The Institute for Clinical Social Work

The Experience of Young Mothers
with Cancer Parenting Children

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Institute for Clinical Social Work in Partial Fulfillment
for the Degree of Doctor of Philosophy

By
Draga Ilievski

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Abstract

The population of young mothers with cancer who parent their children has increased over time. Although many studies have been conducted on women with cancer, few specifically addressed the experience of mothering during cancer treatment. This study explored the thoughts, feelings, and experiences that young mothers with cancer underwent when faced with a chronic, potentially life threatening illness. Using grounded theory, fifteen women were interviewed in an effort to gain an in depth understanding of their experience of mothering their children in the wake of a cancer diagnosis. Findings include having a both psychological and medical experience of the illness, the children being attuned and active participants in the illness with the mother, cancer being experienced an assault on the mother’s gender, notions that surround ‘good enough’ mothering with cancer, and behavioral activities being used to manage anxiety about the possibility of death.
Acknowledgements

I wish to extend my deepest gratitude to my dissertation committee: Dr. Dennis Shelby, Ph.D. (chairman,) Dr. Denise Duval Tsioles Ph.D., and Constance Goldberg M.A. I would like to also thank my dedicated readers, Dr. Paula Ammerman Ph.D., and Dr. Janine Gauthier Ph.D., for supporting me through this very long process. I am humbled by the warmth and support of this committee for encouraging me and recognizing the sensitivity of the material being studied.

I want to thank the resilient young mothers who participated in my study, welcomed me into their homes twice, introduced me to their children, and showed me the terror that surrounds facing a chronic illness with young kids. I walked away from each woman feeling deeply connected and touched by their wisdom and courage.

During the data collection phase, my own father was diagnosed with terminal cancer and passed away after only 4 months. The experience of watching my father cope with; and ultimately succumb to cancer, while studying my participants, created a meaningful sensitivity to my project. I know my father was especially proud of this research topic, and how it provides language for the suffering experienced by any parent with cancer. As an adult child to my father’s illness, my sensitivity to the young children’s anguish in this study was deeply understood, as was the heartbreak of these brave mothers.
For my father,
Tome Ilievski.
1946-2015
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Chapter I

Introduction

General Statement of Purpose

This study explored the experiences of young mothers with cancer in parenting their children. The study sought to:

1. Evaluate mothers’ reactions to a cancer diagnosis; and to understand the feelings, thoughts, and behaviors that these mothers experience as they focus on their relationships with their children in the face of a life threatening diagnosis.

2. Construct theories about maternal distress during cancer treatment and the transformation that occurs in these mothers.

3. Inform oncology social workers of the need to consider carefully the emotional reactions of young mothers during the course of treatment.

4. Support a thoughtful needs assessment for this population. Understanding the subjective experiences of this particular group of women can help guide implementation of psychosocial interventions for cancer patients.

The 2015 data from the American Cancer Society anticipated 230,840 cases of invasive Breast Cancer to occur in women (ACS Cancer Facts and Figures, 2015). The same data also reported that an estimated 40,290 deaths related to Breast Cancer were expected to occur in 2015. The data also elucidates estimated deaths from Colon Cancer
to be 23,600 women in 2015. Female deaths from Leukemia were anticipated at 650 women in 2015. As startling as these figures are for these disease specific types of cancer related deaths, the total estimated deaths for all cancer sites combined in 2015 was 277,280 women. The participants in this study had primarily Breast Cancer, however others had Colon Cancer and Leukemia. Many cases of females with cancer are women with young children. The focus of this study is to consider this large number of women and provide an in-depth understanding of their experience and how emotional distress related to a cancer diagnosis impacts the task of mothering.

Although considerable attention is given to children with cancer treatment, there is little research on the experience of the young mother. Identifying and treating the concept of distress in cancer treatment has national protocols and guidelines. The National Comprehensive Cancer Network (NCCN) issued distress screening guidelines in 2005 that emphasize the role of distress in coping with cancer and the impact on following treatment recommendations (NCCN, 2005.) Most cancer centers have routine screenings for distress and recognize the influence it has on treatment. Some studies considered behavioral life legacy activities that mothers with cancer complete at the end stage of their treatment. Legacy activities are projects that function to pass the “essence” of oneself onto the next generation (Hunter, 2008.) Few studies however explore the meaning behind what motivates these activities, but instead focus on their benefits and wellness.

The effect of parental loss in childhood is well documented (Gray, L; Weller, R; Fristad, M; Weller, E, 2011; Fearnley, R, 2010.) Few studies however have focused on the subjective experiences of the mother with terminal illness. She has the gargantuan
task of dealing with a debilitating illness and the very real possibility of her own death, while simultaneously providing important emotional and physical caretaking functions for her child.

This study was an in depth exploration of the subjective experiences of the mothers diagnosed with cancer, and how the distress about the diagnosis impacts transformation and resilience.

Significance of the Study for Clinical Social Work

The social worker’s role in an oncology setting is critical to one’s understanding not only of the medical aspects of such an illness, but also the psychological aspects of coping with cancer. Social work in oncology became a recognized division of clinical practice in 1984. Organizations such as the Association of Oncology Social Work (AOSW) actively support and provide resources to oncology social workers nationwide. Additionally, the National Association of Social Workers (NASW) supports research endeavors for their members. This study could significantly benefit oncology certified social workers who have interactions with mothers of young children in their cancer centers. An oncology social worker demonstrates core competencies in psychological, emotional, social, practical and financial aspects of cancer treatment (Kennedy, V.; Smolinski, K.M.; Colon, Y. 2010.) An in depth understanding of a mother’s well-being and concerns for her children’s security notwithstanding cancer supports the oncology social worker’s ability to offer advocacy for these unique cases. Behavioral solutions, such as cancer walks and blog writing are commonly used as coping interventions in the care of chronic illness. Yet, we do not have a thorough understanding of the motivations
for these behavioral activities. The study will enable social workers to have a more informed understanding of the experience of mothers with cancer, the bond shared with the child, and what core maternal concerns the behavioral interventions commonly utilized seek to address.

Statement of the Problem to Be Studied and Specific Objectives to Be Achieved

This study was undergirded by the premise that mothers are strongly motivated by the well being of their children and that the relationship between mother and child generates important bonds of attachment (Bowlby, 1958.) This study is also informed by my clinical experience, which suggests that mothers diagnosed with cancer experience significant and intensified worries related to their children’s needs. These intensified worries begin as early as the onset of the diagnostic process. These mothers have concerns that they will not survive the illness, and that the illness will have a long term negative impact on their children’s well being. Primarily, these mothers were naturally preoccupied with their own survival and the meaning of this threat to herself and her children.

Research has identified types of maternal resilience that is demonstrated when faced with a life threatening illness (Billhut & Segesten, 2002.) Additional studies have considered how the mother manages the disease process with normal family life. These studies have found that the mother often is preoccupied with the child’s well-being and takes careful consideration of how children are to be included in the process of decision making, her treatment, and remaining focused on the task of mothering (Elmberger, Bolund and Lutzen, 2000.)
With advanced screening and technology, a diagnosis of cancer in women with young children has significantly increased. With this increasing number, I observed in my own practice the remarkable difference between cancer patients undergoing treatment who had young children and those who did not. It seemed that when a patient had children to care for, her primary focus was on child rearing, and not on her own treatment. Being informed by the mothers in my practice, I incorporated a more focused assessment of the needs of patients who had children. I observed the conflict and anxiety they expressed when facing ideas about their own mortality and child rearing. I sensed the enormous burden these women experienced when they were diagnosed with their illness, the treatment process, and the challenge to cope with this and more.

I further observed that over the course of treatment, some mothers experience what appears to be a transformative shift in emotions ranging from a state of tremendous fear to confidence in their coping abilities. When mothers were provided an opportunity to voice their maternal concerns, in the empathic safety of psychotherapy treatment, this transformative shift often occurred. Over the course of treatment, I observed in some mothers the capacity to transform the shock of the diagnosis into a peaceful awareness of their illness. In others, I observed mothers who de-focused from their illness to their concerns about their children. These however, were clinical observations in treatment. The specific objective of this study was defining and deepening our understanding of maternal preoccupation and concern when there is a diagnosis of cancer. This study explored how the diagnosis of cancer disrupts the process of mothering.
Chapter II

Literature Review

Statement of Relevant Knowledge or Theory and Review of Significant Literature

The current psychosocial oncology literature on mothers contains several themes related to mothers with cancer. The themes identified include:

2. The impact of a mother’s cancer on children.
4. The use of behavioral legacy work for coping.
5. The mother’s attitude toward the child.

Transformations in Coping throughout Treatment

Transformations in coping are observed from the point of diagnosis and into survivorship or palliative care. The cancer illness trajectory includes adjusting to the diagnosis, planning a treatment regimen, recovering from surgery, questioning the type of adjuvant treatment to receive, overcoming side effects, awaiting outcomes, and at times preparing for death (Hack & Degner 2003.) Coping, for women and mothers, begins at the point of diagnosis. It is reported that some of the most stressful times for women are following testing, waiting for the diagnosis, and impending surgery (Drageset, Lindstrom & Underlid, 2009.) Early preoccupations for women include issues related to family
planning, surgery, potential decisions about reconstruction, and career (Ellsworth, Bass, Skoracki and Heller, 2010.) The concept of ‘illness intrusiveness’ for women with cancer is recognized in the oncology literature. The severity of a woman’s illness, body image, physical functioning, bodily pain and fatigue were notable disease factors that determined the ‘illness intrusiveness’ for women (Bloom, Stweart, Johnston & Banks, 1998.) These illness induced physical symptoms produced lifestyle disruptions that created this sense of intrusiveness for women. Specifically, bodily fatigue is a recognized intrusive factor among women in treatment (NCCN, 2008.) These physical factors impact one’s capacity to cope. A consensus of the most recent of the oncology literature showed women with cancer report considerable uncertainty about their future and at times difficulty maintaining hope when experiencing a physical decline.

Longitudinal studies have been conducted with mothers to observe the coping and transformative process over time. Differences have been noted in coping for a younger population of cancer patients when compared to older women. Young breast cancer patients were found to have a poorer quality of life when compared to older women, specifically in the emotional and social domains (Danhauser, Crawford, Farmer and Avis, 2008.) Younger women with cancer have an immediate mixture of emotional reactions that impact coping. Patients with advanced cancer use emotion-focused coping (regulating emotions) more often than problem-focused coping (making a plan of action) during treatment (Thomsen, Hansen & Wagner 2010.) In their study maternal concern and coping factors in younger woman include the need to consider the well-being and care needs of her children.
Themes have emerged in the types of coping strategies most commonly utilized for female cancer patients. Coping strategies can be classified into emotion focused (defined as regulating emotions), problem focused (defined as making a plan of action,) or appraisal focused strategies (Folkman & Lazarus, 1988.) Other studies delineated more specific strategies in coping. In a study conducted in 2009 by Drageset et. al., specific coping strategies of young women with cancer included: taking things step by step, emotionally withdrawing, conducting business as usual, enjoying life, preparing for the worst, and trying to maintain a positive focus. It is notable that women vary in their coping efforts over time. Coping was also found to have an influence on distress, and alternatively, distress influenced coping (Roussi, Krikeli, Hatzidimitriou & Koutri, 2007.) Women were found to have increased levels of psychological distress when a passive coping style was recognized. Passive coping style has been defined as seeking distractions that don’t pertain to the problem at hand, isolating oneself, or the use of substances to avoid anxiety (Pieterse, Van Dooren, Seynaeve, Bartels, Rinjsburger, Koning, Klijn, Van Elderen, Tibben & Duievenoorden, 2007.) Commonly, many women use denial as a defense mechanism in avoiding the anxiety of the diagnosis. Coping strategies have overall been found to influence adjustment to cancer treatment in mothers. It is the distress of living with an incurable condition and an unpredictable course of the disease that creates vulnerability in women with cancer (Johnston, 2010.)

Issues surrounding increased vulnerability raise the question of prognostic awareness in women with cancer. Questions about prognosis are posed to medical professionals in the diagnostic process. Medical professionals struggle with the value of prognostic awareness; it can be harmful to mental health, and yet beneficial to life care
planning (Ray, Block, Friedlander, Zhang, Maciejewski, & Priegerson, 2006.) Researchers suggest that physicians at times overestimate survival times in order to preserve hope for patients. Hope can provide the ability to endure suffering and is considered a powerful coping mechanism for quality of life (Johnson, 2007.) Generally, mothers benefit from prognostic awareness in order to do the vast amount of planning necessary for the lives of their children. The feeling of hopelessness however has been correlated with depressive symptoms. Women who reported feelings of hopelessness and who were alone throughout treatment were especially vulnerable to later depressive symptoms (Brothers & Anderson, 2009.) It has been postulated that another consistent predictor of distress is avoidant coping (denial) of the cancer diagnosis (McCaul, Sandgren, King, O’Donnell, Bransetter & Foreman, 1999.) There is a larger percentage of women, however, who do adapt to the disease and treatment process without severe mental health impact. A study in 2006 indicates that the majority of patients are able to reach a state of peacefulness with a grasp and understanding of their terminal condition (Ray et. al., 2006.) It seems that cancer patients who are at peace with their situations have better mental health outcomes.

Mothers with cancer need psychosocial programs and services to implement the use of coping strategies. A need for family based programs of care has also been identified as a potential solution to improve quality of life for cancer patients who are also dealing with their children (Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004.) Including the entire family in the supportive process seems to facilitate the coping and transformative process for mothers. Some specific interventions have been recognized in the oncology literature. The use of reflective journals and diaries seem to
capture patterns of coping that emerge throughout the treatment course (Gonzalez & Lengacher, 2007.) Individual therapy and support groups are standard treatment interventions for distress. Having a sense of attachment and social integration are important factors in dealing with the emotional toll of cancer (Holland & Holahan, 2003.) Additionally, the use of Internet based support options has also increased as a means of psychosocial support. The use of the Internet for psychosocial issues has allowed for more accessibility in the level of support experienced by women, but not necessarily in an improvement in their coping (Fogel, 2004.) The psychosocial oncology literature also indicates the benefit of adaptable coping strategies. The coping process should be assessed continuously since the demands of cancer treatment are constantly changing (Kyngas, Nousiainen & Vaattovaara, 2001.)

In a study of breast cancer patients five years post diagnosis, it was found that cancer triggered and initiated a transformation in women’s lives (Salander, Lilliehorn, Hamberg & Kero, 2010.) This study found that the cancer diagnosis served as a catalyst for transformation, having new interpersonal experiences, and feelings of being psychologically strengthened. The concept of transforming desolation into consolation has also been observed (Ohlen & Holm, 2006.) In considering women with dependent children and ideas about their suffering, we are lead to consider the potential transformation of desolate feelings into those of consolation. The concept of suffering and how it may be transformed into the grasping of ‘life meaning’ is addressed in the literature. Part of the vital transformative shift that occurs in mothers over the course of treatment is the shift from experiencing desolating fear to accepting suffering. Spiritual wellness is also significant to cancer patients. An inner healing process includes
accepting the emotional suffering that surrounds a desire to maintain ordinary life, while facing the changes in life that accompany a diagnosis of cancer, with its resulting impact on the family. Researchers indicate that inviting women to share their feelings of distress to acknowledge suffering becomes part of the maternal transformation (Ohlen & Holm, 2006.)

**The Impact of Cancer on Her Children**

When diagnosed with cancer, some primary concerns for mothers include: what to tell their children about the cancer, how to talk to their children about cancer, and what to do with their children to help them understand and cope with the disease (Shands, Lewis, Hooper-Zahlis, 2000.) These are just a few of the questions that are raised and may begin the preoccupying concern for mothers undergoing treatment. Mothers seem to also experience a sense of competing conflicts when diagnosed with metastatic cancer. The competing conflicts include: being needed by their children and being unavailable to them; experiencing daily demands and acknowledging their own medical needs; having a will to be strong and allowing themselves to be sick; and telling the truth and protecting children from the truth (Billhult & Segesten, 2003.) Grappling with these compromises has been found to transform resilience in motherhood.

The impact of the mother’s cancer on the child is a reasonable preoccupation. It is well documented that children are profoundly impacted by the disease process of the mother and experience an array of concerns (Zahlis, 2001; Vannatta et.al, 2008; Stiffler et.al, 2008; Hoke, 2001; Kennedy et.al 2009.) Children often become hypervigilent with
their mother’s well-being as their sense of security is threatened. Zahlis, 2001, discovered actual, far-reaching concerns for children and described the following worries:

- Worrying that the mother was going to die
- Feeling confused
- Worrying that something bad would happen
- Worrying about the family and others
- Worrying when mother did not look good
- Worrying that mother would be changed
- Wondering if the family would have to cut back financially
- Worrying about talking to others
- Worrying that the child would get cancer

The vulnerability in children is determined by biophysical, psychological and social components of their lives (Visser et. al, 2007.) Each family unit has its own unique way of functioning.

When the mother has cancer, ‘open communication' leads to more effective coping for children (Kennedy and Lloyd-Williams, 2009.) Keeping children aware of changes in the mother’s condition decreases their level of anxiety, and allows them to feel included in the mother’s world. Although ‘open communication’ is an overarching important concept, emphasis in the literature is given to the importance of an individualized assessment of each child and each family’s subjective experience of the disease (Hoke, 2001.)

The child’s developmental stage is often a predictive determining factor in establishing coping strategies. School aged children whose mothers had cancer were
evaluated in terms of their social behavior with peers, level of acceptance by classmates, and number of friendships at school (Vannatta et.al, 2008.) Clemmens attributed this to his view that the needs of adolescents differ because they have a greater depth of feeling (Clemmens, 2009.) Adolescence is a time of emerging identity and a need to be separating from the family. Clemmens believed this might cause guilt for some teens because they also experience a need to be near their mothers. Adolescent daughters are highlighted in the literature as being more vulnerable (Giesbers et. al 2010.) Giesbers writes that daughters may have strong identifications with their mother and a resulting increase in role responsibilities in the home because of the mother’s illness (Geisbers et. al 2010.) Having actions to take for the child alleviates conflict and perhaps a sense of helplessness. On the other hand, adolescents may have conflictual relationships with their mothers; harbor unconscious aggression and guilt towards her, and then in turn feel that their aggressive fantasies are fulfilled.

Parenting Experiences throughout Cancer Treatment

Since a diagnosis of cancer brings insecurity into the life of a child, maternal concerns surround issues related to parenting. Being diagnosed with cancer affects the family in many ways. Chemotherapy induced side effects may interfere with day to day parenting routines (Stiffler et. al, 2008.) Consideration is given to how cancer impacts methods of care for mothers. Themes identified in parenting concerns include:

- Striving for normality in an abnormal situation
- Focusing on the children’s well-being
• Balancing between different needs
• Expressing both openness and the need for support

These themes reflect both the striving for and need to be ‘good parents’ during the course of cancer treatment (Helseth & Ulfaset, 2005.) Often, mothers will seek support from professionals as to how much or what to tell their children. Some researchers believe the struggle is between in being a ‘parent’ versus being a ‘patient.’ The challenge is to find this balance during treatment (Semple & McCance, 2010.) Researchers note that mothers are often focused on their children and not themselves. It is believed that they set a high priority on parenting and demonstrate more difficulty in prioritizing their needs during treatment (Stiffler et. al, 2008.)

Additionally, mothers often consider what to do to prepare their children for the disease process itself. Here again, studies have addressed and identified how knowledge of child development prepares these mothers for changes in the child during course of treatment. Moore and Rauch, 2010, outline the developmental perspectives of childhood as they relate to mothers with cancer. The study illustrates how parents can benefit from an increased understanding of their children’s capacity to digest the information based on their developmental stage. It provides solutions for these areas of concern.

**The Use of Behavioral Legacy Work for Coping**

The use of legacy activities is commonly practiced in cancer treatment. Legacy activities functions as a means to pass the “essence” of oneself on to the next generation (Hunter, 2008.) Various legacy activities are observed in treatment. Some of these include:
• Scrapbooking with photos
• Video diaries
• Cookbooks
• Audiotaped stories
• Written diaries/Journals

The purpose behind the use of these methods is documented in the literature. Some refer to these activities as a ‘celebration of life’ (Allen, 2009.) Others have explained that they are used as exercises to provide insight into their experiences (Holtslander & Duggleby, 2008.) Others refer to legacy activities as leaving something behind in order to make meaning at the end of life (Hunter, 2008.) Few studies explore in-depth the issues that these mothers are trying to reconcile in the use of legacy activities. Journaling provides a personal record that allows a reconstruction of the traumatic events surrounding the diagnosis of cancer (Alaszewski, 2006.) In these legacy activities that take place during cancer treatment, mothers are participating with others in behavioral exercises that allow for mutual reminiscing and future planning. It is not clear in the literature what the “essence” of legacy activities actually is. One can surmise that actively participating in a behavioral activity for coping allows mothers to reconcile some sense of not being passive victims of the cancer treatment. All of these activities strive to create a coherent narrative. One’s narrative undergirds the continuity and experience of self. Thus, the self does not die with the diagnosis, but allows the illness to be incorporated into the total experience of self.
The Mother’s Attitude toward the Child

Formation of maternal attitude begins from the moment that the mother believes that she is pregnant. Even before birth, the mother begins to integrate the infant into her new life (Glueck, 1928.) Glueck believes that the maternal attitude is highly significant for child development. He also believed that the personality of the mother will align with her parenting behavior in guiding child development (Glueck, 1928.)

From a social psychological perspective, maternal attitude is described as “the atmospheric conditions of the home” (Richards, 1926, p. 241.) In 1943, David Levy studied maternal attitudes and interactions based on emotional needs of the mother. Attitudes related to instances of overprotection, rejection, anxiety and indulgence impact the emotional world of the child. Attitudes can be fluid and complex and must be placed in a context in order to influence a child’s behavior (Holden and Edwards, 1988.) Differences in parental attitudes result in differential outcomes for the child (Holden, 1989.) Negative attitudes that mothers have about their child are caused in part by their own experiences as children. In addition, their current views about their own lives and their individual developmental expectations are some factors that contribute to negative maternal attitudes (Daggett, O’Brien, Zanolli & Peyton, 2000.) Attitudes are influenced by the individual needs and growth of the child. Variability in the mother’s attitude is often unconsciously motivated (Kris and Provence, 1953.) Archaic identifications never fully disappear and influence parent and child relationships throughout the life cycle (Kris and Provence, 1953.)

Additionally, maternal attitudes manifest in child rearing; however, factors such as the mother’s personality and individual situation are causal factors to be considered.
A negative maternal attitude can additionally be related to mental illness and dysfunctional states which have been found to have a negative impact on parenting (Brennan, Williams, Najman & O’Callaghan, 2003.) Emotionally mature attitudes, such as gratitude and empathy, make it possible for children to overcome traumatic experiences and loss.

In summary, my observations in psychotherapy of maternal concern during cancer treatment and the documented literature identify the significance of the potential disruption of mothering during cancer treatment. According to the literature, transformations that occur over time include ideas about illness intrusiveness as well as the peaceful awareness of the illness. These significant elements may emerge in considering the transformative shift in a woman’s emotional world when parenting young children. Helplessness, depression, cosmetic changes, and the impact of everyday life all contribute to transformations in women. Psychosocial oncology research explicates maternal preoccupation and the impact of cancer on children. Research shows that emotional, behavioral, social, physical, and cognitive changes occur in children as a result of parental cancer. Children demonstrate sadness, fear, uncertainty, anger and guilt as a result of parental cancer. Mothers make efforts to balance the telling to their children about their illness with the disclosure of too much about their disease process. The role of parenting is considered by mothers and impacts their distress. Pain and a lack of physical energy impact typical methods of providing care to children. However, mothers who are faced with the possibility of death are extremely focused on the well being of their children.
It is important to understand the way in which mothers begin to utilize legacy behavioral activities as a solution to the disruption in parenting caused by cancer. Behavioral activities are utilized to alleviate the distress associated with the burden of these concerns, and to provide a sense of agency to mothers. The origins of motherhood are complex and encompass the entire personality of the mother, including her emotional state and attitudes toward her infant. From diagnosis through treatment, recurrence, and bereavement, there are variations in the mother’s attitude toward her child. This study will take into account maternal attitude, changes in a mother’s ways of thinking, and the feelings about her children that are evoked through the course of illness. We will consider how life legacy work, or, the re-telling their story, impacts the mother’s sense of herself. This re-telling may allow her to be less depressed and more available to her children.

**Theoretical and Conceptual Framework of the Proposed Study**

From its beginning, psychoanalytic theory has recognized and addressed the significant tie between mother and child. The meaning of this bond has been both elaborated and changed over the years; however, its central importance has remained constant. Originally, Freud viewed the role of the mother solely as an object to satisfy the libidinal needs of the infant. Freud initially stated that a libidinal cathexis is experienced by the infant, as he received physiological gratification from his mother (S.E. VII. p.179-180.) Freud viewed the infant as being in a state of primary narcissism in which he takes himself as his love object before choosing external objects. In a state of primary narcissism, there is no object or other, merely a state of absolute dependence. For the mother, the infant represents a replacement for the previously castrated penis. In
considering the castration complex and femininity, Freud writes of the differences in the identification process between the pre-oedipal and post-oedipal phases of development (S.E., 1931, Vol. 22). Pre-oedipal maternal identification is a powerful, feminine attachment of the girl to her mother; this phase comes to an end with hostility towards the mother, as the child’s development transitions to the oedipal phase of development. In the Oedipal phase transition, the daughter seeks her father as a love object and experiences a relief from the hostility towards the mother caused by her perceived castration (S.E., 1931, Vol. 22). The Oedipal situation therefore represents the first vestiges of identification in the psychoanalytic literature. As for castration anxiety, the infant essentially functions as an autoerotic extension of the mother. During the course of development, the child becomes increasingly interested in objects outside of him or herself to satisfy libidinal drives. Mothers protect children from the dangers of the external world. For an infant or child, the loss of a mother or the fear of losing a mother evokes danger, anxiety, and a state of helplessness (Freud, 1926.)

Melanie Klein embraced Freud’s analytic theory regarding the primacy of drives and identifications. Klein also viewed the mother as a need satisfying object. Klein, like Freud, viewed the relationship with the mother in terms of the intrapsychic phenomena, and not on the real or interpersonal relationship between mother and infant. Klein identified an intrapsychic mechanism which is solely determined by the intensity of the infant’s drives. Her notions of development considered the infant’s ‘phantasies’ in relation to their mothers. Therefore, with the infant’s growth and ongoing development of the ego, a “True relation to reality is gradually established out of this unreal reality”
(Klein, 1930.) For Klein, as for Freud, the external mother had little to do with the infant’s internal experience.

Klein felt that an infant’s emotions, anxieties, introjections, and projections influence character, life experiences, and object relationships (Klein, 1955.)

“Identification by projection implies a combination of splitting off parts of the self and projecting them onto another person” (Klein, 1946.) A working through of the psychotic anxiety of infancy in the paranoid-schizoid position through the depressive position results in psychological integration. A child, from Klein’s perspective, achieves integration with good object relationships. Klein’s ideas of good and bad objects represent a polarity in relation to the external objects, often the mother. If an infant perceives the loss of a ‘good mother’ then it will likely experience the loss of a ‘good self’. Klein writes that the infant experiences anxiety as fear of persecution, and this contributes to mechanisms and defenses, which characterize the paranoid and schizoid positions (Klein, 1946.) If the anxiety in the paranoid-schizoid position has not been worked through, there is not a shift into the depressive position; therefore there is a lack of reparation between infant and mother. In the achievement of the depressive position, the infant attempts to experience both loved and hated aspects of the object and the defenses against them. The infant attempts to synthesize these emotions and work towards intrapsychic integration. “The good internalized object is one of the preconditions for an integrated and stable ego, and good object relationships” (Klein, 1946.) The conflicted attitude about love and hate that the child has towards the mother contributes to a turning away from her as a love object. The mother, for Klein, is the first object for infant’s identification.
In reviewing the theoretical positions of Donald Winnicott, Anna Freud and John Bowlby, the relational tilt from autoerotism to object relationships emerge. These theorists asserted that there was an equally important significance to the role of mother beyond drives, ‘phantasies,’ and physiological nurture.

Winnicott viewed the infant and maternal care as encompassing a unit (Winnicott, 1960.) Beginning in pregnancy, Winnicott theorized that mothers identify themselves with the baby growing within them. He describes a ‘primary maternal preoccupation’ as the period at the end of pregnancy and a few weeks after the birth of an infant. In this phase, the mother is preoccupied with the care of her infant and is identified with the baby. “Through identification of herself with her infant, the mother provides what the infant needs in the way of holding” (Winnicott, 1960, p. 593.) The mechanism of ‘holding’ begins the construction of the maternal and infant unit. The infant is maximally dependent on the mother in the holding phase. During the holding phase, we see the beginning of a distinct mind that is separate from the psyche. The empathic attunement of the mother creates a sense of safety and reliability for the infant. Winnicott describes the concept of maternal reliability in the infant’s recognition of his own individuality. Thus we surmise that maternal reliability is necessary for the transmission of information from parent to child, in that the individual child recognizes his own capacity to react to his parents. Winnicott describes maternal holding as the phase in which the infant’s physiology and psychology are in the process of becoming distinct (Winnicott, 1960.) With the care that the infant receives from his mother, he is able to develop a personal existence, and to build a ‘continuity of being’. Further, Winnicott writes of the development of a true or false self, which are distinguished by the positive or negative
experience of interpersonal and emotional care. Winnicott acknowledges that in order for a baby to move from the phase of Freud’s pleasure principle to the reality principle, a good enough mother is necessary to provide responsive functions to the infant (Winnicott, 1971.) A good relationship between the mother and infant allows for the infant to develop a separate sense of self.

Anna Freud describes the transition for the infant from primary narcissism to object love as an important step, which happens in small stages during the first year of life (A. Freud, 1949.) She emphasizes the libidinal investment as the child’s capacity to maintain the attachment to the mother, whether she satisfies or frustrates drive wishes (A.Freud, 1963.) Freud notes that the emotional reliance on the adult’s world is as significant as the physical dependence that the child has toward the mother. Freud identified a relationship to object love and feeding. Freud writes, “An infant who feeds successfully ‘loves’ the experience of feeding” which is known as narcissistic love. As the infant’s perceptual abilities form, the infant’s love is transferred to the provider of food, also known as object love. The mother’s attitude in relation to feeding her infant coincides with the infant’s unconscious attitude. Herein, the infant takes on the unconscious attitude of the mother when feeding (A. Freud, 1946.) Additionally, Anna Freud describes a mother’s physical illness as an occasion for the infant to feel insecure. The mother then concentrates on her illness, the needs of her body, and her own caregivers, a dependence that is similar to the infant’s dependence on the mother (A. Freud, 1953.) Anna Freud also describes an infant’s emotional, intellectual and moral capacities as being influenced by his environment (A. Freud, 1972.) In Losing and Being Lost, Anna Freud explained the profound impact of maternal loss on the infant (A. Freud,
“By being chronic losers, they live out a double identification, passively with the lost objects which symbolize themselves, actively with the parents whom they experience to be neglectful, indifferent, and unconcerned toward them as they are toward their possessions” (A. Freud, 1967, p. 5.) If a mother experiences her own sense of loss, her child will identify with this loss, thus demonstrating further the identification with the lost mother. A child who is deprived of a mother’s care may adopt a maternal role in health matters, playing mother and child with his own body (A. Freud, 1952.) What triggers this behavior is separation from or bereavement about the lost mother. “In identification with the temporarily or permanently lost mother, they substituted themselves for her by perpetuating the bodily care received by her” (A. Freud, 1952.) In essence, infants feel secure and content when loved by their parents and they become insecure and unhappy if the love is withdrawn or diminished (Freud, 1967.)

Bowlby’s Attachment Theory accentuated intergenerational transmission of parenting behavior (Bowlby, 1969.) He describes four types of attachment known as; secure, insecure, insecure avoidant, and disorganized (Bowlby, 1969.) Bowlby’s Attachment Theory is categorized by phases of separation: protest, despair and detachment, as an infant reacts to being separated from the mother (Bowlby 1973.) Bowlby attributes the secure relationship with the mother as being necessary for infants to explore their environments. If the mother is unavailable, separation anxiety, emotional distress, and protest behavior follows (Bowlby, 1960.) Bowlby’s concept of an ‘internal working model’ refers to the infant’s representation of the maternal relationship (Bowlby, 1969.) For example, an insecure attachment may lead to the internal working model of rejection.
In 1938, Therese Benedek wrote of the infant’s adaptation to reality being confidently established through trust of the mother. The infant’s capacity to master the object world is accomplished by his development of the object-libidinal relationship (Benedek, 1938.) Hence, if this primary relationship is disturbed, Benedek said that the ego’s learning capacity in the infant is inhibited by anxiety. The relationship with mother is predictive of the infant’s successful adaptation. Trustworthy and reliable motherhood is a developmental challenge that evokes either regression or progression in the mother (Benedek, 1970.) Recognition of a mother’s own childhood when she is actively engaged in mothering is an example of parenthood as another developmental phase of growth and development (Benedek, 1959.) Benedek identified that the mother experiences both gratification (when infant needs are satisfied) and frustration (when she cannot satisfy the infant) which equally affect both the mother and the infant’s emotional life. She considered the possibility of depression in the mother’s personality, her mood, and the possible withdrawal from the child resulting in the infant experiencing rejection. A mother’s failure to love her child by demonstrating overprotective and overindulgent behaviors is a direct result of her fears of not being able to love the infant. Benedek states that the infant, as the recipient of the mother’s emotional world, introjects the idea of “good mother as good self,” which establishes confidence in the child. Additionally, Benedek finds that the confident infant is therefore able to establish relationships beyond the mother as a result of integrated self-esteem. She also considered that bidirectionality exists; becoming a parent evokes memories of how one was parented and what it was like to be a small child (Benedek, 1959.) Benedek states that these psychic representations
guide maternal behavior in parenting. Therefore, maternal caretaking can be considered a reworking of childhood internal conflicts that may allow for change in the mother.

In the Psychological Birth of the Child, Margaret Mahler, informed by drive theory, described the child as being propelled toward the process of individuation. This process represents a shift from the pleasure principle to the reality principle. She emphasized the child’s maternal representation as shaping ego development. She described the infant’s emotional dependence on the mother as being a ‘universal truth’ of human existence. Mahler’s developmental theory includes the processes of infant and mother symbiotic relatedness, separation-individuation, and object constancy (Palombo, 2009.) The process by which the child is able to successfully experience himself as separate from the mother while maintaining a sense of wholeness within himself, is one step towards a more interactive view of development. The concept of symbiosis refers to a ‘dual unity’ and ‘omnipotent system’ of mother and infant (Mahler, 1967.) Mahler refers to the mother as the symbiotic organizer and auxiliary ego of the infant (Mahler, 1967.) Next, during the infant’s process of separation-individuation, differentiation is observed between the intrapsychic representation and the self-representation of the object. An infant’s emotional state requires reassurance about the mother’s availability, regardless of the infant’s actions or tendencies towards her. If the mother does not demonstrate warm and maternal behavior towards the infant, a breakdown in individuation will occur (Mahler, 1952.) Mahler, recognized as an ego psychologist and object relations theorist identified autonomous functions of the ego such as judgment, affect, regulation and memory were developed through mutual adaptation between the environment and individual. These functions enabled the child to move toward object
constancy. Further, object constancy, signifies the meaningful connectedness between infant and mother while they are able to also experience separateness from the other. During the phase of object constancy, the mother’s intrapsychic availability toward the child parallels the actual libidinally available mother, who provided sustenance, comfort and love to the infant (Mahler, 1968.) The infant with object constancy has secure recognition of the separate emotional world of the mother. The foundation for object constancy is thus provided by successful separation-individuation of the infant.

The psychological participation of the mother and child development was further elaborated in the 1970’s with the advent of Self Psychology and the theoretical concepts of Heinz Kohut. Heinz Kohut developed the term selfobject, which refers to the psychological functions provided by the mother that are experienced by the child as part of the self. “The child needs the gleam in the mother’s eye in order to maintain the narcissistic libidinal suffusion which now concerns the functions and activities of the various maturational phases” (Kohut, 1966, p. 252.) The child needs the idealized parental object to feel whole. The attitude and personality of the mother however are significant factors in the child’s experience of him or herself. Kohut emphasized the personality of the child’s caretaker as being important in forming psychological structures through the process he refers to as ‘passage through the object.” In this process, the child internalizes the parent’s emotional attitude and responses (Siegel, 1996.) When the idealized object is lost or unavailable, the child experiences trauma. Kohut viewed trauma as a subjective emotional experience for each child based on the intensity of the parent’s affect, which will contribute to the child’s psychic development. In the growth process of transmuting internalization, an unconscious memory of a lost parental object is
retained and becomes part of the child’s personality. This internalization represents a more integrated sense of self. “Psychological structures are internalizations of the soothing, tension-regulating and adaptive functions that have previously been performed by the self-object” (Siegel, 1996, p. 72.) The child’s process of internalization will not occur when a child traumatically loses the idealized parent.

In further elucidating the mother and infant as a unit of subjective experience, Daniel Stern identifies themes which he refers to as “The Motherhood Constellation” (Stern, 1995.) From his developmental research, Stern recognized that human relatedness begins at birth. He described an “affect attunement” between infant and mother (Stern, 1985.) This attunement implies a connection with another’s emotional state. He defined “The Motherhood Constellation” as a psychic organizer for the mother in which she will transition into new thoughts, feelings and fantasies after the birth of her infant (Stern, 1995.) Stern wrote, “As a psychic organizer, this “constellation” will determine a new set of action tendencies, sensibilities, fantasies, fears, and wishes” by the mother (Stern, 1995, p. 170.) The constellation (Stern 1995) includes four themes known as; The Life-Growth Theme, The Primary Relatedness Theme, The Supporting Matrix Theme, and The Identity Reorganization Theme.

The Life-Growth Theme is primarily focused on the mother’s ability to keep the baby alive and assure the baby is thriving. In the Primary Relatedness Theme, the mother’s primary task is to assure that an intense identification with her baby is developed. The focus of The Supporting Matrix Theme is the mother’s need to create a support network to assure she accomplishes the first two tasks of keeping the baby alive and assuring that an environment is created to facilitate the maternal preoccupation. In
The Identity Reorganization Theme, “The new mother must shift her center of identity from daughter to mother, from wife to parent, from careerist to matron, from one generation to the preceding one” (Stern, 1995, p. 180.) Stern emphasized The Motherhood Constellation as a psychic organization rather than simply a life phase that the mother passes through. He described “The Motherhood Constellation” facilitated through “The mother’s discourse with her own mother, her discourse with herself, and her discourse with her baby” (Stern, 1995, p. 172.) These preoccupations and discourses are significant as they shape the mother’s profound thought realignment with more focus in general on women, mothers, growth, development and baby; and less on fathers, careers, or husbands as men (Stern, 1995.) Stern therefore also identified a shift in the mother that occurs as a result of her own dependency needs with an awareness of her own mother’s response to them.

In Identity and the New Mother, Noel Blackburn identified four aspects of identity and becoming a new mother. Blackburn in 2006 found hopes, intentions, a mother’s sense of self worth, and curiosity as aspects of a mother’s identity. These include hope of being an ideal role model, the intention of maintaining a pre-motherhood identity, an augmented sense of self worth and a newly found curiosity of emotional states. “Mothers, in addition to being preoccupied with their child’s well being, were equally concerned with their own survival as mothers and they were impressed by their own sense of self worth.” Blackburn describes a maternal attunement to the child’s emotional states and how this attunement impacted a mother’s internal life and desire for self-understanding. In accordance with Stern’s Life-Growth theme, Blackburn’s findings elucidate the mother’s responsibility for sustaining her newborn’s life. She emphasized
how mothers were challenged by the responsibility for another human being, heightening a mother’s sense of self-worth and her identity as a mother. Blackburn also writes “A woman’s identity cannot be separated from her identity as a mother, as they mutually enhance each other” (Blackburn, 2006.)

In summary, the analytic framework captures the essence of how a child’s tie to the mother is formed and transformed over time. The analytic developmental research, although primarily from the perspective of infant to mother, elucidates the attachment and its complex formation; in the literature however there is a progression from an intrapsychic, separate infant-mother dyad to an interpersonal relationship. The shift is from the concept of a one-person psychology to a two-person psychology, from the pleasure principle to the reality principle. The transformation from intrapsychic to an interpersonal relationship of a mother-infant unit with a shared mind is outlined.

Sigmund Freud’s formative ideas of psychoanalytic literature refer to the infant as an auto-erotic extension of the mother, a definitive differentiated unit. Freud initially gave little credence to the significance of the maternal imperative. Notably, in Freud’s later work on Female sexuality (1931) he finally acknowledges that attachment to the mother precedes dependence on the father (Standard edition, Vol. XXI, 1931.)

Progressively, in a central position between drive theory and object relations, Melanie Klein considers intrapsychic representations of others, not actual object relations. As described, Klein continued in Freud’s intrapsychic perspective, and formulated her ideas of unconscious phantasies and infant drives in relationship to the object (Palombo, 2009.) Further, actual interpersonal relatedness between mother and infant was identified in subsequent psychoanalytic theories. For example, Winnicott’s ideas of the maternal
holding function extend the significance of these two minds in a state of attunement. A holding environment provides a space of equilibrium. Winnicott utilized the environment as an important space for object relationships to be explored and secured. Additionally, the impact of maternal loss was clearly identified by Anna Freud. She identified a child’s identification with parental loss and the subsequent evoked sense of loss in the child. She emphasized the considerable role of the mother and the affection and care she supplies to the infant. Moreover, John Bowlby’s Attachment Theory emphasizes the separation of the infant and caregiver and the creation of the infant’s emotional world. His theory introduces the idea of a primary social bond between mother and infant within which the infant uses the mother to safely explore the environment. He emphasizes ideas about the mother’s role in establishing temperament and regulation through attachment. An infant’s secure relationship with the mother is a regulator for his emotional world. Therese Benedek’s ideas about mutual identifications illustrate the impact of mothering and being a mother. She emphasizes two minds working together because mothers are only gratified and frustrated when attuned to their child’s needs (Benedek, 1959.)

Dependence on the mother was also described by Margaret Mahler as a universal truth. She emphasizes the child’s representation of the mother as separate and how it shapes ego development and object constancy. In the 1970’s however, Daniel Stern identified the motherhood constellation as a psychic organizer (Stern, 1995.) The mother’s own dependency needs and those of the infant were considered by Stern. Additionally, the idea of a mother’s recognition of survival and her own self worth and being concerned about their own survival was identified by Blackburn in the literature.
(Blackburn, 2009.) Her findings contribute to a mother’s sense of identity in adult development.

This study captures the impact of illness on the maternal-child unit. Vestiges of early maternal concern live on in a mother’s preoccupation with her growing child. Once this unit is established, it never fully disappears. Through early childhood, latency and adolescence, most well functioning mothers know where their children are at all times. What this study hopes to capture is the impact of illness on this fundamental maternal-infant unit.

Questions to Be Explored

This study will explore the impact of a cancer diagnosis on a mother’s intrapsychic and interpersonal relations with her children. The study will use in-depth interviews to explore the mother’s experience with cancer. Emphasis will be on the intrapsychic and interpersonal relations with her children. The demographic survey portion will consider specific family variables and how they influence the experience of the mother.

Theoretical and Operational Definitions of Major Concepts

Distress.

The National Comprehensive Cancer Network (NCCN, 2005) defines distress as “A multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional) social, and or spiritual nature that may interfere with a ability to cope effectively with cancer, its physical symptoms and its treatment. Distress extends
along a continuum, ranging from common normal feelings of vulnerability, sadness, and fears to problems that can become disabling, such as depression, anxiety, panic, social isolation, existential and spiritual crisis.”

**Maternal concern.**

For the purposes of this study, maternal concern is defined as the total set of feelings the mother has for her child; a preoccupation to keep the child alive, to know where her child is in time and space, and the ability to imagine the child’s future.

**Statement of Assumptions**

This study is based on a number of assumptions as noted below:

1. Maternal concern is a psychological phenomenon that is an integral part of child rearing. It may be disrupted by a cancer diagnosis and potential loss of life.
2. Mothers’ strong unique feelings for their children are well documented in the psychological literature.
3. For mothers with a cancer diagnosis, maternal concerns change over time from diagnosis to treatment to cure or palliative care.
4. The mother can articulate the range of feelings, anxieties, hopes and dreads that she experiences.
5. The Methodology will help explore and articulate the mother’s transformation.
6. Mothers can be recruited for this study in various stages of their illness.
7. Grounded theory aims to discover basic social processes. I will use the methodology to look at basic mental processes.
Chapter III

Methodology

Introduction

This study utilized grounded theory from the perspective of Corbin and Strauss (2008). Both Corbin and Strauss use grounded theory, “To denote theoretical constructs derived from qualitative analysis of data” (Corbin & Strauss, 2008.) The purpose of grounded theory methodology is also to build theory from data and ascertain the meaning of experience. In this study, grounded theory will be used to help explain how mothers think about their children during cancer treatment and will explore any transformation that occurs in mothers vis-a-vis their children. Data for this study were collected from thirty hours of clinical interviews with the participants.

The 15 research participants were subject to screening criteria. Mothers in this study were diagnosed with cancer before the age of 45 and have at least one child at or under the age of seventeen at the point of diagnosis. Mothers were a minimum age of 20 years old to participate in the study. The study was retrospective in that current interviews considered that status of the mother in the present, and any psychological changes that occurred during the course of her treatment. Participants were elicited from rural and urban oncology centers. Some were obtained through snowball sampling. Once selected,
participants were asked to complete a screening form, which included the following questions:

- The current age of the mother
- The age of the mother at the time of diagnosis
- The number of children she has
- The gender of the children
- Was the mother partnered during the course of her treatment
- What were the mother’s support systems during the course of treatment?
- What is the length of time since the diagnosis
- Is this an initial diagnosis of cancer or a recurrence
- What was the lifestyle of the mother at the time of diagnosis (employed or stay at home)
- Is there a history of depression in the mother

The purpose of having obtained this objective data was to explore whether these factors (i.e. number of children, age of children, the mother’s emotional history etc.) potentially effected the mother’s experience with distress and cancer.

**Scope of Study, Setting, Population and Sampling**

Fifteen mothers were randomly selected to participate in this study. Two sets of in person interviews were completed with each participant. When possible, I conducted the interviews with these mothers in their own homes. Other interviews were conducted in coffee shops or restaurants chosen by the mothers for their convenience and comfort preferences. Interviews were at least sixty minutes with each participant. The interviews
were broken into two phases: the initial interview and a follow up interview in eight to ten weeks. Finally, all participants were invited to participate in Member Checking, in which participants are asked to review and reflect on their readings of drafts of the finished study. Only a portion of the members responded with a willingness to read the document and none of them wished to sit down and review the document for a third interview of clarification in person. Five of them responded with messages of approval.

Convenience sampling ensured that participants were selected directly from sites or events pertaining to the subject being studied. For the purposes of this study, participants were selected from various cancer centers, hospitals, and support groups in both urban and rural settings. The study was advertised through local cancer centers with approved fliers.

Data Collection Methods and Instruments

The instruments used for this study were a short demographic survey and two in person interviews. (Appendix A.)

Again, 15 mothers were randomly selected for two separate in-depth clinical interviews. Each interview lasted a minimum of 60 minutes in length. Field notes of conceptual data and analytic remarks were noted throughout each interview. The field notes contained my own reflections and reactions to each interview, and the observations I had of the mother and her children when available.

Each participant completed the short demographic survey that detailed their family structure with the children. The participants were able to describe their type of cancer and provide any medical or mental health history. None of the participants suffered from any
major mental illness. The clinical interviews were initiated using open ended and sensitizing question such as, “Describe for me what it’s like to have young children and be diagnosed with cancer?” The purpose of the sensitizing question is to “Tune the reader in to what the data might be indicating” (Corbin & Strauss, 2008.) Additional guiding questions were asked in elaboration of this main idea. Some follow up questions included:

- What was it like when you were informed that you have cancer?
- How did you process that information?
- Did you have immediate thoughts about your children?
- How did having this information impact you as a mother?
- To what degree were your children aware of the cancer?
- How difficult was it to talk with your children about cancer?
- Of all your concerns, where do your children rate?
- Do your children ask you about the cancer?
- Tell me about your family and dreams of motherhood and how cancer has impacted those ideas?

**Plan for Data Analysis**

Interviewing and analysis occurred simultaneously. “On the part of the researcher, creative and solid data analysis requires astute questioning, a relentless search for answers, active observation and accurate recall “ (Corbin & Strauss, 2008.) Each research interview was recorded and transcribed. Each transcribed interview provided raw data that was also analyzed using field notes and written memos. Coding is the
extracting of concepts from raw data (Corbin & Strauss, 2008.) Memos taken from each interview helped to determine the codes from that data. Memos were written throughout these transcriptions and considered the field notes and reflections at the time of the interview. Memos for this study also included the location of the interview as well as the day and time. Observations of how the mothers appeared physically as well as the researcher’s initial observations of reactions in the interview were noted in the memos.

Data analysis in grounded theory was conducted in a series of stages. To begin, reading and reviewing the overall data allowed for an opportunity to reflect on its overall meaning (Creswell, 2014.) The researcher sought the tone of the ideas, any personal field notes, and considered the overall impression of the participant data. Once this information was reviewed, the coding process was initiated.

First, open coding was noted as the breaking apart of data and delineating concepts to stand for blocks of raw data (Corbin & Strauss, 2008.) The open coding process began utilizing the memos written from each interview. Further, themes were identified from the initial interview and then built upon to establish new and additional themes in further interviews for data collection. In order to evoke additional themes, theory based questions were continuously used to identify this information.

Axial coding, or the relating of the concepts to each other, were identified in the same interview. Themes and concepts identified built layers of complex analysis (Creswell, 2014.) Axial coding is defined by Corbin and Strauss, (2008) as identifying two concepts in the same memo. While open coding breaks data apart, axial coding is used to relate these concepts and put them back together. Most codes emerged during the
Data collection; however, important ideas were also considered in review of the interviews. These ideas were again identified in the notes and memos.

Data collection continued until theoretical concepts were identified using multiple interviews. There was sufficient data for each theme identified in the thirty hours of clinical interviews. Theoretical sampling is defined as data collection based on concepts that appear to be relevant to the story line (Corbin & Strauss, 2008.) As the mothers in this study provide their experiences, evolving themes of these interviews were collected. Analysis of these themes leads to theoretical sampling. New themes and theories were established by developing a working outline, utilizing theory based questions in guiding the ongoing interviews. I then formulated a final list of concepts and codes from the initial memos and conducted an ongoing comparison of information from second interviews. The concepts developed from field notes and memos reflected from the data were included in re-working an outline of the results.

This study made effort to employ the strategy of member checking before the final drafts of the document were completed. Participants had the opportunity to review and reflect on the data for the purposes of maintaining validity and reliability in the study. Six of the participants were willing to read the document and provided supportive feedback. None of the participants were able to sit down for a third interview to sort through the data further. In respect of the sensitive nature of the subject, I did not pressure these mothers to do so.
Limitations of the Research Plan

One limitation of this research plan was the small sample size used for the study, which makes it not generalizable. Although I obtained rich data from these structured interviews, the overall sample size of fifteen women and thirty clinical hours is small. In addition, the sample is limited by my own bias and ability to conceptualize the data of each theme fully. The categories I derived also accounted for variation and relationships to other concepts. Carefully identifying these variations was based on my data collection and subjective understanding of what I find in the collection of interviews.

Also, the use of grounded theory and interpretation of the date from solely a psychoanalytic frame were additional limitation for this study.

Evaluation

Evaluating for the quality of this research was based on multiple differing conditions specific to this researcher. Corbin and Strauss (2008) identify ten general criteria to evaluate the research study.

1. Fit. In relation to the experience of both the researcher and the participants, fit and resonance are strong evaluative criteria. Important considerations are whether the participants can see themselves in the study even though the specific examples may not have been their own. Through participant feedback, participants felt I captured nuances and details of the cancer experience for mothers. A fit study would also consider if the participants had an emotional reaction to the findings; and whether the themes identified rang true to their own
experience. Feedback from participants indicated that the material deeply resonated with their experience of mothering with cancer.

2. Applicability. Participants should be able to identify new insights from the results and find meaning in these interpretations. The findings should be useful to the participants and readers. The applicability of the findings did resonate with the participants. In the findings, we determined there is an ordering in the experience of mothers with cancer in which they make meaning of their illness in relation to others. A parallel process was observed in the applicability as the participants compared and ordered their children’s experiences in relation to their own.

3. Concepts. The findings of the study should have variations and substance that are clear to the reader and participants. The concepts developed in the study did vary in degree with in depth substance about the possibility of death. This study illuminates and gives language to the possibility of death being the underlying fear that motivated behaviors and decision making for these mothers.

4. Contextualization. The reader needs to be able to understand why events occurred and why meanings were ascribed in specific ways. The Literature Review pointed out the significance of the nature of mother and child ties. This writer’s professional observations of the experience of young mothers in a cancer center also contribute the to significance of the context in this study. Young mothers with a life threatening illness face challenges that can only be imagined by healthy young mothers. The findings demonstrated an overarching experience of young mothers with cancer from entering the experience to the lack of psychological exit.
5. Logic. The reader must be able to make sense of the data and not be left feeling confused about the organizational structure of the study. The flow of the concepts is important and attention to any missing links should be considered. Structuring the findings in conjunction with the experience of the interviews was essential. The first interview with these mothers was about hearing of how they discovered the illness, established treatment plans, and prepared the children. The second interview was an opportunity to learn more in depth of their fears and experiences of the children. Interpreting the results followed the flow of how the experience was established in the research interviews.

6. Depth. The importance of being able to apply findings to clinical practice is based on the depth and richness of the information identified. In having conducted two interviews, a greater depth with the findings was established. The first interviews were significant in understanding how the illness was discovered and how these mothers worked through their own experience of shock. The second interviews allowed the mothers to become comfortable with the researcher and provide a greater depth of information in the emotional realm of the illness and mothering.

7. Variation. Having variation in the findings implies complexity of the subject and accounts for differences in certain dimensions or properties of the data. Variations were observed in the study given the differing developmental stages of the children. Parenting decisions that were observed in these mothers all had degrees of variations based on the children’s developmental stages.
8. Creativity. It is important to consider whether there were new understandings being demonstrated as a result of the information in the study. Although to some degree we anticipated the fears of the children and mothers, the study illuminated this information by examples of how the mother managed and anticipated these fears. Creativity is also significant as we observed information that although logically anticipated, lacked language or meaning that provided depth to the overall experience of mothering with cancer.

9. Sensitivity. Corbin & Strauss identify the importance of the data collection being arrived at through analysis, and not by any preconceived notions or ideas about the study. Sensitivity was evidenced as the interview questions transformed as the interviews progressed. The mothers for instance lead this researcher to inquire about a greater focus on hair loss and cancer. The findings associated with hair loss as an example lead to an entire category on this aspect of the cancer experience. A great deal of the cancer experience was organized around hair loss and how this aspect of treatment influenced both mother and child. The ideas about hair loss prior to this research did not compare to the findings and how they were deeply influenced by this experience for women.

10. Evidence of memos. The importance of the insights, questions and observations during the interviews can only be captured through memos. Having detailed memos provides richness to the findings. Memos were a significant aspect of this study and the experience of this researcher. The use of memos helped this researcher in identifying the experience of mothers as a ‘club,’ or ‘band of women’ that were tightly united by their shared suffering. The overall experience
of this researcher as an outsider trying to gain an understanding of the inclusiveness of this bond was understood through the memos and my experiences in the process.
Chapter IV

Introduction to the Results

The results are disaggregated into six chapters that sequentially capture the experience of young mothers whose lives have been disturbed by a health crisis. Each chapter describes the discourse of the interviews with 15 participants, two interviews each, and 30 hours of clinical data. The document review with member checking provided additional clinical hours of data.

Participants

Fifteen women with breast cancer were interviewed. The women were at various points in the illness continuum. Some had been recently diagnosed, while others were in active treatment. Some had completed treatment and had been cancer free for several years, while others had already experienced cancer recurrences. The participants ranged in age from 18 to 45 at the time of their diagnosis. All of the participants were either married or partnered. Their children varied in developmental stage. Most of the participants worked outside of the home, but some were stay-at-home mothers. Careers ranged from school principals, teachers, social workers, bank executives, medical employees, and administrative workers. The participants resided in Northwest Indiana, Chicago, and Illinois suburbs.
Participants completed two interviews for this project. Although the study was focused on the experience of mothers with their children, the first interviews guided the researcher through the participants’ own cancer stories, including symptoms, the diagnostic process, and treatment plans. Even though the study focused on the participants’ experience with their children, it was necessary to understand how these women entered the world of cancer, and how this experience shaped the context of parenting with illness. During the second interview, a greater emphasis was placed on the children and their experience of the illness.

The mothers first experienced entering the world of cancer. They were faced with managing and accepting their own emotional response to this health crisis. The mothers then prepared their children, experienced treatment with hair loss, and faced the challenges of parenting and survivorship. All of the chapters include a focus on the children, emphasizing the entirety of the mother’s experience as having an influence on her child in some way. Mothers with illness have multiple obligations and arguably “more to lose” then older women. The results of this research, therefore, will demonstrate the flow of young mothers’ experience, from diagnosis, through treatment, and beyond.

**Categories**

In the first category of Entering Cancer, the disruption of cancer to otherwise robust and independent lives was evident. It is noteworthy that these women were faced with a great deal of information and were required to quickly educate themselves about the illness and its potential demands on their time, career, and children. The properties evidenced in this first category are: Fit and Active Women, Entering Cancer, Shock,
Associations to Cancer, Excess Information, and Taking Charge. Fit and Active Women pertains to the women of this study having successful careers and maintaining healthy lifestyles. Entering Cancer was an unexpected experience in an unknown world, where the state of Shock was initially experienced in the early stages of information gathering. The Associations to Cancer were the mothers’ imprints and opinions they already possessed about cancer when they were diagnosed. These influences shaped their ability to cope and understand the situation. Excess Information pertains to the tremendous amount of information about the illness that the women needed to understand and process in order to make decisions about their health and children. Taking Charge of one’s health and plans of care is the resolution of entering cancer, which provided a sense of control to the mothers in this experience.

The second category of results, Managing Emotions, also influenced the participants’ experience of their children. The properties in this category are: Loss of Control, Culture of Winning, Negative Emotions, Dark Days, and Acceptance. The challenge of parenting when there is not a health crisis threatening the family equilibrium is demanding. These mothers were forced to rapidly reconcile their feelings in order to prepare themselves for their treatment, as well as the effect on their children’s psychological well-being. The mothers instantly experienced Loss of Control, as being diagnosed evoked apprehension and helplessness. The Culture of Winning affirmed the efforts of the mothers to create a sense of community that was solely positivistic. These women preferred their friendships and surroundings to be encircled with others in a similar positivistic headspace. While in treatment, the mothers demonstrated a great sensitivity to pessimistic emotions or experiences in others. The experience of Negative
Emotions such as shame, guilt, and a sense of responsibility for the suffering were recurrent throughout the study. Mothers also experienced Dark Days during the course of their treatment in which a sense of hopelessness prevailed and their own physical limitations became frightening. Finally, Acceptance of the illness was reconciled in the course of being diagnosed.

The third category, The Children, demonstrated challenges on the part of the mother to relay the information to her children in such a way that they were left unharmed. Again, the conflict experienced by the mother to protect her children, while also providing honest information about the illness, was consistently evidenced. The Children included the following five properties: Attunement to the Mother, Symptoms in the Children, Children’s Fears, Children’s Statements and Gestures, and Competing Conflicts. Attunement to the Mother was observed in that these children had a sense that something was amiss prior to being told. Psychological Symptoms in the Children were demonstrated as a result of the illness. The fearfulness experienced by both the mothers and the children was observed throughout the study. The children subsequently conveyed Statements and Gestures that illustrated their reactions to the illness. The mothers observed these statements and gestures as means to distinguish how the children were coping. Finally, the Competing Conflicts experienced by the mothers involved the children’s reaction to the illness. At times, the mothers needed the children to be easygoing and entertain themselves, while at other times, they needed the children to recognize the illness and encourage them with a sentiment of support. Mothers felt conflicted by these two needs—one for normalcy in the children and the other for the children to understand the gravity of the circumstances.
The fourth category, Treatment and Hair Loss, clearly illustrates the struggle and influence of physical changes in the mother. The properties in this category are: Fears and Dread, Making it Fun, Loss of Privacy, and Accepting the New Look. It became clear very early in the study that hair loss would become a category of its own as it relates to the children. In coping with the challenge of hair loss, the mothers were creative in finding the means to put a positive stance on this experience in the course of treatment. The fears and reactions the children demonstrated about the hair loss were a hallmark of the treatment process. Some of these reactions were anticipated and others were surprising. The mothers’ understanding of these fears and their efforts to minimize the terror felt by hair loss were instrumental parts of the treatment course. Hair loss signified a loss of privacy for mother and child once it was experienced. This was noted to be a shared fear; however, it was heightened for the mother in her thoughts about the child’s privacy disruption. Finally, Accepting the New Look was an experience over time that brought relief to both mothers and children. The mothers went to extreme measures to work with their children through the treatment process. The most notable side effect of the treatment was the impact of hair loss, which illuminated the illness to both mother and child.

The fifth category, Parenting with Cancer, illustrates the challenges that illness poses to parenting styles. The properties in this category are: Preparing Other Adults, Keeping it Normal, Teachable Moments, Maternal Worries, and Blogs and Legacy Projects. While mothers were often physically exhausted, the duty of parenting required they maintain normal routines and rituals for their children and careers. First, mothers made extra efforts to Prepare Other Adults in the lives of their children. Mothers with
careers were concerned that they would overlook a symptom in their children that might possibly be evidenced when they were not near. They were therefore motivated to give notice to other adults in their lives, in hopes of recognizing any distress in the child. Mothers placed an emphasis on Keeping it Normal for their children. In maintaining some degree of normalcy, the mothers used the experience of cancer to develop Teachable Moments. The mothers found that their illness prompted discussions with their children on the topics of empathy, patience, suffering, and life planning. Maternal Worries influenced decision making in the lives of these mothers and their children. Due to the complexity of these discussions, mothers relied on their instincts, but then questioned whether there were any harmful effects of their decisions. The use of Blogs and Legacy Projects to chronicle the experience for their children was a part of parenting with cancer. The mothers had again hoped that if the children had something tangible to read and examine from the cancer experience, it would be able to provide a lesson or comfort later on.

The final chapter and category was Living with Cancer and Fear. The three properties of this category are: Fear of Recurrence, The Pink World, and Silver Linings. The mother’s fears begin at diagnosis and are experienced along the continuum of being diagnosed, into treatment and survivorship. The Fear of Recurrence is complex, difficult to manage, and experienced intensely off and on over time. Living in the vitality of breast cancer awareness exposes mothers to reminders of the treatment through a pink representation of the illness. Although the participants were not all breast cancer survivors, the majority of women who participated did have this specific cancer. October was a difficult month for these mothers as commercials on television and pink
merchandise triggered traumatic feelings about the illness recurring. The Pink World is another mechanism of re-experiencing traumatic memories of the illness process. Silver Linings, however, were identified after treatment was completed. The mothers sought to make meaning of the suffering they had undergone and acknowledged aspects of themselves that were enlightened as a direct result of the illness. All mothers felt a connection to other mothers experiencing illness, and many gave back in various ways: Two established support organizations, many participated in fitness walks and runs, and others taught cancer classes. Silver Linings affirmed the mothers’ feeling that cancer is a club in which a mutual understanding and respect is developed for others undergoing treatment.
Chapter V

Entering Cancer

The women who participated in this study shared how lively and engaged they were prior to their diagnosis of cancer. They described lives that felt full of hope and optimism. In their minds, there existed a tremendous possibility for accomplishing their family goals and dreams. Entering the world of cancer as a young mother required a rapid recovery from shock, and an immediate shift to crisis management and thoughtful decision making about their lives and their children’s needs. The women entered an intense community of others, in which they became aware of a categorical ordering regarding where their own illness was situated amongst the rest. The properties in this category are: Fit and Active Women, Shock, Associations to Cancer, Excess Information, and Taking Charge.

Fit and Active Women

The women in this study were all very active and shared the element of surprise that their good health and active lifestyles had not served as a protectant in some way. They felt that they had done all the right things in life in regards to their health and screenings for illness. Participants ranged in careers from educators, bank executives, health care workers, and stay-at-home mothers.
I had just ran the Chicago Marathon, and I went to the doctor the next day and this time I had the Nurse Practitioner and I again said that I have this thick area, and she was a little more concerned about it.

The more I think about it, I would come home at night and I was just really tired. I’d want to sit down before I would think about starting to make dinner. It used to be that I would come home and jump right into dinner. I’d find myself sitting on my couch and talking to my kids. So I was tired, it wasn’t getting better, and I thought, something isn’t right.

One factor that was well defined in the lives of these active women was that cancer was a disruption to their very progressive lives. The illness was experienced as not only a devastating medical emergency, but as a psychological injury as well. The insult was evidenced in how the women discussed cancer, including a sense of guilt and shame in their otherwise fiercely independent lives. Cancer had become an occurrence that required urgent attention and priority amidst their already demanding lives.

We were moving from the city. I found out a week before we closed on our house, so we were moving to a whole new community, new school, and I was diagnosed at the same time.

The first time I found a lump, I didn’t think anything of it. I just went about life thinking, I’m young and healthy. My youngest kid was still under 5, so I was thinking it was something possibly from breastfeeding.
Herein, two realities were experienced by mothers when entering cancer. Mothers reported both the medical reality of the illness and the psychological reality of the experience when diagnosed with cancer. When entering cancer, the medical reality was the devastation of the medical illness itself, surgery, and aggressive treatments. The psychological reality was that some had just run marathons or participated in other fitness activities, worked full-time jobs, and were otherwise engaged and healthy. These mothers had to reconcile both experiences as their bodies were threatened and they made efforts to reestablish a sense of good health and restore order.

**Shock**

Given that these women were young, fit, and active, the element of shock was evident in all of the participants. The second property of Entering Cancer is the experience of shock. Shock was observed at the time of diagnosis, especially in those who had experienced recurrences.

I was 31 weeks pregnant and cancer was the farthest thing from my mind. It was right before Christmas, and I didn’t hear from my doctor for like two weeks. Then she called me on December 30 and said there’s something on your lung.

“We were going to have a fifth (baby); instead I got cancer.”

Shock causes feelings of distress when diagnosed with cancer. Cancer is categorically a psychological trauma. A distressed mixture of depressive and anxious symptoms is a characteristic reaction throughout the diagnostic process. There is often an
agonizing period of waiting for test results and consultations, which further enhances distress.

“I just did a mammogram because my neighbor was diagnosed with breast cancer; I didn’t think anything was going to come back out of it.”

“I put on a t-shirt to go to bed and felt something, and I was like, What is this?”

Many women experienced shock and distress throughout the course of treatment. The surprising nature of their diagnosis, or of the recurring illness, was disorienting to the mothers in this study.

I was thinking, they will give me a prescription, I’ll stop at Walgreens to get it filled, take it, and I’ll be fine. My sister said, “No, you need to face this. Finish your appointment and you need to get to the University of Chicago.”

The surprise element of cancer recurrence was especially painful for these women as they forged to assure their own sense of safety in taking charge of their treatment plans and managing the illness. Contending with the feeling of shock away from the children’s view was arduous. As things calmed over time, these mothers were able to recognize the enormity of the circumstances. The severity of the illness is often appreciated and comprehended once shock is mitigated and information is processed over time.

“I didn’t have my mastectomy done until my second cancer. The first one, they wanted to preserve; with my age, they thought it could be treated with radiation and chemo.”

Recurrences were especially painful for the women. They felt that they had worked so hard to do all the right things. However, these decisions along the way become
cautionary tales regarding cancer recurrences. There is an unfeigned recognition in cancer recurrence that the illness is compelling and severe.

**Associations to Cancer**

The third property of Entering Cancer was Associations to Cancer experienced by the participants. When diagnosed with cancer, each of the participants had her own frame of reference to the illness based on her individual life course and her own loved ones who were previously diagnosed. Some of these references had been the participants’ own mothers, sisters, or friends.

I quickly observed that these women experienced a bond that could be described as a “club” containing various hierarchies. When diagnosed, there is a hierarchy of how the illness is understood in this club. The first benchmark appears to involve the type of cancer diagnosed. The second point of reference was whether lymph nodes were involved in the disease process. Finally, chemotherapy, radiation therapy, and the overall treatment plan were also criteria for comparison. These women immediately sought to understand their cancer staging. Once this information was obtained, the women then considered their own associations to cancer, and to those with other forms of the illness and their years of survivorship. Disease progression is therefore a type of psychological ordering that helps to support the mother’s psychological narrative of the illness.

“I went into the biopsy and they were telling me they were doing two spots, and they took five samples or whatever, and that’s when I kind of knew that I was in trouble. That’s not good, I remember.”
From the beginning, a medical narrative and a psychological narrative of the cancer experience began to develop. The medical narrative was the staging process and reference points identified in the disease continuum in which these women found themselves. The psychological narrative was how these women benchmarked themselves in the club of cancer amongst other women and how they interpreted their medical reality. Over time, this could be observed as an internal conflict between women feeling as if they were falling apart and feeling as if they were fine. At times, these competing emotional states were aligned with the medical narrative, while at other times, they were not.

All women immediately began to reference individual associations to cancer. The outcome of these associations was the imprint of the cancer experience in the minds of the mothers. In reference to planning for their children, associations to cancer needed to be worked through and understood.

My mother was diagnosed with what they call stage zero cancer. I was very surprised to find out that my situation was not only fairly advanced, but it was bilateral. I was surprised because I had gone for my mammogram every year.

“I had lost my best friend to breast cancer and she was my middle son’s Godmother, and we had gone through that as a family. They lived here and that’s all I knew about breast cancer.”

“I had a sister-in-law who passed away at age 42 from breast cancer.”

For some women, the diagnosis was familiar and had been experienced by family or friends. Others had no associations or family history of cancer. All of the women, however, shared the commonality of gathering facts and research about their illness. In
thinking of their children, these mothers needed to reconcile their associations to cancer in order to prepare for their own treatment course.

“At that time, my dad’s brothers who had passed away of cancer; at that point, everybody in my family who had cancer had died.”

When associating to loved ones, the women sought to order themselves with those especially close to them. This was difficult as some loved ones had their own arduous courses of treatment and outcomes.

**Excess Information**

Once diagnosed, the need to prepare themselves and make thoughtful decisions immediately began with researching the subject of cancer for themselves and the children. As these mothers quickly realized they were entering a club of women in which they were to find their place and position, they were also met with a wealth of medical information to assist in this process. Many were overcome by the burden of consuming a vast amount of knowledge in a short amount of time, all while parenting their children and trying to not outwardly demonstrate distress. In many cases, the type of surgery to have was considered, and mothers had to delineate their facts and how to move forward with decision making, considering recurrence risks and their children.

You’re trying to digest this information as much as you can, as best as you can and it’s not in your field. You’re having to make the best possible decision that’s going to have a huge effect on your life. One of the key points of this whole experience for me was trying to gulp down as much as I could, as fast as I could, as best as I could.
Understanding the illness includes experiences of breaking the illness down into intelligible facts, trying not to become distracted by the unfavorable information they are coming across. Understanding also includes establishing goals and making careful decisions.

It’s interesting because you could boil it down to statistics, right? And so their whole premise in statistics is to show that there is no increase…there’s not a better survival rate whether you have a lumpectomy or mastectomy, right? The death rate is the same. Your odds of a recurrence with a lumpectomy are 10% and with a mastectomy, it’s like 3%. I’m like, “Well, that’s 7% I wouldn’t do,” you know. Like it just doesn’t make sense to me.

Dealing with statistics and percentages in a time of crisis is difficult. However, these women needed to promptly access this information and make use of the facts in order to plan their treatment in a means that felt satisfying to them.

“You don’t have time to process all of the information, the enormity of the situation you’re not really comprehending at that time.”

Mothers gathered not only information about the illness itself, but also about how to prepare their children for illness in the family. Mothers experienced an immediate concern regarding how to tell their children, and were very apprehensive about the consequences of relaying this information. Mothers felt the need to obtain as much information as possible in order to prepare themselves and their children for the thoughtful decision making that surrounds a chronic illness. It became clear in their research that not all cancer is the same. What was learned in these early stages mainly involved cancer staging, local versus metastatic illness, and all comparisons in the world
of cancer. Breast cancer in particular has a sizeable focus on whether or not lymph nodes are involved or if hormones influenced the cancer growth. All cancers, however, are conceptualized by factors that pertain to local or metastatic disease. Understanding this information assisted the women in determining their place and position within the club of cancer, a club none of these women asked to join. The club, however, is useful in that it is a band of women who share a mutual knowing and respect for one another’s experience of illness.

**Taking Charge**

The final property of Entering Cancer involves the need to take charge of the treatment plan. These women, all mothers, ultimately aligned with the side of safety in their decision making, after carefully studying all data. These mothers were forced to incorporate their illness into their active lifestyles. Some were given treatment options that did not seem to satisfy their fear of recurrence. However, this type of absolute reassurance was impossible to achieve.

My husband knows a surgeon from the hospital and he worked that day, and so he’s in the hallway and said to the surgeon, “This is what’s going on,” and he (surgeon) said, “Well, the blizzard’s coming, I can’t see patients. I can’t do anything.” So, he (surgeon) made some calls and had an opening the very next day. The very next day, I had a bilateral mastectomy.

Some women asked their physicians for extreme measures, even if they were not a recommended course of treatment, in order to assure themselves that everything
possible was done to prevent a future recurrence. Again, ridding oneself psychologically of the recurrence terror is impossible to fully achieve.

They were going to remove my ovaries and leave the rest, and I said, “Isn’t that more places for cancer?” I went into this like tear me to pieces! I want to say that I did everything I could to not have it come back. So we did a full hysterectomy and a double axillary dissection because my underarms were full of breast tissue. The doctor did not want to do it, he told me it was healthy breast tissue and we can keep an eye on it, and I’m like, so forever I’m going to feel this lump in my underarm and wonder if it will turn to cancer? I told him, you WILL go back and take this out.

Some women experienced feelings of guilt for their aggressive choices after the fact, while others were confident that this was the safest route for them. The women only seemed to experience regret if there were negative side effects that resulted from taking charge and going against medical advice.

The PET scan I do yearly, that is such a fear. One of the side effects to having your breasts removed and your hysterectomy is that the cancer can come back and it will attach somewhere else. It could be your lungs. I have this fear that maybe I took too much away. Maybe if I would have kept, you know, my uterus, maybe it could go to that instead, and maybe they could remove it. Did I take it too soon? It’s the fear.

For the majority, taking charge allowed for some sense of agency and empowerment when threatened with this diagnosis; however, feelings of uncertainty were also prevalent. In their decision making, these women had made medical plans for their
future while also formulating psychological plans about how to manage and cope. One participant described not having taken charge during her first diagnosis of cancer, and the horrible regret she lives with as a result.

I do think that my first time, if I would have understood and researched, I think I really would have went ahead with the surgery the first time. I left my health in the doctor’s hands, like you guys just choose and I’ll go along with whatever you tell me to do. I want my girls to have, I want their health to be their decision, I want them to make the final say. Then they can live with that. I am now living with the decision that wasn’t my decision. I wonder how it would feel if it was my decision? I want them (daughters) to know that you make your own decisions.

In the experience of having cancer, at any point along the illness continuum, one learns about the need to take charge. Shock and other defense mechanisms may initially get in the way of taking charge; however, as defense mechanisms loosen, the need to take charge becomes evident.
Chapter VI

Managing Emotions and Acceptance

The first property in Managing Emotions and Acceptance is the recognition of a loss of control for mothers. Coping with emotions in cancer is a process that occurs over time. The initial shock is worked through, leaving behind a host of mixed emotions that are experienced by mothers. The enormity of the situation is difficult to grasp; these mothers must take in a great deal of devastating information in a short amount of time, and must conduct extensive decision making with the data. The women experience significant pressure as they try to reconcile their own emotional responses during this devastating time.

Loss of Control

Efforts to take control as evidenced in Entering Cancer are motivated by feelings of helplessness experienced over time. Changes in coping are observed over time, with many of these mothers experiencing traumatic triggers and fear. These triggers occur over time. Loss of control is experienced at initial diagnosis, surgery, and treatment, and in fear of recurrence.
I found a lump recently and I thought to myself, “No, it can’t be. I’ve had both of my breasts removed and I’ve had a hysterectomy.” Every little thing you feel on my body, it’s just mental. You think the worst.

“I hate the word journey. A journey is something that you choose to take, you know what I mean? If I go on a journey, it’s like an adventure I’ve chosen. None of this stuff is in my control.”

Some women reported surrendering to the helplessness of not being able to predict the course of one’s future. The loss of control was experienced in psychological facets, but also in limited functional abilities following surgeries.

“The surgery, I thought I was releasing every bit of control to someone else. We wake up when the anesthesia wears off. We are not in control of that.”

These women struggled to control not only their illness and outcomes, but also their daily routines and bodily injuries. Efforts made to maintain any sense of being in control were common responses with illness and children.

“I had a lot of arm restrictions, so she (daughter) was helping me put my coat on, or she would go grab something for me. She was very understanding of the situation. I wasn’t at my best. “

“I was going to have the transplant two months before his graduation, so I had a whole group of friends who just came in and said, ‘We’ll take care of his graduation party.’”
I need a break. It’s been a year and a half. I had third degree burns, everyone’s like, “Oh, radiation is a breeze,” and I’m like, “Really, when you get third degree burns and your skin is so pink and it’s peeling like shaved ham?”

The women also experienced loss of control in regards to hair loss. The heavy feeling of needing to cut their hair in anticipation of chemotherapy was one method to try and manage the very delicate loss of hair.

**The Culture of Winning**

Fear of experiencing the complex emotional world of cancer is the second property in Managing Emotions and Acceptance. The depth of emotions felt throughout a diagnosis of cancer and in the course of treatment was profound for these mothers as there was an immediate and ongoing worry for their children. Mothers felt pressure to “act normal” or “act strong” for the children, and often lacked the privacy to be immersed in their emotions. Mothers also assumed a responsibility for providing emotional strength to their children.

A culture of winning prevails for any young mother undergoing cancer treatment. This is more readily accessed with women in their first experience of cancer treatment, where the possibility of death is kept far away.

There has been a lot that has happened recently (cancer recurrence) that has made me realize that you’re not as invincible as you think you are. I can have all the hope in the world, but there is a chance that THIS is what will take me one day.

When cancer recurrence is experienced, the possibility of death becomes emotionally accessible in a more enhanced and preoccupying manner. The culture of
winning carries on, but the positivism becomes shaken. The mother’s inability to allow any aspect of negativity in her headspace keeps cancer in a “beating” or “winning” perspective, one version of reality in which the mother needs her child to remain. The mothers made significant efforts to ward off negativity in order to remain in a high functioning disposition.

If I’m going to get better, then this has got to be about living. Otherwise, I would crawl into a dark hole and never come back out. I’ve worked too hard in life, to have a great family, to have a great job.

The ongoing medical and psychological realities are observed throughout the course of diagnosis, decision making, treatment, and beyond. Sometimes these realities are aligned, while at other times, they are not. Within the psychological realm, the myth can evolve that if these mothers do everything right and stay positive, then the illness will not recur. Mothers were aware of anyone who could destroy their hope and kept a great distance from these individuals. These decisions were made to ensure that their own psychological narrative remained intact.

I really don’t want to hear anybody else’s stories, I really don’t. I could never do a support group. I don’t want to go there and cry and don’t want to listen to you cry. I’m not a pink ribbon flying kind of girl.

The need to maintain a winning and positive culture is evident. In avoiding direct discussions about the alternative to winning, the question is again raised about what the children are actually experiencing when presented with this information. Mothers made efforts to shield the children from the depth of their feelings surrounding a diagnosis of cancer. These women were understandably shaken to their core, and their worlds were
turned upside down as a result of the illness. They came up with ways to manage feelings about a sense of defect through the treatment, and also their own feelings about the possibility of death. There was a “want” in the mothers to be honest with their children about their own fears, which appeared to be followed with a “can’t” attitude in order to protect them. The mothers were worried about inundating their children with the fears that were flooding them.

I was petrified myself, but I didn’t want them to see me scared because I was worried that if they saw me upset, then they would just be even more upset. So I was trying to just comfort them like a mother would do when anybody’s hurt, let alone yourself. So, I think that’s why I felt so proud because I held it together, because it was a hard thing to do. I wanted to sit there and cry too and say, “Yeah, this is awful!”

“If anyone tells us a time limit, they are to be cut off because there is only one person who knows how long I will live here.”

Some mothers and children mutually participated in the culture of winning; however, this did not alleviate the anxiety experienced by both. The children did not receive a “clear” message in these discussions about cancer, but a “complex” one. The children walked away experiencing some degree of both the mother’s attitude of optimism in the culture of winning and some degree of anxiety about the circumstances. Herein lies an opportunity for these mothers as they created teachable moments throughout as to how illness or difficult events are managed in life. Mothers viewed any negativity as a destruction of hope; the culture of winning was necessary for their survival.
Guilt and Shame

The third property of Managing Emotions and Acceptance includes feelings of Guilt and Shame that occur during the course of illness. Mothers felt that the illness was a disruption to the family equilibrium, which left many with feelings of guilt and shame about their changing role in the family and how the children were affected. Difficulty was observed in feeling they have caused worry and fear in their children. Mothers experienced guilt related to feeling as if they burdened the children with a sense of responsibility and possibly caused the children’s psychological symptoms. The children were pulled into the devastation the mother was experiencing, and there was no way to keep them away from it entirely.

“My oldest daughter went through depression and was suicidal. I think it was because I overloaded her with too much information.”

She (infant daughter) had a very low immune system. So I had to be really careful around her because when she got sick, I couldn’t care for her, because we both...so that was like the hardest thing. I mean just you know, not being able to hold your baby.

Guilt was also experienced when telling loved ones about their diagnosis in fear of making them uncomfortable. Mothers noticed guilty feelings surrounding the relationship with their own mothers.

“My mom, this is killing her. This is just killing her and I feel so bad.”

“My mom will give me that motherly look. I feel like she’ll turn her head and look at me.”
Guilt was also induced by fears that their own children might someday be impacted by this illness. Some mothers described this as guilt for their future worry as a woman living in fear of the illness.

Bidirectionally, the mothers experienced guilt for causing their own mothers’ distress, for as mothers themselves, they understood the worry. These mothers feared that if the negative feelings overtook them, they would lose their edge and the disease would progress. Alternatively, they were acutely aware that news of their cancer would devastate their mothers, and watching them break down felt equally as unbearable and dangerous.

She (her mother) is a worrier. I feel bad saying this, but I have probably shut her out a little bit of this. When I called and told her about the diagnosis, I said that I have to tell you something, but here is what I expect. I need you to hold it together. If you are going to freak out, don’t freak out in front of me, because it’s not going to help me.

It was observed that for this reason, some of the women avoided their own mothers, as being in their presence would signify a safe place to break down. Again, breaking down was considered a negative emotion, which were deflected in efforts to remain positive in the culture of winning.

These mothers also felt guilty for the physical changes and how the children, especially infants, experienced the illness.

I fed him on a cancerous boob. I breast fed him. No wonder he didn’t like that right breast. He didn’t like it, and then he even knew when I would pump at work and I would keep the bottle separate, the right and then the left. He hated when I
would warm it up, the right breast bottle. He knew which one was the right one because he wouldn’t drink it.

**Dark Days**

The majority of mothers acknowledged that there were days in which the possibility of death felt near as symptoms of physical decline from chemotherapy were experienced. The women, depending on whether their experience of cancer was an initial diagnosis or recurrence, described dark days in varied degrees. The impact of cancer on their bodies, when at the peak of chemotherapy side effects, was a terrifying experience for mothers.

I’m thinking I have cancer, so why would it now be on my liver? Why would that be something else? My liver has never popped up before. So why would it be something else now? So I convinced myself and my husband that it was bad. I’m thinking, I know this, that when it gets to the liver that you’re in big trouble. I know this. It was devastating. All those things, my daughters’ graduations and all that just hits you, not seeing my husband turn gray (begins to cry), it was just absolutely awful.

Again, these mothers were fit and active women who were surprised by the immobilizing impact of chemotherapy and postoperative stages. At time, cancer reminders also evoked the dark days. These reminders may have included a cancer commercial on television, a pink ribbon on the street, or a somatic feeling or recognition of their immobility during the difficult treatment. Mothers feared losing their edge and vitality, anticipating a poor outcome if they were unable to remain strong throughout the
course of treatment. Again, a parallel process was observed between letting their affect overtake them and a fear of letting the disease overtake them. The medical and psychological narratives did not always align.

I don’t remember what set it off, but I went into the bathroom and I just cried and cried. I was so sad. I remember we were going on a trip, I think, and I told him (husband), “I can’t go. You take the kids, just go.”

I had a meltdown. I was like, “Okay, we have no car, we’re going to lose the house, I’m going to lose my hair, and the kids aren’t going to have a mother.” I was panicking, the worst case scenario.

“I can’t do this. I cannot. I just can’t. My body can’t do it.”

Will I be here? Will I see them? Will they be afraid to be a woman? They saw a completely different person. I went from this loving and caring, hands-on mother, to I couldn’t physically get to hold her. I lost weight.

Despite the debilitating effects of chemotherapy, these mothers, motivated by their children’s needs, moved forward in their daily lives. They made substantial efforts to maintain some sense of normalcy for themselves and their children. A tremendous amount of strength was observed in the actual treatment process and the women’s ability to persevere through physical side effects. The most difficult challenge these women faced appeared to be their inability to care for their children. Herein, these very strong mothers experienced a state of helplessness in the gravity of being unable to truly and fully comfort their children.
“When I was sick, I was sick. I would have to lay on the floor to play dolls or cards, but there were some days where I couldn’t even lift my head.”

These dark days, however, were times of working through the acceptance of the illness on their lives and future. Mothers tended to break down when they were alone. Some described dark moments in bathrooms, driving in their cars to work, and other places where they were away from their children and had the privacy to experience the intense negative emotions. All of these experiences, however, were efforts to manage a horrible situation in which they didn’t have any control.

Acceptance

Although a host of mixed emotions were experienced throughout the course of treatment, the mothers tended to reach a point of accepting the illness and subsequently developing new ways of managing their lives and keeping perspective of their roles as mothers. Acceptance is a process when diagnosed with cancer, not an event. Acceptance has many facets—that of the medical illness as well as the psychological injury. When full acceptance was achieved, the worldview of these mothers shifted from innocence or naïveté about endless time, to a more meaningful perspective of the gift of time in life without illness. This process resulted in finding deeper spiritual meaning and purpose in their role as mothers. These women worked through the acceptance process at varying rates. Variations of acceptance were experienced based on where they found themselves in the “club” of cancer. For instance, women who had initial lymph node involvement instead of recurrent cancer or nodal involvement had an easier time working through the acceptance of the illness. These women had disparate experiences of cancer to accept,
and expressed differing feelings of where they ordered themselves in the “club” of women impacted by cancer. Advanced illness with nodal involvement required a different degree of acceptance and living with uncertainty. Ultimately, the illnesses varied in degrees of survivorship outcomes and women quickly became familiar with these points of reference.

“I was so scared to the point where I thought, if I am going to die, then these kids were going to be growing up without a mom!”

I don’t think I really understood what was going on then. I went into some counseling, but it wasn’t until I was totally finished with my chemo part of treatment and my energy started to come back that I was like, what in the world just happened to me?

Having cancer is a loss, and individuals go through a grief reaction. Acceptance occurs when the shock of the experience has diminished and the mothers have survived a large portion of the aggressive treatment. Acceptance is not of the illness itself, but of the uncertainty about life that comes with the completion of active treatment. Although the women came to accept that active treatment was behind them, the completion did not signify a freedom from the illness; rather, it marked the beginning of a new normal in their worldview about mothering and how they actively live in their day-to-day lives. Acceptance helped these women defend against the dark days and allowed them to move forward in their grief.
Chapter VII

The Children

Considering the needs of the children was evident from the time of diagnosis. As part of the study process, the women first had to explain how they entered cancer and worked through the initial surprise of their diagnosis. The mothers had to strategize how and when to tell the children. All women did this differently according to personal choice. The issue of timing was apparent as some mothers told their children immediately after diagnosis, while others found themselves strategizing with their spouses about how to have these conversations. The immediate instinct to protect the children after the shock of the diagnosis was evident in the intent of all the mothers. The results indicate, however, that despite all efforts to protect the children, it is impossible for this experience to not be observed or witnessed by the children. The properties in this category are: Attunement to the Mother, Symptoms and Reactions of Children, Children’s Fears, Children’s Statements and Gestures, Disappointment in Children.

Attunement to the Mother

The first property in The Children was their Attunement to the Mother. The children all seemed to have some feeling that there was something amiss prior to any discussions about cancer. Participants observed their children having some sense of their
distress and making connections about the hunches they experienced prior to being told.

The mothers were made aware of the perceptive nature of their children.

“Why didn’t you tell us? Well that’s why she brought us breakfast and came over, and then you had to go? That’s why she came by with bagels?”

“I tried to keep it from her the first couple of days, but she was very angry and crabby as she felt like she was being left out.”

She is like an old soul for an 11-year-old. So, I was honest with her at that point. If she recognizes that I don’t feel well, then I’m not going to lie to her. So she knew before we went to Disney World that I was going to have some more tests when I got home.

The question was raised as to whether mothers created a culture suggesting the children “not go there” in regards to the issue of death in these discussions about having cancer. Overall, the mothers prepared for these discussions by presenting the culture of winning, possibly so that the children would not articulate their fear of death to them. However, the findings indicate that children are attuned to this fear and do ask direct questions about death. In preparing for these discussions, several spouses of the mothers suggested that the word “cancer” not be used in the discussions so as to not frighten the children. The children, however, were attuned to their mothers and perceived the distress.

**Symptoms and Reactions in the Children**

The second property in The Children was the Symptoms and Reactions demonstrated by the children. A symptom is an expression of something that cannot be articulated. Some of these negative symptoms were demonstrative of the children’s
perception and anxiety about the inability to ensure absolute safety that is part of this difficult circumstance. The mothers acknowledged the painful reality of their children becoming psychologically symptomatic. This experience was a tangible and emotional pain the mothers felt directly. This emotional pain appeared equally, if not more, challenging than the cancer treatment itself. Discussing cancer with children is not an exact science; it is unable to achieve perfection in the process due to the uncertain nature of illness. Due to these difficult circumstances, it is clear that there is no “getting it right” when talking to children about this trauma. “Good enough” is all that any parent can hope for, given the gravity of what is being discussed.

As a parent, it was my hardest, but most proudest moment ever of being a parent.

It was that conversation with them. As soon as they all started getting hysterical I just went like this; I moved over here and took these two, and I grabbed their hands and my husband just hugged my other one, and I just held it together and I was just there.

Crying was a common reaction for some children when finding out about the cancer diagnosis; however, other children did not demonstrate outward symptoms or reactions until the information was digested. In the category of The Children, the element of helping children cope with the shock is significant. Children demonstrated their own psychological symptoms and reactions to the illness over time.

I know that after; somewhere in between the surgeries, I know he was worried and I remember him coming in at night in the bedroom, in our room. I remember my husband telling me he was worried about me, about losing me, and he would come in and we’d talk and he’d cry and cry and cry and I was comforting him and
telling him I’m not, you know, going anywhere. You don’t have to worry about that, you know.

A side effect that my daughter had were panic attacks and anxiety when she leaves me. Like the first time, we could not figure out why she would get halfway to the bus stop and come back panicking and not breathing and she was just like, “I can’t breathe, I can’t breathe,” and crying. I’m like, “Well, what is wrong? What happened?” “I don’t know, I don’t know.”

Some children demonstrated panic attack symptoms when separated from their mothers and others experienced suicidal ideation. This may be partly due to the children having some idea that the mother is “fighting for them.” Many of the children demonstrated fear and anxiety.

“Mom, my calendar said that you had to go to the doctor, how was it? She keeps track of my appointments. If I have three glasses of wine, she says, “Now mom, I thought it was two glasses?”

Symptoms were aligned to the children’s developmental stages. Younger children described fears with symbols. Teenage girls were observed to become physically symptomatic with anxiety and latency while teenage boys had some level of anger and acting out. Again, the children’s symptoms triggered emotional pain in the mothers that was very difficult to experience.

“Her journal was how I found out she was suicidal. Oh my goodness, her fear was how does a child live without their mom; that was her fear.”
He had some behavior issues and was completely acting out. He’s a sweetheart, but at the time, he was being rude to his brothers and rude to me. One day, I don’t know what set it off, but he was slamming the door, tantrum.

“He was skipping school. The youngest one was skipping school and going to a friend’s house, and just kind of trying to mask the feeling.”

I think she might be a little more clingy, but I really tried not to make a change our life. I mean, I still had to yell at my kids when I was in chemo. I didn’t want to, but I felt like if I didn’t have hair, then I couldn’t have power over my kids, I’m like that’s so stupid.

The children’s reactions seemed to surprise the mothers in discussions about having cancer. Symptoms and reactions were consistent with developmental stages. Fears were notable in the children throughout the mother’s course of treatment. One mother referred to her 15-month-old son’s reaction post operatively.

I mean just the look on his face, like he really didn’t even want to, my husband was leaning him down to just give me a kiss on the face, I mean he just, it was like he looked at me like he was scared, like he was, you know, scared.

The older children may have felt that their mother was fighting for “them.” They may have experienced some pressure to be close in order to help her fight and ultimately stay alive. If the children watched their mother decline with treatment, getting too far away from her may induce symptoms and fear. The mother is left with no easy way to manage this situation. The children are pulled into a devastating experience, and the mother may not be aware of how to best manage her symptoms, as this is an impossible
and devastating trauma. Each child’s developmental stage and gender influences his or her reactions and responses.

**Children’s Fears**

The third property in The Children was the Children’s Fears. Some children avoided asking difficult questions and others were able to give language to their fears. It appeared that the children’s associations to the word “cancer” influenced their reactions. The children’s developmental stage played a large role in how they responded to the mother’s illness.

“My older one is the one who said, ‘Can this happen to us? Can we get this?’”

She is still in counseling. She talks about it. People describe her as being obsessed with breast cancer. Her thing, for example, is that she doesn’t think people should have to wait until they are 40 years old to have a mammogram. I’m glad to see that she wants to know, but I wonder if that is the fear in her.

“Mom, are you going to have cancer on the night of the ice cream social?”

Parents made efforts to elicit information about the children’s expected fears. Some mothers did this by knowingly making efforts to include the children in the treatment process, and others by making arrangements for their children to participate in counseling or organized cancer events for children.

It’s the fear of the unknown, and of all the kids, he is petrified of the doctor and petrified of shots. So I think for him to go in and see, we of course didn’t have
him see me getting blood taken, but to see me getting hooked up, like that it’s not 
scary and this is where mommy goes.

She opened up to us after this event. So they had these strings and they wanted 
you to cut your strings, and they were strings of fears, and what you were afraid 
of. You cut them for how long it was, how afraid you were. So I looked and said 
‘What are all these strings for?’ and she (daughter) said, “Well those are my 
fears,” and they were tied around the doll. Then my daughter gave one end to my 
husband and told him to walk backwards across the room and I was like what the 
heck is that? She (daughter) said, “These are my fears!” and I said, “That big?” 
and I started bawling.

Many efforts were made to prepare discussions about cancer in such a way that 
any long-term effects were mitigated and the talks provided some form of reassurance. 
However, the mothers’ own fear was always present in the background of these 
discussions. Other adults in the children’s lives identified symptoms of fear as well. 
The teacher asked them what they did over the summer and my daughter 
answered the question. I got a call from the principal and my daughter said that 
she wasn’t afraid to die. She’s not fearful of death. I guess they were alarmed, and 
I thought it was funny. I said, I’m her mother and I’ve been through breast cancer 
twice, and we talk about death. They can’t be afraid of it because for you to 
survive, you have to face it. You know she (principal) was on the other end 
thinking, hmm? I don’t think she quite understands.
All mothers walked away from cancer discussions hoping that their children were not gravely impacted by fear. Developmental stages were also considered in preparing these discussions. These children were not completely shielded from cancer, as they knew of other people in their lives who had experienced the illness. The parents faced the challenge of determining the nature of the children’s associations to cancer. The difficulty for these parents was developing a strategy that would keep the fear of death away from the children.

**Children’s Statements and Gestures**

The children, when able to bravely articulate their feelings, had interesting questions and statements as well as loving gestures that were evident in their own experiences.

As soon as I hung up the phone, my older daughter says, “Mom, do you have cancer again?” And I’m like, “Oh, for the love of God, you know, here we go again,” and I said, “I don’t know. I just don’t know,” but I just had that feeling and my feelings had always been right, you know, and I just had that feeling.

“So I tried to explain that there’s a lump and that I can take that out, but it was my older one who was like, ‘Well, you’re going to take them off aren’t you?’”

“Well, why did you tell other people and not us?”

Children were noted to make statements and give feedback regarding how they were told, decisions about treatment, and questions about recurrence. Although mothers made no reference to the possibility of death in discussions with children, it was observed that the children did ask very overtly about dying. Herein lies the attunement to the
mother’s anxiety and emotional response, despite great efforts on the parts of these mothers to protect them from these realities.

So, they didn’t ask those three questions that I read they were going to ask: “Did we cause it?” or “Who’s going to take care of us?” That didn’t occur to them.

What came out was, “Are you going to die?”

“They did ask if I was going to be okay. My middle guy asked if I was going to die, and I said no, we are going to do everything the doctors say.”

The issues that surrounded the children’s own associations to cancer were evident in the children’s statements and responses to cancer. Many of the children demonstrated both loving and hurtful statements during the course of the mother’s treatment. Their statements were often indicative of their own needs at each developmental stage. Ages and cognitive abilities of the children tended to determine the questions they asked.

“He (young son) thought that I swallowed a bumblebee and that it was in my tummy. He said, ‘You swallowed that bumblebee and it’s making you sick. They’ll take it out then.’”

“I remember my son saying we all had a get-better button. My belly button was a get-better button, you just push the button on your body and you get better.”

My daughter came storming into the bathroom and said, “You have no boobs, mom” and I said, “No, they are gone.” She said, “Because they were sick,” and I said, “Yes, because they were sick they cut them off,” and she was like, “Oh that had to hurt,” and I said, “Yes, it was painful,” and she said, “Now you have no hair and no boobs, you are really a boy.” She just kept telling me over and over again that I was a boy.
Some statements were profound in demonstrating the children’s empathy for illness, while others pointed directly to their own psychological needs. In the innocence of the children’s statements, we also hear the mother’s gender being assaulted as the children make references to looking a like a boy, or having some anxiety about being seen without hair.

In one of the hockey games, the coach gives the puck to whoever does a good job, and there was a game of his that she (mother’s best friend with cancer) came to of his, and he gave her the puck. He got the puck and then afterward he came to her and said, “I want to give this to you.”

Other statements yet showed the innocence of younger children in their responses to very serious discussions. These children were attuned to illness in not only their mother, but now others around them as well.

We sat her (daughter) down and we said…..well I couldn’t talk so he (husband) said, “Your mom is going to be really sick for a long time, so you can’t depend on her anymore.” I don’t think she got it because she was like, “My mom’s fine, can I go play now,” she just didn’t buy it.”

**Competing Conflicts**

The fifth property in The Children is Competing Conflicts in the mother, which can cause feelings of disappointment in the children. The mothers’ competing conflicts were demonstrated in terms of needing the children to be “normal” and also having the need for the children to recognize the illness. The mothers’ fears were overloading the children with information about the illness while making efforts to protect them from the
anxiety they would experience in having the information. When the children had
moments of not recognizing the gravity of their mother’s illness, the mothers found
themselves wondering if the children were insensitive or uncaring as they appeared in
those moments.

My daughter would get angry with me if I couldn’t do something. It was one of
the times she had a music performance at the school and I had the stomach flu so I
couldn’t go and she was very angry with me. So my response, and I was pretty
mean about it, was, “Listen, I want to go to your wedding someday, so it’s either
I go to the music performance now, or I go to your wedding,” so she gets it. It’s
not my choice.

“Leave mommy alone, she’s tired.”

I think my youngest, she doesn’t know enough, and I think I’m trying to protect
her because I see my oldest daughter went through a depression and was suicidal,
and I think it was because I overloaded her with too much information, but then
my youngest doesn’t know enough.

The mothers felt guilty for having feelings of anger toward their children. They
felt burdened, responsible, and afraid that the children would potentially have to live
without them. They often experienced a sense of isolation and loneliness when the
children could not recognize their illness, but also felt a sense of relief that the children
were not fully aware of the gravity of the circumstances.

“You tell her because you want her to understand. You don’t want to make them
scared, but it’s a fine line you have to cross.”
I started treatment in January and they (children) were not as helpful this time. I told my husband that I am expecting them to be like, “Are you okay, mom” or “Is there anything I can do for you” and that just never happened. He (husband) goes, “They are still kids.”

Some children, however, did conceptualize the illness. The challenge for the mothers was to engage them in the severity of the illness. If mothers were able to do so, they also experienced a conflict in wanting to protect the children from fears related to the possibility of death.

Most of the mothers shared an interaction with their children that they defined as “blowing it.” They all walked away after talks with children hoping what they said was carefully conveyed and caused no harm to the children, given the gravity of the illness. Considering the complexity of what these mothers were trying to convey to their children, and the tragic trauma that mother and child were bound in together, it would be impossible to have expected any of them to not walk away feeling uncertain of themselves at some points. The illness is complex. Relaying the illness to young children in a way that does not harm them is a delicate and careful task that no one should expect to perform perfectly. The children becoming psychologically symptomatic as a result of their fears about the possibility of their mother’s death was the most devastating aspect of having cancer, per the mothers in this study.
Chapter VIII

Treatment, Hair Loss, and Children

Hair loss during treatment represented many important facets of the illness. The mothers distinguished that the illness became real when hair loss occurred. The women viewed hair loss as an assault on their femininity. Hair loss and surgery represent an injury to women’s sense of self. The idea of “mother” is a feminine, gendered role, and gender was being assaulted in the mothers’ cancer treatment. Mothers carry their infants, nurse them with their breasts, and care for them with tenderness and physical contact. Throughout the course of treatment, gender becomes assaulted with the loss of breasts, and at times other female organs, as well as hair loss.

When hair loss occurred, the children were then immediately involved in the illness, resulting in a loss of privacy for both mothers and their children. The properties in Treatment, Hair Loss, and Children are as follows: Fear and Dread of Hair Loss, Making it Fun, Managing Loss of Privacy, Accepting the New Look.

Fear and Dread of Hair Loss

One of the first questions the mothers had when diagnosed with cancer is whether they would need chemotherapy and if they would lose their hair. Hair loss is a traumatic representation of cancer treatment. Both mothers and their children reported having anxiety about the impending hair loss and making efforts to minimize how large this
assault felt. A sense of relief was observed in some of the participants once the hair loss actually occurred, as the anticipatory anxiety of this loss was dreadful. It was clearly observed, however, that the children also experienced ambivalence about the mother’s hair loss.

“Really, it’s a huge deal and I would never tell anybody, “Oh, don’t worry about it its just hair.” I mean, it’s a huge deal.”

It’s not your choice and, you know, there’s a lot of…even more than losing my breasts, like losing your hair…I think the thing about losing my hair from then on was that I didn’t have the control of sharing my story, like people knew it before I had a chance to decide whether or not I wanted to share and I was very open, like easily open about the whole thing. The whole time, people would say, “Well, I won’t tell anyone.” I said, “No, it’s not a secret. If anyone wants to know, you’re welcome to share the information I’ve given you. It’s not a secret.” But that hair thing really changed the playing field from then on.

I was homebound in my own sense because I looked absolutely horrible. I didn’t even recognize who I was. One of the things that in thinking about my kids, I think when women lose their hair, that is one of the biggest things for kids.

Hair loss was a devastating event for both the mothers and their children in terms of how it was managed and dealt with. Mothers recognized that the hair loss signified a loss of privacy, for both themselves and their children. The psychological reality of the illness at this point could no longer be avoided, and although a new outward appearance was evident, the mothers went to great efforts to avoid a stigmatized identity with illness.
Making It Fun

The second property of Treatment, Hair Loss, and Children was Making it Fun. These mothers worked hard at finding creative means to mitigate the psychological trauma of hair loss. One made efforts to play games of “magic hair” to prepare the children for the loss. Others allowed the children to take part in shaving their heads and cutting their hair. Some preferred to maintain their privacy during the actual loss and welcomed stylists into their homes to shave their hair in privacy. All women, however, recognized this time as a hallmark in the illness and were forced to lose their sense of privacy about having cancer.

“I took my daughter out back and I gave her scissors and said, ‘Do what you want,’ and I let her cut my hair.”

One night when I knew it was starting to happen, I said to my kids, “Why don’t you come and sit here by me on the couch.” I said, “Mommy has magic hair, and look what happens, look what I can do with my hair.” Just a couple times I had to tell her, “You are pulling too hard.”

There is no guide for how to explain and work through the emotions that accompany hair loss. Similarly, there is no one “right” way to perform this task. Given the gravity of the illness and the difficult changes for the mother surrounding treatment, perfection is not expected in working through hair loss with the children. “Good enough” is a fair standard for how this could possibly be expected to transpire given the nature of the trauma.
Managing Loss of Privacy

Hair loss also represented a loss of privacy for both children and mothers. Some children had friends who then became aware of the mother’s illness. The mother’s fears were an inability to protect children from what they would experience from peers when they hear the word “cancer.” Children experienced reactions to the hair loss from their own peers. Overall, hair loss marked the point at which the illness became real for the family system. Efforts to hide the illness were only short term.

“So I heard your mom has breast cancer. That probably means you’re going to get it too.”

“Will you please wear your wig to back-to-school night?”

“I was trying to draw you with a scarf, and I couldn’t draw the scarf, so I just drew you with your hair on.”

Mothers also had to carry on with life events and manage their new look and fears about hair loss.

“We had my daughter baptized and I remember wearing my wig that day. I never felt great wearing it because it just felt like a mop on my head.”

A few of the participants were teachers and struggled with facing not only their own children’s questions and reactions, but those of their students as well. These women struggled with a terrible need to have people not notice; all the while realizing that there was no way around having to explain their circumstances to some degree.
Accepting the New Look

The final property in Treatment, Hair Loss, and Children is Accepting the New Look. Children ultimately resolve the anticipatory anxiety and have a loving response to the mother’s new look. Many of the mothers were taken aback by the loving gestures of the children in accepting them without hair.

One night she woke me up in the middle of the night. While I would try to sleep with something on my head and it was just so hot, you know so I took it off. She came in the middle of the night and woke me up and she was startled at first, but after that it seemed like, “Okay, you know. Oh, it’s not that bad.”

I put a hat on and I think it was less than a day when my daughter was like, “You don’t have to wear anything,” I think she was just scared, but she was like, “It’s fine,” and she’s been my lifesaver.

These women responded differently to their new look. Some mothers had a carefree attitude about hair loss and were comfortable being hairless, while others would never present themselves without something on their heads. The mothers were taken aback by the kind acceptance of the children once the anticipatory anxiety of hair loss was experienced. Developmental stages were also considered, with adolescents in particular expressing some concerns about their mother being bald in public.
Chapter IX

Parenting with Cancer

Mothers were incessantly thinking ahead of the children’s needs and were especially attuned to teachers and other influential adults recognizing any negative emotions in the children. Many contacted other parents for support and assistance for day-to-day matters along the course of treatment. All were astounded by the sense of community they experienced in the willingness of others to come forward and support them in regards to the children. The properties in this category are: Preparing Other Adults, Keeping it Normal, Teachable Moments, Maternal Worries, and Blogs and Legacy Projects.

Preparing Other Adults

Mothers in this study prepared for both their treatment and for what their children may experience as a result of their illness. Mothers also wished to stay attuned to what other adults in their children’s lives may observe. As a result, they chose to make other adults aware as the first step in parenting with illness.

“You just have to let them go through it. You just try to have people in place that they can go to.”
We did tell the teacher immediately, and periodically she would send a note home saying, “Everything’s cool and she’s not, you know, there’s no reaction,” and then when I was going to surgery or had a momentous day like starting chemo or losing my hair, we emailed her.

Mothers wanted to be certain that their children were not compartmentalizing any feelings about the illness that other adults may observe.

**Keeping It Normal**

Mothers found it especially important to keep the lives of their children as normal as possible. At times, this was a daunting task as their own busy schedules were interrupted with the treatment process. Mothers did not want their role as mother disrupted and they preferred to do as much for their children as they normally would.

“I want my kids with me all the time and I remember people would be like, “Oh, let me come pick up the kids,” and do stuff with them, and that is like the last thing I wanted.”

“I’ll be the one to pack their lunches, and I’ll be the one to do the laundry. I tried to maintain all of those things.”

Once I had that two-to-three-day window, it was literally clean your house, go grocery shopping, take them to the park, go outside. I’m worried about scrubbing my toilet and making sure my bathtub is clean. The next week I am down and then my whole house is clean and we have groceries.”
Mothers made efforts to maintain their children’s routines, even in their absence due to surgeries or hospitalizations. They also had to contain their emotional worlds in order to maintain normalcy for the children.

I was sad, but I try to keep things upbeat. I tried to keep things normal. If I cry, they know something is wrong. Even though I do want to cry, I’m going to suck it up because they’re going to see it.

It was very hard for me, going into all the surgeries, because I wanted to control a lot. I had been getting meals from families at work, so I wanted to make sure that we had meals in the freezer. I arranged for someone in the neighborhood to arrange meals when I was having surgery. I had a big calendar to map out who was going to get the kids when.

The mothers hoped that their decisions about treatment would have minimal impact on the children. They wished for their lives to remain normal and centered around the children.

**Teachable Moments**

While under extraordinary pressure, the mothers hoped that they were handling the cancer and children well. They hoped that they were doing the right things and saying the right things at the right times so as not to induce fear in the children. They had hopes that their children would take lessons from the cancer experience, such as seeing the goodness in people, having empathy for others with illness, and choosing the right friendships. They hoped their children would learn how to cope with the emotion of a
serious illness or event. These mothers were motivated by the maternal imperative and responsibility for the children. The children’s needs became teachable moments for both mother and child. Through mutual learning about the children’s needs in these difficult situations, mothers were able to move from a passive state of helplessness from the illness to a more active role in caring for the children. At times, the children were able to recognize the gravity of the pressure their mothers endure.

My daughter said, “You know, mom, people may not understand this, but you get closer then we ever get to anybody, you have to love the little things you do. Like when we dance and get crazy in the kitchen, you have to love those kinds of things, you have to celebrate.” This is coming from my 11-year-old.

The mothers hoped that teachable moments conveyed that the times they had together were times to be treasured. Mothers described changes in parenting, such as taking extra time to snuggle with their children and appreciating doing little things with them.

I thought, you know, if something did turn out for the worst, they might not remember that I was totally honest, but I know that when I say to them, “I was totally honest with you,” that I will be believable because I was totally honest.”

These mothers focused on something greater than themselves while progressing through the treatment. Mothers tried to make discussions with the children teachable moments and to foster a positive outlook in the children during such a difficult experience. This appears to be an impossible situation to get exactly correct, as the children’s attunement to the mother allows for their own and her anxiety to be experienced.
“I want to celebrate life a lot more. I try to not deny the opportunity for kids to do certain things.”

“I’m hands-on everything. School, I volunteer. I go to every game. I go to everything. I don’t want to miss a thing.”

Through their own teachable moments in experiencing cancer, the mothers had a renewed sense of the value and appreciation in the day-to-day activities of their children. Their desire to remain active in their children’s lives also served as an ongoing, protective state of activity. The helpless feelings associated with the illness were kept at bay by continued activity and a focus on the children. Both mothers and children experienced value in the teachable moments.

**Maternal Worries**

Mothers worried about their own future and that of their children. Their instincts lead to questions about their children related to the possibility of death.

I made sure both kids had their physicals for school in the fall, and all of those kind of things, I organized all of that (begins to cry) and I couldn’t tell my husband that I did all of that because it made me too sad, so I told my daughter, I said, “Here are all the very important papers and I’m going to put them on your desk.”

My younger brother had said to me one time, “Why don’t you just move on?”

How do you move on? Especially now. This is who I am. This is who I am and what God has given me to use. Whether I see the good in it now, or if the good
comes from this later for my children or whoever, I said this is what I’ve been given to work with in my life. There is no moving on.

In cases of a genetic mutation leading to a breast cancer diagnosis, worries also surrounded the idea of whether the daughters would be afraid to become adult women and fear the illness. The children were pulled into the mother’s devastation.

I wonder what will happen as she absorbs, she is 9 now. Next year she’ll be 10. At some point, very soon, she is going to absorb the severity of it and I wonder how she’ll react at that point.

“As she gets older, I’ll probably be a little bit more all about, I always want you to make sure you are checking yourself, because it is really important, you know.”

The emotional pain the mothers experienced was heightened when the children were symptomatic with anxiety or depression. The intolerable moments for these mothers were not in the treatment itself, but when observing their own children become psychologically symptomatic as a result of their illness. The mother often felt that they somehow caused their children’s distress, at times unable to attribute these feelings to the unfortunate circumstances. Mothers focused more on what their children were experiencing while trying to maintain and attend to their own medical needs. The distress in the children was a greater challenge for the mothers to contend with.

“She (daughter) hates chemotherapy days. She is afraid something is going to happen. I didn’t know why she was saying, “Can I please go to treatment with you?” Well, she was terrified, and she just wants to be there.”

The mothers were unsure of the degree to which their children understood what was happening, or if they were able to grasp the gravity of the situation. Mothers worried
that their children harbored painful memories of the experience. At times, they were surprised when their children brought up cancer out of the blue.

We were driving home from church and he (son) was in the backseat and just out of the blue he says, “Mom, do you ever think there will be a cure for cancer?” and I said, “Oh, I don’t know buddy, I hope so. It’s going to take awhile and they are learning stuff all the time.” And he said, “I don’t mean breast cancer, I mean any cancer. It would be great if they could find a cure so people don’t have to worry,” so then I’m like, “I think he’s worried.”

Both children and mothers experienced ongoing worry over time about the cancer experience. At times, the mothers were surprised by the degree to which their children understood the circumstances. The worry remained consistent for mothers; while the children give these mothers something to organize around each day, when the children were symptomatic, the mothers experienced a sense of falling apart.

Other ongoing worries were the physical symptoms experienced after treatment. Unusual aches or pains always trigger maternal worry, and are some of the most difficult aspects of managing cancer after treatment is completed.

My days are pretty busy, but if I wake up at 3:00 a.m., that’s what I’m thinking about in my sleep. I’d be like, you’ve got to let this go, and you’ve got to put this aside. If it comes back then deal with it then, but don’t worry. It’s not productive, it’s not useful. I tell myself this can have a negative bearing on your physical state.
The last treatment was May 29, and during that treatment, my doctor had come in as we had a gift for her, and we were just talking with her for a really long time, and I don’t know what she said or who she was talking about, but I left there realizing that this is going to be a struggle. This is just, this is going to be a struggle, forever. I’m just not ever going to be done with this treatment and it’s over.

The surprise of the illness is reexperienced traumatically with any physical changes as the mother tries to move forward. The idea of starting over is triggered by physical symptoms. Once the treatment course of cancer is experienced, mothers know what to expect and what the process entails. The idea of doing it again with worsened fears becomes unbearable for them and serves as an ongoing worry. Themes of maternal worries ultimately surrounded survival and their children.

I think my biggest worry was me not being there for them and not having a mom. Even though I knew we have all these people in our lives, but I also didn’t like the thought of what if I did and he like remarries or something, that some other woman gets to raise my kids. It’s just like weird things pop into your head. I think what would probably make me the most sad is like missing them growing up and all those corny things you hear about, graduating from high school and them getting married. I would hate to miss all of that.

**Blogs and Legacy Projects**

The mothers used technology to create meaning and engage in legacy projects for their children. Some of them did not consciously think through their motivation for the
projects, while others intentionally planned these activities in case they did not survive the illness.

If anything were to play out for the worst, I’m doing what I can now to have information for my daughters, whether it is, you know, saving emails, I email them photos, or I email them, “Today with your friends…” or “You had a play date and we did cupcake wars,” so I email them things.

Other mothers began to blog the experience and later printed hardcover books of their accounts. The motivation for blogging was to avoid having to retell their stories to friends and family. Blogging allowed for an opportunity to inform those who were concerned, while documenting the experience and having a record of those who provided support.

I kept a blog that really kept everyone in touch, what I did at the very end, I put it all together and this was like the weekend after I had my head shaved. So, basically, I have everything here (hard copy of blog) and I have all of their responses and everyone’s comments. I was able to import it into this book.

I just didn’t want to talk about it too much. All of my friends and family read the blog and they didn’t have to ask me how I was when they saw me. So, I didn’t have to repeat myself 1,000 times because that gets boring. It’s really more of an archive for my kids so I can say see, 20 years ago, this is what I did.

Mothers also found themselves blogging about proud parenting moments or the way in which their children managed certain situations. All mothers wrote of these situations with the idea that their children are ultimately the intended readers. Other
technological means for documenting the cancer experience for children was a Facebook page dedicated to their cancer treatment that was invitation only.

Mothers also created legacy activities by participating in Race for the Cure, Avon Breast Cancer Walks, and other fitness activities as a family or with their children. In part, being a part of these fitness activities is a reminder of aliveness, reaffirming the self that the body is at work. The rawness that exists in the fears that accompany the illness presents a tremendous conflict at cancer events, where outward appearances are typically hopeful and high energy.

“What I involve myself in, I involve them in. For 10 years, I was involved in Relay for Life. It was kind of forced family fun, but it’s a big part of their lives.”

I was getting back on my feet, back to where I was, I ran the marathon again because I wanted to prove to myself that I could do it. I wanted to prove that I could get back to where I was. So then they started Livestrong and they hired me and so I get to do it. It’s such a blessing I love to meet all these people and they are older and younger.

In order to make meaning of the cancer experience, two of the mothers developed support programs. One was in the form of a support group for women diagnosed with breast cancer and the other was part of a church community that offered specific cancer support programming. Both of these mothers were very proud of their projects which offered support to other individuals undergoing treatment. Another mother in the study taught cancer fitness classes at a local health club. All mothers looked to surround themselves with others who understood the cancer experience and provided support.
Chapter X

Living with Cancer and Fear

The process of acceptance in the cancer experience involves internalizing an understanding of the uncertainty which remains after active treatment is completed. The uncertainty can feel tormenting to mothers who make efforts at deciphering any physical symptom they experience post treatment. Thoughts immediately shift to cancer recurrence even if realistically unrelated to the illness. The properties in this category are: Fear of Recurrence, The Pink World, and Silver Linings.

Fear of Recurrence

The fear of recurrence is difficult for mothers to manage. Once the possibility of death is consciously considered in the minds of these mothers, their worlds are significantly changed. Often, women seek counseling when active treatment is completed as they have difficulty managing their thoughts about the illness returning. The possibility of death is not a thought that can be easily reconciled. These traumatic thoughts represent the fight which women refer to when talking about their treatment. These women are living in a medical world of facts and statistics; however, they often feel trapped in a different world based in the feelings surrounding the human side of cancer.
You can see the fight in other women. You can see their soul; you see it. Like they are going to make it and they are going to fight through this. It’s interesting because “making it” doesn’t mean survival. It means that you gave it all you got, and people don’t understand that.

Some women noticed that the idea of “making it” is more nuanced. Their worldview on cancer is more deeply understood as a process that entails deep suffering. As some women in this study experienced, the cancer did return and their worst fears were experienced. The psychological possibility of recurrence was then met with a medical reality.

Initially, I was just numb, I really was. I questioned, is there something else I can do for my health, what else can I do? The doctors tell me that I’m making it to all of my appointments and following the plan I needed to, and I thought, I did that before. And it came back.

Mothers were devastated with news of recurrence as they were optimistic at the completion of their first treatment regimens. Some of the women experienced second and third sets of treatment after recurrences. Each experience brought about a new set of challenges for both the mothers and their children. As the possibility of death became closer with each recurrence, the mothers’ perspective changed as a result.

“So this walk has been a little different. The kids, my husband, and I have understood it differently. “

In regards to cancer recurrence, mothers emphasized honesty with their children. They feared that if something happened to them, their children would experience anger for being denied the truth.
“I never wanted them to come to me later and say, “You did not tell me.” I think that in the end, my daughters will be strong women and use this to better themselves in the future.”

Another participant had a similar fear about her daughters and expressed a need for them to be empowered with knowledge and learn from their mother’s cancer experience. All mothers felt that through the fear of recurrence and the painful experience, they hoped lessons were passed on to their children. They had hope that their children would be empowered by their mother’s experience, and with that hope, these mothers continued to move forward, living in an uncertain world of fear.

The Pink World

Another property in Living with Cancer and Fear, The Pink World, pertains to the social hype of breast cancer in particular. Mothers who had other types of cancer experienced similarities in their cancer experiences, but did not relate to the hype of The Pink World associated with breast cancer. Mothers and children experienced a range of emotions in dealing with cancer in the month of October specifically, Breast Cancer Month.

The experience of cancer is categorical in The Pink World. When women are diagnosed, they are seeking to benchmark themselves with others. The first questions asked involve defining the type of cancer and whether lymph nodes are involved.

I remember, coming out of the anesthesia, because that was what I told the nurse before I went into surgery I was just like, “I just really hope my nodes aren’t involved,” and she was like, “I will tell you the moment I know,” and I remember
waking up and being completely out of it but the one thing I remember was her leaning over me and telling me that they were negative. And that was like the preliminary and I knew there was a chance because my sister-in-law that died, hers was negative and then they came back positive after so many days you have to wait. But I thought, I don’t care, you know, that was the one thing I remember because I was so out of it, but I was like, “Oh God, yes,” and then my husband laughs because he said anytime anyone would come in I would tell them, “My nodes are negative!”

Categorizing the type of cancer they had, coupled with whether lymph nodes were involved, established the framework for where and how the women positioned themselves in The Pink World, as well as their perspective, outlook on treatment, and ideas about recurrence. Breast Cancer Month and The Pink World, therefore, had varying associations for these women. These experiences were different for all of the mothers and were contingent on how they had categorized themselves. Some viewed The Pink World as a positive representation of having pushed through the difficulty of treatment, including treatments for local disease where lymph nodes were not involved. Others, on the other hand, experienced The Pink World as a negative representation and trigger for the real possibly of recurrence when lymph nodes were involved in their illness. When first diagnosed, the culture of winning is something that can be held close, as the possibility of death can be kept farther away. Lymph node involvement in cancer changed this experience for these mothers.

When trying to move forward from the psychological impact of cancer, The Pink World and the month of October can be traumatic for both mothers and children.
Although the mothers were able to recognize and identify the positive aspects of a “movement” with Breast Cancer represented in pink, many reminders were triggered by these representations.

I thought about writing a mom’s guide in the sense of being a mom and here’s what’s going to happen. Not only are you dealing with breast cancer, but also you’re dealing with being a mom. You’re dealing with getting dinner on the table. Being pink doesn’t always have to be being positive.

I will support it (pink ribbons) but I don’t need to wear it and I don’t need to advertise it. It’s not going to be the first thing you hear out of my mouth. I felt very homebound last year because I felt very vain about things and I just was like lay low and come out on the other end, move on and put this behind you.

The mothers, however, did express difficulty putting the cancer fully behind them when faced with pink cues and triggers about breast cancer or commercials that advertise cancer treatment on television. The social awareness of cancer also triggers children to gain some understanding of and exposure to the illness. One participant explained that her daughter had to give a speech on something traumatic and how it affected her. She thought of her mother’s breast cancer and chose to speak with her class on that subject.

I wish I would’ve heard it (daughter’s speech) but I probably would have broken down during the speech too. Her teacher called to tell me that she was very brave and shared it and that several other students went up to her afterward and said my mom had breast cancer too.
The Pink World, television commercials, and other pink events and triggers ultimately initiate discussion about cancer for mothers and children. They allow for language to be exchanged about the experience of cancer and feelings and fears to be processed and discussed. Although it is intended to be, The Pink World is not always an encouraging and positive representation. In addition, it serves as a reminder that not all breast cancer, or other type of cancer, is the same. The Pink World means different things to different women. These women could recognize those who truly understood the meaning of the word cancer, and could also identify others who minimized cancer and had an easier treatment course that was not aggressive in nature. This phenomenon is observed at cancer events where women are sometimes ordered with signage in terms of years of survival and separated by who is in active treatment. Placement in the Pink World is not all for one, or one for all.

Silver Linings

Mothers identified “silver linings” as a metaphor for their optimism about the cancer experience. In retrospect about the treatment process, mothers tried to identify and maintain a hopeful perspective about what was experienced with their children throughout the illness.

“We’ve always been a close family, but I think this experience brought us even closer.”

“You know how they talk about how you watch your kids sleep, that is so important to me.”
The silver linings in Living with Cancer and Fear were focused on the mothers’ relationships with their children. The mothers recognized through these relationships that their suffering had meaning and that their relationships with their children were the most important element. Other aspects of optimism observed were the level of involvement in support programs and giving back to others with cancer.

Just that feeling to know that you’re not alone, someone else has gone through this with you or before you. It’s the most amazing feeling. My first time around I spoke to a lady in Illinois over the phone, never met her until I was done with treatment at an Avon walk. That is what I tell everyone, let me help you find someone in this position. Your spouse can tell you that it’s going to be okay, and it’s comforting to a point, sometimes it’s irritating. But when you see that other person and you know they get you and your fears are not small. And then when they say I know how you feel. All this weight is off of you now and you know that you aren’t crazy and it’s a sincere fear.

Two of the mothers developed formal support programs that are utilized as resources for other mothers with cancer.

Ours is specific to breast cancer patients. Our idea is that we just want people to know that you’re not alone, and there are people out here who are more than willing to talk to you, and more importantly, they have become my friends.
Chapter XI

Introduction to Theoretical Findings and Discussion

This chapter will describe six findings in the study and outline the limitations, theoretical implications, and questions that remain for future research.

Finding 1: Entering cancer is an experience that raises the possibility of death, and has no complete psychological exit. Mothers experienced a rapid entrance into the world of having cancer. This experience was also that of an emotional trauma. The mothers responded quickly by digesting a large amount of information that required them to make decisions that were pertinent to life and death matters (Chapter I: Excess Information, Association to Cancer, Taking Charge). The emotional trauma they experienced shattered the illusion of endless time, and no real exit to cancer could be achieved. The diagnosis of cancer and the emotional consequences triggered multiple processes that attempted to address the destabilization of the self.

Finding 2: Children are active participants in the dark days of cancer, both internally and externally with the mother. When mothers recognized the disabling impact of aggressive cancer treatment, their children are what motivated them to function each day (Chapter VI: Dark Days, Loss of Control, Culture of Winning). Internally, mothers had thoughts and feelings surrounding the need to keep going for their kids. The experience of poor physical shape for otherwise fit and active women resulted in a mental regression to “doing it for my kids.” Externally, the mothers had to actively participate in
the day-to-day needs of their children. There was also a need for the mothers to maintain feeling in charge of the daily lives and routines of their children, with great sadness in accepting help for daily tasks they wished to complete themselves.

Finding 3: Discussing cancer with children is ultimately confirming their suspicion that something is wrong. The children, being attuned to their mothers, had some idea that something was terribly wrong in their homes (Chapter VII: Attunement to the Mother, Symptoms and Reactions of Children, Children’s Statements and Gestures). The mothers quickly recognized that there was no easy way or perfect time to have these discussions, and that the children would be impacted by this information, despite all efforts to protect their psyche.

Finding 4: Mothers, under the frightening circumstances of a cancer diagnosis and treatment, should not be expected to demonstrate “perfect” mothering, and should be told this is going to affect how the children are parented. Competing conflicts (Chapter VII) were experienced by mothers as they grasped their own emotional needs and grappled with giving their children a sense of normalcy in their development. Mothers mad efforts to create teachable moments (Chapter IX) in an attempt to make meaning of their suffering for both themselves and their children. A “good enough” mother is all one should expect to see in parenting with emotional trauma.

Finding 5: Cancer is often experienced as an assault on a mother’s gender. Mothers experienced a loss of breasts or other body parts, a loss of hair, and a subsequent loss of privacy (Chapter VIII: Treatment, Hair Loss and Children, Making it Fun, Managing Loss of Privacy, Accepting the New Look). Their sense of self and identity as a woman were shaken. The children were also impacted by this change in their mother’s
physical appearance. The children whose mothers had a genetic mutation leading to a
diagnosis of cancer had a greater degree of identification with the mother’s assault.

Finding 6: Behavioral activities related to cancer treatment are efforts to ward off
anxiety towards the psychological possibility of death. Mothers engaged in the culture of
winning (Chapter VI) and demonstrated their survivorship beliefs through active efforts
in supporting others. Others documented their experience in blogs and journals in hopes
of making meaning and presenting teachable moments for their children (Chapter IX).
Mothers became involved in fitness events related to cancer, as the possibility of death
was difficult to acknowledge. Mothers warded off anxiety towards death in their efforts
to maintain the culture of winning with others.

Finding 1: Entering Cancer Is an Experience That Raises the Possibility of Death,
and Has No Complete Psychological Exit

In the category, Entering Cancer, the women were overcome by information and
had to quickly adapt to a new reality from which there is ultimately no psychological exit.
As the gravity of the diagnosis created a sense of shock for these otherwise healthy
women, the extent of their new reality was an experience that took time to fully
comprehend. The experience of emotional trauma in having cancer as a young mother is
profound, and the psychological turmoil is worked through over time.

A diagnosis of cancer is often traumatic and is experienced through varying
degrees over time. What are shattered in the nature of trauma and cancer are the
absolutisms of everyday life (Stolorow, 2007.) When a young mother tucks her child into
bed and says, “Goodnight and see you in the morning,” such a statement has new
meaning when having entered the world of cancer. Stolorow (2007) made references to such statements as “naïve realism” and “optimism” that allow the world to be experienced as stable and predictable. The women in this study provided examples that illustrate the knowing and shattering of their previous existence of naïve realism and optimism.

In the property, Silver Linings, we see that mothers experienced a shift in how they absorbed and treasured each minute of the mothering experience.

“I want to celebrate life a lot more. I try not to deny the opportunity to do things with the kids.”

“I’m hands-on everything. School, I volunteer. I go to every game. I go to everything. I don’t want to miss a thing.”

These mothers experienced the loss of an idealized world of optimism and endless time prior to a diagnosis of cancer. Prior to entering cancer, these women lived modest lives in which they worked in their careers and parented their children without thoughts about the possibility of death or illness.

It is unnatural and tragic for children to lose their mothers. Bowlby (1958) argued that maternal deprivation can be directly harmful to children if separation occurs in the child’s first three years of life. The threat of their own mortality and such loss for children is looming and weighs heavily on mothers with cancer, creating a lack of psychological exit. The threat wavers in severity over time and distance from the illness itself. When entering cancer, the threat is experienced clearly. As emotions are worked through during cancer treatment and beyond, anxiety towards death for mothers becomes
naturally enacted. In the category, Maternal Worries, the recognition of the mother’s mortality is observed.

I’m thinking I have cancer, so why would it now be on my liver? Why would that be something else? My liver has never popped up before. So why would it be something else now? So I convinced myself and my husband that it was bad. I’m thinking, I know this, that when it gets to the liver that you’re in big trouble. I know this. It was devastating. All those things, my daughters’ graduations and all that just hits you, not seeing my husband turn grey (begins to cry), it was just absolutely awful.

The false illusion of optimism and endless time is a headspace that mothers with cancer are forced to surrender. The data clearly indicate that a cancer diagnosis can be understood as a threat to psychic continuity. Ornstein (1994) wrote of trauma, memory, and psychic continuity, where traumatic memories can threaten maintenance of a sense of continuity over time.

For the mothers in this study, the possibility of death was experienced with the diagnosis. The anguish was isolating in nature as they considered what the diagnosis meant for the lives of themselves and their children over time. As these women completed active treatment courses, the disavowal of the experience lessened, allowing the women to experience the emotional toll of the cancer process for themselves and their children.

Stolorow’s work on intersubjectivity is rooted in the philosophical underpinning of Martin Heidegger. The German philosopher, Martin Heidegger, influenced psychoanalytic theory with his concepts of Being and Time (Heidegger, 1927). He wrote
of the importance of recognizing finitude in life in order to experience an authentic existence. Heidegger’s acknowledgement of Being-Towards-Death points to a purposeful existence in which “knowing” about one’s own distinctive possibility of death allows one to live a truly authentic life.

In acknowledging the relational space of another, anxiety towards death and can be worked through to create a more meaningful and connected existence. Atwood and Stolorow (2014) referenced an intersubjective space that can be healing in relation to another. Cancer is often referred to as a “sisterhood” or a “club,” and the “knowing” that comes from a mutual anguish and subsequent psychological estrangement from others who do not understand the illness at times unites women with cancer. In the property of Silver Linings, these connections to others are explained.

I tell everyone, let me help you find someone in this position. Your spouse can tell you that it’s going to be okay, and it’s comforting to a point, sometimes it’s irritating. But when you see that other person and you know they get you and your fears are not small.

The emotional trauma of cancer is recognized in this club, and only other women going through this experience can truly comprehend the isolating solitude of the diagnosis. Once the anxiety towards death is experienced, the data show that it stays there (Shelby, 1992). While these mothers found ways to adapt to this anxiety, it never completely goes away. In the category of Maternal Worries, one mother described her intimate fears.

I think my biggest worry was me not being there for them, and not having a mom.

Even though I knew we have all these people in our lives, but I also didn’t like the
thought of what if I did and he like remarries or something, that some other woman gets to raise my kids. It’s just like weird things pop into your head. I think what would probably make me the most sad is like missing them growing up and all those corny things you hear about, graduating from high school and them getting married. I would hate to miss all of that.

Deep human bonding was demonstrated in young mothers with cancer. Through the interviews conducted for this study, it became clear that every woman was concerned for the other women in my study, and had a sense of connectedness in this experience. Vogel (1994) referred to the idiomatic expression, “Kinship in the same darkness,” to describe the experience of truly knowing the finitude of life and suffering in another. Entering cancer is the shattering of innocence about endless time. In the experience of cancer, however, deep human bonding and mutuality in the recognition of another’s suffering leads to a more meaningful human existence. The context of another woman or mother who can share in the isolating experience of suffering supports the connectedness experienced by mothers with cancer.

Time changes the ability for these women to work through the emotional warfare of having entered cancer. In the category of Treatment, Hair Loss, and Children, the trauma is evidenced in how these mothers were impacted by the changes to their body.

I felt very homebound last year because I felt very vain about things and I just was like lay low and come out the other end and move on and put this behind me, and yes it will always be daily reminders for myself, but I don’t have to let it be the first thing out of me.
Ornstein’s (1994) concept of trauma and psychic continuity informs us that working through this experience of trauma is a lifelong process. This band of women understood that cancer is not an event, but a new reality that stays with you. Over time, their disavowal of having cancer loosened, and they were better able to articulate the anguish of the experience and reduce their use of behavioral solutions. Once the possibility of death opens up, it never completely closes. Stolorow’s (2014) work does not demonstrate a recovery of trauma, but rather a new reality that is experienced. It was apparent that these mothers grew to tolerate the new reality and achieved a sense of optimism through survivorship; however, their anxiety towards death was not completely diminished.

Finding 2: Children Are Active Participants in the Dark Days of Cancer, both Internally and Externally with the Mother

The question explored in this study was how cancer impacts the relationship between mother and child. The mothers in this study described dark days, such as those that followed surgery or aggressive treatment, in which they found themselves literally immobilized and unable to care for their children. As we have evidenced, the trauma of cancer is worked through and experienced over time. Some painful recognition occurred in moments when these mothers could not physically care for their children. In the property of Dark Days, the mothers described the trauma of not providing their children with certain maternal functions.

She (infant daughter) had a very low immune system. So I had to be really careful around her because when she got sick, I couldn’t care for her, because we
both….so that was like the hardest thing. I mean just you know, not being able to hold your baby.

At times throughout the course of treatment, it was more difficult for the women to deny the possibility of death. These women became exhausted over the process of cancer treatment. They survived the diagnostic testing process, aggressive surgeries, chemotherapy, and radiation treatments. Some needed additional targeted therapy as well. All were life-saving measures in response to cancer and aggressive treatment. In the category of Managing Emotions and Acceptance, a participant described the exhaustion and helplessness involved in her process.

I need a break. It’s been a year and a half. I had third degree burns, everyone’s like, “Oh, radiation is a breeze,” and I’m like, “Really, when you get third degree burns and your skin is so pink and it’s peeling like shaved ham?”

In 1914, Freud wrote, “At the most touch point of the narcissistic system, the immortality of the ego, which is so hard pressed by reality, securely is achieved by taking refuge in the child” (p. 91). Freud wrote of the parent functioning through the child’s drives to allow the child to believe he or she has immortality. In the category, The Children, a participant described the need to maintain normalcy in parenting during this traumatic experience and recognition of the possibility of death.

I think she might be a little more clingy but I really tried not to make a change our life. I mean I still had to yell at my kids when I was in chemo. I didn’t want to, but I felt like if I didn’t have hair, then I couldn’t have power over my kids, I’m like, that’s so stupid.
The mothers described the children as not only their motivation, but also a central organizer for functioning when their bodies could not. The mothers used their children’s libido as their own life-affirming vehicle. Freud wrote of infants and their complete dependency for survival upon the external world (Freud, 1911). The biological instincts from the time of birth represent the maternal responsibility to the child as instinctual. Benedek (1960) referred to “mammalian instincts” as preparing mothers for feeding their children after birth.

Maternal instincts were challenged in the dark days of cancer treatment. The mothers described feelings of despair during the dark days related to their desire to do the routine work of mothering on a day-to-day basis. Although others would willingly offer support for daily parenting routines during the dark days, the mothers were deeply saddened by their inability to complete these tasks. In the category of Parenting with Cancer, a mother described her unwillingness to surrender her duty to her children.

“I want my kids with me all the time and I remember people would be like, ‘Oh, let me come pick up the kids,’ and do stuff with them, and that is like the last thing I wanted.”

Anxiety was heightened as a direct result of this deprived desire, which caused these mothers to use their children as their motivation during dark days. The children were life affirming and served as motivating factors for their functioning.

Benedek (1956) further differentiated motivation and action as requiring balance during acts of mothering. She wrote of the “mother’s love and her (symbiotic) need for her infant” and the “ego aspiration to be a good mother” (Benedek, 1956, p. 418) as
gratification in normal motherhood. In the category of Managing Emotions and Acceptance, one mother described her guilt and fear.

Will I be here? Will I see them? Will they be afraid to be a woman? They saw a completely different person. I went from this loving and caring hands on mother, to I couldn’t physically get to hold her. I lost weight.

These maternal aspirations compete with fears during cancer treatment. The mothers recognized that parenting their children was simply all they asked for. Their main desire was to see this duty through to completion, and the dark days forced them to question if that would be possible. In the category of Parenting with Cancer, maternal worries were described.

I made sure both kids had their physicals for school in the fall, and all of those kind of things, I organized all of that (begins to cry), and I couldn’t tell my husband that I did all of that because it made me too sad, so I told my daughter, I said, “Here are all the very important papers and I’m going to put them on your desk.”

The instinctive need and aspiration to be a good mother is a strong motivator for these women to restore their bodies to normalcy and precancer functioning. Cancer is not only an assault on the body, but also an assault on the self. The mothers needed to reaffirm that their bodies were still working after treatment. Again, in the Dark Days, the mothers had a painful recognition of their limited capacity for strength. For the participants, it was the first experience of being unable to care for their children without strenuous and difficult efforts. A fear of “nonbeing” was evoked and the possibility of
death acknowledged when the mother’s body was assaulted by side effects from treatment.

Winnicott (1971) wrote of a mirroring that occurs between mother and child, in which the child sees and perceives him- or herself through the eyes of the mother. He wrote, “The mother is looking at the baby and what she looks like, is related to what she sees there” (Winnicott, 1971, p. 111). Winnicott implied that the mother gives back to the baby the baby’s own self perception based on her emotional state. Winnicott discussed mirroring as a meaningful, two-way process between mother and child. In the category, The Children, evidence of attunement to the mother and the children’s questions were described.

I totally forgot for a few minutes that my kids were with me and I just was like okay, okay, okay, and crying and crying and crying. As soon as I hung up the phone my older daughter says, “Mom, do you have cancer again?” And I’m like, “Oh for the love of God, you know, here we go again,” and I told her, “I don’t know, I just don’t know, and I just had that feeling and my feelings had always been right, you know and I just had that feeling.”

This study found that the child’s libido is life affirming for the mother. In this way, that which the mother sees in her child during the dark days is used as motivation for her functioning. If the child perceives the mother’s darkness and lack of functioning, he or she may be at risk to mirror these negative emotions. Evidence of children’s symptoms in response to the mother’s illness is articulated later in these findings.
Kohut (1966) wrote,

Man’s capacity to acknowledge the finiteness of his existence, and to act in 
accordance with this painful discovery, may well be his greatest psychological 
achievement, despite the fact that it can often be demonstrated that a manifest 
acceptance of transience may go hand in hand with covert denials. (p. 263)

For the participants, this was a gradual recognition over time. In the category of 
Parenting with Cancer, these maternal worries were explained.

The last treatment was May 29, and during that treatment, my doctor had come in 
as we had a gift for her, and we were just talking with her for a really long time, 
and I don’t know what she said or who she was talking about, but I left there 
realizing that this is going to be a struggle. This is just, this is going to be a 
struggle, forever. I’m just not ever going to be done with this treatment and it’s 
over.

During the Dark Days, these mothers are forced to recognize the gravity of their 
condition and limitations of their strength. Once this is experienced and worked through, 
these mothers access both vulnerability and resilience.

My younger brother had said to me one time, why don’t you just move on? How 
do you move on? Especially now. This is who I am. This is who I am and what 
God has given me to use. Whether I see the good in it now, or if the good comes 
from this later for my children or whoever, I said this is what I’ve been given to 
work with in my life. There is no moving on.

Kohut (1966) wrote of the acceptance of ourselves as impermanent as a higher 
form of narcissism, which is not hopeless, but a position of pride. He discussed
transcendence in individuals who have understood human existence in this way. One implication of this is that these mothers need to be gentle with themselves and the expectations they have for their bodies during treatment and throughout the psychological transition to accepting this new reality as irreversible. Some of the mothers did indeed reaffirm their body’s renewed ability to work hard and returned to their normal functioning with their children. Others, however, experienced cancer recurrences and actively reexperienced the acceptance of the new reality. All mothers recalled the point at which their functioning was paralyzed—a very frightening recognition, but also an opportunity to become accustomed to living in the new reality.

**Finding 3: Discussing Cancer with Children Is Ultimately Confirming Their Suspicion That Something Is Wrong**

Introducing their children to the experience of cancer was a challenge for all of the mothers. Children are attuned to parents, and this discussion is a confirmation that something is wrong. In Chapter VII: The Children, this attunement to the mother is evidenced.

“Why didn’t you tell us? Well that’s why she brought us breakfast and came over, and then you had to go? That’s why she came by with bagels?”

“I tried to keep it from her the first couple of days, but she was very angry and crabby as she felt like she was being left out.”

This study determined that there is no right way for mothers to discuss cancer with their children. In addition, developmental stage plays a role in the children’s response.
Despite all efforts on the parts of these mothers to protect their children from the cancer experience, there is ultimately no way to shield them from it. The literature describes an attunement to the mother, and the participants provided data indicating that their children had some idea that something was terribly wrong. In the category of The Children, one participant described the attunement between her and her daughter.

She is like an old soul for an 11-year-old. So, I was honest with her at that point. If she recognizes that I don’t feel well then I’m not going to lie to her. So she knew before we went to Disney World that I was going to have some more tests when I got home.

The literature points to identifications between mothers and children. Identification refers to a mental process by which an individual becomes like another in one or several aspects (Moore & Fine, 1990). The intrapsychic bond with mothers, described early in the psychoanalytic literature of Freud and Klein, points to the mother and child sharing an affective experience. Projective identification is a defense mechanism used by children in the study. In 1932, Klein referred to projective identification as the subject’s self that is projected onto an outside object. Parts of the self are split off and projected onto an external object which identifies with the split-off part of the subject and is possessed and controlled by the split-off element (Klein, 1952). Projective identification is evidenced in the category, The Children, where participants noticed visceral symptoms demonstrated in the child in relation to the mother’s illness. A side effect that my daughter had were panic attacks and anxiety when she leaves me. Like the first time, we could not figure out why she would get halfway to the bus stop and come back panicking and not breathing and she was just like,
“I can’t breathe, I can’t breathe,” and crying. I’m like, “Well, what is wrong? What happened?” “I don’t know, I don’t know.”

In this example, the intrapsychic tie with the child is evidenced, as the child both experiences and is controlled by the mother’s own terror of the illness. The children in this study were not only attuned to their mother’s circumstances, but were subsequently involved symptomatically with projective identification, given the nature of the intrapsychic tie between mother and child.

Developmental stages of the children also informed the outcomes of what was observed between mothers and children. An infant is unable to differentiate between the mother and the self, as the introjects are not new. Object representations are self-representations in infancy. The infant’s ego undergoes a maturational process, in which the child learns the difference between self and other, as well as increasingly tolerates new affect experience (Moore & Fine, 1990). In early childhood, however, the child remains closely identified with the mother, so if the mother is sick, the child can identify with the sickness.

“He (nursing infant) knew, he turned away from that breast and wouldn’t feed from that side. He knew there was cancer there.”

In early childhood, we also observed children recognizing the illness and finding language to make connections to the sickness. In Chapter VII: The Children, the statements from younger children made reference to the mother’s cancer.

“He (young son) thought that I swallowed a bumblebee and that it was in my tummy. He said, ‘You swallowed that bumblebee and it’s making you sick. They’ll take it out then.’”
“I remember my son saying we all had a get-better button. My belly button was a get-better button, you just push the button on your body and you get better.”

As outlined in the literature, the intrapsychic bond between mother and child evolves into an interpersonal relationship. Although the psychoanalytic literature is understood from the angle of infant to mother relating, in this study, we found that the mothers needed to “use” the children for their own survival. Many of these participants pointed to their children as their primary support system. In the category, The Children, mothers recognized the interpersonal nature of the relationship and the importance to the child’s own health.

“’Mom, my calendar said that you had to go to the doctor, how was it?’ She keeps track of my appointments. If I have three glasses of wine, she says, ‘Now mom, I thought it was two glasses?,’”

“You tell her because you want her to understand. You don’t want to make them scared, but it’s a fine line you have to cross.”

In Living with Cancer and Fear, a participant further spoke of the nature of the interpersonal relationship as she viewed it to possibly be in the future.

“I never wanted them to come to me later and say you did not tell me. I think that in the end, my daughters will be strong women and use this to better themselves in the future.”

The intrapsychic and interpersonal bonds are bridged by the concept of projective identification. In 1979, Ogden wrote of this transition from intrapsychic to interpersonal relating. Ogden described the experience of projecting a part of oneself into another
person; the projected feelings are experienced by the other and are also “psychologically processed” by the recipient, only to be reinternalized by the projector.

With this bridge in the theory being clear evidence of the shift from one-person to two-person psychology, the children are unable to be shielded from the mother’s experience of cancer on an intrapsychic or interpersonal level. Although developmental stages shaped the responsiveness of the children to the mother’s cancer, all children were impacted to some degree by the illness. In the category, The Children, we continue to observe the various responses indicative of differing developmental stages and the children’s experiences.

“Her journal was how I found out she was suicidal. Oh my goodness, her fear was how does a child live without their mom; that was her fear.”

He had some behavior issues and was completely acting out. He’s a sweetheart, but at the time he was being rude to his brothers and rude to me. One day, I don’t know what set it off, but he was slamming the door, tantrum.

“He was skipping school. The youngest one was skipping school and going to a friend’s house, and just kind of trying to mask the feeling.”

In these particular examples, the children do not demonstrate the ability to access the emotions or use language to express their distress for the mother’s experience. Regression causes the child to respond with behavioral enactments of the projected elements of the mother’s circumstances. These traumatic memories and affects experienced by the children will ideally be eventually worked through for their suffering to be relieved. Shelby (1992) wrote of time travel in working through traumatic memories and affect: “An enduring element of trauma theories is the past coming into the present.
The retelling, the reliving of un-integrated experiences in the presence of the clinician leads to a different outcome.” Over time and with further development, these children will ideally have the ability to understand and give language to the shared suffering experienced with the mother’s illness.

What is clear is that the children were unable to be protected from cancer, despite the mothers’ attempts to do so. The complexity of the mothers’ competing conflicts was observed in this study as well. On one hand, the mothers hoped that their children could live their lives independent of them and not be impacted by cancer in any way. On the other hand, the mothers felt conflicted in their need for the children to notice their illness and provide nurturing support. What was troublesome for the mothers was their observation of the former, when their children were simply being children and were neglectful of the mother’s illness. Some mothers in this study felt hurt and angry over their children’s developmental, egocentric attitude during their health crisis. In the category, Managing Emotions and Acceptance, these competing conflicts for the mother were evidenced.

My daughter would get angry with me if I couldn’t do something. It was one of the times she had a music performance at the school and I had the stomach flu so I couldn’t go and she was very angry with me. So my response, and I was pretty mean about it, was “Listen, I want to go to your wedding someday, so it’s either I go to the music performance now, or I go to your wedding,” so she gets it. It’s not my choice.

A part of the complexity experienced is that children do not stop being children. While they can see that their mother is ill, they retain their own naïve expectations as
children would. On one hand, the child is aware that the mother is ill, but on the other, the
child wants his or her needs attended to. Another participant described working through
her mixed feelings towards her children by talking with her spouse, who reminded her of
their age and naïve innocence.

I started treatment in January and they (children) were not as helpful this time. I
told my husband that I am expecting them to be like, ‘Are you okay, mom?” or ‘Is
there anything I can do for you’ and that just never happened. He (husband) goes,
“They are still kids.”

Anna Freud (1967) wrote of alterations to the mother-to-infant libidinal processes
and investments. She observed that children who are frustrated or dissatisfied with the
parents, but are unable to display this aggression towards the parents, may turn this
aggression towards destructive behavior (Freud, 1967). The children in this study were
forced to accept the changes that maternal illness brought onto the household functioning
and their own day-to-day life. Their own anxiety about their mother’s illness did not
always have an outlet for verbal expression at this point in their development. The
mothers once again faced the dilemma of sharing too much or too little information about
the illness with their children. Once again, this study demonstrates that there is no easy
way to discuss the topic of a mother’s cancer with children.

Bowlby (1980) wrote of attachment and defined emotional security as a reflection
of confidence in the availability of the attachment figure. When children in this study
demonstrated enactments in their behavior, that security was threatened. Implications
remain that there is no easy way for these mothers to have discussions about illness with
their children.
Finding 4: Mothers, under the Frightening Circumstances of a Cancer Diagnosis and Treatment, Should Not Be Expected to Demonstrate “Perfect” Mothering, and Should Be Told the Experience Is Going to Affect How the Children Are Parented

Competing conflicts were observed throughout the study in the mothers’ need to deal with their illness and the needs of their children. The mothers faced challenges such as telling the children too much or too little, and wanting the children to be prepared, but also not wanting them to worry. The reactions of the children to their mother’s illness lead us to an understanding of the ties between mother and child and why the children’s negative reactions should be expected.

Parenting with cancer and understanding the impact on the child leads us to consider Freud’s tripartite model of the self (Id, Ego, Superego) and the process of introjection with mothers and children. The nature of the ties between mother and child can also be understood through object relations and self-psychology theories. Freud (1914) wrote of mothers turning libido from the cathected object back onto themselves during illness. Introjected components of the mother become part of self’s representation. The threat of loss can be experienced by children and acted out symptomatically, as it threatens their own sense of equilibrium. For the children, the mothers are an introjected mental representation of themselves. We can therefore expect to see the shared intrapsychic experience demonstrated in the children. The children in this study evidenced symptoms of regression when the mothers became ill. Naturally, due to the illness, the mother’s libido was turned back onto herself due to the illness. Through the analytic literature, we learn that in the process of introjection, object representations are
transformed into self-representations (Moore & Fine, 1990). In the Category, The Children, examples of these ties and how they are impact the children are evident.

A side effect that my daughter had were panic attacks and anxiety when she leaves me. Like the first time, we could not figure out why she would get halfway to the bus stop and come back panicking and not breathing and she was just like, “I can’t breathe, I can’t breathe,” and crying. I’m like, “Well, what is wrong? What happened?” “I don’t know, I don’t know.”

She opened up to us after this event. So they had these strings and they wanted you to cut your strings, and they were strings of fears, and what you were afraid of. You cut them for how long it was, how afraid you were. So I looked and said, “What are all these strings for?” and she (daughter) said, “Well those are my fears,” and they were tied around the doll. Then my daughter gave one end to my husband and told him to walk backwards across the room and I was like what the heck is that? She (daughter) said, “These are my fears!” and I said, “That big?” and I started bawling.”

The introjected moments and experiences described by these children were similar to the internal mental state of the mother, and her own fears about the possibility of death. The anxiety and fear we observed in these children were expected given the nature of their ties. These mothers made every effort to outwardly shield the children from this anguish with no real ability to do so. The terror experienced by the mother is shared with the child, and it is necessary for these mothers to realize that attaining perfection in their parenting efforts becomes impossible under these circumstances.
“Good enough” parenting is all we can expect to see as the children are pulled into this experience, despite all efforts to protect them.

Object relations theory leads us to further understanding of the mother and child relationship during illness. Winnicott’s work bridges the intrapsychic and interpersonal relations between child and mother. Winnicott’s use of the “actual” mother in his theory pinpoints a transition between intrapsychic ties to the interpersonal relationship factors in relating for mothers and children. Winnicott’s focus on the actual mother and how she survives the infant’s destructiveness through holding leads us to possible methods for parenting during illness (Winnicott, 1969.) The “good enough mother,” per Winnicott, offers a holding environment with comfort and consistency that allows the child to use the mother and explore the world on his or her own. “The subject does not destroy the subjective object (projection material), destruction turns up and becomes a central feature in so far as the object is objectively perceived, has autonomy, and belongs to ‘shared’ reality” (Winnicott, 1969, p. 712). His theory emphasizes the child’s “destruction” as being necessary in order for the child to understand him- or herself as separate from the mother in object relating. Surviving the children’s reactions during cancer treatment is complex as the mother, too, is vulnerable and has difficulty asserting herself when feeling weak and experiencing dark days.

I was sad, but I try to keep things upbeat. I tried to keep things normal. If I cry, they know something is wrong. Even though I do want to cry, I’m going to suck it up because they’re going to see it.
He had some behavior issues and was completely acting out. He’s a sweetheart, but at the time he was being rude to his brothers and rude to me. One day, I don’t know what set it off, but he was slamming the door, tantrum.

The mother’s illness introduced vulnerability to the innocent lives of these children. The mothers made efforts to provide a sense of holding for the child during the difficult times when the children became symptomatic. Winnicott (1960) referred to an infant’s “continuity of being” becoming established through good enough mothering and a consistent holding environment. However, in this situation, the mother is faced with her own destruction. It is fair that we should expect to observe disturbances in the mother’s ability to provide a consistent holding environment when she is faced with the possibility of death. We cannot and should not expect gravely ill mothers not to waiver in their provision of a holding environment. Winnicott’s ideas about surviving destruction were written in reference to a normative environment in development. The circumstance of a mother having cancer is not a normative environment, and therefore the mother is worried about her own destruction and survival. This will understandably impact her ability to be a steady holding function.

Self-psychology is characterized by the unconscious experience of selfhood and the self in relation to its sustaining selfobjects. Selfobjects are one’s experience of another person who provides a sustaining function to the self within a relationship. The mothers in this study were faced the task of maintaining an empathic stance with the children that provided optimal responses to their children’s needs. Chronic illness and the possibility of death are painful realities that these mothers face, all the while trying to maintain a sense of normalcy for the children. In 1985, Goldberg wrote of the
“comprehension of fear and total abandonment” experienced by dying patients and the usefulness of the self-selfobject model being in these circumstances.

We were driving home from church and he (son) was in the backseat and just out of the blue he says, “Mom, do you ever think there will be a cure for cancer?” and I said, “Oh, I don’t know buddy, I hope so. It’s going to take awhile and they are learning stuff all the time.” And he said, “I don’t mean breast cancer, I mean any cancer. It would be great if they could find a cure so people don’t have to worry,” so then I’m like, “I think he’s worried.”

Mothers naturally serve as selfobject functions to their children. Kohut (1971) defined optimal child development as that of persistent sustaining selfobjects throughout adolescence and adult life. He viewed development as containing both optimal and less than optimal frustration. What endangers and fragments the self, per Kohut, is an excess of less than optimal frustration (Kohut, 1971). Kohut viewed empathic responses by caregivers as essential to development. However, as conveyed in the current study, there are times when empathy fails and the mother’s ability to be a steady selfobject is impaired. In the category, The Children, we are provided with examples of how difficult it was to empathically manage hair loss for these mothers.

“I took my daughter out back and I gave her scissors and said, ‘Do you what you want,’ and I let her cut my hair.”

One night when I knew it was starting to happen I said to my kids, “Why don’t you come and sit here by me on the couch.” I said, “Mommy has magic hair, and look what happens, look what I can do with my hair.” Just a couple times I had to tell her, “You are pulling too hard.”
Winnicott wrote of the good enough mother knowing what the infant’s needs are through the mother’s identification with the infant (Winnicott, 1962). Allowing the children to be the agents of hair loss seemed like the right thing to do for some mothers in the study. It is difficult to determine, however, what that experience was like for the children. With the kind encouragement of their mothers, it was hoped that the children’s fears would be mitigated. The children, however, may develop fears of the outcome and feel they had something to do with the hair loss and illness. The experience may create a negative memory for the child of the mother and child relationship.

Finding 5: Cancer Is Often Experienced as an Assault on a Mother’s Gender

Hair loss as well as loss of breasts and other organs can be experienced as an assault on a mother’s gender, as breasts and hair symbolize beauty in our culture. Due to the gravity of the illness, these mothers found themselves feeling guilty that they were distressed over body image changes as a result of the illness. Mourning of the loss of their body parts and hair was complex for these women. Common complaints were weight gain, lymphedema, and menopausal symptoms. The focus on the children and duty to their needs implied a higher order of responsibility, and their body images, although distressed, were a secondary difficulty.

In the psychoanalytic literature, Freud referred to the body ego as a reference to the early stages of self-representation. This study found that when the body ego was injured with cancer, it caused a massive disruption to the women’s sense of self and femininity. In the literature, Freud emphasized the importance of body ego and its influence on differentiation of the self from the object world, while pointing out that the
functions of those organs, which establish contact with the world outside, gradually come under the control of the child’s ego over time (Hartmann, 1950). Freud made the point that nursing is the infant’s earliest form of self-representation.

Women, as females, become pregnant, give birth, and breastfeed their children. Mothers describe the process of breastfeeding as an opportunity for developing a special connection to their child. Participants described losing everything familiar about being a woman in the experience of having cancer. They experienced their femininity being assaulted, as their maternal role is a gendered, female role.

Further, gender embodiment refers to an earnest involvement with the physical body (Balsam, 2012). Mothers share the experience of being a female with their children. Daughters will have both feelings of desire and rivalry towards the mother. Mothers identify with their own past self and body through their daughters with total identification (Bernstein, 2005). Cancer, however, interrupts the symbiosis and mutuality experienced by mothers and daughters. This interruption is potentially heightened by genetically linked cancer, when daughters also become aware that this illness may happen to them. In addition, daughters may step back from mothers and force the symbiosis to be interrupted if they, as young girls, harbor their own fears of cancer. The connection to the mother is both needed and denied by the daughter as a result of the illness and the daughter’s own fears. This study found that the daughter develops competing conflicts for the mother with cancer, just as it determined that the mother experiences competing conflicts for the daughter.
In Chapter VII: Treatment, Hair Loss, and Children, the mothers described the fear and dread that accompany such an assault to their gender. These women may wonder what gender identity they are handing off to their daughters.

“Really, it’s a huge deal and I would never tell anybody, ‘Oh don’t worry about it it’s just hair.’ I mean, it’s a huge deal.”

It’s not your choice and, you know, there’s a lot of…even more than losing my breasts, like losing your hair…I think the thing about losing my hair from then on was that I didn’t have the control of sharing my story, like people knew it before I had a chance to decide whether or not I wanted to share and I was very open, like easily open about the whole thing. The whole time, people would say, “Well, I won’t tell anyone.” I said, “No, it’s not a secret. If anyone wants to know, you’re welcome to share the information I’ve given you. It’s not a secret.” But that hair thing really changed the playing field from then on.

These mothers described their hair loss as the hallmark of the treatment process and as the point in time when their children were most impacted by their illness. Their children were with them during the hair loss and experienced this fear along with the mothers. The women struggled with themselves not only as mothers, but also as women. In his 1995 book, *The Motherhood Constellation*, Daniel Stern viewed motherhood as a mental state that splits off a woman’s sexuality from motherhood. Women in this study organized around their children for survival, all the while feeling that their self-esteem and feminine sense of self were being assaulted.
I was homebound in my own sense because I looked absolutely horrible. I didn’t even recognize who I was. One of the things that in thinking about my kids, I think when women lose their hair, that is one of the biggest things for kids.

Mothers and daughters both share in having a female body. Bernstein (2004) stated that a daughter’s relationship to a mother’s body, and a mother’s relationship to a daughter’s body, are experienced through mutual identification.

In further analytic literature, it becomes apparent that the mother plays a very important role in the daughter’s psyche and sense of self (Chodorow, 1978). Chodorow (1996), however, made clear distinctions between circumstances and the environmental influence on maternal behavior. She wrote of this being symbolized in the psychoanalytic literature as a mother’s breast possibly representing nurture or rejection—a welcoming or angry breast (Chodorow, 1996). Chodorow also made the point of thirdness and intersubjectivity in relation to women and gender. She wrote of being unable to predict anyone’s internal world, as only the individual has this shared experience with her mother. Gender gains meaning from a personally experienced emotion in relation to a person of that label (Chodorow, 1996). In the context of a cancer experience, mothers and children have a shared experience.

As we observed in this study, mothers experience conflicts in relation to their own bodies, and the question is therefore raised as to how the children may respond. The children may need to preserve the mother as an image in her healthy state, but cancer interrupts that image. The daughter in particular may develop her own competing conflicts towards the mother in response to her own fears about cancer. She may experience a need for separateness from the mother, or the recognition of her own
intersubjective space, as an effort to reconcile her own fears of the illness. Benjamin’s theories of separate subjectivities may serve as a form of protection for the fears of the daughter.

This raises a question regarding the worry these mothers have for their daughters as they become women. The study did not provide any direct data on this subject, but it leaves us to wonder what types of gender messages are transmitted to the daughter when the mother feels her gender is compromised to the disease. In Chapter IX: Parenting with Cancer, the mothers outlined the big picture of this experience and how it can be understood for their daughters as women someday.

I wonder what will happen as she absorbs, she is 9 now. Next year she’ll be 10. At some point, very soon, she is going to absorb the severity of it and I wonder how she’ll react at that point.

“As she gets older, I’ll probably be a little bit more all about, I always want you to make sure you are checking yourself, because it is really important, you know.”

In Chapter VII, The Children, the mothers outlined how the children responded in relation to themselves. One participant stated that it was her son who asked about a genetic link. Again, a conflict exists for the mother regarding whether to give “too much” or “too little” information to the child in the experience of cancer. In return, the child may need to keep the mother in a separate subjectivity in order to be able to absorb the information and manage his or her own fears. Both mother and daughter experience different versions of competing conflicts. Male and female children express fears of the illness. “My older one is the one who said, can this happen to us? Can we get this?” Another participant spoke of her adolescent daughter’s fears in Chapter VII.
She is still in counseling. She talks about it. People describe her as being obsessed with breast cancer. Her thing, for example, is that she doesn’t think people should have to wait until they are 40 years old to have a mammogram. I’m glad to see that she wants to know, but I wonder if that is the fear in her.

These fears, from a traditional psychoanalytic lens, are merging fears, experienced by both mother and child. Jessica Benjamin wrote of the recognition of intersubjectivity as creating the space of “thirdness” in object relating. She wrote, “The mother must be seen not merely as the child’s object, but also another subject” (Benjamin, 1990, p. 209). Benjamin emphasized that the self can grow in relation with the mother. The mother must be able to reflect separateness back to the child. Benjamin (1988) considered how the mother protects the child from her own anxiety, so that it can separate from her. This separateness and thirdness may be a way of relating and coping with fears of cancer for the children, as they grow older, as well as for the mothers.

**Finding 6: Behavioral Activities Related to Cancer Treatment Are Efforts to Ward off Anxiety towards the Psychological Possibility of Death**

A diagnosis of cancer raises the psychological possibility of death. For these mothers, ideas of death and not being able to parent their children are painful thoughts that arouse symptoms of anxiety that need to be managed. Freud (1914) wrote of an investment in the children’s libido for survival. Fears of death and death anxiety manifest in many ways for these young mothers. Yalom (2008) stated, “We generate methods to soften death’s terror” (p. 5). He also wrote about projecting oneself through one’s
children as a means towards survival. In the category, Dark Days, one participant described her recognition of possible death.

I’m thinking I have cancer, so why would it now be on my liver? Why would that be something else? My liver has never popped up before. So why would it be something else now? So I convinced myself and my husband that it was bad. I’m thinking, I know this, that when it gets to the liver that you’re in big trouble. I know this. It was devastating. All those things, my daughters’ graduations and all that just hits you, not seeing my husband turn grey (begins to cry), it was just absolutely awful.

These painful recognitions of disease progression evoke feelings that surround death anxiety. The literature points to efforts at mastering the dangers that threaten life for self-preservation (Zilboorg, 1943). The analytic literature refers to the aggressive drives as being connected to thoughts of death. Freud (1922) wrote of the death instinct as being an unconscious aim, or wish to die, that is silent and produces a feeling of tension and insecurity. Efforts to manage these “tensions” were observed in the current study as mothers engaged in behavioral activities while undergoing treatment and beyond.

It was very hard for me, going into all the surgeries, because I wanted to control a lot. I had been getting meals from families at work, so I wanted to make sure that we had meals in the freezer. I arranged for someone in the neighborhood to arrange meals when I was having surgery. I had a big calendar to map out who was going to get the kids when.
One participant described needing affirmation that her body was able to remain in
good shape before and after treatment. She ran the Chicago Marathon before being
diagnosed and wished to do it again in what appears to be a life-affirming effort after her
treatment was completed. In the property, Blogs and Legacy Projects, one woman
described her efforts at reaffirming her bodily strength.

I was getting back on my feet, back to where I was, I ran the marathon again
because I wanted to prove to myself that I could do it. I wanted to prove that I
could get back to where I was. So then they started Livestrong, and they hired me,
and so I got to do it. It’s such a blessing I love to meet all these people, and they
are older and younger.

These women demonstrated and sought to prove their perseverance during and
after the hardship of their cancer experience. The literature also shows that one’s spiritual
coping is correlated strongly with health promoting behaviors (Gauthier, 2001.) The need
for resilience remains ongoing, as seen in these women’s efforts to stay actively involved
in cancer events. In the property, Blogs and Legacy Projects, one woman described an
ongoing effort to remain connected with the cancer community.

“What I involve myself in, I involve them in. For 10 years, I was involved in
Relay for Life. It was kind of forced family fun, but it’s a big part of their lives.”

Kubler-Ross (1975) described the meaning of death as an experience that allows
one to experience personal growth. Frankyl (1963) also stated that efforts to manage
death anxiety in searching for meaning of life are useful strategies. Issues that surround
the possibility of death can be understood and experienced in the context of one’s close
relationships with others. Feelings about the possibility of death are intense and often
require behavioral solutions in order to regain some sense of control over one’s life and body. These women sought support with other women who could understand the depth of their pain and share a sense of community. Some formed organizations of their own in order to connect and network with other young women in the shared cancer experience. The connection experienced in this band of women allowed for their painful states to have a relational connection.

Ours is specific to breast cancer patients. Our idea is that we just want people to know that you’re not alone, and there are people out here who are more than willing to talk to you, and more importantly, they have become my friends.

Involvement with others in the cancer experience is another behavioral effort at managing the psychological possibility of death. In the analytic literature, Freud implied that the ego is unable to consciously grasp the possibility of death, and the narcissistic system is organized around immortality. Heidegger (1929), however, wrote of “existence towards death” in a conscious realm as being necessary to live fully. His writings imply that knowledge of death is a conscious factor of life, but for Freud, it remains unconscious and is observed with efforts to defend against this finality. In returning to the first finding that there is no real psychological exit to cancer, I noticed my own experience around these women and others over the years at cancer events. The culture of winning indeed prevails at these events; a false self of sorts is implied and fear appears to be disavowed. Mothers in this study were clear about their zero tolerance for anyone near them who brought a negative tone, or threatened resilience. Cancer events are largely focused on celebratory tones, and only occasionally have brief moments of silence towards loss. The possibility of death is to be kept far away from the participants’
psychological experience of the illness. The significance of psychotherapy for these mothers is important to work through the schemas after cancer that they developed about themselves and themselves in relation to others.

Horowitz writes of Role Relationship Models and personal schemas for processing information about illness and recreating new personal schemas about oneself (Horowitz, 1994.) Stabilizing one state of mind to work through a dreaded alternate state is part of Horowitz’s cognitive theories, which takes into account the influence of the unconscious defenses (Horowitz, 1994.) Interventions that cognitively support and recognize the changing mental states through cancer treatment can be useful in managing anxiety towards death.
Chapter XII

Implications

This study shed light on the complex experience of mothers with cancer and their children. Implications are useful for front line clinicians to understand from both a clinical and research perspective.

Clinical Implications

The ways in which the young mothers in this study navigated the complexities of parenting in the face of a life-threatening illness offer insight for those working with this population. Their approaches to life-threatening illness and organization around their children for survival were observed to be a relational experience. Understanding the complexity of navigating a cancer diagnosis for a young mother is useful for clinical practice.

A significant finding of this study is that when being diagnosed with cancer, there is no real psychological exit. Grasping the reality of a chronic illness is painful for both mothers and children. In normal development, the child’s resolution of the depressive position is the first experience of mourning. This, in turn, is also the child’s first experience of anxiety as he or she is able to conceptualize the mother’s separateness. The good enough mother is available to her child and emotional object constancy is experienced. The difficulty with being threatened by cancer is that the sense of safety in
this constancy is shattered. What was experienced by the child in normal development as
crudeness omnipotence with the mother is shaken. As a mother works through managing
her emotions and accepting the illness, support is needed in openly addressing the
possibility of death. We observed the behaviors these mothers engaged in to avoid
addressing the possibility of death. What we learned that may be useful for clinical
practice is that in having cancer, accepting the illness is a necessary element of disease
progression. This acceptance is difficult, however, in that it raises the possibility of death,
which is instinctually defended against. As we observed in this study, death anxiety is
defended against with behavioral tools. Helping a mother come to understand the feelings
that underlie these behaviors is significant. Providing the mother with a relational space
in an empathic therapy setting to work through anxiety will support her psychological
and spiritual well-being.

This study also illuminated the painful reality that children experience elements of
the mother’s illness both internally and externally. Object relations theory informs us of
the total identification experienced between mothers and children. We observed children
in this study become actively symptomatic and experience the terror of their mother’s
fears through projective identification. Helping these mothers to understand symptoms in
their children will offer means to expect, support, and nurture the children’s symptoms.
As clinicians, it is important to offer the mother an empathic relational space to work
through her own reactions to the illness in order to offer some protectant to the children.
What we observed in this study is that despite all efforts to maintain normalcy, the
children remain attuned to the mother and could recognize when something was amiss. In
order to gain an important understanding for an empathic stance, clinicians must be aware
that there is no real protectant for the children against the mother’s dark days. This attunement to mothers is especially important when discussing cancer with children. The need for children to know the truth can be reassuring to them in their attunement with the mother. What we observed in this study is that children do know something is wrong.

This study further illuminated that there is no such thing as perfect mothering in the difficult circumstances of experiencing a cancer diagnosis. We observed mothers in this study make every effort to do no harm to their children in their attempts to psychologically protect them from the painful realities of this experience. The American Cancer Society informs us in their brochure, “Helping Children When a Family Member Has Cancer,” that children must be told the following:

- No one caused the parent to get cancer.
- You can’t catch cancer like the cold or the flu; it’s okay to hug or kiss the person with cancer.
- The family will work together to cope with cancer and its treatment.
- Even though the sick parent may not have much time with them, the children are loved and will be taken care of when the parent is sick.

The American Cancer Society also indicated that children may ask if the parent is going to die, and provided sample responses, making the point that ultimately the children need to know they were told the truth. Indeed, children in this study did ask their mothers if they were going to die. Clinically, it is significant to be aware of the magnitude of such a question and how important it is to intricately prepare mothers for these discussions. These discussions can assist mothers in their strivings for teachable moments in these difficult circumstances. This study found that teachable moments were
incredibly important for mothers to pass along in this experience. In support, what this study demonstrated is that depending on the developmental stage, older children tend to immediately ask if the parent is going to die. This study also illuminated the children’s attunement to the mother in that telling the children about the cancer ultimately affirmed their suspicions that something was very wrong. The mothers in this study illustrated that this is a complex and delicate matter that requires the mother to work through her own emotions first. The research discussed the mother as being a holding function for her child’s emotional reactions. Front line clinicians need to be aware that the mother’s ability to hold steady is impacted by her own sense of personal destructiveness. This is natural and expected given the nature of the information the mother is forced to quickly absorb. This study informs us that these mothers absorbed a great deal of information about their particular illness in a way that helped them find their place in the order of cancer, as they attempted to rapidly educate themselves about their illness. These women made efforts to situate themselves amongst the other women and to learn from others how to work with the children. Under these challenging circumstances, there is no expectation for “perfect” mothering.

It is important for front line clinicians to understand that the most intricate difficulty observed in this study was not only the discussion of death, but also navigating hair loss. Mothers struggled with how to share ideas about hair loss, what to expect, and how to go about removing their hair in order to avoid the experience of patches falling out. Understandably, there is no easy way for this to happen, and mothers need to be gentle with themselves surrounding issues of hair loss. Some mothers allowed their children to cut their hair in efforts to make it fun, and others shielded them from the
experience. Clinically, we observed that this element of the cancer experience was the most challenging to navigate, as the illness became “real” for both mother and child. In addition, it is important for clinicians to understand that the loss of hair for mothers also represents the loss of their privacy in having an illness. This is a painful aspect of the cancer experience and one that we can help prepare women to expect.

Further, it is significant to recognize that women struggle with losses that pertain to their own sense of femininity, separate from their role as mothers. It is important for clinicians to understand that not only are the complexities in mothering present for these women, but also that their sense of self as a woman is injured. The loss of body parts that represent their female identities, including the loss of hair, takes an emotional toll on these women as painful facets outside of mothering. Accepting the new normal of their appearance is significant for these mothers in working towards a more cohesive sense of self. A cancer diagnosis sometimes impacts feminine and reproductive organs. It is important for clinicians to allow space to let these mothers grieve and understand the grave losses that accompany the changes to their bodies.

Finally, it is important for clinicians to understand that behavioral activities observed in the course of cancer treatment may be efforts to master their anxiety towards the possibility of death. As clinicians, we encourage women to participate in cancer-related events; however, it is important to have an understanding of the deeper meaning in such connections. For some mothers, the ability to be physically active reaffirms their body integrity to themselves. For others, connecting with other young mothers is the only way they feel truly understood. Creating legacy projects for their children was another way in which mothers sought to make meaning of their experience and have some sense
of control in their circumstances. It is important for clinicians to understand behavioral activities as a quest for mastery and defense against painful feelings that surround the possibility of death.

**Research Implications**

It is significant to understand the implications for further research in psychosocial oncology as it pertains to mothers with cancer and their children. It would be interesting to review long-term studies of women in survivorship of greater than 15 years and how they are coping emotionally with the psychological possibility of death and issues related to parenting their children.

It would be interesting to understand their ideas about how cancer ultimately influenced their child rearing over time, and how the children are functioning many years post treatment. With the cooperation of adult children and mothers who underwent cancer treatment, we may be able to ascertain how competing conflicts were experienced and absorbed by the children. Was the information given to children too much or too little for them? Did the children experience being helpful to the mother or recall a sense of needing to just be a child away from cancer? Did they feel their mothers did a “good enough” job under these challenging circumstances? All of these questions would be significant for future research.

In addition, it would be interesting to determine how the daughters viewed the assault on their mother’s gender and reproductive organs over time. Future research on these daughters and how they viewed their own gender and sense of self would be informative. What we observed in this research is that cancer felt like an assault on the
female sense of self. Over time, the impact on young daughters would be informative to observe.

Women with genetically-based cancer held a separate sense of worry for themselves and the impact of the illness on the children. Further research may shed light on how these children managed such concerns over time and how these concerns influenced their personal development.

In respect to behavioral activities such as cancer fitness events, blogs, and support organizations, it would be helpful to understand how effective these activities were in mitigating women’s anxiety about the illness. It would be instrumental to understand how these events and activities facilitated moving these mothers into a sense of their new normal and how they helped to manage their anxiety over time.
Appendix A

Mothers with Cancer Research Survey
Appendix A
Mothers with Cancer Research Survey

1. Do you have children?

2. If you responded to my flyer, you have or had cancer, right? Were you between the ages of 20 and 45?

3. Do you also have children who were under the age of eighteen when you were diagnosed and treated? How many children do you have?

4. What is the gender of your children?

5. What is your current age?

6. How old were at the time of diagnosis?

7. Were you partnered during the course of treatment?

8. What was your support system during the course of treatment?

9. How long has it been since the time of your diagnosis?

10. Can you help me understand if your diagnosis at the time you had children was your first experience with cancer or a recurrence?

11. What types of activities were you participating in around the time of your diagnosis?

12. Do you think you’ve been unusually depressed lately, or would you say you’re very depressed? Do you have a major mental illness like bipolar disorder, high functioning autism, or schizophrenia?
Appendix B

Interview Protocol
Mothers with Cancer Research Survey
Interview Guide Questions

- The following questions will be asked of the patient during the research project interview. The demographic questions will be answered first, and the research questions in Part Two will be discussed thereafter.

Part One: Demographic Division

13. What is your current age?
14. What type of cancer do you have?
15. What stage is your cancer?
16. How long have you been diagnosed with cancer?
17. How old were you at the time of diagnosis?
18. How many children do you have?
19. What is the gender of your children?
20. Were you partnered during the course of treatment?
21. What is the length of time since your diagnosis?
22. Is this an initial diagnosis of cancer or a recurrence?

Part Two: Interview Questions

1. Can you tell me about your initial thoughts once you were diagnosed with cancer?
2. Can you help me understand your thoughts about your children following the diagnosis?
3. Did your children ask you questions about your illness?
4. Did you feel the need to explain what was going on to your children?
5. Can you help me understand how you determined what may have been too much or too little information to share with your children?
6. Did you and your spouse talk about your illness in relation to the children?
7. What types of thoughts and issues did you feel stood out the most in regards to your children?

8. Can you tell me about your support system during the course of treatment?

9. What were the hardest parts of finding out about the illness?

10. Did you engage in any legacy work activities in relation to your diagnosis?

11. If you engaged in legacy activities for your children, can you help me understand how you found it helpful?

12. Can you help me understand what your lifestyle was like prior to your diagnosis and how the illness may or may not have changed that?

13. What parts of your parenting have been the most challenging since the diagnosis?

14. How did your parenting change as a result of the diagnosis?

15. Can you describe for me the bond you have with your child?

16. Can you help me understand if or how that bond was threatened as a direct result of the illness?
Appendix C

Participant Recruitment Flyer
Please consider participating in a research project that will look at your experience of being a mother during the course of cancer treatment.

Being a mother with cancer is a unique experience as you have an immediate worry for your children. With your participation, this project hopes to obtain an in depth understanding of the needs of mothers who have cancer, and provide education and information about mothering with cancer.

Do you qualify?
- Were you diagnosed with cancer before the age of 45?
- Do you have at least one child who is under the age of 18?

What would happen if you took part?
- Phone interview to introduce the project and screen for qualifications.
- Face to face interviews (two to three) 45 minutes in length in a private office setting.
- Participants will receive one gift card from Starbucks.

For more information or to take part in this project, please contact the primary researcher, Ms. Draga Beckner, LCSW at dbecknerLCSW@gmail.com or 219-742-4983
Appendix D

Participant Informed Consent
Institute for Clinical Social Work
Research Information and Consent for Participation in Social Behavioral Research
An Exploration of Mothers with Cancer Parenting their Children

I, ____________________________, acting for myself agree to take part in the research entitled: An Exploration of Mothers with Cancer Parenting their Children.

This work will be carried out by Draga Beckner, LCSW, (Principal Researcher) under the supervision of Dr. Dennis Shelby (Dissertation Chair or Sponsoring Faculty)

This work is being conducted under the auspices of the Institute for Clinical Social Work; At Robert Morris Center, 401 South State Street; Suite 822, Chicago, IL 60605; (312) 935-4232.

Purpose
The purpose of this study is to explore the experiences of mothers with cancer who have children. The research will result in an in depth understanding of the mother’s relationship with her children in the face of a life threatening illness. The study will capture the essence of being a mother with cancer.

PROCEDURES USED IN THE STUDY AND THE DURATION
This research study is being conducted by having two to three face-to-face interviews that will last forty-five minutes in length. The interviews will be recorded and transcribed for data analysis.

Benefits
The benefits of the study are a $10.00 gift card to Starbucks and your contribution to the scientific understanding of cancer patients and their feelings, etc. which will help professionals in their work together with them.

Costs
There are no costs to the participants.

Possible Risks and/or Side Effects
Risks involved in this study pertain to distressing feelings that may arise when discussing this very sensitive topic. If any painful reaction is experienced during the process, the participant will immediately be given the option to stop the interview and forgo further participation. Participants can drop out of the study at any time without penalty. Referrals for mental health providers will also be provided if the participant wishes to talk further about these reactions.
Privacy and Confidentiality
All participation is confidential and the identity of the participants will be protected. The interviews will be recorded and transcribed. After the transcription, recordings will be destroyed. All transcripts will be assigned an identifying number. Other identifying information will be stored in a locked filing cabinet and disposed of after five years.

Subject Assurances
The following is the format that should be followed in creating the assurances:
By signing this consent form, I agree to take part in this study. I have not given up any of my rights (my child’s rights) or released this institution from responsibility for carelessness.

I may cancel my consent and refuse to continue in this study at any time without penalty or loss of benefits. My relationship with the staff of the ICSW will not be affected in any way, now or in the future, if I refuse to take part, or if I begin the study and then withdraw.

If I have any questions about the research methods, I can contact Draga Beckner, LCSW (Principal Researcher) or Dr. Dennis Shelby (Dissertation Chair/Sponsoring Faculty), at this phone number 219-406-0571.

If I have any questions about my rights as a research subject, I may contact Dr. John Ridings, Chair of Institutional Review Board; ICSW; At Robert Morris Center, 401 South State Street; Suite 822, Chicago, IL 60605; (312) 935-4232.

Signatures
[All consent forms must be signed and dated. They must be explained to the participants and witnessed by the person who is explaining the procedure.]

I have read this consent form and I agree to take part (or, to have my child take part) in this study as it is explained in this consent form.

_________________________  _____________________
Signature of Participant      Date

I certify that I have explained the research to________________________ and believe that they understand and that they have agreed to participate freely. I agree to answer any additional questions when they arise during the research or afterward.

_________________________  _____________________
Signature of Researcher      Date

Revised 31 Oct 2013
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