequences of their decisions.

Mothers used a common strategy to come to a decision, whether the decision was more social or medical in nature. Mothers revealed their decision-making process involved: 1) goal setting; 2) gathering information; 3) appraising the options; and 4) moving forward.

Goal setting. Goal setting begins when a mother recognizes the need for a decision to be made. Each decision has both medical and social dimensions that must be recognized, analyzed and weighed as the mother identifies and prioritizes her goals. The overarching theme that characterized this process was mothers' consideration of their children's best interests:

“I think every decision that we made along the way has been primarily been made around them. Their needs and their understanding of things has been the priority and still is. I mean, it's still the paramount thing that I think about. How all of this has affected them. How all of this would affect them.” (Interview 7)

The goal that mothers prioritized in their decision-making was preservation of the mother-child bond. They were keenly aware of the potential influence of their illness their children's attachment security. For some mothers, the goal of maintaining their bonds with their children led them to choose the treatment that would maximize the time they could spend with their children in the future: “I guess that goes back to the feeling that I want to be here for my kids and I want to do as much as I possibly can in order to be here long-term” (Interview 5). But for others, this goal led them to choose the treatment that would maximize the time they could spend with their children in the present: “I made [my treatment decision] on the basis of time with my daughter. I didn't really make it on basis of my medical prognosis” (Interview 1). Therefore, although mothers' medical decisions differed, the goals underlying them were the same.

Goals were protected for as long as the mother was able. One mother was presented differing prognoses from different doctors. At one point she was told that she would not live long as a result of her cancer while a second opinion stated that this was not necessarily true. This mother said, “I’m determined to fight this so that I can be here for the long-term. I’m focused on being here for longer than what we were initially told (Interview 4).” As long as a mother could work toward meeting her goal of lessening the impact of her disease on her children, she would follow strategies that she thought would help her do so.

Gathering information. After setting a goal, mothers sought information. Mothers gathered information from trusted sources, which included health professionals, family and friends, and online resources. Because of time constraints, low energy, or what was described as a “busy mind”, the sources they consulted were restricted in scope and, as a result, much of the information they gathered was unverified or “hearsay”. Mothers tended to look to others with experience, particularly other mothers who had experienced cancer: “I tried to find an option that was used before [by another mother with cancer]. Just to have that background because it’s just so new to me. I didn’t have that experience. I wanted to know how others had dealt with it with children. And that helps a lot as well” (Interview 4).

Appraising the options. After gathering information, mothers identified their options. Interestingly in most decision-making situations the mothers did not use an analytic strategy, but relied on others’ opinions and their “gut” feelings regarding how the option coincided with the mother’s understanding of her children and how it matched her goal.

After appraising the option mothers quickly selected or ignored the option. If the option was ignored, the mother would pursue the next available option presented or an option she considered to be a secondary choice, or a back-up, that was available from the outset. This

strategy of selecting and ignoring options happened rapidly, so rapidly that many alternatives were not verbalized at the time of the decision. One mother described that she felt that she did not have many choices, “Sometimes we just make decisions by elimination” (Interview 2). It is unknown from these findings the extent that “instinct” plays in selecting and ignoring options in the decision-making process. Mothers revealed that they tended to make their decisions on the basis of their comfort levels, more than on the basis of objective information. For example, when deciding whether to have a lumpectomy or a mastectomy, one mother said, “I just knew that I didn’t want to have a lumpectomy. I just thought that wasn’t the way to go at all. I felt that I would feel way more comfortable having a bilateral mastectomy done” (Interview 5). This mother’s comfort level was influenced by her knowledge of her medical status, her trust in her oncologist, and her family history.

In many cases, mothers’ initial choice precipitated a range of secondary decisions that had to be made, which were approached in the same way until the decision-making that addressed the original goal was complete. After the final decision point was reached and the decision-making was complete, the mothers moved to the last phase of the decision-making process.

Moving forward. After a decision was made, mothers took responsibility and prepared to follow through. While they often had solicited opinions from others to help them make their decisions, they generally took ownership of their choices: “This is the path I chose. You can’t go back, right? I’m totally aware of all the things... if something happens, then it happens and I have to deal with it when it happens. You can’t think it’s [cancer] going to come back” (Interview 1).

Mothers vigilantly watched their children's behaviour for indications of the impact of their decisions upon them, intervening when necessary to help their children through times of distress. In particular, mothers watched their children for change in behavior, regression of development, difficulty in school settings and attachment to others. This watching became a part of the mothering role when following through with a decision.

The theme of hope emerged in mothers' narratives as they described this process of moving forward. They anticipated their futures and the futures of their families, and referred to their good future health as well as activities they were planning with their children:

"I'm hoping for a road trip... I want to be able to take him to the amusement park... things like that. And he'd really like to do those again so those are my goals. To be able to take him places and have some fun. Yeah, fun is good. We really like to have fun."

(Interview 3)

Another mother was hopeful of creating everyday memories of fun with her children. She said, "I'm trying to make an effort to do more fun things... even if it's just having picnics and putting in a garden" (Interview 2).

Mothers with cancer found comfort in future plans with their children. The attitude of hopefulness was a common characteristic of the post-decision atmosphere. Mothers follow through with their decisions and, although they have many times of feeling vulnerable, they carry-on with a spirit of hopefulness.

Conclusion

Mothers with cancer make decisions in complicated conditions in which the presence of fear is central. This fear provides meaning to the decisions that mothers make, that every decision is intended to contribute toward maintaining the mother-child bond. The concept of “maintaining” is revealed by mothers as they make use of purposeful strategies regarding managing distance from their children, maintaining their bodies as mothers, and disclosing news to their children. Mothers of young children use a decision-making process that puts the goal of maintaining bonds with children at the fore.

CHAPTER 4

Discussion and Recommendations

The purpose of this study was to explore the decision-making process of women diagnosed with cancer who are mothers of young children. Specifically, my objectives were to identify the types of decisions these women face, the process they use to make them, the conditions that influence their decision-making, and the meanings they assign to their decisions. Through qualitative analysis of in-depth interviews with a sample of women in this population, findings were obtained that can contribute to the knowledge base, as well as to the design of programs to support these women and their families.

The Presence of Fear

One of the most striking findings was the omnipresence of fear in the lives of these women. Mothers with cancer feel vulnerable to a shortened life and this resulting fear distinguishes mothers with cancer from mothers with chronic disease, whose primary emotion is frustration (Evans & de Sousa, 2008). While it is known that patients with cancer must find ways of managing their fear as they navigate the disease (McMurty & Bultz, 2005; Yoo et al., 2010), little is known about the effect of fear on their decision-making.

Research on “affective forecasting” has addressed the effect of emotion on decision-making. Affective forecasting is the process of predicting how one will adjust emotionally to living with disease (Gligorov, 2009; Halpern & Arnold, 2008; Swab, 2008), either positively or negatively (Gligorov, 2009). According to Halpern and Arnold (2008), current shared medical decision-making models assume that doctors contribute medical facts and patients contribute their values. This combination of facts and values enable a patient to make a decision. But, as Halpern and Arnold (2008) point out, “this model fails to include the beliefs patients hold about

their ability to adapt emotionally, which along with their values, determine their decisions” (p. 1708). If this is the case, a mother’s prediction of how well she will manage her fear will, together with medical facts and her own values, influence her decision-making.

An additional dimension of affective forecasting and its impact on decision-making that was revealed in this study is the challenge for a mother of predicting how her children will adjust to her illness. Current models of affective forecasting do not take into account the impact of forecasting the emotional adaptation of the patient’s family members, particularly children, to the patient’s disease and its potential outcomes. Existing literature addresses child adjustment in the case of maternal death but does not address the mothers’ tendency to forecast how her children will adjust after her death. This study highlights the need to understand more about the effect that predicting the adjustment of family members has on decision-making.

Transition theory (Goodman et al., 2006) also relates to this process. It describes a process through which, in the circumstance of a life-threatening illness, a person transitions through three stages: 1) “endings” which describes the ending of a pre-cancer existence and the resistance to a life with cancer; 2) “neutral zone” typified by anxiety and confusion; and 3) “new beginnings” when the person with cancer makes meaning and opportunity from the cancer experience (Elmberger et al., 2008; Rancour, 2008). The mothers in the present study described a process of moving from the sudden shock of diagnosis and overwhelming fear (the “endings” stage) to a more reflective state as time passed. While the fear remained, it was not as overpowering as it had been immediately after diagnosis. Some of this shift might be due to mothers’ tendency to seek information from others with similar experiences or from counselors. But the mothers in this study did not describe a state of enhanced adjustment as time passed in

the “neutral zone” or “new beginnings” stages. These stages described by transition theory do not capture the psychological states of mothers who are unsure that they will survive.

Another theory relating to the effect of fear is the work of Barney Glaser and Anselm Strauss in the 1960s in which four constructs were developed regarding the awareness of dying (Andrews & Nathaniel, 2009; Hyde, 2010). Of these constructs, the construct of “mutual pretense awareness” explains that many people are aware that a person is dying but would not acknowledge the impending death (Andrews & Nathaniel, 2009; Hyde, 2010). The concept of mutual pretense awareness can be used to explain situations of silence in times of fear that does not necessarily include impending death (Hyde, 2010). In this study, mothers were in silence about their fears of a shortened life and the mothers were also met with silence from their family members and friends. Mothers acknowledged that they made decisions based on their fears of a shortened life and the resulting need to maintain the mother-child bond and yet this was unsaid to their family members and friends who have influence in the lives of the children. The effect of this silence on decision-making needs to be more fully understood. What would be the effect of a listening family member? Would this provide some reassurance for the mother regarding the wellbeing of her children in the event of her worst fear - a shortened life – and allow her to make decisions differently?

Decision-Making as Meaning-Making

While research on meaning-making in the context of cancer is expanding, it has been largely limited to survivorship (Bolen, 1998; Frank, 1997; Lee, 2008; Lethborg et al., 2008; Vachon, 2001) and how women make meaning of disease, particularly in the case of breast cancer (Dent, 2004; Fallbjork et al., 2010). Scant literature is available regarding meaning-making among mothers specifically (Fallbjork et al., 2010). The research that exists has focused

on how women find meaning in their life changes following a cancer diagnosis, revealing that mothers experience a change in roles (Coyne & Borbasi, 2006; Dent, J., 2004) and conflicting feelings about what being a “good” mother is in times of illness (Semple & McCance, 2010). Therefore, research to date has primarily described the impact of diagnosis on the woman herself. But the overriding theme of the decision-making process among this sample of mothers was the mothers’ concern about the impact of their decisions on their young children, extending the focus of the existing literature from the mother herself (what meaning does a mother make of a cancer diagnosis) to her concern for her children (what her cancer diagnosis means for her relationship with her children and for the future of her children). Mothers were primarily driven by a desire to maintain the mother-child bond and this heavily influenced their decisions and their actions.

This finding supports family systems theory. This theory posits that family members operate interdependently, each member influencing the others (Faulkner & Davey, 2002) within a context of emotional connectedness among family members (Chibucos & Leite, 2005). The present findings are consistent with this theory in that these mothers acted on the basis of their perceived influence on their children, described the reciprocity in both benefits and distress among their family members, and demonstrated an amplified emotional connection to their children during the experience of a life-threatening illness. In their research on young women with breast cancer, Coyne & Borbasi (2006) identified the complexities involved in these women’s adjustment if they were mothers. They described these mothers’ attempts to protect their children by showing courage and hiding their emotional distress. But the emotional struggle involved in mothers’ desire to keep their children close and simultaneously to create distance from them, as revealed in the present study, has not been described in previous research.

Another of the present study's findings that has not emerged in other studies is the meaning of bodily changes within the context of motherhood, and the impact of that meaning on decision-making. While Fallbjork et al. (2010) investigated body image among young women with breast cancer the meaning of physical changes within the context of motherhood was not addressed. The present findings reveal that mothers often seek to maintain their bodies, or protect themselves from body loss, in part because they are mothers. They consider the impact of their physical changes on their children and take their children's needs into account when making decisions that will affect their bodies.

Mothers' decisions around disclosing their illness to their children were related to their need to maintain the mother-child bond. Previous research by Semple & McCance (2010) revealed that "communicating with children about a mother or father's cancer required a lot of decision making, mainly around the timing, wording, and amount of information"(p.116). and others have explored the reasons why parents disclose or do not disclose information about their illness (Barnes et al., 2000; Zhang & Siminoff, 2003). But the present findings expand our understanding of this process in revealing that mothers may avoid disclosure because of their own emotions and points of adjustment, not only those of their children.

The Decision-making Process

The descriptions of decision-making by mothers in this study do not reflect the classical treatment of decision-making theory or "rational theory of choice" (LeBoeuf & Shafir, 2005). Multiple-process decision-making theories distinguish between fast and intuitive cognitive operations and slow and rule-based operations (Evans, 2008; Kahneman & Fredrick, 2005; LeBoeuf & Sharir, 2005; Reyna, 2008; Sanfey & Chang, 2008). In the case of decision-making among mothers with cancer, multiple-process theories are an appropriate starting point to describe the complexity of the process but they do not account for the affective component of the

process among these women. There appeared to be a considerable amount of emotional work for mothers to contend with when making a decision. The emotional component of decision-making is not addressed by current multiple-process decision-making theory.

Mothers appear to use their intuition to set goals and appraise options and yet there is literature to suggest that mothers are using much more than their intuition alone. Klein (1999) reports that persons making decisions in difficult conditions that are pressured by time and uncertainty often make decisions based on “singular evaluation,” that is to consider one option at a time and select it or reject it and move on to another option. Klein (1999) considers this to be an efficient method of making decisions quickly in a difficult context. How do people use singular evaluation? Klein (1999) presents several methods, the most probable in this context is that mothers may use “mental simulation”, or thinking through how they imagine the outcomes might impact their children. Mental simulation is related to the concept of “availability heuristics” referred to in the literature (McDermott, 2008). This heuristic describes how some choices are easier for a person to imagine and therefore more mentally available (McDermott, 2008). Choosing an option that is mentally available skews the risks/benefits in the perception of the patient and creates confidence in the decision whether, or not it is objectively warranted (McDermott, 2008).

While singular evaluation and mental simulation seem to fit with the process of decision-making among mothers with cancer, Klein was studying people who were experienced in their field of decision-making, such as firefighters and commanding officers (Klein, 1999). The author posits that experts make decisions that appear to be intuitive but the decisions are a result of the experience of making previous decisions and being able to recognize typical and atypical patterns. Interestingly, mothers with cancer recognized that they are novices at making decisions

in the cancer trajectory. It would be useful to further uncover how singular evaluation and mental simulation contribute to the decision-making of individuals who must suddenly make profound decisions in an area that is brand new to them.

Existing decision-making literature over-simplifies the complex emotional needs of a mother making decisions in the context of her cancer. Mothers revealed that they did not make decisions in a rigid and analytical way, nor did they make them entirely non-analytically or as an expert might. The mothers in this study felt the weight of emotional connectedness to their children as they made every decision. Fear of separation and an intense desire to mother their children as long as possible, led mothers to devise strategies of mothering that might maintain the mother-child bond in this complex and highly emotional context.

Finally, when mothers move forward with their decisions, they express hopefulness. Literature regarding hope reveals the intriguing concept that hope is bound together with hopelessness (Hammer et al., 2009). The interconnectedness of hope and hopelessness is consistent with the present findings concerning the meaning of diagnosis- the fear of leaving a child without a mother because of the threat of cancer - and the related meaning of the decision which is the mother's need to maintain that bond. Yet these feelings of vulnerability and times of despair are countered by the mention of hope by mothers in the present study. This is consistent with Hammer et al. (2009) in describing the relational dimension of hope. Hope is reciprocal between loved ones as hope grows out of love and relationship with family (Hammer et al., 2009). Mothers with cancer experience hopelessness but they also plan for the future, think positively and enjoy both loving and being loved (Hammer et al., 2009).

Study Limitations

The aim of this study was to explore a process that does not appear in the research literature, so the grounded theory method was chosen to carry it out. While this method is appropriate for exploring an area where theory is not well-developed, and an issue that merits depth of understanding, it also has limitations. Of note, the amount of data generated by in-depth interviews produces a large number of themes, each of which warrants further exploration in broadening our understanding of decision-making among mothers with cancer.

Recommendations for Future Research

The findings of this study indicate the need to focus future research on areas which will enable patients, their families, and health professionals to understand the complexities involved in decision-making when a parent is experiencing a life-threatening illness. Several questions were raised by this study that would be important to follow up in future research. First, the interrelationship between medical and social decision-making was made very clear in this study. Mothers do not separate the two, and each influences the other. Therefore, it would be useful to explore this aspect of decision-making in greater depth so that medical professionals, family members and counselors can support mothers who are struggling with these complex, multi-faceted decisions.

Second, the silence surrounding mothers' fears was a strong theme and suggests that family members and professionals must better understand mothers' need to talk openly about their fears. Future studies should focus on this dimension of mothers' decision-making to increase our understanding of their needs, and to identify avenues for assisting mothers and their families to cope with their own fears.

Third, it was revealed that mothers' feelings about maintaining their bodies and their decisions regarding reconstructive surgery depend to an extent on their identities as mothers. It would be helpful to understand this dynamic in greater depth, and to explore the feelings and decisions of mothers of young children to those of men, women without children and women with grown children.

Fourth, all of the participants in this study were parents, but they also were women. Very little research has been carried out on father's experience of cancer or their decision-making in the context of fatherhood. A comparative study of mothers' and fathers' experiences would help to unravel the gender and parenting dimensions of decision-making in the context of cancer.

Fifth, the process of affective forecasting appears to have important implications for mothers' decision-making in this context. To date, research on this process has focused on mothers' predictions about their own emotional adaptation. But the findings of this study suggest that mother's predictions about their children's emotional adaptation play a powerful role in their decisions. Future research should focus on how mothers make these predictions, and how families can assist in this process so that decisions can be based more on reality than speculation.

Sixth, most literature describing the relationship between hopelessness and hope focuses on palliative care but mothers in this study also revealed fear and hopelessness countered by hope in the event of a positive prognosis. The connection between hopelessness and hope, as well as the ability to cope with the past and anticipate the future, needs to be further explored in the context of parents with cancer in order for health care providers to better understand their patients' emotional lives..

Recommendations for Practice and Education

A preliminary model of decision-making by mother with cancer that is based on the core concept of a desire to maintain the mother-child bond has been presented. This model has several implications for practitioners. First, the strong emphasis that mothers place on the impact of their decisions on their children needs to be understood. In some cases, mothers are making medical decisions more on the basis of their relationships with their children than on what might be considered objectively to be in their best medical interests. If practitioners understand this dynamic, they will be better able to provide sensitive and constructive advice to their patients.

Second, although women in this situation might be experts in most parts of their lives, they tend to feel like novices in the face of cancer. The skills that they have relied on in all other situations may not be those that are needed in this new situation. As a result, they might rely on others' experiences or make decisions based on fear. Practitioners should be aware that their patients need guidance from informed individuals with a depth of experience. At the same time, mothers find it very helpful to talk with other women who have lived through a similar experience. Perhaps expert medical advice, given with adequate recognition of women's needs as mothers, coupled with pragmatic advice from women who have gone through similar experiences, would help mothers to navigate this new and frightening situation more confidently. Understanding that unexpressed fear surrounds all of these women's decisions is important, and practitioners should consider referring these patients to counselors who are comfortable discussing their fears with them.

The findings of this study also have implications for educators. It would be very useful to work with mothers and their families to create materials describing the physical and emotional dimensions of cancer within the context of motherhood, and including useful suggestions to help them through their decision-making. Written materials, videos, websites, and chat rooms could

help to normalize some aspects of this shockingly new experience for mothers and their families. Lists of resources should be compiled for these families that can support and guide them through the complex medical-social decisions they must make. Partners need to be supported through facing their own fears so that they can understand women's need to talk about the possibility of death and know that their children will be cared for. All professionals working with mothers with cancer need to understand the importance of the maternal identity in the decisions that these women make.

Conclusion

Mothers of young children making decisions in the context of cancer do so with a primary focus on maintaining their bonds with their children in the face of vulnerability and fear of a shortened life. This focus brings complex meaning to every decision they make. They recognize that their medical and social decisions are interconnected, as they strive to fulfill their mothering responsibilities amid complicated family relationships and the chaos and strain of the cancer journey. It is in this situation of fear and uncertainty, that these women simultaneously experience the grief of anticipated losses and the joy of mothering. While they experience the darkness of fear and despair, they are strengthened by loving and being loved by their children, and they create hope as they confront their greatest fear.

Appendices

Appendix A: Recruitment Poster



Decision-making: Mothers with Cancer

**Have you been
diagnosed with cancer
in the past five years?**

**Were any of your
children age 6 or
younger at the time?**



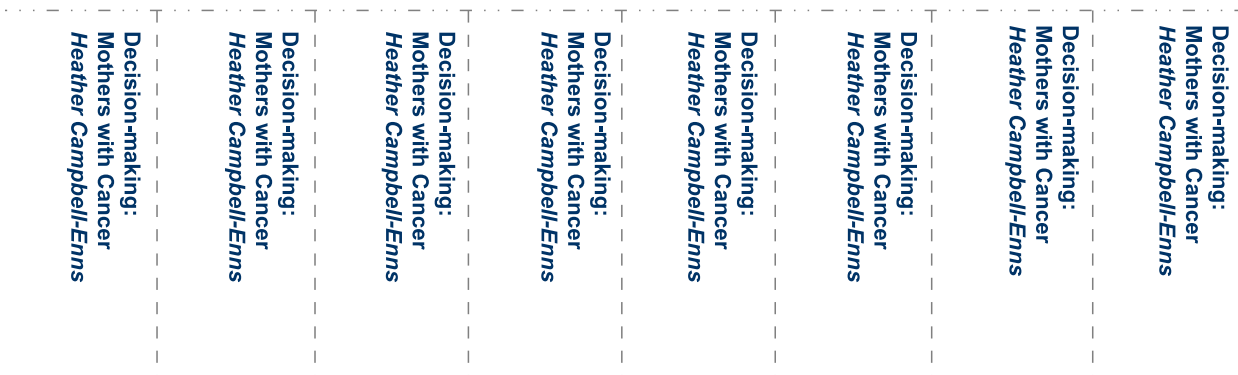
You are invited to take part in a study that explores how mothers of young children make decisions after the mother's cancer diagnosis.

Please call or email for more information.

Contact:

Name: Heather Campbell-Enns
Title: Decision-making: Mothers with Cancer
Phone:
Email:

This study has been reviewed and received ethics approval through the Joint-Faculty Research Ethics Board, University of Manitoba, February 3, 2010





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Appendix B: Invitation Letter

Faculty of Human Ecology
Family Social Sciences

Winnipeg, Manitoba
Canada R3T 2N2

Dear Parent,

As you will know better than anyone, the lives of women with cancer are complex – particularly when they are mothers of young children. Many important decisions must be made, sometimes very quickly. While we understand much more than we used to about the process of decision-making during illness, we still do not understand how motherhood influences women's decisions during the cancer experience.

This is why I am writing to you. I am a graduate student in the Department of Family Social Sciences at the University of Manitoba. I am conducting a study that will help us to understand better how mothers make decisions after their cancer diagnosis. This information will help us to develop better supports for mothers and their families undergoing this experience. If you have been diagnosed with cancer and, at the time of diagnosis, you have a child under the age of 7 – and no children over the age of 11 - I invite you to take part in this study.

If you are interested in participating, please call or email me for more information and I can answer any questions that you have. If you decide to participate, I will call you to arrange a convenient time and place for an interview. I will ask you some questions about your cancer experience as a mother and about making a significant decision after your diagnosis. The interview will take approximately one hour. Information on resources will be provided to all participants.

This project has been approved by the Joint Faculty Research Ethics Board at the University of Manitoba. This study will be used to fulfill the requirements of a Master's of Science, supervised by Dr. Joan Durrant.

All interviews will be kept strictly confidential. I am the only person who will have access to the transcripts and records. Direct quotations will be used from the interviews but careful measures will be taken to ensure that participants are not identified in any reports that are generated from the study. The interview will be non-intrusive, conversational and supportive. Participants are free to withdraw from this study at any time and for any reason.

If you are interested in participating, or if you would like to get more information, please contact me at XXX-XXX-XXXX.

Thank you for considering this invitation.

Sincerely,

Heather Campbell-Enns, M.Sc. Candidate
Department of Family Social Sciences
University of Manitoba

Dr. Joan Durrant, PhD, Professor
Department of Family Social Sciences
University of Manitoba



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Appendix C: Letter of Consent

Faculty of Human Ecology
Family Social Sciences

Winnipeg, Manitoba
Canada R3T 2N2

Letter of Consent

Research Project Title: Decision-making across the cancer trajectory: Mothers with cancer

Researcher: Heather Campbell-Enns
M.Sc. Candidate, Department of Family Social Sciences
University of Manitoba

I am a graduate student in the Department of Family Social Sciences at the University of Manitoba. I am conducting a study to explore the decision-making process of mothers who have been diagnosed with cancer.

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

1. Purpose of the Research

I understand that this study aims to increase understanding of the decision-making process among women with cancer who are mothers with young children.

2. Research Procedure

I understand that I will be asked to complete a background questionnaire and an interview that will focus on my approach to decision-making since my diagnosis. The interview is expected to be approximately one hour in length.

3. Risk Assessment

I understand that talking about my illness might cause some emotional distress. My feelings will be respected and I will not be asked intrusive questions. I am free to end the interview at any time. I will be given information on free counseling services from CancerCare Manitoba as well as other resources and supports.

4. Recording Devices

I understand that the interview will be audio recorded and the interviewer will take notes to ensure the accuracy of the record.

5. Confidentiality

I understand that I will be assigned a pseudonym, which will be used in all written notes and transcriptions of the interview, as well as in any presentations and publications that result from the study. Any other individuals to whom I refer will also be given pseudonyms. While some of my statements may be quoted in reports of the findings of this study, my identity will not be revealed. All written and taped recordings of the interview will be kept in a locked and secure

location to which only Heather Campbell-Enns has access. Taped recordings will be destroyed upon completion of this project. Heather Campbell-Enns is the only person who will transcribe the interview.

6. Feedback

I understand that I will receive a summary of the findings of this study if I wish.

7. Participation and Compensation

I understand that my participation in this study is completely voluntary. I am free to withdraw at any time and for any reason with no negative consequences to me or any services I am receiving. I also am free to not respond to particular questions. I will not receive financial compensation for taking part in this study. I may be contacted again by Heather Campbell-Enns as the study progresses if she needs clarification about any of my statements. My participation at that time will be voluntary and I will be asked to provide consent at that time.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and/or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation.

Researcher: Heather Campbell-Enns (XXX-XXX-XXXX)

Advisor: Dr. Joan Durrant (XXX-XXX-XXXX)

This research has been approved by the Joint Faculty Research Ethics Board. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Secretariat at XXX-XXXX, or email

A copy of this consent form has been given to you to keep for your records and reference.

participant's signature

date

address to send a copy of the summary report

Appendix D: Demographic Questionnaire
Demographic Questionnaire

1. What is your birthdate? / /
 mm dd year
2. What is your marital status? Are you:
- | | |
|------------------------------------|--|
| <input type="checkbox"/> married | <input type="checkbox"/> widowed |
| <input type="checkbox"/> divorced | <input type="checkbox"/> never been married |
| <input type="checkbox"/> separated | <input type="checkbox"/> a member of a common-law couple |
3. How would you describe your race or ethnicity?
-
4. What is your employment status? (check all that apply)
- unpaid work at home is primary work activity
- paid employment (full time / part time)
- Position: _____
- self-employed (full time / part time)
- Position: _____
- seeking paid work
- student
5. Highest education completed:
- elementary
- some high school
- high school graduate
- some college or university
- college or university graduate (degree: _____)
- some graduate school
- graduate program complete (degree: _____)

6. How many children live in your household? _____

7. Do these children live with you:

_____ full time _____ part time

If part time, where do these children live when they are not with you?

8. Please complete the table below with information about each of your children:

	Male/ Female	Birthdate: month/day/year	Does this child have a special need that must be attended to?
Child 1			
Child 2			
Child 3			
Child 4			
Child 5			
Child 6			

9. What is your cancer diagnosis? _____

When were you diagnosed? _____

Are you currently on treatment? _____

When was your last treatment? _____

10. Is there any other information about you or your family that you would like me to know?

Appendix E: Interview Guide 1

1. *The Context of the Cancer Diagnosis*
Please tell me about your experience with cancer, from when you first suspected or were told you had cancer to the present?

2. *The Family Context of Decision-Making*
Has family life changed since your diagnosis?
If “yes”: Tell me more about these changes.
If “no”: Tell me how it has remained the same.

3. *Decision-Making Prior to Diagnosis*
Tell me about making major decisions before your diagnosis.
Probes:
What was your life like then?
What process did you go to arrive at a decision?
What influenced your decision?
Were you a mother? If so, how did being a mother influence your decision?
What was it like to put this decision into action?

4. *A Significant Decision Since Diagnosis*
What are some significant decisions that you had to make since your diagnosis?
Tell me about a decision you have made since your diagnosis
Probes:
Why was this decision significant for you?
What was your life like then?
What process did you go through to arrive at a decision?
Who else, if anyone, was involved in this decision?
 Tell me about how he/she/they influenced your decision-making.
What else influenced your decision?
How long did it take to make this decision?
Did the fact that you are a mother influence your decision?
What was it like to put this decision into action?
What happened next?
How do you feel now about that decision?

4. *Ongoing Development of the Decision-making Process*
Tell me about the decisions you have made since then.
Probes:
Has the process been similar or has it changed?
How do you feel about your ability to make significant decisions in the future?
What kinds of supports do you need to help you to make decisions?

Appendix F: Interview Guide 2

1. *Can you tell me about your cancer story- from the time that you suspected you had cancer or learned you had cancer- until now?*
 - How has your family life changed?

2. *Thinking about your life since your cancer diagnosis, is there a specific experience of making a decision that you would like to tell me about?*
 - How did you come to that decision?
 - What other options were possible?
 - Did you consider them?
 - What factors led you to choose the option you described?
 - Why was this significant to you?
 - What was your goal?
 - Were there other goals you considered?
 - What was your life like at that time?
 - What influenced your decision? Why?
 - Does being a mother influence your decision?
 - What happened next? What did this lead to?
 - Expected, unexpected, or surprises...
 - What was it like to be a mother during this process?
 - How do you feel about your identity as a mother (before/after?)
 - If changed assessment (transforming knowledge): What did you notice when...?
 - Hypotheticals:
 - What would you have done if ___? You weren't a mother?
 - How would you react if you could not have ___?
 - What mistakes might someone else have made? Why?

4. *Is making a decision in the context of cancer different from making decisions before cancer?*

5. *Another decision...*

6. *Is there an issue that you are currently making a decision about?*
 - Can you tell me what you are thinking?
 - Why is this significant for you?
 - What influences your decision?
 - What are the options you are considering?
 - Compare it to another experience?
 - Imagining how it will unfold?

7. *Is there anything else I should know to help me understand the process of decision-making better?*

Appendix G: Interview Guide 3

1. *Can you tell me about your cancer story- from the time that you suspected you had cancer or learned you had cancer- until now?*
 - How has your family life changed?
2. *Thinking about your life since your cancer diagnosis, is there a specific experience of making a decision that you would like to tell me about?*
 - Determine a timeline: when & how long
 - Look for how one state of knowledge transforms to another (causal chains)
 - Note situation awareness at each stage (big picture)
 - How did you come to that decision?
 - What other options were possible?
 - Did you consider them?
 - What factors led you to choose the option you described?
 - Why was this significant to you?
 - What was your goal?
 - Were there other goals you considered?
 - What was your life like at that time?
 - What influenced your decision? Why?
 - Does being a mother influence your decision?
 - What happened next? What did this lead to?
 - Expected, unexpected, or surprises...
 - What was it like to be a mother during this process?
 - How do you feel about your identity as a mother (before/after?)
 - If changed assessment (transforming knowledge): What did you notice when...?
 - Hypotheticals:
 - What would you have done if ___? You weren't a mother?
 - How would you react if you could not have ___?
 - What mistakes might someone else have made? Why?
4. *Is making a decision in the context of cancer different from making decisions before cancer?*
5. *Another decision...*
6. *Is there an issue that you are currently making a decision about?*
 - Can you tell me what you are thinking?
 - Why is this significant for you?
 - What influences your decision?
 - What are the options you are considering?
 - Compare it to another experience?
 - Imagining how it will unfold?
7. *Is there anything else I should know to help me understand the process of decision-making better?*

Appendix H: Interview Guide 4

1. *What was your life like at the time you were diagnosed with cancer?*
2. *How did mothering change with your diagnosis?*
 - How has your family life changed?
 - What were the main emotions as a mother?
3. *Thinking back to your first diagnosis, is there a specific experience of making a decision that you would like to tell me about?*

Determine a timeline: when & how long

Pay attention to: goal/motivation, conditions, emotion, strategy/process, consequences

- How did you come to that decision?
 - What other options were possible?
 - Did you consider them?
 - What factors led you to choose the option you described?
 - Why was this significant to you?
 - What was your goal?
 - Were there other goals you considered?
 - What was your life like at that time?
 - What influenced your decision? Why?
 - Does being a mother influence your decision?
 - What happened next? What did this lead to?
 - Expected, unexpected, or surprises...
 - What was it like to be a mother during this process?
 - How do you feel about your identity as a mother (before/after?)
 - If changed assessment (transforming knowledge): What did you notice when...?
 - Hypotheticals:
 - What would you have done if ___? You weren't a mother?
 - How would you react if you could not have ___?
 - What mistakes might someone else have made? Why?
4. *Is making a decision in the context of cancer different from making decisions before cancer?*
 5. *You have recently experienced a recurrence, can you tell me about that?*
 6. *Decisions relating to changes...*
 7. *Is there an issue that you are currently making a decision about?*
 - Can you tell me what you are thinking?
 - Why is this significant for you?
 - What influences your decision?
 - What are the options you are considering?
 - Compare it to another experience?
 - Imagining how it will unfold?
 8. *Is there anything else I should know to help me understand the process of decision-making better?*

Appendix I: Interview Guide 5

1. *What was your life like at the time you were diagnosed with cancer?*
2. *How did mothering change with your diagnosis?*
 - How has your family life changed?
3. *Thinking back to your diagnosis and time following, is there a specific experience of making a decision that you would like to tell me about?*
Determine a timeline: when & how long
Pay attention to: goal/motivation, conditions, emotion, strategy/process, consequences
 - How did you come to that decision?
 - What other options were possible?
 - Did you consider them? What factors led you to choose the option you described?
 - What was your goal?
 - What was your life like at that time?
 - What influenced your decision? Why? Does being a mother influence your decision?
 - What happened next? What did this lead to?
 - What was it like to be a mother during this process?
 - How do you feel about your identity as a mother (before/after?)
 - Hypotheticals:
 - What would you have done if ___? You weren't a mother?
 - How would you react if you could not have ___?
 - What mistakes might someone else have made? Why?
4. *Is making a decision in the context of cancer different from making decisions before cancer? Or from making decisions more removed in time from your diagnosis?*
 - What were the main emotions as a mother?
 - How did this affect your life at the time? How is (emotion) a factor?
 - “worry”, “fear”, “grief”, ?
5. *Another decision...*
7. *Is there an issue that you are currently making a decision about?*
 - Can you tell me what you are thinking?
 - Why is this significant for you? What is the goal?
 - What influences your decision?
 - What are the options you are considering?
8. *Is there anything else I should know to help me understand the process of decision-making better?*

Appendix J: University of Manitoba Ethical Approval

Letter of Approval removed to protect personal information of others.

Appendix K: CancerCare Manitoba Approval

Letter of Approval removed to protect personal information of others.

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