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"Bent but not Broken": A Mixed Methods Study of Mothering During Chemotherapy for Breast Cancer

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“BENT BUT NOT BROKEN”: A MIXED METHODS STUDY OF MOTHERING DURING CHEMOTHERAPY FOR BREAST CANCER

DISSERTATION

A dissertation submitted in partial fulfillment of
the requirements for the degree of Doctor of Philosophy in the
College of Health Sciences
at the University of Kentucky

By

Julie Ann Baltisberger

Lexington, Kentucky

Co-Directors: Dr. Dana Howell, Professor of Occupational Therapy

And Dr. Carl Mattacola, Professor of Athletic Training

Lexington, Kentucky

ABSTRACT OF DISSERTATION

"BENT BUT NOT BROKEN": A MIXED METHODS STUDY OF MOTHERING DURING CHEMOTHERAPY FOR BREAST CANCER

Breast cancer is the most common cancer diagnosis of women, with an estimated 232,670 new cases in 2014. With 89.2% of breast cancer patients surviving five years or longer, studies are needed to investigate the long-term impact of breast cancer on women and families (National Cancer Institute, 2014).

The purpose of this study was to examine, using a mixed methods approach, the impact of chemotherapy on mothering occupations for patients diagnosed with breast cancer. Thirty-one women (mean age=39.6, SD=5.79), with breast cancer of any stage, who were currently undergoing chemotherapy and had at least one child under the age of 18 living in the home, were recruited from a comprehensive breast cancer care center.

These participants completed the Fatigue Symptom Inventory Then Test, the Parent Disability Inventory, the FACT-G quality of life inventory, and a demographic questionnaire. Of these 30 participants, ten participants were selected using purposeful sampling to participate in semi-structured interviews focusing on the impact of chemotherapy on mothering occupations. Qualitative data were analyzed using a grounded theory approach (Corbin & Strauss, 2008) and quantitative data were analyzed using SPSS version 22 to determine descriptive statistics and correlations among variables.

After analysis, the central category that emerged from the data was "Keeping life the same while weathering cancer treatments," which was developed from categories of learning, adapting, accepting support, growing and normalcy. Quantitative analyses found a correlation between fatigue and parent disability (Spearman rho correlation = -0.476, $p < 0.05$), quality of life and fatigue interference (-0.481, $p < 0.001$) and parent disability and quality of life (0.745, $p<0.001$). Implications for future occupational therapy practice are discussed.

KEYWORDS: Breast cancer, mothering, occupational therapy, mixed methods research, women's health

Julie Baltisberger
Student's Signature

February 12, 2015
Date

"BENT BUT NOT BROKEN": A MIXED METHODS STUDY OF MOTHERING DURING CHEMOTHERAPY FOR BREAST CANCER

By

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February 12, 2015
Date

This dissertation is dedicated to my husband Jay and my daughter Katie who lived many similar experiences first hand in our own lives. I will forever be grateful to each of you for your love and support.

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Thank you to my wonderful family, Jay, Katie, Cosi, Maggie and Lola. You all gave me a respite from the hard work and loving place to come home to every night. Thank you to my best friends, Elaine and Jane. I am so blessed to have you in my life!

Last but not least, thank you to all of the participants of my studies. Your generosity in sharing your stories with me touches my soul. I wish all the best for you and your families, and I am grateful for the time you gave to me.

TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

CHAPTER ONE: INTRODUCTION

As I sit down to write this dissertation, I am faced with a situation similar to one that I experienced 14 and a half years ago. One of my students, one of my favorites, is at the end of life from ocular melanoma. She and her husband recently adopted a baby, who is now 13 months old. Her time now is focused on spending time with her son while she is in hospice—making memories for herself, her son, and her husband. As I observe this conclusion of this tragic story on Facebook, I think about how fortunate I am, 15 years post an incurable cancer diagnosis, to still be here, raising my daughter. My daughter, now 16, relies upon me while she explores college choices, embarks upon dating, and looks toward what her future will bring. The subject of mothering during cancer has been a topic of interest for me since the day I heard the words, "You have cancer." What would happen to my daughter? Who would take care of her? How would my husband, who is wonderful but not a mother, help her with all of those things in life most suited for mothers, such as menstruation, dating, childbirth, outfits, shopping and getting married? What would happen to her? Now I am struck with this feeling that, although I am glad I survived, why did I get so lucky? There was nothing special that I did to survive. All of the women in my study wanted to survive at all costs. They wanted to be there in the future for their children. This is the thought that superseded every medical decision they made—what would be best for their children. At the same time, medical professionals are tasked with keeping the mother alive and to cure, if possible, the cancer, or at least abate symptoms. These two points of view do not always coincide.

For a mother with cancer, the first thought is what will happen to her children if she doesn't survive. She may think: Who will care for them? How will I tell my children I have cancer? Who will take care of them if I am too sick? Am I still a good parent even though I am sick? What if I die and cannot be there to see my child grow up?" How will this experience affect my child in the long term? Several research studies have explored these questions and have found that parents with cancer place concerns for their children at the forefront (Elmberger, Bolund, & Lutzen, 2005; Elmberger, Bolund, & Lützén, 2000; Elmberger, Bolund, Magnusson, Lutzen, & Andershed, 2008; Helseth & Ulfsaet, 2003, 2005a; Moore, Muriel, Beiser, Pirl, & Rauch, 2006; Moore & Rauch, 2006; Rauch, 2007; Rauch & Muriel, 2004; Semple & McCance, 2010a, 2010b; Stiffler, Barada, Hosei, & Haase, 2008a; Stiffler, Haase, Hosei, & Barada, 2008b). These studies highlight how, in spite of being seriously ill, parenting is still a highly valued role in cancer patients.

My interest in parenting with cancer came from my experience as a mother while undergoing chemotherapy and a stem cell transplant when my daughter was between 1 and 4 years old. This experience caused me to question what it is to be a good mother and how could I meet my child's needs while sick. Difficulties I experienced, such as fatigue, guilt, worry and physical side effects, have been echoed in the literature of mothers with cancer (Elmberger et al., 2005; Elmberger et al., 2000; Elmberger et al., 2008; Helseth & Ulfsaet, 2005a; Moore et al., 2006; Moore & Rauch, 2006; Rauch, 2007; Rauch & Muriel, 2004), although with less emphasis on the debilitating fatigue that I experienced while parenting my young daughter. Rauch, in her introduction to a parenting issue of the journal *Psycho-Oncology* entitled "You are Only as Happy as Your Most Unhappy Child" (2007), describes her experience as a psychiatrist in a cancer clinic. She writes,

> In almost a decade of providing parent guidance consultations in a large cancer center, I am struck by how often I have heard from patients, “My first thought after hearing the diagnosis was MY CHILDREN!” The distress about the impact of parental cancer on children is manifold. It is felt in the parents, their families, the medical team, the staff, and the community” (p. 99).

Despite this anecdotal report about the importance of parenting in cancer patients, parenting is addressed by few oncology health care professionals (Rauch & Muriel, 2004). Why, then, if parenting is of such paramount concern for cancer patients, is there not more focus on this important role? This was the issue that troubled me as I went through my cancer journey. I wanted studies that would describe my situation and give me guidance to cope with my side effects and distress while still being a good mother. From a health care provider perspective, the life-and-death nature of cancer treatments would place medical treatments at the top of the list of what to address. Patients who are facing an urgent health care crisis may not consider parenting of paramount importance as I did. Practitioners need research to understand the complex needs of cancer patients. For example, do all parents with cancer worry about their children as much as the above anecdote describes, or is this just something that certain parents experience? Do mothers experience this worry about their children more than fathers? And how do cancer treatments change the way parents care for their children? How do children influence the choice of cancer treatments? The search for the answers to these questions is exactly what inspired me to research the impact of cancer on mothering.

From a rehabilitation perspective, women with cancer may be seen in therapy clinics and hospitals for cancer- and treatment-related issues (Silver & Gilchrist, 2011).

Occupational therapy practitioners can work with cancer patients on daily living skills and valued activities to improve overall quality of life (Soderback & Paulsson, 1997). Occupational therapy is a healthcare profession aimed at helping individuals to participate in valued daily activities. Occupations are meaningful daily activities that include activities of daily living such as self-care, instrumental activities of daily living, which includes childcare, rest/sleep, education, work, play, leisure and social participation (American Occupational Therapy Association, 2008a). In the American Occupational Therapy Association's fact sheet on occupational therapy in oncology care, Longpré and Newman state, "Occupational therapy intervention methods can remediate, compensate, or adapt a client's abilities to assist him or her in achieving a maximum level of independence and quality of life" (2011, p. 1). They describe how the occupational therapy practitioner can help cancer patients to participate in meaningful life roles and activities, of which parenting can be a part.

Background and Need

There exists a need to address cancer survivor issues. Cancer survival rates are increasing due to improvements in chemotherapy, radiation and immunotherapies, which has resulted in a growing population of cancer survivors (Aziz, 2009). In recent years, there has been a call for research on survivorship issues to study the impact of cancer treatments on daily life (Aziz, 2002, 2007, 2009). For example, the National Cancer Institute (NCI) has increased its focus on cancer survivorship by creating the Office of Cancer Survivorship (OCS), which has the following goal:

> The goal of **cancer survivorship research** supported by the OCS is to address the health and life of a person with a history of cancer beyond the acute diagnosis

> and treatment phase. As well as supporting exploratory levels of research, the OCS seeks to expand its research portfolio to include (a) theory-based descriptive and analytical studies that document the physiologic, psychosocial, and economic effects of cancer and its treatment on survivors' quality of life, functioning, and health, and (b) intervention studies that seek to develop and test novel strategies to prevent or reduce adverse outcomes and/or promote optimal health or well-being after cancer treatment (National Cancer Institute, 2011, p. 1).

Additionally, the OCS specifically mentions survivorship issues pertaining to families, of which parenting is a part. A topical area of interest identified by OCS is " Family and Caregiver Studies that examine or address the impact of cancer treatment on health and well-being, and the sequelae of cancer survivorship, on a family unit, family member, or caregiver" (p. 1). The proposed study aims to meet the OCS's goal of studying the impact of cancer on the function, quality of life and perceptions of wellbeing of mothers.

Cancer Survivors

It has been well-documented that cancer treatments can negatively impact survivors' quality of life by causing deficits such as fatigue, memory impairments and reproductive difficulties (Ganz et al., 2002). These deficits in turn may impair participation in parenting activities. A mother who is exhausted physically and mentally has a hard time keeping up with children (Elmberger et al., 2000). A mother may worry about how to communicate with her children about their cancer (Huizinga, Visser, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2005; Thorne, Hislop, Stajduhar, & Oglov, 2009). Children may not understand what is happening to their mother through the cancer treatment process thereby causing distress for both parent and child. (Huizinga, Visser, et al., 2003). All of these issues can compound the difficulties the mother with cancer has in coping with treatments.

Cancer Survival Rates for Women with Cancer who are Parenting. In order to understand the importance of studying mothers with cancer, it is important to highlight the prevalence of cancer. According to the American Cancer Society, approximately 810,320 women will be diagnosed with some form of cancer in the United States in 2014, and approximately 275,710 women will die of cancer in the same year (American Cancer Society, 2014) The probability of women being diagnosed with a form of cancer from birth to age 59 is 1 in 9.

The Centers for Disease Control (2009) estimates that over 99% of child births in 2008 occurred between the maternal ages of 18 and 44 years. Therefore, it can be reasonably assumed that, if there is a high incidence of cancer diagnosis for women from 18 to 59, many of these women have children living in the home during diagnosis and treatment. In the 1990s, the National Cancer Institute (NCI) estimated that 24% of all women with cancer have children under age 18 living in the home (National Cancer Institute, 1992).

These data highlight the broad extent of the impact of parenting while undergoing cancer treatments. This is particularly important since cancer and treatment related side effects have been demonstrated to decrease the quality of life of cancer patients who are parents (Gazendam-Donofrio et al., 2008).

Cancer and the Family

A woman's cancer diagnosis affects the entire family, including the spouse and children. Much research has been dedicated to the challenges facing the woman with cancer, but very little research exists studying the mother's cancer in a family context. Although there are studies that suggest that some family relationships are strengthened during cancer treatments (Elmberger et al., 2000; Helseth & Ulfsaet, 2005b), there is evidence that families can suffer emotional and physical stress when faced with a cancer diagnosis of a parent (Compas et al., 1994b; Compas, Worsham, Ey, & Howell, 1996; Davey, Gulish, Askew, Godette, & Childs, 2005). This distress can make caring for children much more difficult and further compound the distress.

Although literature exists examining the psychosocial impact of cancer on the family (Rolland, 2005), there has been little published research on the physical impact of cancer treatments on parenting. Research on the impact of parental cancer on children has largely focused on the child's psychosocial adjustment (Welch, Wadsworth, & Compas, 1996), distress (Compas et al., 1994b), school functioning (Vannatta, Grollman, Noll, & Gerhardt, 2008b), and the family's ability to cope with a cancer diagnosis (Bloom, 2000). Although all members of the family are important to its functioning (Rolland, 2005), the mother is often given the responsibility of providing much of the care for children (Esdaile & Olsen, 2004). For a mother with cancer, other members of the family are often asked to provide additional care. In order to understand the role of the mother it is important to define mothering.

What is Mothering?

Mothering is defined as the physical and psychological tasks that provide for the nourishment and protection of children (Primeau, 2004). Ruddick defines the term "mother" as a social category for "those people who assume the responsibility for childcare and make its work a regular and substantial part of their working lives" (1985,

p. 97). Ruddick described three major tasks of mothering, which are preservation, growth and social acceptability (Ruddick, 1980). Preservation is the process of providing safety and protection to the child, which can take the form of providing food, shelter and safety for the child. Growth is the process of facilitating the child's physical, intellectual and emotional development and involves providing the child with proper support and feedback for the optimal development of the child's self-esteem. Social acceptability is the process by which mothers train the child to behave in a manner that is acceptable to the mother and the society overall. Teaching is how the mother helps the child to engage in a social world and have meaningful relationships. These three tasks, preservation, growth and social acceptability, are what makes maternal work vitally important to the wellbeing of children (Ruddick, 1980).

Background of Mothering with Cancer

Cancer treatment side effects cause the most difficulty for mothers in caring for their children and include: nausea, vomiting, anemia, pain, hair loss, fatigue, diarrhea, loss of appetite, weight loss, weight gain, neurological problems, infections, memory deficits, sexual and fertility problems, skin changes, and fertility loss (National Cancer Institute, 2007a). In addition to these treatment side effects, mothers with cancer have difficulties in meeting the physical, developmental, social and emotional needs of their children, which include providing for the physical care of the child through dressing, carrying, diapering, playing with, feeding and keeping the child safe due to fatigue, nausea, weaknesses and medical precautions (Visser, Huizinga, van der Graaf, Hoekstra, & Hoekstra-Weebers, 2004)

Previous studies investigating mothering during and after cancer treatment highlight the difficulty caused by fatigue, fear of dying, lack of social support, paucity of financial resources, and emotional and behavioral problems for both the mother and child (Compas & Luecken, 2002; Compas et al., 1994b; Compas et al., 1996; Elmberger et al., 2005; Elmberger et al., 2000; Helseth & Ulfsaet, 2005b; Moore et al., 2006; Stiffler, Haase, Hosei, & Barada, 2008a; Visser et al., 2004; Welch et al., 1996). Several American and European studies have investigated the impact of maternal cancer on the child, all with varying results as to the extent and severity of the impact of the mother's cancer on the child's psychosocial health (Compas & Luecken, 2002; Compas et al., 1994a, 1994b; Hoke, 2001; Huizinga, van der Graaf, Visser, Dijkstra, & Hoekstra-Weebers, 2003; Huizinga, Visser, et al., 2003; Visser et al., 2003; Visser et al., 2007). For example, Hoke (2001) found that mothers with cancer reported their children as having great emotional, social and functional difficulties due to their cancer. In other words, mothers reported distress in their children in coping with maternal cancer, which may increase the distress experienced by the mothers.

The trajectory of a cancer diagnosis, treatment and recovery can cause challenges for mothers with cancer, including psychological, social and physical problems. A new diagnosis of cancer can be a very stressful time for the mother and the family, causing great anxiety, depression and overall distress (Boyer & Cantor, 2005; Compas & Luecken, 2002). Cancer treatments can lead to body image issues (Ganz et al., 1996), strain on social relationships (Bloom, 2000) emotional, behavior, social and cognitive impairments (Compas et al., 1994b).

Fatigue can be especially debilitating for mothers undergoing cancer treatments since parenting is already a highly demanding role in terms of physical energy. Many individuals undergoing cancer treatments experience cancer-related fatigue (CRF). According to the National Comprehensive Cancer Network, CRF is a persistent and distressing sense of tiredness in relation to cancer and its treatment that interferes with functioning (Mock et al., 2007). Cancer-related fatigue is one of the most commonly reported symptoms of cancer treatments and can be so pervasive that it impacts the daily routines of individuals who experience it (Cella, Davis, Breitbart, & Curt, 2001; Cella, Lai, Chang, Peterman, & Slavin, 2002; Stone, Richards, & Hardy, 1998). For women with cancer, this pervasive fatigue can impact the ability to meet the physical and psychosocial needs of their children. In one study (Fitch, Bunston, & Elliot, 1999), a mother reported the physical difficulty of providing care for her children, stating, "I just physically cannot do it. So that's been difficult that way. Physically you are not able to do what you normally were used to doing" (p. 60). Another mother described the combination of fatigue and nausea after treatment. "The first days after chemotherapy I've had to remind them that I can't do things now because I'm not feeling well" (Helseth & Ulfsaet, 2003, p. 42). Despite these difficulties, mothers in the studies described "pushing through" to meet the needs of their children, often to the point of physical exhaustion (Elmberger et al., 2005; Elmberger et al., 2000; Elmberger et al., 2008; Fitch et al., 1999; Helseth & Ulfsaet, 2003).

The societal notion of the "supermom" often causes healthy mothers to sacrifice all of their time to care for their children, spouses and homes (Choi, Henshaw, Baker, & Tree, 2005). Mothers with cancer feel even more pressure to be "good" mothers in order to circumvent any psychological or developmental problems their children may face as a consequence of maternal cancer (Elmberger et al., 2005; Helseth & Ulfsaet, 2005b; Kennedy & Lloyd-Williams, 2009a; Stiffler, Haase, et al., 2008a).

In summary, mothering occupations for women undergoing breast cancer treatments are an area that deserve further research in order to understand barriers and supports to providing for the care for children living within the home. Although there have been several studies of mothering during cancer treatments, there are no studies to date to look at mothering through the lens of occupational therapy, and more specifically, no studies looking at the physical impact of cancer treatments on the day to day mothering activities. This study strives to take information from these previous studies and further investigate specific occupations, performance skills and client factors that impact mothering.

Study Overview

This mixed methods study combined qualitative and quantitative research approaches to understand the parenting experiences of mothers with cancer while undergoing chemotherapy for breast cancer. The qualitative approach will combine in-depth interviews and field notes to describe the experience of mothering while undergoing cancer treatments. A grounded theory research approach will be used to elicit the story "what are the mothers' experiences with cancer from diagnosis, treatment and recovery, and the impact of these phases on their ability to provide physical care for their children." The quantitative portion of the study will focus the relationship among cancer-related fatigue, quality of life and demographic factors. Together, both qualitative and quantitative information, will provide a better picture of the experience of mothers undergoing treatment for cancer so that we may better form a theoretical description of the experiences of these women in this study. The reason for collecting both quantitative and qualitative data is to provide a more comprehensive picture of mothering during adjuvant cancer treatments and the challenges and barriers these women face and the strategies they use to overcome them.

Problem

Mothers with cancer experience difficulties in providing day-to-day care of their children while undergoing cancer treatments. Few studies have been conducted in the United States examining how women with cancer negotiate parenting responsibilities when faced with the physical side effects of treatment. This study will greatly add to the body of knowledge about cancer survivorship and mothering, will support rehabilitation services for mothers with cancer, and will later inform occupational therapy interventions in order to maximize a mother's participation in this valued role.

Study Purpose

The purpose of this study is to describe the impact of breast cancer and chemotherapy on a mother's ability to provide physical care for her children from an occupation-based perspective. This study will generate knowledge about the specific rehabilitation needs of mothers undergoing chemotherapy for breast cancer.

Significance

Breast cancer for a mother can be a devastating diagnosis due to concerns for her children. This study is significant in that it will provide valuable information about the impact of breast cancer treatments on carrying out mothering occupations. Anecdotal information (Rauch, 2007; Rauch & Muriel, 2004) demonstrates the importance of parenting for cancer patients, but few studies conducted in the United States address the parenting needs of women with breast cancer, especially the impact of side effects on the physical aspect of providing care (Stiffler, Barada, Hosei, & Haase, 2008b; Stiffler, Haase, et al., 2008a). This study will provide valuable information from the patient's perspective of rehabilitation needs in oncology thereby assisting therapists with intervention planning.

Special Considerations

Since I am a cancer survivor and a mother, I was worried that my own experience would alter the data collection, analysis and interpretation of findings. To deal with this concern head on, I conducted an autoethnography in order to better understand my own experience as a mother with cancer leading to a process of reflexive bracketing. Reflexive bracketing is the iterative process of the researcher examining her assumptions and biases, setting them aside, engaging with the data analysis, and then returning to her assumptions and biases (Ahern, 1999; Gearing, 2004). As part of this autoethnography, I journaled about my experiences and coded those journal entries. In addition, I interviewed my husband, my daughter, my best friend and my parents, and included that in the data analysis. This autoethography allowed me to understand that I hold a number of assumptions about being a mother with cancer, which are that mothers should do whatever they can to survive for their children, that the needs of my child superseded my own needs, and that I tend to favor medical model treatments rather than alternative ones. After completing this autoethnography, I am much better able to separate my own experience from my participants' experiences. Hopefully I was able to put my assumptions and biases about being a mother with cancer to the side. This study was submitted to the *International Journal of Qualitative Methods* and is currently in review (Baltisberger, In review).

Definition and Abbreviation of Terms

Construct	Definition
Breast cancer diagnosis	The breast cancer diagnosis of the mothers in this study will be self-reported and includes breast neoplasms at any stage (I – IV) and any type as recognized by the National Cancer Institute at www.cancer.gov.
Cancer-related fatigue (CRF)	A persistent and distressing sense of tiredness in relation to cancer and its treatment that interferes with functioning (Mock et al., 2007).
Child under 18 living in the home	An individual under the age of 18 who is living within the same premises as his or her biological, adopted, step- or foster mother for five or more nights a week.
Mothering	The process of providing for the protection, nurturance and teaching of children living in the home under the age of 18 (Ruddick, 1980).
Occupation	"[A]ctivities…of everyday life, named, organized, and given value and meaning by individuals and a culture. Occupation is everything people do to occupy themselves, including looking after

	themselves…enjoying life…and contributing to the social and economic fabric of their communities" (Law, Polatajko, Baptiste, & Townsend, 1997, p. 39)
Occupational therapy	"[T]he therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of participation in roles and situations in home, school, workplace, community, and other settings… Occupational therapy addresses the physical, cognitive, psychosocial, sensory, and other aspects of performance in a variety of contexts to support engagement in everyday life activities that affect health, well-being, and quality of life" (American Occupational Therapy Association, 2008b, p. 673).
Parent disability	The degree to which parents have difficulty in carrying out childcare activities, including feeding, picking-up or carrying child/children under 6, and helping child with homework for children over 6, and, for all children, playing with the child, and caring for the child when sick. (Katz, Pasch, & Wong, 2003)
Quality of life	An individual's self-appraisal of and satisfaction with his or her current level of performance compared with

	his or her ideal standard (Cella & Tulsky, 1993b).
Rural county of residence	A rural county of residence is one that meets the United States Department of Agriculture (USDA) definition on the Rural-urban continuum. This continuum ranges from 1 to 9, with 1, 2, and 3 being urban metro counties and 4, 5, 6, 7, 8 and 9 being rural counties (United States Department of Agriculture, 2013)

Research Questions

This study proposes to answer the following questions:

Grand Tour Question: What is the theory that describes the process of being a mother while undergoing chemotherapy treatments for breast cancer?

Qualitative Research Questions:

Ql 1 How do mothers with breast cancer describe their transformation during the process of their experience with breast cancer diagnosis, treatment, and recovery?

Q12 How do mothers with breast cancer describe the impact of social support from spouses and/or other family members on their ability to carry out care for their children living in the home?

Ql 3 What challenges for carrying out mothering occupations do mothers with breast cancer describe?

    Ql 3a. What is the impact of cancer-related fatigue on mothering occupations?

    Ql 3b. How is quality of life impacted by cancer treatments?

Ql 4 What strategies for carrying out mothering occupations do mothers with breast cancer use to overcome challenges?

Quantitative Research Questions:

Qt 1 What is the relationship among cancer-related fatigue (CRF), parent disability and quality of life (QOL) for mothers with cancer?

Qt 2 How do cancer diagnosis, stage of cancer, age of mother, ethnic background, geographical location, marital status, socioeconomic status, number and age of children relate to parent disability in mothers with cancer?

Qt3 How do cancer diagnosis, stage of cancer, age of mother, ethnic background, geographical location, marital status, socioeconomic status, number of children, and age of children relate to CRF in mothers with cancer?

Qt 4 How do cancer diagnosis, stage of cancer, age of mother, ethnic background, geographical location, marital status, socioeconomic status, number of children, and age of children relate to QOL in mothers with cancer?

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Qt3 How do cancer diagnosis, stage of cancer, age of mother, ethnic background, geographical location, marital status, socioeconomic status, number of children, and age of children relate to CRF in mothers with cancer?

Qt 4 How do cancer diagnosis, stage of cancer, age of mother, ethnic background, geographical location, marital status, socioeconomic status, number of children, and age of children relate to QOL in mothers with cancer?

Mixed Methods Questions:

MM 1 How do parent disability, CRF and QOL relate to the experience of mothering during chemotherapy treatments for breast cancer?

MM 2 How do age of mother, marital status, socioeconomic status, number of children, and age of children impact the experience of being a mother undergoing chemotherapy for breast cancer?

Quantitative Research Questions Hypotheses

HQt 1 Women with higher levels of CRF will rate their QOL as lower; therefore there will be an inverse relationship between CRF and QOL.

Directional hypothesis: $CRF \propto \frac{1}{QOL}; \uparrow CRF = \downarrow QOL$

HQt 2 Women who have more aggressive disease, have more advanced disease, are older, are unmarried, report lower SES, have lower education, live in rural locations, have more children, and/or have younger children will report lower QOL than other mothers.

Directional hypotheses: For mothers undergoing cancer treatments,

HQt 2a: $\uparrow cancer\ stage\ \propto \downarrow QOL$

HQt 2b: $\uparrow age \propto \downarrow QOL$

HQt 2c: $\downarrow income \propto \downarrow QOL$

HQt 2d: $\downarrow education\ level\ \propto \downarrow QOL$

HQt 2e: $rural\ \propto \downarrow QOL$

HQt 2f: $\uparrow \#\ children \propto \downarrow QOL$

HQt 2g: $\downarrow age\ of\ children\ \propto \downarrow QOL$

HQt 3 Women who have more advanced disease, are older, report lower SES, have lower education, live in rural locations, have more children, and/or have younger children will report higher levels of CRF than other mothers.

Directional hypotheses: For mothers undergoing cancer treatments,

HQt 3a: $\uparrow cancer\ stage\ \propto \uparrow CRF$

HQt 3b: $\uparrow age \propto \uparrow CRF$

HQt 3c: $\downarrow income \propto \uparrow CRF$

HQt 3d: $\downarrow education\ level\ \propto \uparrow CRF$

HQt 3e: $rural\ \propto \uparrow CRF$

HQt 3f: $\uparrow \#\ children \propto \uparrow CRF$

HQt 3g: $\downarrow age\ of\ children\ \propto \uparrow CRF$

HQt 4 Women who have more advanced disease, are older, report lower income, have lower education, live in rural locations, have more children, and/or have younger children will have higher levels of disability on the PDI than other mothers.

Directional hypotheses: For mothers undergoing cancer treatments, HQt 4a: $\uparrow cancer\ stage\ \propto \uparrow parent\ disability$

HQt 4b: $\uparrow age \propto \uparrow parent\ disability$

HQt 4c: $\downarrow income \propto \uparrow parent\ disability$

HQt 4d: $\downarrow education\ level\ \propto \uparrow parent\ disability$

HQt 4e: $rural\ \propto \uparrow parent\ disability$

HQt 4f: $\uparrow \#\ children \propto \uparrow parent\ disability$

HQt 4g: $\downarrow age\ of\ children\ \propto \uparrow parent\ disability$

Limitations

The major limitation of the quantitative portion of this study is the lack of generalizability of its findings due to a small sample size and geographical location of its participants. Another limitation is that individuals who are willing to discuss their experience with cancer may not be truly representative of the population at large. For example, women who have experienced a great deal of distress or physical impairments may not be able or willing to participate in the study. In addition, since I have direct experience with the phenomenon under study, this may influence my interpretation of the data to reflect my own experience. I will address this limitation by keeping a reflexivity journal in which I write about my own biases and assumptions so that I may minimize their impact. One step that has already been taken toward this end is to complete an autoethnography of my experience as a mother with cancer. I will often refer to these data and their interpretation in order to keep my experience separate from this study.

Delimitations

This study focuses on the experiences of the mother. Therefore, it does not intend to gain the perspective of the family members other than through the lens of the mother. As this study will be conducted in Kentucky, perspectives of individuals living in this region will be obtained. Therefore, geographical comparisons for different regions of the United States will not be possible unless participants have experience living in different regions. Mothers with children under the age 18 will only be considered. Therefore, mothers with children over 18 living in the home will be excluded.

Summary

Breast cancer can have devastating effects on mothers undergoing chemotherapy, often causing physical, social and psychological problems that impact a mother's ability to carry out this important role. The proposed study will use a mixed methods approach to describe the impact of cancer treatment on mothering for women with children under age 18 living in the home. It is hoped that this study will inform occupational therapy practitioners about areas of intervention for mothers with cancer.

CHAPTER TWO: REVIEW OF THE LITERATURE

Mothering is a valued social role for many women (Esdaile & Olsen, 2004; Larson, 2000b), and has frequently been the focus of occupational therapy research (Backman, Smith, Smith, Montie, & Suto, 2007; Crowe, 2002; Crowe & Florez, 2006; Crowe, VanLeit, & Berghmans, 2000; Crowe, VanLeit, Berghmans, & Mann, 1997; Farber, 2000, 2004; Francis-Connolly, 2000, 2002; Larson, 2000a, 2000b; Pierce & Marshall, 2004). Mothers with cancer, other serious illnesses and disabilities have difficulty in fully participating in this role due to the physical and psychosocial impact of their condition (Compas et al., 1994b; Farber, 2004; Larson, 2000a; Prilleltensky, 2003, 2004). Despite having difficulties in caring for their children, many mothers with cancer still feel a moral obligation to care for their children (Elmberger et al., 2005). Mothers with cancer face the added difficulty of treatments that can lead to fatigue, nausea, distress, depression and cognitive effects (Baider, Goldzweig, Ever-Hadani, & Peretz, 2008; Barsevick, Dudley, & Beck, 2006; Cella et al., 2002; Janelsins et al., 2011; National Cancer Institute, 2007a, 2007b), which can severely limit participation in valued roles.

This literature review will describe the extant literature pertaining to mothers with breast cancer. First, I will describe the Occupational Therapy Practice Framework: Domain and Process (3rd. Edition) and how it serves as a framework for understanding an occupational therapy perspective on mothering during breast cancer treatments. Second, I will describe a description of cancer in women, including incidence. Third, I will describe the literature addressing the impact of cancer on mothers through a description of mothering, mothers with chronic illnesses and mothers with cancer. Fourth, I will explore the physical and psychosocial impact of cancer on the mother. The purpose of this literature review is to provide an in-depth background of mothering with cancer, as well as a case for where the literature is lacking in terms of research in this area.

An Occupational Therapy Perspective of Mothering with Breast Cancer

The American Occupational Therapy Association has published guidelines for occupational therapy practice called the *Occupational Therapy Practice Framework, Third Edition* ("the *Framework*"), (American Occupational Therapy Association, 2014). In the *Framework*, mothering is considered an instrumental activity of daily living, which is defined as "activities to support daily life within the home and community that often require more complex interactions than those used in [activities of daily living]" (p. S19). Therefore, mothering and all of its associated activities fall under the domain and concern of occupational therapy practice. Occupational therapy practice is defined as "the therapeutic use of everyday life activities (occupations) with individuals or groups for the purpose of enhancing or enabling participation in roles, habits, and routines in home, school, workplace, community and other settings" (American Occupational Therapy Association, 2014, p. S1). For a mother with breast cancer, the occupational therapist can provide interventions to support her participation in this role through restoring previous function, maintaining current abilities, modifying and adapting tasks and environments to compensate for cancer-related deficits, and to prevent future disability (American Occupational Therapy Association, 2014; Longpré & Newman, 2011).

In order to better understand this study's foundation in occupation, I will describe the *Framework* as it pertains to mothering with cancer. The *Framework* was written to guide occupational therapy practice in terms of its relevant domain of concern and the process of practice. In the *Framework*, occupation is defined as “daily life activities in which people engage [and] occur in context and are influenced by the interplay of client factors, performance skills and performance patterns” (American Occupational Therapy Association, 2014, p. S6). Therefore, occupational therapy practice occurs within various contexts and looks at the characteristics of the individual, the activity demands of the occupation he or she engages in, the patterns of occupation, and the overall level of participation in occupation.

Client factors are characteristics within the individual. For a mother with breast cancer, client factors would be her values and beliefs about health, spirituality, body functions including emotional regulation, sensory function, muscle power and endurance and organ system function. Performance skills are components of action that can be observed and have a functional performance. For a mother with breast cancer, examples of performance skills are motor skills of picking up and carrying the child, initiating and completing a childcare task such as feeding, and social interactions with the child. Performance patterns are habits, routines, roles and rituals. Habits are automatic behaviors performed the same way over multiple repetitions. For a mother with breast cancer, an example of a habit is to fasten the child in the car seat when traveling by car. Routines are regular and repetitive patterns of behavior. An example of a routine for a mother with breast cancer is follow a sequence of activities to get the child dressed and fed in the morning. Rituals are activities that usually have a spiritual or cultural meaning. For a mother with breast cancer, rituals may include taking her children to church every week or cooking holiday meals. Roles are a set of behaviors that are expected by society. For the mother with breast cancer, her role as a mother may be important even though her role as patient occupies much of her time (American Occupational Therapy Association, 2014).

An occupational therapist may intervene in all of the above-mentioned aspects of occupational performance. For example, if the mother with breast cancer is having difficulty with the client factor of endurance, the occupational therapist could work with her on increasing her endurance through planned activities (thereby remediating the difficulty) or the therapist could work on energy conservation strategies of prioritizing activities, sitting while completing tasks and using large muscle groups (thereby compensating for the difficulty). If she is having difficulty with the client factor of remembering appointments, she could use the compensatory strategy of using an organizer to remind her. If she is having difficulty getting her children ready in the morning (morning routine), the occupational therapist can help problem solve new strategies for carrying out needed tasks. Perhaps the mother with breast cancer is no longer able to cook the holiday meal for the family. The occupational therapist can work with her to identify aspects of this ritual in which she could successfully participate (Longpré & Newman, 2011).

Another crucial aspect of the *Framework* is the context and environment. The Framework uses the term “environment” for social and physical conditions, while it uses context for conditions more closely related to the individual such as cultural, personal, temporal and virtual. The physical environment is comprised of the natural and built surroundings. An occupational therapist may work with a mother with breast cancer on adapting her physical environment in order to make childcare easier (e.g. putting diaper changing materials within reach). The social environment is the network of relationships with others. For the mother with breast cancer, treatments may cause a strain on her relationship with her spouse or other family members. The therapist can work with her to express her needs and wants and to communicate more clearly and assertively. The cultural context includes societal beliefs, customs and expectations for behavior. The therapist may work within the mother's cultural context by supporting norms and cultural practices. The personal context is comprised of non-health related characteristics such as age and socioeconomic status. The temporal context is comprised of the time related aspects of the day, such as keeping a schedule using a planner. The virtual context is electronic in nature through communication via computers and/or telephones. The therapist may direct the mother to online support groups or informational websites about cancer (American Occupational Therapy Association, 2014).

In summary, the *Framework* is useful as a means of organizing this discussion of mothering with breast cancer with an occupation-based focus. I will discuss the study's results in relation to the *Framework* in Chapter 5. I will now turn to a discussion of cancer and its impact on mothering occupations.

Cancer in Women

Cancer

According to the National Cancer Institute, cancer is uncontrolled growth of renegade cells in the body that do not enter the apoptosis (cell death) pathway or the mitotic (cell division) pathway. These cells do not respond to cellular repair mechanisms and therefore continue to divide unabated (National Cancer Institute, 2009).

Cancer Incidence

The American Cancer Society estimates that 739,940 women were diagnosed with some form of cancer in 2010 and 270,290 died of cancer in the same year (American Cancer Society, 2011a). The probability of developing cancer from birth to age 39 is 1 in 48; from 40 to 59: 1 in 11 (Centers for Disease Control and Statistics, 2011). Weaver, Rowland, Alfano and McNeel (2010), in their epidemiological study of cancer survivors who participated in the United States National Health Interview Survey (NHIS) between 2000 and 2007, found that 18.3% of recently diagnosed and 14.0% of the total sample reported living with a minor child. As of 2010, Weaver, Rowland, Alfano and McNeel estimate that 562,000 U.S. children lived with a parent in the early phases of cancer treatment and recovery. This high number of children living with a parent with cancer highlights the importance of research about the special challenges such families face.

Of those women diagnosed with cancer in the United States, approximately 270,230 women died during 2010 (Centers for Disease Control and Statistics, 2011). From these data, the most common cancer diagnosis in the United States for women in 2010 was breast (207,090, or 28%) followed by lung and bronchus (105,770, or 14%) and colorectal (70,480 or 10%). For cancer deaths, lung and bronchus and breast cancer are reversed, with lung and bronchus cancer causing 71,080 (26%) of cancer deaths in females in 2010, and breast causing 39,840 (15%) and colorectal causing 24,790 (9%).

Breast cancer research has dominated cancer scholarship in the past decade. A Pub-Med search in the past 10 years for “breast cancer” and “women” yielded 84,712 entries, while a search for “lung cancer” and “women” yielded 16,264 entries. Other forms of cancer typically associated with women including uterine, cervical and ovarian cancer combined yielded 61,469 studies in the past 10 years. Many of these studies include cancer treatments, genetic determinants and cancer and other medical treatment literature. The sheer volume of these studies highlights the extent to which cancer in women is being studied worldwide in the past decade, leading to increased survival and quality of life outcomes.

Mothering with cancer

Typical Mothering

In order to understand mothering with cancer, it is important to first understand the literature on typical mothers. In the past decade and a half, there has been a dramatic increase in the level of scholarship on mothering. The focus of this scholarship has been on the theory of mothering and studies of the mothering experience (Arendell, 2000). In the occupational therapy and occupational science literature, there has also been an increase in scholarship on mothering as theoretical and research pieces. This research has focused on the typical experience of mothering (Ellegaard, 2006; Horne, Corr, & Earle, 2005; Larson, 2000a, 2000b; Levin & Helfrich, 2004; Pierce & Frank, 1992; Pierce & Marshall, 2004; Sanders & Morse, 2005), mothering a child with disabilities (Case-Smith & Nastro, 1993; Cronin, 2004; Crowe, 2002; Crowe & Florez, 2006; Crowe et al., 2000; Crowe et al., 1997; Donovan, VanLeit, Crowe, & Keefe, 2005; Esdaile & Olsen, 2004; Kellegrew, 2000; Olson & Esdaile, 2000; Stewart & Meyer, 2004; VanLeit & Crowe, 2002), and mothers with disabilities (Farber, 2000).

Mothering is defined as a the physical and psychological tasks that provide for the nourishment and protection of children (Primeau, 2004). Ruddick defines the term "mother" as a social category for "those people who assume the responsibility for childcare and make its work a regular and substantial part of their working lives" (1985, p. 97). Ruddick described three primary tasks of mothering that make it a unique role in a child's life. They are preservation, growth and social acceptability (Ruddick, 1980). Ruddick later revised her terminology to preservation, nurturance and teaching (Ruddick, 1995). Preservation is the process of providing safety and protection to the child. This can take the form of providing food, shelter and safety for the child. Growth or nurturance is the process of facilitating the child's physical, intellectual and emotional development. This includes providing developmentally appropriate activities and structuring the environment to optimize development. Nurturance also involves providing the child with proper support and feedback for the optimal development of the child's self-esteem. Social acceptability or teaching is the process by which mothers train the child to behave in a manner that is acceptable to the mother and the society overall. It is through teaching that the mother helps the child to engage in a social world and have meaningful social relationships. These three tasks, preservation, nurturance and teaching, are what makes maternal work vitally important to the wellbeing of children.

According to Ruddick, the three primary tasks of mothering, or maternal work, are inextricably linked with peacefulness. Mothers engage in peacefulness in three separate ways: The rejection of violence, the willingness to fight for and protect those whom they love, and peacemaking. This propensity for peace has often led society to of mothers as selfless and self-sacrificing (Primeau, 2004). Mothers who pursue a career path are often seen as putting their own needs above that of their children's and ultimately society's needs (Crittenden, 2001). Despite the increase in the number of working mothers today, the supports afforded to mothers in the United States has not increased.

Mothering is typically a role that is fulfilled by women, but not necessarily so. In fact, Ruddick (1995) asserts that men can engage in "mothering" as well if they engage in the primary tasks of mothering. Ruddick highlights that certain tasks, such as childbirth and breast-feeding, are inherently feminine. However, this physical definition of mothering is not the majority of the work of mothers, and thus may be carried out by either sex as long as he or she fulfills the responsibilities for nourishment and protection of the child (Primeau, 2004). Most of the mothering tasks, however, such as day to day care of children, fall to women, but these family roles are changing as more women enter the workforce and more men are assuming primary caregiver roles (Doucet, 2006; Harmon & Perry, 2011; Latshaw, 2011; Shin, Choi, Kim, & Kim, 2010; West et al., 2009).

Mothering is an extremely complex occupation that involves simultaneous management of many phenomena. Larson (2000b) described mothering as a process of orchestration in which the mother needs to manage many steps in mothering occupations. In her qualitative study of six Mexican-origin mothers living in Los Angeles, Larson found that mothers go through a process of planning, organizing, balancing, anticipating, interpreting, forecasting, perspective shifting and meaning making. The first step, planning, involves creating daily routines and enacting them. Often times, mothers identified not having enough time to enact their ideal routines, which leads to the second step, which is organizing. Organizing involves developing a functional routine that is realistic in mothers' daily life, such as reducing the number of hours worked in order to get everything done. The third step, balancing, involves taking into consideration the preferences of all of the members of the family and prioritizing accordingly. For example, one mother decided to leave her child with behavioral difficulties at home when going shopping in order to more efficiently complete the shopping. The fourth step, anticipating, is when mothers get things ready in advance in order to facilitate the daily routine. For example, one mother keeps a calendar for her child and plans for events on this calendar before leaving the house. The fifth step, interpreting, involves the mother's conception of her child's needs, wants and preferences and acting accordingly. For example, one mother described how her child made a particular noise when she wanted a snack, and the mother provided that snack. The sixth step, forecasting, involves predicting the needs of her children and planning for these changes in the future. For example, one mother observed her nieces who were older than her daughter and was able to anticipate that her child would soon be needing items the older children had. The seventh and eighth steps, perspective shifting and meaning making, are overarching processes focused on how mothers revise perceptions of previous events and find spiritual and positive meaning in events. For example, mothers may turn to faith and optimism to deal with daily roadblocks in providing care for children. This study examining the orchestration of mothering occupations highlights the complexity and multi-faceted nature of carrying out a daily routine while caring for children.

In another occupational therapy study of the typical experience of mothering, Francis-Connolly (2000) compared the experiences of mothers of children in two different life stages. This grounded theory study compared 20 mothers of preschool age children and 20 mothers of young adult children. She found that, as would be expected, mothers of preschool age children had far different experiences than did those of the older children. Overall themes from this study were: "The taboo around discussing mothering negatives, the influence of advice from others, the different view of mothering for the two groups, and the role of fathers" (p. 283). Themes that emerged from the interviews of the mothers of preschoolers were the total immersion in motherhood and enfolding of mothering activities. Mothers of preschoolers described being extremely busy with the day-to-day demands of caring for their young children, especially with the physical demands of providing care. Many of these women reported feeling overwhelmed with life as a mother of a young child. One mother stated:

> The overwhelming piece is that it's a constant, that it never goes away. You can't prepare yourself for that. A friend of mine is 6 months [pregnant] and she's life, "this is going to be so much fun." I think people have their fantasy of what it's going to be life, and what it's really like is different (p. 284).

The other theme the preschool mothers reported in this study was that of enfolded activities, which means that mothers combined teaching, nurturing and protective activities together. One mother described this process as being carried out differently between herself and her husband:

> When I am diapering or bathing my kids, we're playing at the same time. I don't really think of it as a task; to me, it's as important [an] interaction as reading a story. When my husband is changing a diaper, he's changing a diaper. He's task oriented, he's not there to have fun but to do the task. Where[as] for me, I am playing while doing the diapering or bathing (p. 284).

Mothers of young adults reported different experiences than the preschool mothers, with a theme emerging of mothers being an emotionally invested participant in the daily lives of their children. One mother reported thinking about her children many times a day:

> Oh, many times during the day. I think about what they're doing. Now that they're grown, maybe I don't think about them as much because I'm busy with my own activities. But I always think about them in the morning and evening; I'm anxious to hear from them if I haven't heard. Then I give them a call (p. 286).

This study highlights the different demands that are required of mothers of children at different life stages, which is reflected in the development of the Parent Disability Inventory (Katz et al., 2003) for women with arthritis. The Parent Disability Inventory measures parents' perceptions of their ability to participate in different parenting tasks. This assessment takes into consideration the different parenting demands of different age children by having a scale for children 0 to 5 years old and 6 to 18 years old.

Like the Francis-Connolly (2000) study, Marken, Pierce and Baltisberger (2010), in their study comparing mothers and custodial grandmothers of children under 2 years of age, similarly found that mothers of young children found the unrelenting nature of caring for a small child to be daunting and that mothers found the need to catch up on household tasks while the baby was sleeping. Additionally, mothers and grandmothers described enfolding their babies into their daily routines as did the mothers in the Francis-Connolly study. These two studies highlight how different life stages of children and parents have different demands that need to be met. Mothering a younger child requires more physical caregiving, while mothering an older child requires more emotional caregiving. For the mother with cancer, it is unclear in the literature as to which of these two life stages would pose the greater difficulty.

These above studies highlight the types of studies of the typical mothering experience in the occupational therapy literature, which aligns with Arendell's (2000) recommendation to increase mothering research. She writes, "We need more attention to the lives of particular mothers—to mothers' own voices—and the lives and voices of diverse groups of mothers" (p. 1202). I will now describe key studies of mothers with chronic illnesses that pertain to this dissertation study.

Studies of Mothers with Chronic Illnesses

Several studies in the occupational therapy literature have looked at what mothers do to provide care to their children (Ellegaard, 2006; Horne et al., 2005; Larson, 2000a, 2000b; Levin & Helfrich, 2004; Pierce & Frank, 1992; Pierce & Marshall, 2004; Sanders & Morse, 2005) and the difficulties experienced by mothers with chronic illnesses such as scleroderma (Poole, Willer, & Mendelson, 2009), rheumatoid arthritis (Backman et al., 2007), multiple sclerosis (Crist, 1993; Opacich & Savage, 2002), and HIV/AIDS (Farber, 2004). Each of these studies will be discussed as to how mothers' medical conditions impact their ability to provide care for their children.

A study by Poole, Willer and Mendelson (2009) focused on mothering occupations for women with scleroderma. Data was collected including demographic information, a measure of fatigue using the Multidimensional Assessment of Fatigue Scale, activity limitations measured by the Health Assessment Questionnaire, and levels of parent disability using the Parent Disability Inventory. This study found that for mothers with scleroderma, parent disability was positively correlated with pain, fatigue and activity limitations. Although these mothers had a different diagnosis from the focus of this dissertation study, fatigue is a common symptom in both conditions. Therefore, this study has relevance as a point for comparison for the proposed study.

Another contribution in the occupational therapy literature on mothering is the 2004 volume *Mothering Occupations: Challenge, Agency, and Participation* edited by Esdaile and Olsen. In this volume, everyday challenges of mothers are described along with mothering in the context of special challenges such as having a child with a disability or the mother having a disability or illness. In the section of mothering in the context of special challenges for mothers, there are two chapters describing studies of mothering with physical disabilities (Farber, 2004), and mothering with chronic illnesses such as HIV/AIDS (Farber, 2004). In Farber's qualitative study of 10 mothers with diverse physical disabilities, she found that mothers compared themselves to other mothers, participation in mothering occupations ranged from nonparticipation to full participation, mothers attempted to foster normalcy and adequacy, and mothers experienced feelings of marginalization and inadequacy. In the end, despite their physical challenges, these mothers took great pride in their mothering role and in the care they could provide for their children.

Studies of Mothers with Cancer

Research on the impact of cancer in parents has had multiple foci, including that of the family as a unit, that of the parental perspective, and that of the children (Rolland, 1999; Rolland, 2005). Research focusing on parents with cancer has largely focused on the psychosocial impact of cancer (Compas et al., 1994a; Compas et al., 1996; Moore et al., 2006; Moore & Rauch, 2006). Research on the impact of parental cancer on children has found that children, especially adolescent girls, have difficulty adjusting to the parental cancer diagnosis (Welch et al., 1996). These children have demonstrated psychological distress (Compas et al., 1994a), and difficulty in school functioning (Vannatta, Grollman, Noll, & Gerhardt, 2008a).

Elmberger, Bolund and Lützén (2000) found that mothers often described the process of adjusting to cancer in their daily lives as transformational. In their qualitative study of nine women with children ages 4 to 23, Elmberger et al. found that the mothers described were exhausted both physically and emotionally when faced with a cancer diagnosis. They described lack of sensitivity from professionals about their concerns of their children's emotional well-being due to having a mother with cancer. Disruptions to family life included hospitalizations, unemployment, side effects of cancer treatments, and emotional stress of facing a life threatening illness. Economic concerns were seen as exhausting as well, especially for those mothers who were the sole caretakers for their children. Physical exhaustion of cancer treatments compounded this emotional exhaustion, leading to mothers expressing becoming completely overwhelmed with the diagnosis. Several mothers discussed that their children kept constant watch over their mothers due to worries about death. This exhaustion was expressed along with feelings of guilt for not being able to devote her full attention and energy to mothering.

The transformation from exhausting to energizing occurred when the mothers went through a process known as the health-illness-health transition (Meleis, Sawyer, Im, Messias, & Schumacher, 2000). In health-illness-health transition model, the individual undergoes a major life transition when faced with a serious illness. This illness puts the individual at risk for psychosocial and physical problems. Like the Institute of Medicine model of disability (Brandt & Pope, 1997), Meleis' model highlights the importance of factors, called facilitators and inhibitors, that move the individual on a continuum from illness to health. These facilitators or inhibitors may be found in the person (such as meaning, cultural beliefs and attitudes, socioeconomic, or knowledge about the illness), in the community (family and social support), or in society (the overall culture). The mothers with cancer in the Elmberger et al. (2000) study went through a process of accepting their illness, finding meaning in their lives, seeking information and support, and making plans for the future. These mothers made these transitions (and thereby became energized in the process) by learning strategies to improve emotional well-being, recognizing a sense of mastery over her environment, including an improved sense of her own competence as a mother.

In their qualitative interview study of three women with breast cancer, Vrkljan and Miller-Polger (2001) found that major personal crisis of a cancer diagnosis disrupted their occupational routines, which challenged their identities as a healthy person. From these interviews, several themes emerged, including "Doing = Living," deconstruction of occupational self, transition, reconstruction of occupational self, messages perceived through occupational engagement and transition to "I am a person living with cancer." The primary theme expressed by the women, "Doing = Living," speaks to the power of engagement in occupations to cancer survival. The women described needing to make adaptations to which occupations they engaged in and how they carried them out due to physical side effects from treatment and activity restrictions. Despite these adaptations, these women spoke to the importance of doing to the survival experience. Although not specifically addressed in this study, all three of the participants were mothers, although only one had children still living at home.

One study of mothers (Elmberger et al., 2005) highlighted the moral responsibility of being a mother with cancer. In their qualitative study of ten mothers with cancer, Elmberger et al. discovered five major themes: Interrupted mothering, facing the life-threatening illness and children's reactions, striving to be a good mother, dealing with moral responsibility, and coming to terms with mothering. The mothers described how the mothering process was interrupted by cancer. Mothers also worried about their children's emotional response to their cancer. Mothers attempted to carry out their own and society's conception of what being a "good" mother was. Mothers discussed the moral dilemma of not living up to their ideal estimation of a good mother. The mothers described coming to terms with being a mother by adjusting their attitudes about what it is to be a good mother.

A woman's cancer diagnosis affects the entire family, including the spouse and children. Much research has been dedicated to the challenges facing the woman with cancer, but very little research exists looking at the mother's cancer in a family context (Visser et al., 2004). The woman with cancer has a unique interaction with her physical, social, emotional and cultural contexts. Although there are studies that suggest that some family relationships are strengthened during cancer treatments (Elmberger et al., 2000; Helseth & Ulfsaet, 2005b), there is evidence that families can suffer emotional and physical stress when a family member is diagnosed with cancer. Several studies (Compas et al., 1994a; Compas et al., 1996; Davey et al., 2005) have demonstrated that children, especially adolescent girls experienced significant emotional stress when their mothers were undergoing cancer treatments.

This literature review demonstrates that mothers with cancer experience great difficulty in engaging in mothering occupations in the same manner as they had prior to their diagnosis. Some mothers experienced guilt and worry about how their children feel about her cancer. Other mothers were able to come to terms with their cancer and find a new sense of meaning to their lives. Overall, this literature review reflects the complexity of raising children when a woman has cancer.

Ideal Mothering and Women with Cancer

Several theorists have described norms of ideal mothering and how these can be psychologically harmful to women (Choi et al., 2005; Ladd-Taylor & Umanski, 1998; Larson, 2000a; Rich, 1976). Such mothering norms pertain to mothering with cancer in that some studies have reported that, in spite of experiencing severe side effects from cancer treatments such as fatigue, nausea and pain, women with cancer still feel the responsibility to care for children (Elmberger et al., 2005; Elmberger et al., 2000; Helseth & Ulfsaet, 2005b; Stiffler, Haase, et al., 2008a). In her study of 10 mothers with cancer, Elmberger, Bolund and Lützén (2000) found that, despite facing a life-threatening illness, participants framed their entire day around caring for children, remaining positive and saving energy for her children. Mothers also reported feelings of guilt for not being a good enough mother and often pushed themselves to the point of exhaustion to meet this ideal.

The complexity of mothering may lead mothers to feeling overwhelmed by responsibility, which can be compounded for mothers with cancer. In the feminist literature, there has been some concern that mothering is idealized to the point that Western women feel the pressure to be "supermoms" (Choi et al., 2005). In other words, an ideal mother protects children at all costs, provides intense attention to children, and sees that children behave as expected at all times. A mother who does not faithfully carry out these duties is portrayed as a "bad" mother. Ruddick writes, "An idealized figure of the Good Mother casts a long shadow on many actual mothers' lives. Our days include few if any perfect moments, perfect children perfectly cared for" (1995, p. 31). Many women feel as if they must also perform the mothering role in superhuman and self-sacrificing ways (Choi et al., 2005; Rich, 1976; Ruddick, 1995). "Ideal mothering" involves the mother being selfless, caring, patient, cheerful, energetic (Malacrida, 2009), fertile (May, 1998) and competent (Ruddick, 1995). Any deviation from this ideal flips the switch and turns the mother from a "good mother" to a "bad mother." This concrete, either/or thinking does not sufficiently capture the essence of human experience, which is composed of many shades of gray.

Adrienne Rich (1976) also wrote about the oppressive idealization of mothering in her book *Of Woman Born*. She provides journal excerpts from when she was engaged in mothering very young children, and the intense guilt she felt over her ambivalence and sometimes hostility toward her children. She writes, "My children cause me the most exquisite suffering of which I have any experience" and that she sometimes saw herself as a "monster of selfishness and intolerance" (p. 21).

Choi, Krenshaw, Baker and Tee (2005), in their qualitative study of 24 mothers, found that participants felt inadequate to meet ideal social norms of mothering. These women, through the process of mothering, came to realize that meeting this ideal is unattainable and felt defeated by the process. The authors founds that these women instead engaged in performed the ideal to their best ability without actually meeting it. This echoes Butler's (1990) notion of gender performativity, in which women perform according to the discourses of perfect women. The myth of perfect motherhood to which these women aspire is unattainable, so they masqueraded as competent, confident and ideal mothers by not asking for help, not taking breaks and wrapping their entire lives around their children. These women report that the drawback of this performativity was that they felt trapped, unhappy and depressed.

The above studies highlight the need for mothers with cancer to still adhere to mothering norms of the culture in which they live. I now turn to the physical and psychosocial impact of cancer on the mother, and how this impacts her ability to care for her children.

Physical and Psychosocial Impact of Cancer on Mothers

Cancer can greatly impact a mother's ability to engage in daily valued occupations due to both physical and psychosocial conditions associated with cancer and its treatments (Longpré & Newman, 2011). In terms of physical effects of cancer, the mother may experience cancer-related fatigue (CRF), nausea, infections due to a reduced immune response, anemia (decreased red blood cells), hair loss, pain, and lymphedema, to name a few (American Cancer Society, 2011c). Just as debilitating are the psychosocial effects, including decreased quality of life, distress, anxiety, fear, depression, and social isolation (American Cancer Society, 2011b). Each of these side effects will be discussed along with their implications for mothers with cancer.

Physical Effects of Cancer

Cancer Related fatigue. Parents typically report increased fatigue when providing childcare, especially with a new baby (Gay, Lee, & Shih-Yu Lee, 2004). Mothers with chronic illnesses such as rheumatoid arthritis and multiple sclerosis have been found to have significantly increased fatigue that persists into their children's later years, which can impact on the ability to carry out mothering tasks (Backman et al., 2007; Deatrick, Brennan, & Cameron, 1998; Pedersen & Revenson, 2005). Mothers with cancer have also reported difficulties in participating in mothering tasks due to treatment side effects (Elmberger et al., 2000), and have difficulties in meeting the physical, developmental, social and emotional needs of their children due to the physical and emotional difficulties of cancer and its treatment (Visser et al., 2004). One such side effect of cancer treatment that can impact daily activities cancer-related fatigue (CRF) (Cella et al., 2001).

According to the National Comprehensive Cancer Network (NCCN), CRF is "a distressing, persistent, subjective sense of physical, emotional and/or cognitive tiredness or exhaustion related to cancer or cancer treatment that is not proportional to recent activity and interferes with usual functioning" (Mock et al., 2007, p. 1). CRF is one of the most commonly reported symptoms of cancer treatments. This fatigue can be so pervasive that it impacts the functional performance of those whom it affects (Cella et al., 2001; Cella et al., 2002; Stone et al., 1998). For young women with breast cancer, this pervasive fatigue can impact the ability to meet the physical and psychosocial demands of caring for their children.

The incidence of CRF in women with breast cancer has been found to be around

30%, although a subset of that group was found to have persistent fatigue with co-morbid depression (Bower et al., 2000). Occupational therapy services in oncology are considered an emerging area of practice, meaning that it is estimated that occupational therapy practitioners will have an increasing role in this arena in the near future (Longpré & Newman, 2011). Putting these two areas of practice together, oncology and mothering, however, has not been addressed in the occupational therapy research literature.

Other physical symptoms of cancer and cancer treatments, including nausea, infections, anemia, hair loss, and lymphedema. Cancer patients may experience several distressing symptoms during cancer treatments that may impact their ability to participate in valued occupations. Nausea can be a debilitating side effect of chemotherapy and radiation (American Cancer Society, 2011c), although great strides in managing nausea in cancer have been made in recent years due to new drugs on the market (Hamling, 2011). Low blood cell counts can lead to low white blood cell count and anemia, which can leave the cancer patient vulnerable to life-threatening infections and debilitating fatigue (American Cancer Society, 2011c). One drug to treat anemia that has been used in treating cancer patients is Epoetin Alfa, which has been demonstrated in a large, prospective clinical trial to increase quality of life in cancer patients (Demetri, Kris, Wade, Degos, & Cella, 1998). Hair loss can be a distressing side effect of treatment, especially for women (Gallagher, 1992; Hansen, 2007; Randall & Ream, 2005). Some women decide to shave their head in anticipation for hair loss, which is a form of taking control over the cancer rather than vice versa (Frith, Harcourt, & Fussell, 2007). Lymphedema is another debilitating side effect of cancer treatments that is often associated with breast cancer due to axillary node dissection as part of the staging procedure, with one study reporting its prevalence of 42% of women treated for breast cancer. However, lymphedema has been found to be present in other cancer diagnoses, with an overall prevalence of 15% (Cormier et al., 2010). Women with cancer who have lymphedema are often seen in rehabilitation settings for lymphedema management (Cohen, 2005; Dennis, 1993; Nesbit, 2004). Lymphedema is a chronic and painful accumulation of lymph fluid in the tissues as a result of a disruption in the lymphatic system (Cormier et al., 2010). As the above mentioned studies highlight, women undergoing cancer treatments experience many difficult physical side effects that may impact their ability to participate in daily occupations.

Psychosocial Effects of Cancer

In addition to the above mentioned physical effects of cancer, cancer patients can experience a number of psychosocial effects as well. These effects can include, but are not limited to, changes in quality of life, post-traumatic growth, strain on social relationships, and psychological conditions such as depression, anxiety and fear. The first of these effects to be considered, quality of life, has been studied extensively in cancer patients.

Quality of Life. Quality of life (QOL) is defined as a global construct that describes the subjective appraisal of an individual's well-being and welfare (Cella & Tulsky, 1993a). According to Cella and Tulsky (1993a), QOL is used in three ways in cancer research: To determine the patient's rehabilitation needs, as a treatment outcome, or as a predictor of future treatment response. After determining which facets of QOL are impacted, therapists can design a rehabilitation program to meet those needs. Using a measure of QOL as a treatment outcome serves as a point of comparison for different treatment regimens. Quality of life is a widely accepted outcome of cancer treatment, as opposed to length of life (Allison, Locker, & Feine, 1997; Arora et al., 2007; Aziz, 2009; Aziz & Rowland, 2002; Cella, 1994; Cella & Tulsky, 1993a; Ganz et al., 1996; Ganz et al., 2002; Helseth & Ulfsaet, 2003; Lindley, Vasa, Sawyer, & Winer, 1998).

Quality of life as a dynamic construct. Quality of life can be seen as a dynamic construct in that each individual's subjective interpretation and experiences can alter how he or she rates QOL (Allison, 1997). When an individual experiences a phenomenon such as cancer diagnosis and treatment, his or her interpretation of that experience can change the magnitude of self-reported ratings. For example, in the case of a patient undergoing chemotherapy, she may rate her QOL as poor prior to commencement of treatment due to fatigue and pain. However, once she begins chemotherapy and experiences side effects such as nausea and further fatigue, she may rerate her QOL prior to treatment as higher than she had previously because she now has a point of comparison. Therefore, her QOL rating has shifted due to her subjective experience. In this case, her QOL rating prior to treatment is now higher, and therefore her shift from pre-treatment to during treatment is greater. In another example, a patient who has a great deal of pain due to a tumor, after surgery, radiation and chemotherapy have shrunken the tumor may look back and rate her QOL as lower prior to intervention now that those symptoms have subsided. In other words, feeling better now makes the patient realize how bad she really felt before her treatment.

Sprangers (1999) wrote about the following story of a Dutch physician and his patient to describe response shift in QOL research:

> An orthopaedic surgeon once commented that it must be difficult to study quality of life (QOL) since it not only means different things to different people, but can also mean different things to the same person over a disease trajectory. He recounts the story of a woman who, after hearing her diagnosis of osteosarcoma, told him that if her bone tumor prevented her from being able to walk, life would no longer be meaningful to her and she would prefer euthanasia. When the time came that this woman was confined to a wheelchair, she informed him that life still held value for her but that if she were to become incontinent or bedridden, then life would loose [sic] its meaning and that she would prefer euthanasia. However, when the time came that she was incontinent and bedridden, the woman stated vehemently that life still held meaning for her and that she was not yet ready for euthanasia (pp. 1507-1508).

Despite the obvious difference in end-of-life options between the Netherlands and the United States (i.e. euthanasia), this example highlights how a patient's cognitive reappraisal of what she could handle in life changed as she experienced it. This concept is useful for studying cancer patients since their subjective ratings of QOL can greatly vary depending on their stage of treatment. Sprangers and Schwartz (1999) developed a theoretical model for the process of response shift in patients. First, the patient experiences a catalyst, which may be medical treatment. The antecedents are the personal characteristics of the patient, such as sociodemographics, personality, expectations, and spiritual identity. Mechanisms are processes that the patient may use to cope with the catalyst, including coping, social comparison, social support, goal reordering, reframing expectations and spiritual practices. These mechanisms lead to a response shift, which comes from a change in internal standards, values and conceptualization of illness. The end result is perceived QOL, which may be altered due to this process.

Then ratings. One way to handle a response shift in QOL ratings is to complete a “then ratings” assessment. In this method, the researcher asks the participant to look back to one-week prior to the commencement of treatment to rate QOL, which then becomes a baseline. After treatment, or at the desired intervals, the researcher asks the patient to rate QOL at that moment. The “true” QOL rating is the difference between the current QOL and the before-treatment QOL. This approach has been used in a number of studies of QOL in cancer patients due to the dynamic nature of this construct (Hinz et al., 2011; Jansen, Stiggelbout, Nooij, Noordijk, & Kievit, 2000; Schwartz, Andresen, Nosek, Krahn, & M, 2007).

Transformation, post-traumatic growth and psychosocial adaptation in cancer patients. Although the negative psychosocial and physical effects of cancer are evident in many cancer patients, some individuals demonstrate positive changes in their psychological health and social relationships secondary to cancer. These changes have been described as “transformation,” “post-traumatic growth” and “psychosocial adaptation.” These terms denote how the journey through cancer diagnosis, treatment and recovery can be an adaptive process leading to an improved perception of one’s quality of life.

Carpenter, Brockopp and Andrykowski (1999), in their mixed methods study of breast cancer survivors, found that their study participants demonstrated three different patterns of coping with cancer: positive transformation, minimal transformation and feeling stuck. Women who experienced a positive transformation went through a reflective process of personal mortality, leading to dramatic changes in their lives. Women who experienced minimal transformation went through the increased introspection, but came to a rapid acceptance of their life circumstances. Women who were unable to make any changes to their lives but experienced a deep introspection into life events were characterized as "stuck" and unable to improve their lives based on the cancer experience. The authors found a significant relationship between feeling stuck and self-esteem. Therefore, women with lower self-esteem had a harder time adjusting to breast cancer.

In a study of mothers with cancer, Elmberger, Bolund and Lützén (2000) found that mothers reappraised their notion of being a good parent and characterized this process as moving from exhausting to energizing. The women in this study, in retrospect, came to see their cancer journey as a good experience that brought about positive changes in their parenting and satisfaction with life. Similarly, Andrykowski et al. found that recipients of hematopoietic stem-cell transplants experienced poorer physical and psychosocial functioning than matched healthy participants, but they also experienced more psychological and interpersonal growth as measured by the Post-traumatic Growth Inventory, or PTGI (Tedeschi & Calhoun, 1996).

Taubman-Ben-Ari, Findler and Sharon (2011) found that the concept of post-traumatic growth as measured by the PTGI is useful in describing the process of adaptation that healthy mothers experience when adjusting to being a mother. Through a series of three studies, Taubman-Ben-Ari, Findler and Sharon found that mothers reported a significant amount of personal growth within the first four years of their children's lives.

Social Support. The degree of social support can greatly impact the psychological outcomes of the cancer patient. In a cross-sectional study of 863 adult long-term cancer survivors, Zucca, Boyes, Lecathelinais and Girgis (2010) found that one of the most common predictors of difficulty coping with cancer is social support. Cohen (2004) proposed that social support is just one part of the social environment. The social environment can be thought of as encompassing three different concepts: social support, social integration and negative interaction. Social support is what others provide to help that individual to better cope with stress. For the mother with cancer, social support is what family, friends and members of the community do to make her adjustment to the cancer diagnosis and coping during treatment easier, such as by providing childcare, making food, and completing household tasks. Social integration is the active engagement in a variety of social relationships. For the mother with cancer, social integration could occur in being a member of a cancer support group or a church community that provides various opportunities for social interaction. Negative interactions are detrimental social interactions, such as a non-supportive family member or friend during cancer treatments.

During cancer treatments, the mother with cancer may have the most frequent interactions with family members as a social environment. In the volume *Cancer and the Family* edited by Baider, Cooper and Kaplan De-Nour (2000), family is "an intricate system of both potential distress and effective support when confronted with the reality of cancer" (p. xxiii). Weiss and Reiss (2000) (Weihs & Reiss, 2000) described how better family functioning can lead to better coping and even survival rates. However, Lewis et al. (2000) addressed myths by using data-based arguments about family cohesion during cancer. They found that families do not always cope well, and that children of cancer patients do not feel comfortable discussing cancer with their parents and that spouses or partners of the cancer patient may experience distress due to the cancer diagnosis which may impact the child.

Other psychosocial impact of cancer, including distress, anxiety, fear, depression, guilt and anger. Many studies in the psychosocial oncology literature have explored the impact of cancer on a number of constructs. Distress in cancer patients has been found to be experienced by an average of 35% of cancer patients (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). According to the National Comprehensive Cancer Network,

> Distress is a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the 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, and existential and spiritual crisis (National Comprehensive Cancer Network, 2011, pp. DIS-2).

Studies of parents with cancer and their children have shown that children experience a significant degree of distress due to the parent's illness (Kennedy & Lloyd-

Williams, 2009a, 2009b). However, few medical personnel have addressed these concerns (Rauch & Moore, 2010; Rauch, 2007; Rauch & Muriel, 2004).

Anxiety, fear, guilt and depression may also be common psychological effects experienced by cancer patients (American Cancer Society, 2011b). Although these are beyond the scope of this study, these effects are worth mentioning because they may impact a mother’s ability to care for her children during cancer treatments (Semple & McCance, 2010b).

Summary

The above review of the literature describes cancer in women, mothering, mothering with cancer and chronic illnesses, and psychosocial and physical side effects of cancer treatments. The literature of the many facets of mothers with cancer provides a background for this study of mothers with cancer, although it also highlights areas of needed research contribution. No studies exist in the occupational therapy literature addressing mothering occupations with a cancer diagnosis. In addition, much of the literature on mothering with cancer has focused on the psychosocial impact of cancer on the mother and the child. There is a gap in the literature on the physical process of providing care for children during the cancer experience.

CHAPTER THREE: METHODS

Study Design

I employed a mixed method approach to better understand the impact of chemotherapy on mothering occupations for women with children under 18 years of age living in the home. For the qualitative piece of the study, I used grounded theory methods to understand the process of mothering during chemotherapy. For the quantitative part of the study, data was collected on parent disability, quality of life (QOL), cancer-related fatigue (CRF), and demographic factors to gain a better understanding of the relationship among these constructs.

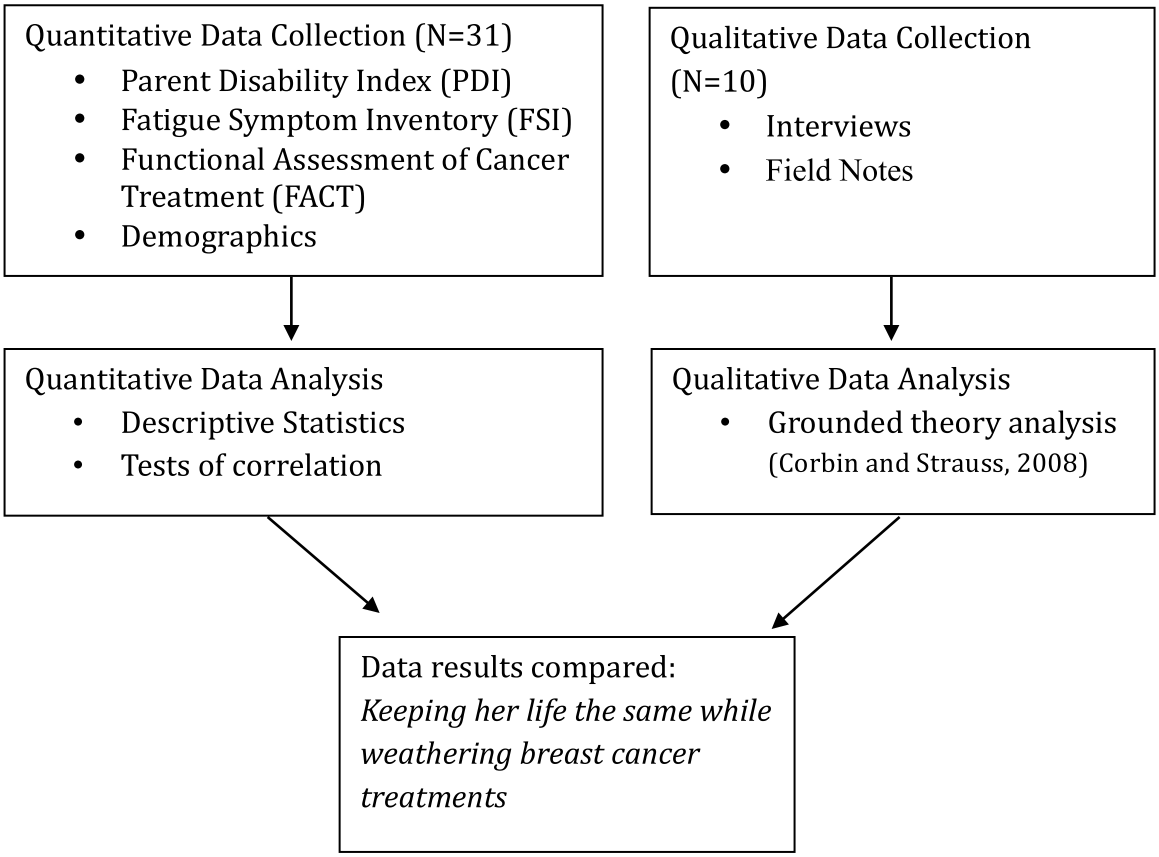
For the purpose of this study, mothering occupations are defined as those activities that a mother carries out to provide for the preservation, growth, and social acceptability of the child (Ruddick, 1980). Activities included in preservation are feeding, bathing, diapering, dressing and other tasks that enable the mother to provide physical day to day care for the child. Activities included in growth are playing with, reading to, and providing enriching and educational experiences for the child. Activities included in social acceptability are teaching the child to behave appropriately at home, at school and with others, following rules and displaying proper manners.

Mixed methods research is a pragmatic approach that provides a breadth and depth of understanding of a phenomenon under study (Creswell & Plano Clark, 2007). In this type of research, qualitative and quantitative data are collected, analyzed separately, and then combined to answer the study's research questions. I chose a mixed methods approach for this study because of the complexity of the phenomenon of mothering during chemotherapy for breast cancer. In addition, there are several valid and reliable quantitative measures used in psychosocial oncology research, including fatigue inventories and quality of life measures, and this data adds a breadth to the information gleaned from this study. The quantitative data also served as a means of triangulation for the grounded theory interpretation of interview data.

I combined quantitative measures of parent disability, quality of life and cancer related fatigue with in-depth interviews of mothers with cancer to describe how chemotherapy impacts the ability to care for children. The research questions and measurement tools for each of these questions are found in Table 1. I employed a convergent parallel mixed methods design (Figure 3.1). In a convergent parallel mixed design, qualitative and quantitative data are collected in parallel, analyzed separately, and then merged. I used the analysis of qualitative and quantitative data to serve as a means of confirming and offsetting the weakness of either type of data. Collecting multiple types of data provides a more comprehensive picture of mothering with breast cancer and will further ensure the trustworthiness of the findings.

I used measures of parent disability (Parent Disability Inventory, PDI), and CRF (the Fatigue Symptom Inventory Then Test, FSI-TT) and QOL (Functional Assessment of Cancer Therapy, FACT) to investigate the impact of cancer treatments on mothering. Additionally, I collected demographics, including stage of diagnosis, length of treatment, number of children, annual income, level of education, race/ethnicity, marital status, number of children, age of children and age of mothers (Appendix A). I compared these data with parent disability, QOL and CRF through statistical analysis. The qualitative data, including in-depth interviews, relevant documents and field notes, described the processes and interactions the participants went through during their experience.

Figure 3.1. *Convergent Parallel Mixed Methods Design*



Adapted from Creswell (2009).

For the qualitative portion of the study, I used a grounded theory approach as described by Corbin and Strauss (2008). Grounded theory is an inductive methodology that is used to construct a theory to describe the data collected in the study. This process is rigorous and involves the systematic analysis of qualitative data by breaking the data apart and attaching codes, then grouping the codes into concepts and then into categories. It is from these categories from which the core category is derived, leading to the development of a theory that directly comes from the data, or is grounded in the data.

This theory culminates in a theoretical model that explains the data obtained from the first person perspectives of participants.

For the mixed methods part of the study, I went back and forth between qualitative and quantitative data to gain better perspective of the experiences of my participants. At the end of the study, I incorporated results from the quantitative portion of the study in order to provide an overall picture of the experiences of mothers in my study who were undergoing chemotherapy. I obtained a mixed methods result by considering both qualitative and quantitative data to develop a model of mothering with breast cancer and to further explain how mothers undergoing chemotherapy participate in the mothering role. The role of each type of data source is to confirm and support each other, and to provide a broader and more complete picture of the phenomenon under study (Teddlie & Tashakkori, 2009).

Each research question and the instruments for gathering data about it is summarized in Table 3.1, and the overall research process is summarized in Figure 3.1.

Table 3.1. *Research questions and instruments*

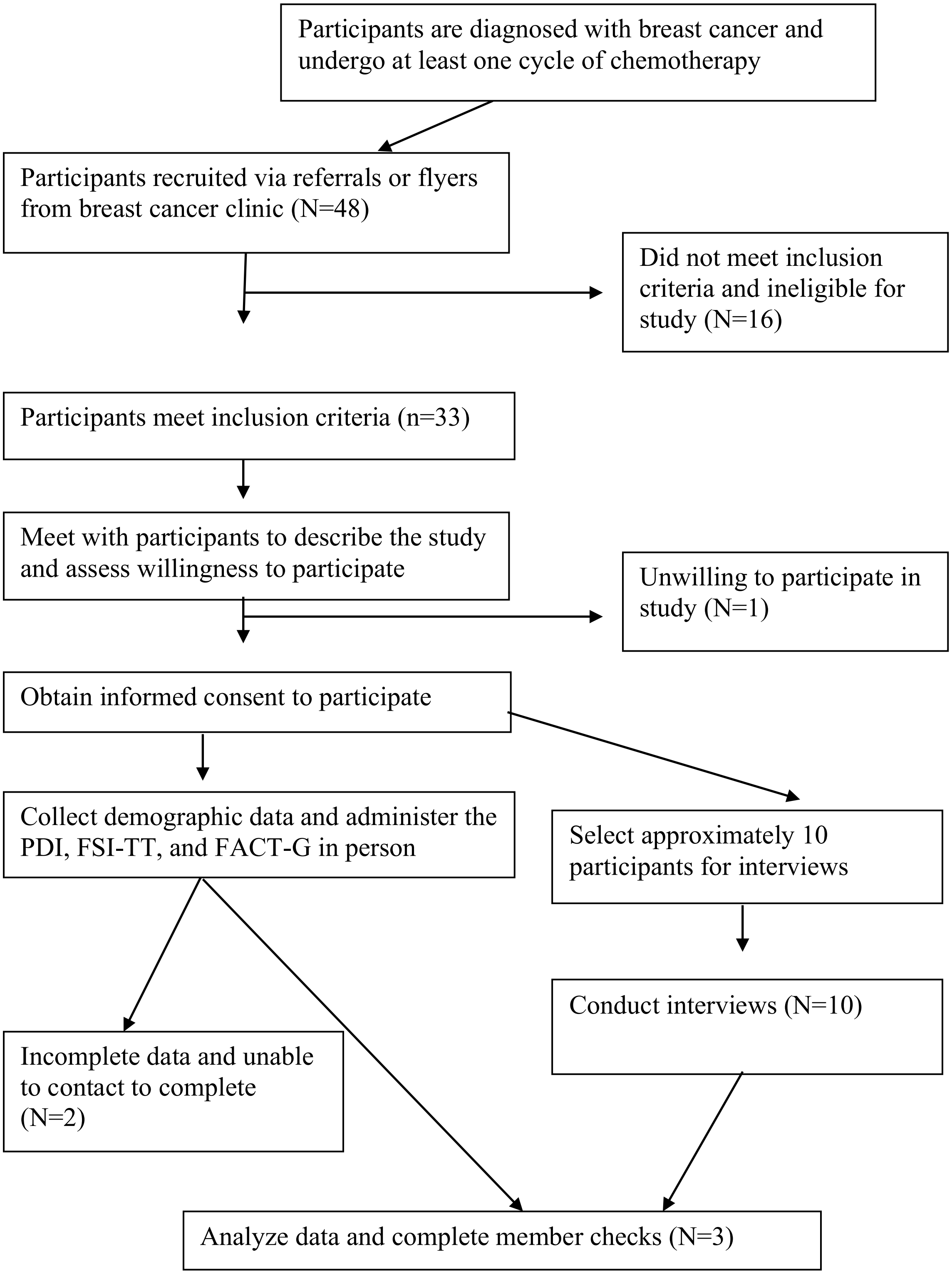
Research Question	Instrument(s)
Grand Tour Question: What is the theory that describes the process of being a mother while undergoing chemotherapy treatments for breast cancer?	Semi-structured interviews
Ql 1 How do mothers with breast cancer describe their transformation during the process of their experience with breast cancer diagnosis, treatment, and recovery?	Semi-structured interviews
Q12 How do mothers with breast cancer describe the impact of social support from spouses and/or other family members on their ability to carry out care for their children living in the home	Semi-structured interviews
Ql 3 What challenges for carrying out mothering occupations do mothers with breast cancer describe?	Semi-structured interviews
Ql 3a. What is the impact of cancer-related fatigue on mothering occupations?	Semi-structured interviews
Ql 3b. How is quality of life impacted by cancer treatments?	Semi-structured interviews
Ql 4 What strategies for carrying out mothering	Semi-structured interviews

Research Question		Instrument(s)
	occupations do mothers with breast cancer use to overcome challenges?	
Qt 1	What is the relationship among cancer-related fatigue (CRF), parent disability and quality of life (QOL) for mothers with cancer?	Fatigue Symptom Inventory Then Test (FSI-TT) Functional Assessment of Cancer Therapy (FACT) Parent Disability Inventory (PDI)
Qt 2	How do cancer diagnosis, stage of cancer, age of mother, ethnic background, geographical location, marital status, socioeconomic status, number and age of children relate to parent disability in mothers with cancer?	Demographic Survey PDI
Qt3	How do cancer diagnosis, stage of cancer, age of mother, ethnic background, geographical location, marital status, socioeconomic status, number of children, and age of children relate to CRF in mothers with cancer?	Demographic Survey FSI-TT
Qt 4	How do cancer diagnosis, stage of cancer, age of mother, ethnic background, geographical location, marital status, socioeconomic status, number of children, and age of children relate	Demographic Survey FACT

Research Question		Instrument(s)
	to QOL in mothers with cancer?	
MM 1	How do parent disability, CRF and QOL relate to the experience of mothering during chemotherapy treatments for breast cancer?	Semi-structured interviews FSI-TT FACT PDI
MM 2	How do age of mother, marital status, socioeconomic status, number of children, and age of children impact the experience of being a mother undergoing chemotherapy for breast cancer?	Semi-structured interviews Demographic survey

Note: mothers with children under 18 living in the home and undergoing cancer treatments is abbreviated as “mothers with cancer”

Figure 3.2. *Research Process Flow Diagram*



Study Participants

I recruited study participants from University of Kentucky Markey Cancer Center Comprehensive Breast Care Center through fliers and referrals from clinic staff, including nurses and the genetic counselor. Potential study participants were contacted face to face in the clinic by describing the study and going over the informed consent and the type of information that was collected. At the time of informed consent, if participants were willing to be interviewed, they initialed a place on the demographic form and wrote their contact information on the form.

Inclusion Criteria. Women who met the following criteria were eligible for the study:

1. Had been diagnosed with any stage or type of breast cancer.
2. Were currently undergoing chemotherapy treatment (including cytotoxic and adjuvant immunological therapy) at the time of recruitment.
3. Had one or more child(ren) under the age of 18 living in the home.
4. Could speak and understand English.
5. Were able to provide informed consent to participate in the study.
6. Were able to tolerate one to two in-depth interview sessions lasting 1 hour each.

Exclusion Criteria. Women were excluded from the study for the following reasons:

1. Resided with children under 18 who were not biological, foster, step- or adoptive children (such as siblings, friends, distant relatives).
2. Had children who reside within another home for 5 of 7 or more days a week.

Protection of Human Subjects

There were no expected risks of participating in this study, although I made every effort to minimize risk and discomfort to study participants. Before conducting this study, I submitted a proposal to the Institutional Review Boards (IRB) at Eastern Kentucky University and University of Kentucky. I am a faculty member at Eastern Kentucky University, so it was necessary to obtain IRB approval at both institutions. I made every effort to preserve the safety and confidentiality of each participant by assigning numbers to participants and removing all identifying information from study materials. The master list of participants and all study related data were stored on a secured computer in an encrypted file within a locked office in the Dizney Building at Eastern Kentucky University.

Data Collection

For the quantitative phase of the study, I conducted a power analysis to determine that 28 participants would be necessary for a strong effect size and a power of .80 with a probability of 0.05 of Type I error. Thirty-two women were recruited for this study from a sample of convenience of Markey Cancer Center breast cancer clinic participants. Each of these 32 participants completed the demographic questionnaire, the PDI, the FSI-TT and the FACT via mail, email or in person. Of these 32 participants, 10 were selected for in-depth interviews. Interviewees were selected based on 1) willingness to be interviewed, 2) demographic characteristics leading to a diverse sample, and 3) availability for the interview. Recruitment of participants for interviews continued until theoretical saturation was achieved, which occurred at N=10. Participants selected for in-depth interviews were contacted via telephone and met in a mutually agreed upon location. In-depth interviews consisted of one 45 to 90 minutes for each participant. Interviews occurred face-to-face at a location that was convenient to the participant. Participants requested to be interviewed in a variety of locations, including their homes, clinic private rooms, a hospital room, private chemotherapy infusion rooms and places of work.

Quantitative. Four sets of quantitative data were collected, specifically measures of parent functioning, QOL, CRF and participant demographics. Parent functioning was measured using the Parent Disability Index (PDI). Quality of life was measured by the FACT. Fatigue was measured using the Fatigue Symptom Inventory Then Test (FSI-TT).

The PDI is a self-report inventory that measures parental function and disability (Appendix G). The PDI is broken into separate sets of questions about parent functioning according to age of child (one set for young children 0 to 5 years, and one set for older children 6 to 18 years). The focus of the young child questions is on physical requirements for childcare, such as diapering, feeding and picking up the child. The focus of questions for older child is taking the child to social outings, maintaining discipline, and helping the child with homework. This inventory was originally developed for parents with rheumatoid arthritis and was administered to 231 women with varying ages, number of children and degree of symptoms as a result of rheumatoid arthritis. Validity of this instrument was demonstrated by correlations among psychosocial and symptom measures of constructs similar to parental function (Katz et al., 2003). The PDI was further evaluated on 75 mothers with scleroderma. This assessment demonstrated good congruence between PDI ratings, fatigue and quality of life measures (Poole et al., 2009). The PDI yields scores from 0 (no difficulty) to 3 (unable to do). Scores above 1 on an item indicate moderate to severe difficulty in a parenting task (Katz et al., 2003). No reliability studies of this assessment have been conducted to date. The PDI has been modified for use in this study by permission from the first author to change the words "rheumatoid arthritis" to "cancer."

The FACT-G (version 4, Appendix E) is a 27-item inventory to measure health-related quality of life for cancer patients (Cella et al., 1993). It measures *well being* across four different domains: Emotional well-being, functional well-being, physical well-being and social/family well-being. A 5-point likert scale is used to rate the degree to which the individual experiences the item with 0=not at all, 1=a little bit, 2=somewhat, 3=quite a bit, and 4=very much. This instrument has been demonstrated to be a valid and reliable measure of quality of life in cancer patients (Cella, 1994; Cella & Tulsky, 1993a; Cella et al., 1993).

The FSI (Appendix G) is a 14-item self-report scale that measures cancer-related fatigue by measuring severity, frequency, duration and functional impact of fatigue. Fatigue is rated on an 11-point scale for most, average and least fatigue severity (0=not at all fatigued and 10=fatigued as I could be) and for the interference of fatigue in daily life (0=no interference and 10=extreme interference). An 8-point scale is used for number of days of fatigue (0=no days and 7=7 days). A 5-point scale is used for daily pattern of fatigue (0=not at all fatigued, 1=worse in the morning, 2=worse in the afternoon, 3=worse in the evening, and 4=no consistent pattern of fatigue). The FSI has been demonstrated to have good validity and reliability (Donovan & Jacobsen, 2010; Hann, Denniston, & Baker, 2000; Hann et al., 1998b), and has been demonstrated to be sensitive to changes in CRF during treatment. The FSI-TT is modified to account for a response shift in perception of fatigue severity by using the "then test" (Andrykowski, Donovan, & Jacobsen, 2009; Hann et al., 1998a). Like the FSI, the FSI-TT is a 14-item scale that measures the frequency, severity, duration and functional impact of fatigue. However, two items have been changed (Items #1 and #3) from "during the past week" to "during the week prior to cancer treatments."

Qualitative. I interviewed each study participant on a separate occasion from when I obtained informed consent and collection of quantitative data. I conducted interviews in a location that was convenient to the participants, which resulted in a variety of interview locations. These were at a participant's home (Kimberly), in a private chemotherapy infusion room (Rebecca, Sarah and Denise), in a private room in the clinic (Ellen, Lori and Cheryl), outdoors in a quiet location (Melissa), at private office at a local university (Shannon), and in the participant's office at her workplace (Shirley). These locations were quiet with relatively few distractions. For Rebecca, Sarah and Denise, a family member was present during the interview, but did not participate in the interview.

Interviews were recorded and transcribed verbatim. Transcription occurred immediately after conducting each interview, except for four interviews were transcribed approximately one month after the interview occurred. Interviews were transcribed verbatim using HyperTranscribe 1.6.1 and analyzed using HyperResearch 3.0. This computer remained in a locked room at all times.

Participants were assigned a pseudonym that had a similar level of popularity in the year of her birth by looking up the name on the Name Voyager on www.babynamewizard.com. Participants were informed that if at any time the participant stated that she was too fatigued or could not continue the interview for any reason, the interview would be ended. However, none of the participants requested to do this. Follow-up questions were asked for further clarification and elaboration of responses (Patton, 2002).

Participants were asked questions about the impact of adjuvant cancer treatments on parenting experiences loosely following the interview guide in Appendix B. However, I diverged from the guide in order to follow up on any interesting points mentioned by the participants. For example, one participant showed me photographs of her family and a tree in her front yard, which inspired the metaphor describing the qualitative data of the study. I focused these interviews on the individual experience of being a mother with breast cancer and undergoing chemotherapy. Specifically, I asked mothers about the day to day occupations required of parenting, such as childcare, household chores, cooking and discipline, as well as work, support from others and participation in community organizations pertaining to cancer survivorship.

After each interview, I took notes observing the affect and non-verbal communication of the participant, changes in affect during storytelling, and any interactions with children and other family members occurred during the interview. These notes were typed and analyzed along with the interview transcripts by adding them to the transcripts. For example, one mother cried during her interview, and I put my observations in brackets [ ] to denote that this was nonverbal.

After each transcription, I wrote an analytical memo that summarized my interpretations of and reaction to the interviews. Each memo was used as a stepping off point for the data analysis.

Data Analysis

Quantitative and qualitative data were analyzed separately and then combined during the final analysis of the study. Each phase of data analysis, quantitative, qualitative and mixed methods, is described below.

Quantitative. The criterion for statistical significance was set at $P < 0.05$ *a priori*. Statistical data analyses were conducted using the SPSS Package (IBM, version 22). Descriptive statistics and tests of normality (Kolmogorov-Smirnov) were calculated. It was determined that the data had a non-parametric distribution. Therefore, a Spearman Rho test of correlation for ordinal data was conducted. The PDI, FACT-G and FSI-TT all yielded ordinal data since they employ Likert-type scales for ranking of items. Therefore, range, median and mode were calculated rather than average and standard deviations.

Qualitative. In this section, I will address procedures used to analyze and interpret qualitative data from interviews and observations.

I analyzed data using a grounded theory approach as described by Corbin and Strauss (2008). In this approach, portions of data are coded using an iterative process, going back and forth between data sets using constant comparison. Corbin and Strauss described a rigorous and systematic process for data analysis that requires the researcher to delve into the data several times, first by doing open coding, then forming concepts, then collapsing those concepts categories, and then discovering the core category that describes the data. The ultimate goal is to develop a theory from the data specific to the perception of the participants. I used the method described by Scott (2004), and Scott and Howell (2008). In this strategy, data are coded using open coding, which is a process of reading each line of the transcript and summarizing the meaning of that text with a code. When possible, I used *in vivo* coding, which classifies the words of the participants to create the code. From the ten interviews, I attached a total of 318 open codes to the data, which will be further described in Chapter Four: Results. At that point, codes were collapsed into 21 categories, which were groupings of open codes (Table 4.3). I created a table that lists each category along with all codes attached to that category, the participants who mentioned this category, and a representative quote of the category (Table 4.4). After that, I further collapsed categories into processes, properties, dimensions, contexts, and modes for understanding the consequences as described by Scott (2004) and Scott and Howell (2011) in a Conditional Relationship Guide (Table 4.5). This was a difficult process of closely reading, rereading, analyzing, and going back and forth among interview data. From there, I chose processes from the Conditional Relationship Guide that best represented the process of mothering during breast cancer treatments, and created a Reflective Coding Matrix (Table 4.6). From this Reflective Coding Matrix, I developed a storyline. I will further describe the emergence of major categories and the core category in the Results section.

Mixed Methods Analysis.

After completing both the qualitative and quantitative analyses, I merged these two sources of data with the goal of developing a theoretical model to describe mothering during breast cancer treatments (see Figure 3.1). As in qualitative data analysis, mixed methods data analysis involved an iterative process of going back and forth between qualitative and quantitative data. I analyzed each separately using a grounded theory methodology and statistical analyses, respectively, but I used each type of data analysis to inform my interpretation of the study overall. For example, when I was analyzing the quantitative data, I found that there was a correlation between fatigue and being able to do specific parenting tasks, such as taking children all the places they need to go. Therefore, when analyzing the interview data, I looked for participant statements that supported the qualitative finding. In the end, I incorporated the quantitative data into my theoretical model by using the constructs of quality of life, cancer related fatigue and parent disability as challenges to participation in mothering. These results will be described in Chapter Four: Results, and the interpretation will be described in Chapter Five: Interpretation of Results.

Trustworthiness

Trustworthiness is a means of validating the findings of a study (Creswell, 2009). It involves looking at multiple data sources, having more than one individual code the data, asking the participants if my interpretation is correct (member checks), having a clear audit trail, and having frequent discussions about my analysis and interpretation with a mentor. I achieved trustworthiness in this study through several means, as are described below. I will describe specific data that confirm the trustworthiness of the study in Chapter Five: Interpretation of Findings.

Trustworthiness of data analysis was achieved through the following means:

1. **Triangulation through multiple data sources**: I conducted one to two interviews with study participants and created field notes of observations. I used

the quantitative data to confirm qualitative findings by analysis of data from the PDI, FACT-G, FSI-TT and demographics.

2. **Multiple coders**: I coded each interview, and asked another coder to independently code portions of interviews from a representative sample of the interviews. Discrepancies were discussed and resolved by reanalyzing
3. **Member checks**: Interpretation of data was presented to study participants to discern the degree of congruence of data with their own experience. After conclusion of the second interview and after the completion of data analysis, the coding scheme and interpretation was presented to study participants to determine if the interpretation fits their experience.
4. **Audit Trail**: I kept careful records of the data collection and analysis in order to serve as a means of documenting all steps of the research process.
5. **Mentor Debriefing**: I discussed my analysis scheme with Dr. Howell almost weekly. This ensured that my analysis and interpretation were on target. As she is a skilled grounded theory researcher, her insights helped me analyze and interpret the data in a systematic and logical manner.

Summary

This study employed a mixed methods approach to explore the experiences of mothers with breast cancer. A group of 32 participants were recruited and administered the quantitative measures (demographic data, the Parent Disability Inventory, Fatigue Symptom Inventory Then Test and the Short Form 36). Of this group, 10 participants were selected and interviewed on one separate occasion. Quantitative data were analyzed using SPSS 22 statistical package to calculate descriptive statistics and correlations.

Qualitative data were analyzed using a narrative research approach using HyperResearch computer-assisted qualitative data analysis software. Results were shared with participants through member checks in order to ensure trustworthiness.

CHAPTER FOUR: RESULTS

Summary of Study Participants

I recruited 32 participants from Markey Cancer Center's Comprehensive Breast Care Center at the University of Kentucky Medical Center. Participants were identified by clinic staff and were approached within the clinic space about willingness to participate. Of the 32 participants who were willing to participate, one participant was removed from the study because she only lives with her children two of five days a week (failure to meet inclusion criteria). Two participants had missing data, although available data were analyzed with completed data. Of the 32 participants, 10 completed interviews.

All 32 participants completed the informed consent forms followed by quantitative measures that included a demographic cover sheet, the Fatigue Symptom Inventory Then Test (FSI-TT), and Functional Assessment of Cancer Treatment-General (FACT-G) and the Parent Disability Index (PDI). Table 4.1 summarizes demographic information provided by the study participants. The mean age of participants was 39.67 years (SD=6.39) with a range of 25 to 54 years of age. For the interview subset of the sample (n=10), the mean age was 41.90 years (SD=7.28), with a range of 30 to 54 years of age. Demographics of the interviewees are summarized in Table 4.2.

Summary of Interviewees

The lives of ten women who participated in interviews are summarized below. These profiles were complied from their demographic forms and information they provided during their interviews.

Cheryl was an energetic and friendly 48-year-old mother of three children, ages 11, 17 and 20 years. In July of 2005, she was diagnosed with breast cancer and was treated with chemotherapy and radiation, leading to remission. She was newly divorced and continued to care for her children and work full-time during the diagnosis and treatment. In September 2012, she was having vision problems, which resulted in a diagnosis of Stage IV metastatic breast cancer. The vision problems were a result of a brain tumor that was a breast cancer metastasis. At the time of the interview, she was taking IV chemotherapy every three weeks for an indefinite period of time. Although she had the most progressive disease of all of the interviewees, she had the highest quality of life measures and lowest reported fatigue. She worked fulltime, as she had done during both cancer bouts of cancer treatments.

Denise was a 29-year-old mother and stepmother of five children (ages 15, 14, 14, 12 and 10 years), all who resided with her and her husband. Denise had a direct and humorous demeanor, and her favorite things to do, both before and after her cancer diagnosis, involved spending time with her children. At the time of the interview, she was having an infusion of her last of six chemotherapy sessions. She was not working due to being laid off since she was unable to perform her job duties because of breast cancer.

Ellen was a cheerful and friendly mother of one child, age 2. She was a stay at home mom with her son, and she lived with him and her husband, who had a well-paying job at a local electronics company. She was very involved in various cancer organizations including the Susan G. Koman Foundation, the Kentucky Pink Connection, the Relay for Life, and the Leukemia Lymphoma Society Team in Training. Her son was just five months old when she found a lump in her breast, which her physician thought was just a milk duct from breastfeeding. However, Ellen continued to pursue ruling out cancer and discovered that she had a very rare condition of having two different types of breast cancer at the same time. At the time of the interview, she was just declared to be in remission from her oncologists. She presented with a variety of chemotherapy-induced side effects, such as a frozen shoulder, hearing loss, and nausea secondary to a C. diff infection.

Kimberly was a 45-year-old mother of two children, ages 9 and 19. Her older daughter was currently a college student, and at the time of the interview, was home on summer break. This current breast cancer recurrence was her fourth occurrence of breast cancer. She worked full-time and continued to work during each occurrence, with the exception of time off after chemotherapy sessions.

Lori was a married 46-year-old mother of two children, ages 1.5 and 4 years. At the time of the interview, she had just received news that she is in remission. She was not working outside the home at the time of the interview, and she assumed responsibility for care for her children after they returned from day care. Her husband started working most days of the week due to unpaid medical bills and Lori’s inability to work due to cancer treatments.

Melissa was a married 44-year-old mother with one son, who was 15 years old. At the time of the interview, she just had breast reconstruction surgery and was in a lot of pain. She was an elementary school teacher in a rural school district, which allowed her to have the summer to recover from cancer treatments. During chemotherapy, she had severe nausea that got worse from treatment to treatment. She was on Tamoxofen and still experienced quite a bit of nausea at the time of the interview.

Rebecca was a 45-year-old divorced mother of one daughter, age 13. At the time of the interview, she was in remission but taking Herceptin treatments. She worked full-time, as she had done during the chemotherapy process. She just now started to get back to her favorite activities, such as hiking and camping, although she still experienced some fatigue secondary to chemotherapy.

Sarah was a 38-year-old married mother of one son, age 7. She was an attorney before her son was born and did not work secondary to health issues. At the time of the interview, she was finished with cytotoxic chemotherapy but was getting infusions of Herceptin. She was well-educated and articulate, and she was responsible for most of the childcare and household activities.

Shannon was a 38-year-old single mother of two daughters, ages 13 and 17 years. This was her second occurrence of breast cancer, and she was currently getting infusions of Herceptin at the time of the interview. She was an energetic and positive person who continued to work during all cancer treatments.

Shirley was a 56-year-old mother of two daughters, ages 15 and 20 years old, both of whom lived with her. Her older daughter also had a 6-month-old baby for whom Shirley helped provide care. Two months before her cancer diagnosis, her husband died of kidney disease. At the time of the interview, she had just found out that she is in remission.

Table 4.1. *Characteristics of participants*

Characteristic	All participants	Interviewees
Number of participants (N)	31	10
Age at time of survey (years)		
Mean	39.67	41.90
SD	6.39	7.28
Recurrences		
Mean	.25	.50
SD	.62	.97
County of residence		
Rural	53.1%	10%
Urban	46.9%	90%
Education		
Some high school	12.5%	20%
High school diploma	6.3%	0%
Some college	34.4%	20%
College degree	21.9%	40%
Graduate school	25.0%	20%
Race		
Black or African American	9.4%	10%
White	90.6%	90%
Income		
Less than $15,000	20.0%	0%
$15,000 to $24,999	26.7%	20.0%
$25,000 to $39,999	13.3%	30.0%
$40,000 to $54,999	6.7%	20.0%
$55,000 to $69,999	3.3%	10%
$70,000 to $84,999	6.7%	10%
$85,000 to $99,999	3.3%	0%
Over $100,000	20.0%	0%
Number of children living at home		2.20
Mean	2.25	
SD	1.016	1.23
Age of children		12.42
Mean (years)	11.12	
SD	4.312	4.64
Stage		40%
I	20.7%	
II	34.5%	20%
III	20.7%	0%
IV	24.1%	40%

Table 4.2. *Characteristics of interviewees*

Pseudonym	Age	Number of children at home	Ages (years)	Urban vs. Rural	Marital Status
Cheryl	48	3	11, 17, 20	Urban	Divorced
Denise	29	5	10, 12, 14, 14, 15	Urban	Married
Ellen	35	1	2	Urban	Married
Kimberly	45	2	8, 19	Urban	Divorced
Lori	47	2	1.5, 4	Urban	Married
Melissa	44	1	15	Rural	Married
Rebecca	46	1	14	Urban	Divorced
Sarah	38	1	7	Urban	Married
Shannon	39	2	13, 17	Urban	Unmarried
Shirley	55	3	15, 20, .5 (grandchild)	Urban	Widowed

I will first describe the quantitative results and statistical analysis followed by the qualitative results. The final section of this chapter will describe results for the intersection between these two data sources for the mixed methods results.

Quantitative Data Analysis

I calculated descriptive statistics and Spearman Rho rank correlations for demographic data, PDI items, FACT-G items, and FSI-TT items. These results are shown in the following seven tables (Table 4.3 through 4.9). For mothers with children 0 to 5 years old, Table 4.3 summarizes frequencies of levels of difficulty for parenting tasks on the PDI. Due to the small sample (N=7), these results are not generalizable. However, there were some parenting tasks that were more difficult for mothers than others. Five of seven mothers (71.1%) responded having a lot of difficulty or being unable to pick up and carry her child, while only one of six (16.7%) mothers had a lot of difficulty or was unable to open medicine or childproof containers. Five of seven mothers (71.4%) responded that they had no difficulty in keeping their child out of unsafe situations. Regardless of the parenting task, between 16.7% and 83.3% of mothers responded that they did respective parenting tasks less because of breast cancer treatments. For the column "did less," this is the frequency of participants who still participated in the activity but did that activity less than before cancer. Therefore, this calculation represents the degree to which the mothers participated in the activity less often.

For mothers with children 6 to 18 years old, Table 4.4 summarizes frequencies of levels of difficulty for parenting tasks on the PDI. Mothers had the most difficulty with tasks involving having other children in their home (41.3% had a lot of difficulty or was unable to do), and doing household chores or shopping (35.7% had a lot of difficulty or were unable to do). The item that mothers of children over 6 had the least amount of difficulty with was keeping her child out of unsafe situations (85.2% had no or some difficulty).

Table 4.5 summarizes the Spearman Rho (r) correlation coefficients between PDI items and elements of QOL from the FACT-G. For mothers of children 0 to 5 years of age, there were a number of parenting items that were correlated with physical wellbeing. Physical wellbeing was correlated with difficulty in diapering or dressing, feeding children, taking care of the child while out of the house, getting up and down to the floor to play, keeping child out of unsafe situations, getting up with child, having other children in the home, and using a car seat. Items significantly correlated with functional wellbeing were diaper and dressing the child, and keeping the child out of unsafe situations. Items that mothers rated as doing less because of breast cancer and poor physical wellbeing were keeping the child out of unsafe situations, having other children in their home, using a stroller, and using a car seat. However, there were only seven participants with children under age 6 living in the home, and one participant had missing data on the PDI, therefore this is a limitation to the generalizability of these inferences.

Table 4.6 summarizes the Spearman Rho Rank Correlation between PDI items for mothers of children 6 to 18 years old and total QOL and the FACT-G subsections of physical wellbeing, social wellbeing, emotional wellbeing, and functional wellbeing. Physical wellbeing items that were significantly correlated with PDI tasks were taking the child to all of the places s/he needs to go, being involved in the child’s school functions, helping the child with homework or school projects, playing with the child outdoors, having other children in the home, going with the child to social events or recreational activities, getting up with the child, taking care of the child when sick, keeping child out of unsafe situations, cooking or preparing food, and doing household chores or shopping. The item that correlated with poorer social wellbeing was being involved in school functions. Items that correlated with poorer emotional wellbeing were taking the child to all the places s/he needs to go, being involved in school functions, helping the child with homework or school projects, playing outdoors, having other children in the home, going with the child to social events or recreational activities, getting up with the child, taking care of the child when sick, keeping child out of unsafe situations, maintaining discipline, cooking or preparing food, and household chores or shopping. PDI items that were significantly correlated with functional wellbeing were taking the child to all of the places s/he needs to go, being involved in school functions, helping the child with homework, playing with the child outdoors, having other children in the home, going with the child to social events or recreational activities, getting up with the child, taking care of the child when sick, keeping the child out of unsafe situations, maintaining discipline, cooking or preparing food, and doing household chores or shopping. Similarly, PDI items that were correlated with total QOL were taking the child to all of the places s/he needs to go, being involved in school functions, helping the child with homework, playing with the child outdoors, having other children in the home, going with the child to social events or recreational activities, getting up with the child, taking care of the child when sick, keeping the child out of unsafe situations, maintaining discipline, and cooking or preparing food.

For the PDI, a higher score on an item represents more difficulty in participating in the task. Following the method of Katz, Pasch and Wong (2003), who designed the survey for mothers with rheumatoid arthritis, I changed the task score to 2 for items that mothers rated “did not do for reasons other than cancer” because these were still items of difficulty for the mother. However, Tables 4.3 and 4.4 show the frequencies for items before this adjustment was made. Showing frequencies before this adjustment gives a picture of how many items the mothers did not do because of reasons other than cancer. For correlation tests, I used this technique of changing the score to 2. For the FACT-G, a higher score means a participant rated her quality of life as better. I reported a total QOL score, which was the sum of each item after conversion according to the test administration guidelines (Appendix F). For the FSI-TT, items that rate the degree that fatigue interfered with activities (items 5, 6, 7, 8, 9, 10, and 11) were combined for a Fatigue Interference score. A higher Fatigue Interference score means a higher degree that fatigue interfered with daily activities.

Since the PDI items provided a lot of data, I combined parenting tasks that were similar in nature for better clarification of correlation results. I combined parenting tasks occurring in the home together (see Table 4.7), which included items of home daily care routines and activities such as diapering and feeding the child. I grouped parenting tasks that were based in the community together, which included taking the child all the places he or she needs to go and going to school functions. Finally, I grouped the parenting tasks that required a high degree of physical effort together, which included picking up and carrying the child and playing with the child outdoors.

Table 4.8 summarizes the frequencies of difficulty and intensity ratings for each PDI grouping. For example, for the home grouping, 49.7% of mothers of younger children and 59.0% of mothers of older children said they did these tasks less because of cancer. In another example, for physical activities, 4 of 7 mothers of younger children (53.3%) rated having a lot of difficulty or being unable to do those items. Due to missing data, the N in each group may be slightly different, but the percentage represents the total of participants who responded to that question.

Table 4.9 shows the median, mode and range for items on the FSI-TT and the FACT-G. An important thing to note is the wide range of scores on all items, with some participants responding having no fatigue or poorer QOL due to cancer treatments, to having daily fatigue that interferes with most functional activities and poorer QOL. I will discuss disparity of scores for individual participants in Chapter 5: Interpretation of Results.

Table 4.10 shows the Spearman Rho correlation between PDI groups and FACT-G domains. An important finding to note is that physical wellbeing, functional wellbeing, and emotional wellbeing for the older children ($P<.001$), but not for social wellbeing or for any item groupings for younger children.

For doing less because of cancer, a negative correlation meant that mothers with a poorer quality of life scored doing this activity less because of cancer. See Tables 4.11 and 4.12 for a summary of items mothers rated as doing less because of cancer at the level of significance. Some examples of note are taking child to all the places s/he needs to go for physical wellbeing and total QOL and helping with homework.

Table 4.3. *PDI Difficulty ratings for tasks involving younger children (ages 0 –5 years)*

		Frequency and percent total of difficulty rating							
PDI Younger Children Item	N	None	Some	A lot	Unable	Did not do	None/ some	A lot/ Unable	Did less
Diapering, dressing, or helping your child with dressing	7	4 57.1%	1 14.3%	1 14.3%	1 14.3%	0 0%	5 71.4%	2 28.6%	4 57.1%
Taking care of your child's hygiene needs	7	3 42.9%	4 57.1%	0 0%	0 0%	0 0%	7 100.0%	0 0.0%	4 57.1%
Feeding your child, or preparing food	7	2 28.6%	3 42.9%	1 14.3%	1 14.3%	0 0%	5 71.5%	2 28.6%	3 42.9%
Picking up or carrying your child	7	1 14.3%	0 0%	1 14.3%	4 57.1%	1 14.3%	1 14.3%	5 71.4%	3 42.9%
Taking care of your child while out of the house	7	2 28.6%	2 28.6%	0 0%	2 28.6%	1 14.3%	4 57.1%	2 28.6%	4 57.1%
Taking your child out in the car	7	3 42.9%	1 14.3%	0 0%	2 28.6%	1 14.3%	4 57.1%	2 28.6%	4 57.1%
Getting up and down to the floor to play with your child	7	2 28.6%	3 42.9%	1 14.3%	1 14.3%	0 0%	5 71.5%	2 28.6%	4 57.1%
Keeping your child out of unsafe situations	7	5 71.4%	0 0%	1 14.3%	1 14.3%	0 0%	5 71.4%	2 28.6%	2 28.6%

		Frequency and percent total of difficulty rating							
PDI Younger Children Item	N	None	Some	A lot	Unable	Did not do	None/ some	A lot/ Unable	Did less
Getting up with your child, either during the night or early in the morning	7	2 28.6%	2 28.6%	3 42.9%	0 0%	0 0%	4 57.2%	3 42.9%	5 71.4%
Playing with your child outdoors	7	1 14.3%	1 14.3%	4 57.1%	1 14.3%	0 0%	2 28.6%	5 71.4%	5 71.4%
Having other children in your home	7	2 28.6%	2 28.6%	0 0%	3 42.9%	0 0%	4 57.2%	3 42.9%	4 57.1%
Taking your child to social events or recreational activities	7	3 42.9%	1 14.3%	1 14.3%	1 14.3%	1 14.3%	4 57.2%	2 28.6%	3 42.9%
Taking care of your child when s/he is sick	7	2 28.6%	3 42.9%	2 28.6%	0 0%	0 0%	5 71.5%	2 28.6%	4 57.1%
Maintaining discipline with your child	7	3 42.9%	2 28.6%	2 28.6%	0 0%	0 0%	5 71.5%	2 28.6%	5 71.4%
Doing household chores or shopping	6	1 16.7%	1 16.7%	3 50.0%	1 16.7%	0 0%	2 33.3%	4 66.7%	5 83.3%
Using a stroller	6	1 16.7%	2 33.3%	2 33.3%	0 0%	1 16.7%	3 50.0%	2 33.3%	2 33.3%

		Frequency and percent total of difficulty rating							
PDI Younger Children Item	N	None	Some	A lot	Unable	Did not do	None/ some	A lot/ Unable	Did less
Using a car seat	6	4 66.7%	1 16.7%	1 16.7%	0 0%	0 0%	5 83.3%	1 16.7%	2 16.7%
Opening safety latches or locks	6	5 83.3%	0 0%	1 16.7%	0 0%	0 0%	5 83.3%	1 16.7%	1 16.7%
Opening medicine or childproof containers	6	5 83.3%	0 0%	0 0%	1 16.7%	0 0%	5 83.3%	1 16.7%	1 16.7%

Table 4.4. Difficulty ratings for older children (ages 6 - 18 years)

		Frequency and percent of total of difficulty rating							
PDI Older Children Item	N	None	Some	A lot	Unable	Did not do	None/ some	A lot/ Unable	Did less
Taking your child to all the places s/he needs to go	29	10 34.5%	11 37.9%	5 16.1%	3 10.3%	0 0%	21 72.4%	8 27.5%	20 69.0%
Being involved in your child's school functions	29	8 27.6%	13 44.8%	5 17.2%	3 10.3%	0 0%	21 72.4%	8 27.5%	20 69.0%
Helping your child with homework or school projects	29	12 41.4%	11 37.9%	5 17.2%	1 3.4%	0 0%	23 79.3%	6 20.6%	17 58.6%
Playing with your child outdoors	29	6 20.7%	12 41.4%	6 20.7%	4 13.8%	1 3.4%	18 62.1%	10 34.5%	23 79.3%
Having other children in your home	29	6 20.7%	9 31.0%	7 24.1%	5 17.2%	2 6.8%	15 54.7%	12 41.3%	19 65.5%
Going with your child to social events or recreational activities	28	7 25.0%	13 46.4%	3 10.7%	5 17.9%	0 0%	20 71.4%	8 28.6%	20 71.4%
Getting up with your child, either during the night or early in the morning	27	11 40.7%	10 37.0%	5 18.5%	1 3.7%	0 0%	21 77.7%	6 22.2%	16 59.3%
Taking care of your child when s/he is sick	27	15 55.6%	6 22.2%	3 11.1%	3 11.1%	0 0%	21 77.7%	6 22.2%	12 44.4%

PDI Older Children Item	N	Frequency and percent of total of difficulty rating							
		None	Some	A lot	Unable	Did not do	None/ some	A lot/ Unable	Did less
Keeping your child out of unsafe situations	27	17 63.0%	6 22.2%	2 6.4%	1 3.2%	1 3.2%	23 85.2%	3 9.6%	11 40.7%
Maintaining discipline with your child	27	11 40.7%	11 40.7%	3 11.1%	1 3.7%	1 3.7%	22 81.4%	4 14.8%	17 63.0%
Cooking or preparing food for your child	27	9 33.3%	9 33.3%	6 22.2%	3 11.1%	0 0%	18 66.6%	9 33.3%	17 63.0%
Doing household chores or shopping	28	7 25.0%	11 39.3%	8 28.6%	2 7.1%	0 0%	18 64.3%	10 35.7%	22 78.6%

Table 4.5. *Spearman Rho correlation between Parent Disability Inventory Items for Ages 0 - 5 and FACT-G*

PDI Younger Children Item	Test Statistics	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Diapering, dressing, or helping your child with dressing	Spearman rho	-.803*	-.880*	.516	-.092	-.355
	Sig. (2-tailed)	.030	.021	.236	.862	.435
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.514	-.414	0.000	-.525	.144
	Sig. (2-tailed)	.237	.414	1.000	.285	.758
	N	7	6	7	6	7
Taking care of your child's hygiene needs	Spearman rho	-.686	-.618	.093	-.179	-.094
	Sig. (2-tailed)	.089	.191	.842	.734	.842
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.514	-.414	0.000	-.525	.144
	Sig. (2-tailed)	.237	.414	1.000	.285	.758
	N	7	6	7	6	7
Feeding your child	Spearman rho	-.905**	-.638	0.000	-.062	.019
	Sig. (2-tailed)	.005	.173	1.000	.908	.968
	N	7	6	7	6	7

PDI Younger Children Item	Test Statistics	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Did less because of cancer	Spearman rho	-.514	-.414	0.000	-.525	.144
	Sig. (2-tailed)	.237	.414	1.000	.285	.758
	N	7	6	7	6	7
Picking up or carrying your child	Spearman rho	-.639	-.034	-.522	-.051	.239
	Sig. (2-tailed)	.122	.949	.230	.923	.606
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.514	-.293	-.180	0.000	0.000
	Sig. (2-tailed)	.237	.573	.699	1.000	1.000
	N	7	6	7	6	7
Taking care of your child while out of the house	Spearman rho	-.897**	-.794	.160	-.313	-.055
	Sig. (2-tailed)	.006	.059	.731	.545	.907
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.661	0.000	-.540	.105	.289
	Sig. (2-tailed)	.106	1.000	.211	.843	.530
	N	7	6	7	6	7

PDI Younger Children Item	Test Statistics	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Taking your child out in the car	Spearman rho	-.743	-.794	.280	-.299	-.168
	Sig. (2-tailed)	.056	.059	.543	.565	.718
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.294	-.207	0.000	.420	0.000
	Sig. (2-tailed)	.522	.694	1.000	.407	1.000
	N	7	6	7	6	7
Getting up and down to the floor to play with your child	Spearman rho	-.905**	-.638	0.000	-.062	.019
	Sig. (2-tailed)	.005	.173	1.000	.908	.968
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.514	-.414	0.000	-.525	.144
	Sig. (2-tailed)	.237	.414	1.000	.285	.758
	N	7	6	7	6	7
Keeping your child out of unsafe situations	Spearman rho	-.794*	-.845*	.389	-.017	-.490
	Sig. (2-tailed)	.033	.034	.389	.974	.264
	N	7	6	7	6	7

PDI Younger Children Item	Test Statistics	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Did less because of cancer	Spearman rho	-.805*	-.828*	.394	.105	-.474
	Sig. (2-tailed)	.029	.042	.381	.843	.282
	N	7	6	7	6	7
Getting up with your child, either during the night or early in the morning	Spearman rho	-.828*	-.741	.165	-.501	.038
	Sig. (2-tailed)	.022	.092	.724	.311	.936
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.725	-.131	-.394	-.531	.474
	Sig. (2-tailed)	.065	.805	.381	.278	.282
	N	7	6	7	6	7
Playing with your child outdoors	Spearman rho	-.572	-.507	.197	.257	.118
	Sig. (2-tailed)	.180	.305	.673	.623	.801
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.725	-.131	-.394	-.531	.474
	Sig. (2-tailed)	.065	.805	.381	.278	.282
	N	7	6	7	6	7

PDI Younger Children Item	Test Statistics	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Having other children in your home	Spearman rho	-.828*	-.741	.165	-.501	.038
	Sig. (2-tailed)	.022	.092	.724	.311	.936
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.882**	-.621	.180	-.315	0.000
	Sig. (2-tailed)	.009	.188	.699	.543	1.000
	N	7	6	7	6	7
Taking your child to social events or recreational activities	Spearman rho	-.696	-.706	.280	-.224	-.094
	Sig. (2-tailed)	.083	.117	.543	.670	.842
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.735	-.878*	.540	-.396	-.289
	Sig. (2-tailed)	.060	.021	.211	.437	.530
	N	7	6	7	6	7
Taking care of your child when s/he is sick	Spearman rho	-.520	-.741	.448	-.485	-.340
	Sig. (2-tailed)	.232	.092	.314	.329	.455
	N	7	6	7	6	7

PDI Younger Children Item	Test Statistics	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Did less because of cancer	Spearman rho	-.520	-.741	.448	-.485	-.340
	Sig. (2-tailed)	.232	.092	.314	.329	.455
	N	7	6	7	6	7
Maintaining discipline with your child	Spearman rho	.231	-.309	.189	-.845*	-.472
	Sig. (2-tailed)	.618	.552	.686	.034	.284
	N	7	6	7	6	7
Did less because of cancer	Spearman rho	-.081	-.414	.197	-.525	-.316
	Sig. (2-tailed)	.864	.414	.672	.285	.490
	N	7	6	7	6	7
Doing household chores or shopping	Spearman rho	-.563	-.577	.144	-.616	-.395
	Sig. (2-tailed)	.245	.231	.786	.193	.439
	N	6	6	6	6	6
Did less because of cancer	Spearman rho	-.539	-.131	-.310	-.531	.131
	Sig. (2-tailed)	.269	.805	.550	.278	.805
	N	6	6	6	6	6

PDI Younger Children Item	Test Statistics	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Using a stroller	Spearman rho	-.509	-.278	-.018	-.736	-.031
	Sig. (2-tailed)	.303	.594	.973	.095	.954
	N	6	6	6	6	6
Did less because of cancer	Spearman rho	-.853*	-.828*	.490	.105	-.828*
	Sig. (2-tailed)	.031	.042	.324	.843	.042
	N	6	6	6	6	6
Using a car seat	Spearman rho	-.836*	-.845*	.480	-.017	-.845*
	Sig. (2-tailed)	.038	.034	.335	.974	.034
	N	6	6	6	6	6
Did less because of cancer	Spearman rho	-.853*	-.828*	.490	.105	-.828*
	Sig. (2-tailed)	.031	.042	.324	.843	.042
	N	6	6	6	6	6
Opening safety latches or locks	Spearman rho	-.539	-.655	.310	-.399	-.655
	Sig. (2-tailed)	.269	.158	.550	.434	.158
	N	6	6	6	6	6

PDI Younger Children Item	Test Statistics	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Did less because of cancer	Spearman rho	-.539	-.655	.310	-.399	-.655
	Sig. (2-tailed)	.269	.158	.550	.434	.158
	N	6	6	6	6	6
Opening medicine or childproof containers	Spearman rho	.775	.775	-.544	.258	.775
	Sig. (2-tailed)	.225	.225	.456	.742	.225
	N	4	4	4	4	4
Did less because of cancer	Spearman rho	-.539	-.655	.310	-.399	-.655
	Sig. (2-tailed)	.269	.158	.550	.434	.158
	N	6	6	6	6	6

** *P*-value < .01
* *P*-value < .05

Table 4.6. *Spearman Rho Rank Order Correlation between PDI for older children and QOL*

PDI Older Children Item	Test Statistic	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Taking your child to all the places s/he needs to go	Spearman rho	-.614**	-.494**	-.189	-.517**	-.408*
	Sig. (2-tailed)	.000	.009	.326	.005	.028
	N	29	27	29	28	29
Did less because of cancer	Spearman rho	-.558**	-.371	-.322	-.492**	-.348
	Sig. (2-tailed)	.002	.057	.088	.008	.065
	N	29	27	29	28	29
Being involved in your child's school functions	Spearman rho	-.683**	-.634**	-.380*	-.564**	-.555**
	Sig. (2-tailed)	.000	.000	.042	.002	.002
	N	29	27	29	28	29
Did less because of cancer	Spearman rho	-.603**	-.355	-.188	-.413*	-.339
	Sig. (2-tailed)	.001	.069	.329	.029	.072
	N	29	27	29	28	29
Helping your child with homework or school projects	Spearman rho	-.519**	-.554**	-.227	-.545**	-.454*
	Sig. (2-tailed)	.004	.003	.236	.003	.013
	N	29	27	29	28	29

PDI Older Children Item	Test Statistic	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Did less because of cancer	Spearman rho	-.541**	-.553**	-.151	-.564**	-.444*
	Sig. (2-tailed)	.002	.003	.433	.002	.016
	N	29	27	29	28	29
Playing with your child outdoors	Spearman rho	-.718**	-.636**	-.219	-.615**	-.491**
	Sig. (2-tailed)	.000	.000	.254	.000	.007
	N	29	27	29	28	29
Did less because of cancer	Spearman rho	-.454*	-.362	-.286	-.568**	-.239
	Sig. (2-tailed)	.013	.063	.132	.002	.211
	N	29	27	29	28	29
Having other children in your home	Spearman rho	-.594**	-.614**	-.207	-.502**	-.582**
	Sig. (2-tailed)	.001	.001	.281	.007	.001
	N	29	27	29	28	29
Did less because of cancer	Spearman rho	-.569**	-.460*	-.192	-.400*	-.373*
	Sig. (2-tailed)	.001	.016	.319	.035	.046
	N	29	27	29	28	29

PDI Older Children Item	Test Statistic	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Going with your child to social events or recreational activities	Spearman rho	-.607**	-.446*	-.346	-.440*	-.496**
	Sig. (2-tailed)	.001	.020	.071	.019	.007
	N	28	27	28	28	28
Did less because of cancer	Spearman rho	-.496**	-.319	-.290	-.374	-.401*
	Sig. (2-tailed)	.007	.105	.134	.050	.034
	N	28	27	28	28	28
Getting up with your child, either during the night or early in the morning	Spearman rho	-.641**	-.551**	-.160	-.512**	-.478*
	Sig. (2-tailed)	.000	.004	.425	.006	.012
	N	27	26	27	27	27
Did less because of cancer	Spearman rho	-.466*	-.365	-.097	-.443*	-.378
	Sig. (2-tailed)	.014	.067	.629	.021	.052
	N	27	26	27	27	27
Taking care of your child when s/he is sick	Spearman rho	-.547**	-.476*	-.171	-.422*	-.496**
	Sig. (2-tailed)	.003	.014	.393	.029	.008
	N	27	26	27	27	27

PDI Older Children Item	Test Statistic	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Did less because of cancer	Spearman rho	-.552**	-.490*	-.063	-.414*	-.526**
	Sig. (2-tailed)	.003	.011	.757	.032	.005
	N	27	26	27	27	27
Keeping your child out of unsafe situations	Spearman rho	-.434*	-.454*	-.108	-.415*	-.383*
	Sig. (2-tailed)	.024	.020	.593	.031	.049
	N	27	26	27	27	27
Did less because of cancer	Spearman rho	-.500**	-.453*	-.063	-.477*	-.397*
	Sig. (2-tailed)	.008	.020	.754	.012	.040
	N	27	26	27	27	27
Maintaining discipline with your child	Spearman rho	-.360	-.504**	-.343	-.666**	-.479*
	Sig. (2-tailed)	.065	.009	.080	.000	.011
	N	27	26	27	27	27
Did less because of cancer	Spearman rho	-.301	-.301	-.218	-.500**	-.295
	Sig. (2-tailed)	.127	.135	.275	.008	.135
	N	27	26	27	27	27

PDI Older Children Item	Test Statistic	Physical Wellbeing	Functional Wellbeing	Social Wellbeing	Emotional Wellbeing	Total QOL
Cooking or preparing food for your child	Spearman rho	-.563**	-.547**	-.264	-.604**	-.586**
	Sig. (2-tailed)	.002	.004	.183	.001	.001
	N	27	26	27	27	27
Did less because of cancer	Spearman rho	-.449*	-.434*	-.168	-.470*	-.497**
	Sig. (2-tailed)	.019	.027	.402	.013	.008
	N	27	26	27	27	27
Doing household chores or shopping	Spearman rho	-.532**	-.454*	-.194	-.547**	-.367
	Sig. (2-tailed)	.004	.020	.322	.003	.055
	N	28	26	28	27	28
Did less because of cancer	Spearman rho	-.459*	-.405*	-.303	-.597**	-.264
	Sig. (2-tailed)	.014	.040	.117	.001	.175
	N	28	26	28	27	28

** *P*-value < .01 * *P*-value < .05

Table 4.7. *PDI groupings for younger child and older child items*

Grouping	**Younger child items**	**Older child items**
Home daily childcare routines	• Diapering, dressing • Hygiene • Feeding • Getting up with child • Having children over • Taking care of child when sick • Opening safety latches • Opening medicine bottles	• Helping with homework • Having children over • Getting up with child • Taking care of child when sick • Maintaining discipline • Preparing food for child
Community activities	• Providing care outside the home • Taking child out in the car • Taking child to social events • Using a car seat • Using a stroller	• Taking child to places • Being involved in child's school • Going with child to social events
Physical activities	• Picking up or carrying child • Getting up and down from the floor to play • Keeping child safe • Playing with child outdoors • Household chores, shopping	• Playing with child outdoors • Keeping child safe • Household chores, shopping

Table 4.8. *PDI groupings, difficulty and frequency of parenting tasks*

Grouping	**A lot/unable to do N (%)**	**Did less because of cancer N (%)**
Home		
0-5	2 (27.1%)	3 (49.7%)
6-18	7 (25.7%)	17 (59.0%)
Community		
0-5	2 (27.1%)	3 (41.4%)
6-18	6 (24.7%)	15 (52.4%)
Physical		
0-5	4 (53.3%)	4 (56.7%)
6-18	8 (26.6%)	18 (66.2%)
Overall Average		
0-5	3 (34.5%)	3 (46.9%)
6-18	8 (26.6%)	18 (63.5%)

Table 4.9. *Median, mode and range of ratings on the FSI-TT and FACT-G*

Measure	Median	Mode	Range
Physical Wellbeing	19	11	28
Social wellbeing	23	24	20
Emotional wellbeing	17.5	16	21
Functional wellbeing	19	19	24.5
Total QOL	74	74	77
Fatigue on day before treatment	3	3	10
Least fatigued last week	3	3	10
Fatigue average before treatment	3	3	10
Fatigue now	4	4	10
Fatigue interference	20	0	65
Days fatigued last week	4	7	10
How much of the day fatigued	4	7	10
Daily Pattern of fatigue	3	3	4

Table 4.10. *Spearman Rho Correlations between PDI groupings and FACT-G domains*

Parent disability grouping	**Physical well-being**		**Functional well-being**		**Emotional well-being**		**Social well-being**	
Age (years)	0-5	6-18	0-5	6-18	0-5	6-18	0-5	6-18
Home routines	-.765 (.076)	-.673 (<.001)**	-.771 (.072)	-.687 (<.001)**	-.435 (.389)	-.674 (<.001)**	.372 (.468)	-.233 (.241)
Community	-.687 (.132)	-.669 (<.001)**	-.771 (.072)	-.545 (.003)**	-.435 (.389)	-.533 (.003)**	.372 (.468)	-.292 (.131)
Physical	-.687 (.132)	-.669 (<.001)**	-.580 (.228)	-.605 (.001)**	-.221 (.674)	-.634 (<.001)**	-.127 (.795)	.154 (.443)

** *P*-value < .01 * *P*-value < .05

Table 4.11. *Spearman Rho Rank Correlation between Parent Disability Inventory and Fatigue Interference from the FSI-TT*

PDI Younger Children Item	Test Statistic	Fatigue before	Least last week	Ave. before	Fatigue Now	Days fatigued	% of day fatigued	Daily pattern	Fatigue Interfere
Diapering, dressing, or helping your child with dressing	Spearman rho	.692	.532	.132	.552	.803*	.532	-.730	.256
	Sig. (2-tailed)	.085	.219	.778	.199	.030	.219	.063	.579
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	.441	.220	0.000	.147	.882**	0.000	-.764*	.433
	Sig. (2-tailed)	.322	.635	1.000	.753	.009	1.000	.046	.332
	N	7	7	7	7	7	7	7	7
Taking care of your child's hygiene needs	Spearman rho	.457	.553	.038	.362	.972**	.381	-.644	.318
	Sig. (2-tailed)	.302	.198	.935	.425	.000	.399	.119	.487
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	.441	.220	0.000	.147	.882**	0.000	-.764*	.433
	Sig. (2-tailed)	.322	.635	1.000	.753	.009	1.000	.046	.332
	N	7	7	7	7	7	7	7	7
Feeding your child, or preparing food	Spearman rho	.343	.648	-.269	.629	.905**	.553	-.792*	.374
	Sig. (2-tailed)	.451	.116	.559	.130	.005	.198	.034	.408
	N	7	7	7	7	7	7	7	7

PDI Younger Children Item	Test Statistic	Fatigue before	Least last week	Ave. before	Fatigue Now	Days fatigued	% of day fatigued	Daily pattern	Fatigue Interfere
Did less because of cancer	Spearman rho	.441	.220	0.000	.147	.882**	0.000	-.764*	.433
	Sig. (2-tailed)	.322	.635	1.000	.753	.009	1.000	.046	.332
	N	7	7	7	7	7	7	7	7
Picking up or carrying your child	Spearman rho	-.091	.517	-.461	.456	.639	.456	-.474	.299
	Sig. (2-tailed)	.846	.234	.298	.303	.122	.303	.282	.515
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	.220	.588	-.074	.220	.882**	.367	-.382	.144
	Sig. (2-tailed)	.635	.165	.874	.635	.009	.417	.398	.758
	N	7	7	7	7	7	7	7	7
Taking care of your child while out of the house	Spearman rho	.421	.570	-.085	.645	.897**	.495	-.826*	.514
	Sig. (2-tailed)	.347	.181	.856	.118	.006	.258	.022	.238
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	-.220	.661	-.519	.514	.661	.514	-.382	.289
	Sig. (2-tailed)	.635	.106	.232	.237	.106	.237	.398	.530
	N	7	7	7	7	7	7	7	7

PDI Younger Children Item	Test Statistic	Fatigue before	Least last week	Ave. before	Fatigue Now	Days fatigued	% of day fatigued	Daily pattern	Fatigue Interfere
Taking your child out in the car	Spearman rho	.572	.495	.115	.438	.934**	.381	-.743	.393
	Sig. (2-tailed)	.180	.258	.805	.325	.002	.399	.056	.383
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	0.000	.661	0.000	.147	.661	.294	0.000	0.000
	Sig. (2-tailed)	1.000	.106	1.000	.753	.106	.522	1.000	1.000
	N	7	7	7	7	7	7	7	7
Getting up and down to the floor to play with your child	Spearman rho	.343	.648	-.269	.629	.905**	.553	-.792*	.374
	Sig. (2-tailed)	.451	.116	.559	.130	.005	.198	.034	.408
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	.441	.220	0.000	.147	.882**	0.000	-.764*	.433
	Sig. (2-tailed)	.322	.635	1.000	.753	.009	1.000	.046	.332
	N	7	7	7	7	7	7	7	7
Keeping your child out of unsafe situations	Spearman rho	.408	.816*	.252	.680	.794*	.816*	-.354	.267
	Sig. (2-tailed)	.363	.025	.586	.093	.033	.025	.437	.562
	N	7	7	7	7	7	7	7	7

PDI Younger Children Item	Test Statistic	Fatigue before	Least last week	Ave. before	Fatigue Now	Days fatigued	% of day fatigued	Daily pattern	Fatigue Interfere
Did less because of cancer	Spearman rho	.483	.805*	.163	.644	.805*	.805*	-.418	.158
	Sig. (2-tailed)	.272	.029	.728	.118	.029	.029	.350	.735
	N	7	7	7	7	7	7	7	7
Getting up with your child, either during the night or early in the morning	Spearman rho	.433	.395	-.087	.568	.828*	.318	-.900**	.586
	Sig. (2-tailed)	.332	.381	.852	.184	.022	.488	.006	.167
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	0.000	.322	-.488	.483	.725	.161	-.837*	.632
	Sig. (2-tailed)	1.000	.481	.267	.272	.065	.730	.019	.127
	N	7	7	7	7	7	7	7	7
Playing with your child outdoors	Spearman rho	.391	.502	-.203	.251	.823*	.171	-.626	.118
	Sig. (2-tailed)	.385	.251	.663	.587	.023	.715	.133	.801
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	0.000	.322	-.488	.483	.725	.161	-.837*	.632
	Sig. (2-tailed)	1.000	.481	.267	.272	.065	.730	.019	.127
	N	7	7	7	7	7	7	7	7

PDI Younger Children Item	Test Statistic	Fatigue before	Least last week	Ave. before	Fatigue Now	Days fatigued	% of day fatigued	Daily pattern	Fatigue Interfere
Having other children in your home	Spearman rho	.433	.395	-.087	.568	.828*	.318	-.900**	.586
	Sig. (2-tailed)	.332	.381	.852	.184	.022	.488	.006	.167
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	.220	.441	-.223	.808*	.514	.514	-.764*	.577
	Sig. (2-tailed)	.635	.322	.631	.028	.237	.237	.046	.175
	N	7	7	7	7	7	7	7	7
Taking your child to social events or recreational activities	Spearman rho	.657	.372	0.000	.333	.886**	.257	-.842*	.281
	Sig. (2-tailed)	.109	.412	1.000	.465	.008	.578	.018	.542
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	.661	.367	.223	.514	.735	.367	-.764*	.433
	Sig. (2-tailed)	.106	.417	.631	.237	.060	.417	.046	.332
	N	7	7	7	7	7	7	7	7
Taking care of your child when s/he is sick	Spearman rho	.779*	.164	.340	.221	.712	.202	-.700	.283
	Sig. (2-tailed)	.039	.726	.456	.633	.073	.664	.080	.538
	N	7	7	7	7	7	7	7	7

PDI Younger Children Item	Test Statistic	Fatigue before	Least last week	Ave. before	Fatigue Now	Days fatigued	% of day fatigued	Daily pattern	Fatigue Interfere
Did less because of cancer	Spearman rho	.882**	0.000	.593	.147	.294	.294	-.382	0.000
	Sig. (2-tailed)	.009	1.000	.160	.753	.522	.522	.398	1.000
	N	7	7	7	7	7	7	7	7
Maintaining discipline with your child	Spearman rho	.260	-.250	.777*	-.202	.010	-.048	.200	.189
	Sig. (2-tailed)	.574	.588	.040	.664	.984	.918	.667	.685
	N	7	7	7	7	7	7	7	7
Did less because of cancer	Spearman rho	.725	-.161	.406	-.242	.483	-.081	-.418	0.000
	Sig. (2-tailed)	.065	.730	.366	.602	.272	.864	.350	1.000
	N	7	7	7	7	7	7	7	7
Doing household chores or shopping	Spearman rho	.554	.308	.438	.308	.875*	.339	-.492	.516
	Sig. (2-tailed)	.254	.553	.385	.553	.022	.511	.322	.295
	N	6	6	6	6	6	6	6	6
Did less because of cancer	Spearman rho	.266	0.000	-.270	.266	.539	.133	-.707	.393
	Sig. (2-tailed)	.611	1.000	.605	.611	.269	.802	.116	.441
	N	6	6	6	6	6	6	6	6

PDI Younger Children Item	Test Statistic	Fatigue before	Least last week	Ave. before	Fatigue Now	Days fatigued	% of day fatigued	Daily pattern	Fatigue Interfere
Using a stroller	Spearman rho	.016	0.000	.064	.564	.111	.204	-.417	.833*
	Sig. (2-tailed)	.977	1.000	.905	.244	.834	.699	.411	.039
	N	6	6	6	6	6	6	6	6
Did less because of cancer	Spearman rho	.630	.840*	.320	.630	.853*	.840*	-.335	0.000
	Sig. (2-tailed)	.180	.036	.537	.180	.031	.036	.516	1.000
	N	6	6	6	6	6	6	6	6
Using a car seat	Spearman rho	.549	.857*	.435	.686	.836*	.857*	-.237	.169
	Sig. (2-tailed)	.259	.029	.388	.132	.038	.029	.651	.749
	N	6	6	6	6	6	6	6	6
Did less because of cancer	Spearman rho	.630	.840*	.320	.630	.853*	.840*	-.335	0.000
	Sig. (2-tailed)	.180	.036	.537	.180	.031	.036	.516	1.000
	N	6	6	6	6	6	6	6	6
Opening safety latches or locks	Spearman rho	.133	.664	.674	.664	.539	.664	.141	.655
	Sig. (2-tailed)	.802	.150	.142	.150	.269	.150	.789	.158
	N	6	6	6	6	6	6	6	6

PDI Younger Children Item	Test Statistic	Fatigue before	Least last week	Ave. before	Fatigue Now	Days fatigued	% of day fatigued	Daily pattern	Fatigue Interfere
Did less because of cancer	Spearman rho	.133	.664	.674	.664	.539	.664	.141	.655
	Sig. (2-tailed)	.802	.150	.142	.150	.269	.150	.789	.158
	N	6	6	6	6	6	6	6	6
Opening medicine or childproof containers	Spearman rho	.133	.664	.674	.664	.539	.664	.141	.655
	Sig. (2-tailed)	.802	.150	.142	.150	.269	.150	.789	.158
	N	6	6	6	6	6	6	6	6
Did less because of cancer	Spearman rho	.133	.664	.674	.664	.539	.664	.141	.655
	Sig. (2-tailed)	.802	.150	.142	.150	.269	.150	.789	.158
	N	6	6	6	6	6	6	6	6

** $P < .01$
* $P < .05$

Table 4.12. Spearman Rho correlation between Parent Disability Inventory (Ages over 6 years) and FSI-TT items

PDI Older Children Item	Test Statistic	Fatigue before	Least last week	Average Fatigue Before	Fatigue Now	Days fatigued	% of day fatigued	Fatigue Daily Pattern	Fatigue interfere
Taking your child to all the places s/he needs to go	Spearman rho	-.019	.212	.059	.566**	.432*	.366	.089	.419*
	Sig. (2-tailed)	.920	.271	.761	.001	.022	.055	.651	.024
	N	29	29	29	29	28	28	28	29
Did less because of cancer	Spearman rho	-.005	.099	-.231	.444*	.517**	.247	-.010	.361
	Sig. (2-tailed)	.981	.608	.227	.016	.005	.204	.959	.054
	N	29	29	29	29	28	28	28	29
Being involved in your child's school functions	Spearman rho	-.064	.411*	.104	.499**	.372	.486**	.352	.396*
	Sig. (2-tailed)	.743	.027	.592	.006	.051	.009	.066	.033
	N	29	29	29	29	28	28	28	29
Did less because of cancer	Spearman rho	.041	.235	-.095	.417*	.398*	.346	-.108	.375*
	Sig. (2-tailed)	.834	.220	.623	.024	.036	.071	.585	.045
	N	29	29	29	29	28	28	28	29
Helping your child with homework or school projects	Spearman rho	-.133	.220	-.004	.504**	.312	.332	.096	.398*
	Sig. (2-tailed)	.490	.252	.983	.005	.107	.084	.627	.032
	N	29	29	29	29	28	28	28	29

PDI Older Children Item	Test Statistic	Fatigue before	Least last week	Average Fatigue Before	Fatigue Now	Days fatigued	% of day fatigued	Fatigue Daily Pattern	Fatigue interfere
Did less because of cancer	Spearman rho	.021	.170	.026	.514**	.377*	.339	-.019	.352
	Sig. (2-tailed)	.913	.379	.895	.004	.048	.078	.924	.061
	N	29	29	29	29	28	28	28	29
Playing with your child outdoors	Spearman rho	.067	.376*	.064	.573**	.582**	.626**	.135	.536**
	Sig. (2-tailed)	.729	.044	.743	.001	.001	.000	.495	.003
	N	29	29	29	29	28	28	28	29
Did less because of cancer	Spearman rho	.217	.222	.010	.312	.540**	.373	-.018	.357
	Sig. (2-tailed)	.258	.248	.957	.099	.003	.050	.927	.058
	N	29	29	29	29	28	28	28	29
Having other children in your home	Spearman rho	.169	.419*	.200	.400*	.329	.520**	.221	.311
	Sig. (2-tailed)	.379	.024	.299	.032	.088	.005	.257	.100
	N	29	29	29	29	28	28	28	29
Did less because of cancer	Spearman rho	.150	.356	.088	.393*	.471*	.507**	.035	.464*
	Sig. (2-tailed)	.438	.058	.649	.035	.011	.006	.861	.011
	N	29	29	29	29	28	28	28	29

PDI Older Children Item	Test Statistic	Fatigue before	Least last week	Average Fatigue Before	Fatigue Now	Days fatigued	% of day fatigued	Fatigue Daily Pattern	Fatigue interfere
Going with your child to social events or recreational activities	Spearman rho	.059	.402*	.060	.291	.322	.455*	.269	.370
	Sig. (2-tailed)	.766	.034	.763	.134	.102	.017	.175	.053
	N	28	28	28	28	27	27	27	28
Did less because of cancer	Spearman rho	.174	.164	.030	.335	.293	.389*	.069	.402*
	Sig. (2-tailed)	.376	.405	.880	.081	.138	.045	.734	.034
	N	28	28	28	28	27	27	27	28
Getting up with your child, either during the night or early in the morning	Spearman rho	.105	.487**	.250	.502**	.345	.670**	.341	.386*
	Sig. (2-tailed)	.604	.010	.208	.008	.085	.000	.088	.046
	N	27	27	27	27	26	26	26	27
Did less because of cancer	Spearman rho	.108	.309	.277	.356	.268	.591**	.328	.271
	Sig. (2-tailed)	.590	.117	.162	.068	.186	.001	.102	.171
	N	27	27	27	27	26	26	26	27
Taking care of your child when s/he is sick	Spearman rho	-.034	.213	.101	.273	.239	.322	.229	.299
	Sig. (2-tailed)	.868	.285	.616	.169	.240	.108	.261	.130
	N	27	27	27	27	26	26	26	27

PDI Older Children Item	Test Statistic	Fatigue before	Least last week	Average Fatigue Before	Fatigue Now	Days fatigued	% of day fatigued	Fatigue Daily Pattern	Fatigue interfere
Did less because of cancer	Spearman rho	.234	.136	.308	.366	.131	.395*	.005	.249
	Sig. (2-tailed)	.240	.499	.118	.060	.524	.046	.979	.210
	N	27	27	27	27	26	26	26	27
Keeping your child out of unsafe situations	Spearman rho	-.282	.298	.085	.344	.186	.401*	.226	.319
	Sig. (2-tailed)	.155	.132	.675	.079	.362	.042	.267	.105
	N	27	27	27	27	26	26	26	27
Did less because of cancer	Spearman rho	-.128	.368	.129	.580**	.322	.697**	.148	.388*
	Sig. (2-tailed)	.524	.059	.522	.002	.109	.000	.472	.046
	N	27	27	27	27	26	26	26	27
Maintaining discipline with your child	Spearman rho	-.091	.165	.023	.263	.238	.229	.180	.120
	Sig. (2-tailed)	.653	.412	.911	.185	.242	.261	.378	.552
	N	27	27	27	27	26	26	26	27
Did less because of cancer	Spearman rho	.030	.030	.045	.233	.236	.131	-.068	.084
	Sig. (2-tailed)	.882	.882	.822	.242	.247	.525	.741	.678
	N	27	27	27	27	26	26	26	27

PDI Older Children Item	Test Statistic	Fatigue before	Least last week	Average Fatigue Before	Fatigue Now	Days fatigued	% of day fatigued	Fatigue Daily Pattern	Fatigue interfere
Cooking or preparing food for your child	Spearman rho	.201	.245	.113	.343	.216	.411*	.162	.311
	Sig. (2-tailed)	.314	.219	.574	.080	.288	.037	.428	.115
	N	27	27	27	27	26	26	26	27
Did less because of cancer	Spearman rho	.311	.065	.070	.268	.148	.310	-.085	.291
	Sig. (2-tailed)	.114	.748	.727	.177	.471	.123	.679	.141
	N	27	27	27	27	26	26	26	27
Doing household chores or shopping	Spearman rho	.250	.272	.029	.264	.520**	.373	.108	.377*
	Sig. (2-tailed)	.200	.161	.885	.175	.005	.056	.592	.048
	N	28	28	28	28	27	27	27	28
Did less because of cancer	Spearman rho	.219	.208	-.016	.358	.553**	.371	-.013	.367
	Sig. (2-tailed)	.262	.289	.934	.061	.003	.056	.949	.055
	N	28	28	28	28	27	27	27	28

** $P < .01$
* $P < .05$

Table 4.13. *Spearman Rho correlation among PDI groupings and FACT-G domains (P-value)*

Parent disability grouping	**Physical wellbeing**		**Functional wellbeing**		**Emotional wellbeing**		**Social wellbeing**	
Age (years)	0-5	6-18	0-5	6-18	0-5	6-18	0-5	6-18
Home routines	-.765 (.076)	-.673** (<.001)	-.771 (.072)	-.687** (<.001)	-.435 (.389)	-.674** (<.001)	.372 (.468)	-.233 (.241)
Community	-.687 (.132)	-.669** (<.001)	-.771 (.072)	-.545** (.003)	-.435 (.389)	-.533** (.003)	.372 (.468)	-.292 (.131)
Physical	-.687 (.132)	-.669** (<.001)	-.580 (.228)	-.605** (.001)	-.221 (.674)	-.634** (<.001)	-.127 (.795)	.154 (.443)

** $P < .01$
* $P < .05$

Quantitative Research Questions Hypotheses

In Chapter 1, I created hypotheses about the relationship among different quantitative variables in the study. Table 4.14 provides the hypotheses tested and the Spearman Rho value and level of significance. The first hypothesis, HQt1, predicts that an increase of quality of life will result in a decrease in fatigue interference. However, only two FACT-G subtests were correlated enough to allow me to reject the null hypothesis, physical wellbeing and functional wellbeing. Otherwise, none of the variables were significantly correlated with each other.

Table 4.14. *Directional hypotheses and status of the null hypothesis for FSI-TT, FACT-G, and PDI ratings*

Hypothesis	Measures	Spearman Rho (P-value)	Status of null hypothesis
HQt1 : $CRF \propto \frac{1}{QOL}; \uparrow CRF = \downarrow QOL$ $\mathrm{CRF} \propto \frac{1}{\mathrm{QOL}}; \uparrow \mathrm{CRF} =\downarrow \mathrm{QOL}$	Fatigue Interference, total FACT-G QOL score	-.320 (.079)	Fail to reject
	Fatigue Interference, physical well being	-.575 (.001)	Rejected
	Fatigue Interference, social well being	-.151 (.471)	Fail to reject
	Fatigue Interference, emotional well being	-.341 (0.65)	Fail to reject
	Fatigue interference, Functional Well Being	-.413 (.026)	Rejected
HQt 2a: $\uparrow cancer\ stage \propto \downarrow QOL$ $\uparrow \mathrm{cancerstage} \propto\downarrow \mathrm{QOL}$	Stage, total FACT-G QOL score	.230 (.239)	Fail to reject
	Stage, physical well being	-.180 (.359)	Fail to reject
	Stage, social well being	.175 (.372)	Fail to reject
	Stage, emotional well being	.053 (.792)	Fail to reject
	Stage, functional well being	.048 (.815)	Fail to reject
HQt 2b: $\uparrow age \propto \downarrow QOL$	Age, total FACT-G QOL score	.308 (.092)	Fail to reject
	Age, physical well being	.255 (.167)	Fail to reject
	Age, social well being	.331 (.069)	Fail to reject
	Age, emotional well being	.275 (.142)	Fail to reject
	Age, functional well being	.333 (.077)	Fail to reject

Hypothesis	Measures	Spearman Rho (P-value)	Status of null hypothesis
HQt 2c: $\downarrow income \propto \downarrow QOL$	Income, total FACT-G QOL score	.052 (.789)	Fail to reject
	Income, physical well being	.102 (.598)	Fail to reject
	Income, social well being	.206 (.283)	Fail to reject
	Income, emotional well being	.021 (.917)	Fail to reject
	Income, functional well being	.043 (.832)	Fail to reject
HQt 2d: $\downarrow education\ level \propto \downarrow QOL$	Education, total FACT-G QOL score	-.046 (.806)	Fail to reject
	Education, physical well being	-.053 (.777)	Fail to reject
	Education, social well being	.034 (.856)	Fail to reject
	Education, emotional well being	.026 (.890)	Fail to reject
	Education, functional well being	.022 (.911)	Fail to reject
HQt 2e: $rural \propto \downarrow QOL$	Rural, total FACT-G QOL score	-.054 (.771)	Fail to reject
	Rural, physical well being	-.174 (.348)	Fail to reject
	Rural, social well being	.212 (.253)	Fail to reject
	Rural, emotional well being	-182 (.335)	Fail to reject
	Rural, functional well being	-.195 (.310)	Fail to reject
HQt 2f: $\uparrow \#\ children \propto \downarrow QOL$	# children, total FACT-G QOL score	-.177 (.341)	Fail to reject
	# children, physical well being	.030 (.878)	Fail to reject
	# children, social well being	-.058 (.758)	Fail to reject

Hypothesis	Measures	Spearman Rho (P-value)	Status of null hypothesis
	# children, emotional well being	-.261 (.164)	Fail to reject
	# children, functional well being	-.146 (.449)	Fail to reject
HQt 2g: $\downarrow age\ of\ children\ \propto \downarrow QOL$	Age of children, total FACT-G QOL score	.129 (.497)	Fail to reject
	Age of children, physical well being	.139 (.465)	Fail to reject
	Age of children, social well being	.114 (.549)	Fail to reject
	Age of children, emotional well being	.064(.740)	Fail to reject
	Age of children, functional well being	.039 (.845)	Fail to reject
HQt 3a: $\uparrow stage\ \propto \uparrow CRF$	Stage, fatigue interference	.030 (.878)	Fail to reject
HQt 3b: $\uparrow age \propto \uparrow CRF$	Age, fatigue interference	-139 (.465)	Fail to reject
HQt 3c: $\downarrow income \propto \uparrow CRF$	Income, fatigue interference	.051 (.792)	Fail to reject
HQt 3d: $\downarrow education\ level\ \propto \uparrow CRF$	Education, fatigue interference	.110 (.557)	Fail to reject
HQt 3e: $rural\ \propto \uparrow CRF$	Rural, fatigue interference	.276 (.133)	Fail to reject
HQt 3f: $\uparrow \#\ children \propto \uparrow CRF$	# children, fatigue interference	.020 (.914)	Fail to reject
HQt 3g: $\downarrow age\ of\ children\ \propto \uparrow CRF$	Age of children, fatigue interference	-.139 (.465)	Fail to reject

Quantitative Question 4, and its corresponding hypotheses, is listed below:

HQt 4 Women who have more advanced disease, are older, report lower income, have lower education, live in rural locations, have more children, and/or have younger children will have higher levels of disability on the PDI than other mothers.

Directional hypotheses: For mothers undergoing cancer treatments,

HQt 4a: $\uparrow cancer\ stage \propto \uparrow parent\ disability$

HQt 4b: $\uparrow age \propto \uparrow parent\ disability$

HQt 4c: $\downarrow income \propto \uparrow parent\ disability$

HQt 4d: $\downarrow education\ level \propto \uparrow parent\ disability$

HQt 4e: $rural \propto \uparrow parent\ disability$

HQt 4f: $\uparrow \#\ children \propto \uparrow parent\ disability$

HQt 4g: $\downarrow age\ children \propto \uparrow parent\ disability$

I summarized hypothesis testing and results in Table 4.14 by providing the Spearman Rho correlation tests and demographic data for younger children items on the PDI. If the correlation failed to reach the level of significance of less than .05, then I rejected the null hypothesis. If the level of significance was less than .05, then I failed to reject the hypothesis. I found significant correlations between stage of cancer and PDI younger child items of taking care of the child's hygiene needs, feeding child or preparing food, picking up or carrying child, taking care of the child while out of the house, and getting up and down to the floor to play with the child. So for these items, a higher cancer stage correlated with more difficulty in carrying out these parenting tasks. I found significant a significant correlation between the mothers' level of education and difficulty in playing with children outdoors, which means that mothers with a higher level of education reported more difficulty with this parenting task. I found significant correlations between the number of children in the home and taking care of the child's hygiene, taking the children out in the car, playing with the child outdoors, taking the child to social events or recreational activities, which means that the more children the mother has in the home, the less difficulty with these tasks. There were no significant correlations between PDI younger child items and age or income. In summary, a higher cancer stage correlated with more difficulty in hygiene, picking up the child and getting down on the floor to play with the child.

Table 4.15. *Spearman rho correlations and levels of significance for PDI Younger children items and demographics*

	Demographics Spearman rho (P-value)						
PDI Younger Children Item	Stage	Age	Income	Education	Rural	# Children	Age children
Diapering, dressing, or helping your child with dressing	.557	.109	.541	.469	--	-.671	-.698
	.194	.815	.268	.288	--	.099	.123
Taking care of your child's hygiene needs	$.863^{*}$	.160	.698	.743	--	$-.892^{**}$	-.736
	.012	.731	.123	.056	--	.007	.096
Feeding your child, or preparing food	$.882^{**}$	-.019	.370	.545	--	-.667	-.577
	.009	.968	.470	.206	--	.102	.231
Picking up or carrying your child	$.908^{**}$	-.302	-.031	.316	--	-.438	-.207
	.005	.511	.954	.490	--	.325	.694
Taking care of your child while out of the house	$.789^{*}$	.111	.530	.486	--	-.615	-.530
	.035	.813	.280	.269	--	.141	.280
Taking your child out in the car	.745	.198	.759	.644	--	$-.794^{*}$	-.677
	.055	.670	.080	.119	--	.033	.140

PDI Younger Children Item	Demographics Spearman rho (P-value) Stage	Age	Income	Education	Rural	# Children	Age children
Getting up and down to the floor to play with your child	.882**	-.019	.370	.545	--	-.667	-.577
	.009	.968	.470	.206	--	.102	.231
Keeping your child out of unsafe situations	.653	.157	.131	.354	--	-.700	-.778
	.111	.736	.805	.437	--	.080	.069
Getting up with your child, either during the night or early in the morning	.693	.143	.598	.450	--	-.505	-.339
	.084	.760	.210	.311	--	.248	.510
Playing with your child outdoors	.568	.418	.638	.886**	--	-.764*	-.516
	.184	.351	.173	.008	--	.046	.295
Having other children in your home	.693	.143	.598	.450	--	-.505	-.339
	.084	.760	.210	.311	--	.248	.510
Taking your child to social events or recreational activities	.686	.113	.759	.693	--	-.775*	-.618
	.089	.809	.080	.084	--	.041	.191
Taking care of your child when s/he is sick	.495	.029	.717	.450	--	-.663	-.617
	.259	.951	.109	.311	--	.104	.192
Maintaining discipline with your child	.010	-.076	.247	-.200	--	-.139	-.239
	.983	.871	.637	.667	--	.767	.648

PDI Younger Children Item	Demographics Spearman rho (P-value)						
	Stage	Age	Income	Education	Rural	# Children	Age children
Doing household chores or shopping	.742	-.031	.783	.361	--	-.625	-.671
	.091	.954	.118	.482	--	.184	.215
Using a stroller	.164	-.235	.158	-.533	--	.302	.577
	.756	.654	.800	.276	--	.561	.308
Using a car seat	.647	.017	0.000	.237	--	-.679	-.783
	.165	.974	1.000	.651	--	.138	.118
Opening safety latches or locks	.417	.399		-.141	--	-.270	-.354
	.410	.434		.789	--	.605	.559
Opening medicine or childproof containers	.417	.399		-.141	--	-.270	-.354
	.410	.434		.789	--	.605	.559

Note: There were no rural participants who had children under 6 years old living in the home.
** *P* < .01, reject the null hypothesis
* *P* < .05, reject the null hypothesis

Table 4.16. *Spearman Rho correlations and levels of significance between PDI Older children items and demographic items*

PDI Older Children Item	Demographics Spearman rho (P-value) Stage	Age	Income	Education	Rural	# Children	Age children
Taking your child to all the places s/he needs to go	-.265	.153	.093	.193	.278	.161	-.278
	.166	.454	.638	.317	.144	.404	.152
Being involved in your child's school functions	-.343	.038	-.005	.137	.224	.044	-.117
	.069	.855	.981	.477	.243	.821	.552
Helping your child with homework or school projects	-.111	-.187	.230	.302	.203	-.121	-.158
	.567	.361	.239	.111	.290	.531	.423
Playing with your child outdoors	-.246	.198	.089	.225	.390*	-.029	-.127
	.197	.333	.652	.241	.036	.879	.520
Having other children in your home	-.133	-.162	.186	.188	.188	-.022	-.043
	.492	.428	.343	.329	.328	.911	.828
Going with your child to social events or recreational activities	-.249	.079	-.029	.168	.160	.051	-.195
	.201	.706	.885	.393	.415	.797	.330

	Demographics Spearman rho (P-value)						
PDI Older Children Item	Stage	Age	Income	Education	Rural	# Children	Age children
Getting up with your child, either during the night or early in the morning	-.487*	.204	-.043	-.064	.132	.326	-.164
	.010	.339	.836	.752	.511	.097	.423
Taking care of your child when s/he is sick	-.147	.195	.117	.197	.363	.062	-.188
	.465	.360	.568	.325	.062	.758	.357
Keeping your child out of unsafe situations	-.095	-.031	.133	.018	.216	.371	-.071
	.637	.886	.518	.928	.279	.057	.731
Maintaining discipline with your child	-.289	.164	.091	.130	.092	-.095	-.437*
	.143	.445	.659	.518	.647	.638	.025
Cooking or preparing food for your child	-.194	-.086	.107	.198	.104	-.005	-.142
	.332	.691	.603	.323	.604	.980	.490
Doing household chores or shopping	-.075	.122	.283	.324	.140	-.104	-.032
	.706	.562	.152	.093	.477	.597	.874

** $P < .01$

* $P < .05$

Qualitative Results

As was discussed in Chapter 2: Methods, I used a grounded theory methodology to analyze interview data (Corbin and Strauss, 2008). In this methodology, data are analyzed in multiple phases, going back and forth between data sources, making comparisons among concepts, developing categories, and ending up with a theory that emerges directly from the data. In the first stage, open coding, I attached a code that summarized what the participant is saying in a section of text. Next, I collapsed codes into categories (Tables 4.17 and 4.18) that represented the meaning of the open codes. The next phase, axial coding, involved looking at the relationship among categories, resulting in the Conditional Relationship Guide (Table 4.19), which better allowed me to identify the key processes in mothering with breast cancer. In the final phase of coding, I created a Reflective Coding Matrix to help develop the storyline of the process of mothering during breast cancer treatments. From the Reflective Coding Matrix, the central category of "keeping life the same while weathering breast cancer treatments" emerged. I used the grounded theory analytical model described by Scott (2004) and Scott and Howell (2011) to guide the coding and theory generation process.

Open Coding. First, I personally transcribed each interview, taking notes and writing a memo after transcription with initial thoughts on each. Then, I conducted open coding in which I attached a code to approximately each line of interview data using the program HyperResearch. I focused on using codes that were *in vivo* (coded with words actually said by the participant). This process resulted in 318 total open codes. From here, I used an iterative process of going back and forth between the data and my analysis to collapse the 318 codes into 21 major categories. These major categories are listed in alphabetical order in Table 4.17.

Table 4.18 shows the results of this analytic process. I took each category and listed all of the open codes corresponding to that category, the number of participants who mentioned this category, and relevant quotes to demonstrate different aspects of this category. For example, under the category of being a mom comes first, I listed all of the 15 open codes corresponding to that category. All but one participant, Cheryl, mentioned concepts related to this category within the interview. I then provided relevant quotes that represented the meaning of this category. For example, Rebecca said,

> Well, your first concern as a mother, and even as a single mother is for your child. OK, worst case scenario, something happens to me, and I don't make it. And who's gonna take care of my baby? [cries].

I summarized (via collapsing codes into a category) the meaning of this quote as being a mom comes first because Shannon talked about how her first concern when she found out she had cancer was for the wellbeing of her daughter.

Table 4.17. *The 21 Major Categories in Alphabetical Order*

Being a mom comes first
Characteristics of child impact the child’s reaction to cancer
Coping strategies used by mother
Dealing with low energy
Financial impact of cancer
Having fun in spite of cancer
Helping child cope
Household activities
Life before cancer
Mother’s reaction to cancer diagnosis
Mother’s relationship with child(ren)
Mother’s relationship with others
Mother’s relationship with spouse
Navigating the medical world
Post traumatic growth of child
Post traumatic growth of mother
Side effects of treatment
Routines
Support that is helpful
Support that is unhelpful
Taking care of child(ren) during chemotherapy

Table 4.18. *Categories Derived from Open Coding of Interviews*

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
Being a mom comes first (25 codes)	Being there for child in the future Breaking the rules to be with the children Can't not take care of children Can't provide care Child given in to because mom is sick Child is first concern Child keeping you more active Child not at home because mom is too sick Don't want children defined by cancer Fighting for your children Getting child raised to be independent It's my job to be mom Making decisions based on what is best for the children Making memories for the children and not regrets Mom pushing herself too hard Mom should provide care because she's not working No one else can do it like mom Not getting to do mom things	Rebecca, Kimberly, Ellen, Sarah, Shirley, Shannon, Lori, Melissa, Denise	Well, your first concern as a mother, and even as a single mother is for your child. OK, worst case scenario, something happens to me, and I don't make it. And who's gonna take care of my baby? [cries]. (Rebecca) Everything I have done from the get go, it's not, "Oh my gosh, I've got cancer." It's, "OK, I've got cancer, what do I do now because I've got to think about living and being his mother for years and years and years." (Ellen) My job now is to survive. I have to do everything I can to survive. I have to take care of my body, I have to rest when I need to rest. I have people who are helping me, I need to let them do it because all I could think was long term. I can't think short term. Short term, disciplining him. But that's not, that may not have helped me. I had to think, I want to be with him for 5, 10, 15, 20 years. He needs a mother. He wants someone with him while he's growing up. And if I don't do everything I can now, I may not get that chance. (Ellen) And even my surgery, I just did the outpatient. And one reason that I did that is you can have a lumpectomy or a mastectomy, it's your choice. I

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	because she is too sick Not wanting child to grow up without a mother Overdoing it Putting children first Staying up with the children Survive at all costs Mom wants children home What would happen if mom dies?		could not, I had to have the least possible surgery because I have to take care of my son. (Sarah) The only thing, I mean, that's what really gave me a lot of strength was fighting for my daughters and the new grandbaby, because I knew that I was they had since I had lost my husband. (Shirley) You know, my everything is what's gonna, you know, what's best for them, what's gonna, how it's gonna impact them. You know, it just, it's so, they're gonna have, the choices, you're gonna have to make choices. And, you know, so they're gonna have to clean house, and they're probably not gonna get to go to Disney, but you can't put a price on it. (Lori)
Characteristics of child impact how he or she reacts to mother's cancer (28 codes)	Age of child Behavior Being honest with child Child afraid because dog died of cancer Child coming to clinic with mom Child didn't remember previous cancer bout Child different because so many people are around Child entertaining self Child feeling like she has to be	All	Yes, he's always been such a smart, intuitive little boy. I mean, he knew from the get go, he was like, "Ah, she can barely pick me up. She's gonna drop me!" (Ellen) It's definitely a different parenting style because she has a different personality too. I wonder if it's influenced by because when all these people would come by, she was just learning to walk, and they wanted her to be a baby, and I was like, "No, she has to walk! I cannot carry her." (Lori)

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	upbeat Child going to counseling Child having school problems Child hovering Child knows mom is sick Child learning to be gentle with mom Child mental health problems Child needing to walk because mom can’t carry her Child not wanting to know Child reaction to hair loss Child remembers how it used to be Child using cancer to his advantage Child’s intelligence Child’s qualities Child’s relationships with friends and family Child’s stress due to mom’s cancer diagnosis Fear that mom will die Children wanting chemo to be over Maturity of child Resilience		You know, she did pretty well behavior wise, um, but I think the biggest thing that I noticed later, and even late late, was the drop in her grades. (Rebecca) He asks me for my old hair back. It was about to here [points to shoulder] and it was caramel color, and he's, he tells me I look, I look bad. [laughs] I’m just hearing, "It will grow back, but I liked you better." I mean, he's, he's never gonna have any tact [laughs]. (Sarah) She's just so sweet, and that's what she had said when I, after my surgery, I guess at the end of last year when she had her little breakdown. She said, Oh mommy, I just feel like I have to be upbeat all of the time. (Shirley) She, for two weeks, she was real quiet. And I told the other kids to help with the housework, and she wasn't really listening. So I went to school and I had her by herself. And I was like, "You know, Addie, it's real. It's not going anywhere." And she was like, "No it's not." She was in denial big time. Then so I pulled the school counselor to the side, which is good because she's her aunt. And I was like, "Amy, you're gonna have to talk to her, because she's really in denial. She really believes I'm lying, that it's not gonna happen, that my hair's

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
			not gonna fall out. The whole nine yards." And it took the counselor two weeks to get it into her head that it was there. (Denise) They're resilient. Kids can handle things very well. You know, and uh, they've got their lives, they're very, very busy. And they don't require a lot from me. And um, I think probably because of the way I handle it the way I do, they forget sometimes. (Cheryl)
Dealing with it—Coping strategies used by the mother (29 codes)	Avoiding negative people Being more laid back Being positive Believing in yourself Can live with anything Comparing situation to a worse one Dealing with it head on Death is worse than symptoms Funeral plans Getting hair cut short Giving cancer a run for its money Good mental place Gotta do what you gotta do	Rebecca, Kimberly, Ellen, Sarah, Shirley, Shannon, Lori, Melissa, Cheryl	But, you know, it's like, we're alive, we have all our limbs, we could have been in a car accident. Our son's healthy. It's not that bad, really. We don't have to live in a concentration camp. (Sarah) Um, I just think it's so important keeping a positive attitude. And just not getting discouraged and depressed. And down. Um, which I thrive more on just doing things, you know, keeping the routine and doing things by myself. And I think that just kinda helps me mentally and physically. Because I've seen, I've seen people that are just so negative, and I just really think that affects your health. I really just do. And just being positive. (Shannon)

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	I shouldn't complain Illness puts things in perspective It could be worse It was worth it It's only hair It's treatable Just something you have to go through Letting things go Mind over body Not so bad compared to what it could be Outlast Play it by ear Religion Realize it's OK to sometimes feel sorry for self There's an end to treatment Treating yourself		She stayed on a sippy cup longer than she would have, and still has a pacifier, but she gets it at night. But I never would have done that before, but you gotta do what you gotta do. (Lori) Well, let me tell you what it is, God is a huge part of this. OK, probably the biggest part of anything in my life, but I look at it as, this is what it is, you can't change it, you can help it, maybe if it works out that way, but it could always be worse. It could always be worse. I can walk down the hallway at work everyday, and I will see somebody that is in worse shape than I am in. (Cheryl)
Dealing with low energy (23 codes)	Cleaning during steroid high Doing harder tasks during best time of day Doing less Exercise Finding low energy activities to do with children Forcing self to rest Getting child into outside	Rebecca, Kimberly, Ellen, Sarah, Shirley, Shannon, Lori, Cheryl, Denise	I know, because I'll work, and then if we have a ball game, and it's like, if there isn't something left over in the fridge, we'll just grab something on the way. Because I am not going to go fix dinner. (Kimberly) It's just, it's dirty. And I would try, you know, when I was on chemo, I would have the Decadron, the steroids. And I would clean the house on

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	activities Getting take-out food Giving children chores Having a day to yourself Limiting number of laundry loads Play dates so mom can rest Putting school on hold during chemo Quiet focus activities Reigning yourself in Relying on daycare to provide healthy meals Rest while children are at school Screen time Slowing down Staying in the car to watch children's games Taking naps Taking time off work Using daycare		steroid day. (Sarah) But if I have to do the bills, not if I have to. When I have to do the bills, I usually get a cup of coffee and I try to do it in the morning and there cannot be any kids. (Lori) But they would, we bought them a little broom, if I could find them a little mop. They fought, the best thing ever, $20 Dustbuster on a stick. They fight over who's gonna vacuum. I did have to get a different vacuum. I had an Oreck, and we had gotten a new one. And it wasn't an Oreck. I'd gotten some Hoover, and it was too heavy and I couldn't use it. As soon as I brought it home, they were fighting over it. They still fight over it. And actually the boy will get it out the closet and sweep his room if he's made a mess. (Lori) And then, I mean, I really one day I was so tired and we were outside, and so we laid down on the grass and looked at clouds. So you really have to, but you know, they'll remember that. (Lori)
Dealing with the financial impact of cancer (5 codes)	Expensive Husband working hard to make money Insurance	Sarah, Shirley, Lori, Melissa, Denise	Yeah, I have medical bills and then I can't tell them I don't have the money [whispers]… And I didn't have anybody, but I got to the point where I'm like, Well my retirement savings is gone to medical

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	Medical bills Worry about finances		bills, but I was thinking, well if you could pay somebody to help, pay if you have somebody… I don't have insurance. I pay for a high deductible. So I really got hit. And then it started in October, so then I had to pay the deductible, and then in January I had to pay it all again. So, I don't even, I'm just gonna be on a five year plan to pay. (Sarah) But he's self-employed, so he, he didn't work a lot last year. So business is booming now, and he doesn't want to turn anybody down because he wants us to get out of debt and he wants me to stay home so it's put some more pressure on him. (Lori) I called to get unemployment and they told me absolutely not, because of my illness I was not able to go out and hunt for a job. So because I can't hunt for a job, I cannot qualify for unemployment… I filed for disability at the end of February or March, and I still ain't seen it. I mean, the last time I talked to them, they said they were waiting for medical records. (Denise)
Having fun in spite of cancer (7 codes)	Being active Humor Leisure time Outdoor activities	All	I think we're better now and also we can joke about, you know, Mommy, you can go rest now. [laughs] Oh, you, I know what you are trying to do. You are trying to get more screen, right? Right. So why

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	Playing games with children Taking pictures Vacation		don't you just tell me. So we're able to joke about it. (Sarah) They were at their New Year's Day party, and she said, [in English accent] Cheerio, mother. And we were talking in this British accent. And I said, hello chap chap. What are you blah blah blah. I said you had me on speakerphone? [laughs] And then, they said, they looked at her and said, “My mother would never act like that”, and their mothers are ***way*** younger than me, because I'm an old one. And Danielle said, Oh yeah, we act like that all of the time. And was just like, we do that all the time. And she said, they were just laughing and my mother would never act like that. Yes, enjoy life. And we act crazy, and make up silly songs, and do all that kind of stuff. (Shirley) I like to do pictures, I like to stay at the house with the kids, If they gotta go someplace, I like going with them. I like doing things with the kids. if it consists of getting up in the morning and getting dressed and going to the ball field and playing with our family, that's where I want to be. Otherwise I don't want to go. (Denise) We do all kinds of goofy things. We fill balloons full of, what did we put in, shaving cream? The kids got older, and they got tired of playing tag, so I

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
			took some balloons and I filled shaving cream in them and I only filled them up so far, so they would be harder to bust. Then I tied a string to the end of them and the string to their leg. They chased each other all over the yard, and the last one to have the balloon won. (Denise)
Helping child cope (11 codes)	Acting like everything is fine Children having friends over Encouraging daughter to start a blog Faking it Hiding feeling bad Keeping things normal Not showing fear Not telling children about cancer so they wouldn't worry Painting a rosy picture Signing children up for fun activities	All	You know, when I went in to work on Friday, she said, you don't look good. Are you feeling bad? And I said, I've felt bad this whole week, and she said, well you sure didn't let on that you felt bad. But I was like, "well, I try not to." (Kimberly) And I had to not show fear. And I didn't really feel a lot of fear, I guess because of my faith, I was just like, what's gonna be is going to be. Sometimes I get discouraged, but it's not, you know, in front of them. And I think that helped me a lot. (Shirley) But of course I told them, "Nothing changes." Day to day, everything they do, nothing changes. They go to school, they make good grades, they do this, they do that, nothing changes. (Denise)
Household activities (4 codes)	Cleaning Cooking Housework Laundry	All	And Kelsey has been really good about helping to fix dinner and take care of things and do the dishes and clean house. (Kimberly) I'm sort of down to two loads a week. I've told my

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
			husband he's on his own. Just I'm gonna do a load of colors and a load of white. And I can remember that. And I do it on the weekend, and I know my son has clothes… I can barely do his. Because you gotta walk up and down the steps. (Sarah) And sometimes the kids would go and I would wipe down all of the surfaces, Clorox everything, maybe do a little laundry. (Lori) I do have somebody come in and clean the house. I have somebody who comes in every other week. Um, but, I do all the, 90% of the cooking and the straightening, which is a chore when you have three teenagers; they consider their space as everywhere. (Cheryl) And when I get up off the couch, I can only do limited stuff, but what I don't do, I have them do it for me. I can't carry a vacuum cleaner through the house, so I make them stroll it through the house. I can push it, I can try, I can do it for a few minutes, but then I have to hand it off. (Denise) I don't lift any of the laundry. As far as the laundry goes, my girls carry the laundry baskets to me and empty them. (Denise)
Life before cancer	Childcare before cancer	All	Physically as far as physical capabilities? Uh, no I

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
(7 codes)	Energy before cancer Health before cancer Homebody Job before cancer On the go person Prior functioning		don't think so. I think I have times where I was particularly tired when I came home from work, but that's natural because I have a very physical job. And she is at a very independent age now too. (Rebecca) Yeah, just, yeah, I was healthy, I've never been sick. (Sarah) I was one of these people who went from daylight ‘til dark. And I helped with everything under the sun. I just went constantly. (Melissa) I was. I was always outside. My sister called me Martha Stewart, making something from scrap. (Denise)
Mother’s reaction to cancer (17 codes)	Don’t want to be labeled a cancer patient It can’t be cancer Disbelief Crying Depression Devastation Don’t have time for this Glad I’m going to make it Intuition that it was something Never forget the details	All	It was very traumatizing. When you hear the word "Cancer," you think you're gonna die, with two small children. So it was really hard, really hard. (Kimberly) And then I got diagnosed. So it was, look, I've got to work, and everything… I think most moms or anybody with families think, “I just don't have time for this.” (Sarah) Just, you know, you can cry, and you can, and I do

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	Sadness Shock Survivor guilt Traumatic Wanting to be treated like nothing has happened Wanting to blend in Worried		have my, very few and far between, I've probably had maybe three episodes where I really felt like, I felt sorry for myself, and I worked through it. (Cheryl)
Mother’s relationship with others (14 codes)	Co-worker not supportive Communication with school Family coming to chemo Family reaction to diagnosis Not wanting others to feel awkward about cancer Other’s reaction to children’s chores People not thinking you look sick People not understanding Relationship with clinic staff Relationship with doctor Relationship with own mother Relationships with family Relationships with children’s friends Telling others about cancer	All	There was only one or two who said, "she needs to do this, " or "we're having a problem with that" or just hasn't been turned it, but that was just on a couple of occasions. For the most part, they didn't contact me. They had an online system where you could go online and see the assignments and stuff, and the grades. And that was when I realized when I would see all of that. She has passing grades, but I know she can do better than Cs and Ds. That's passing, but that's just not very good. She's normally an A/B person. (Rebecca) She and I don't, I don't want people to feel uncomfortable or feel awkward. Exactly. I mean, if someone's [hushed tone], "Oh my gosh." And I don't want them to feel like that. I don't want to put them in that position. (Shannon) You know, my sister really wanted to come to chemo one day, and I said, "OK, you can come,"

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
			and she came, and I guess she just wanted to see what it was like. (Cheryl) I would rather help someone else., and I feel like I've helped some people that have gone through, you know, been diagnosed, and you know, one of the friends I had, a teacher actually, I wasn't great friends with her but my daughter had her, and she said, "She wants to know if she could talk to you." And, you know, I just said, you know, because she didn't like her doctor. And I said, "First thing you do is, you need to find a doctor that you love, not like, love. And trust. Someone you trust." And she did, she changed doctors, (Cheryl) Right, and that's something I can't stand is for someone to come up to me and be like, "Are you alright? Are you OK?" "Dude, I just had both of my breasts removed and my hair fell out, and I take chemo. Why are you asking? It's not OK. It's just something that I have to do." (Denise)
Mother's relationship with spouse (14 codes)	Child came home from in-laws after husband left Death of husband Husband anxious Husband couldn't take care of both her and the child	Kimberly, Ellen, Sarah, Shirley, Shannon, Lori, Melissa, Denise	He's been fantastic and supportive throughout. I mean, I can't begin to imagine what this has been like for him, to have to, you know, take on so much responsibility and have in the back of his mind of, if I'm not going to be around. Is he gonna lose me? I can't imagine thoughts like that. Um, that has to

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	Husband doesn't want to talk about it Husband helps with discipline Husband moved out Husband relying on her more and more Husband remarrying Husband tired of cancer Husband tolerating house not neat Husband wants everything to be OK Husband worried Not having dates with spouse		be the most painful thing, um, and it did, it affected him. It was hard for him to sleep. For me, all I could think was I, I am going to win. When you hear you know they give you the chemo and they try to push you as close to death as possible without actually killing you, and it's really true. (Ellen) But he's really good about me taking a nap, he's really good about the house being dirty, and the clothes not being folded--they're clean, they're just not necessarily folded and put away. (Lori) Let me tell you something. There's a difference between me and his voice. I can say it on some things, and they know I mean it, and some things he says, when his voice gets deep, it's shutdown. They all, no Seriously. They all go to their rooms and you hear the doors slam, and you don't hear another word. It is the peacefullest house you have ever heard with five kids in it. It's wonderful. (Denise)
Navigating the medical world (In the clinic) (20 codes)	Breast cancer characteristics Chemo routine Chemotherapy Child not allowed at the clinic Diagnostic process Dressing self Family history Finding cancer	All	Yes, I had ductal carcinoma in situ and the other one was the adenocystic carcinoma, the rapidly growing one. And everything, it was rapidly growing, both of the tumors. So it took us about a week or a little over a week before we actually knew what type of cancer because um, Lexington Clinic had no idea what they were dealing with. So they had to send it off to Mayo Clinic. And Mayo

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	Genes Hospital Learning how it affects your body Learning medical details Leave from work Lifting restrictions Lymphedema management Making decisions about treatment Medications Other health conditions Radiation Surgery		Clinic was trying to see what they were dealing with. (Ellen) Yes. I had a really bad chemo experience this time. I was really upset. It was very specific what happened. And this never happened before so I was really surprised. But when I went in for first chemo treatment they didn't know I was supposed to be there. And you know how stressful it is going for your first chemo treatment anyway, and she was like, I don't think you have an appointment, and I was like, "Uh, yeah, I think I do!" I wasn't on the list. And they kept lookin' and lookin' and went upstairs to see what they say. So when the nurse was calling Dr. R., the other nurse was like, "Oh, here, I found your name." And I was like, OK, great. So I was supposed to be here today. So she took me back to get all my vitals done, and the nurse said, "well I'm on lunch break." And I was just like, "Are you kiddin' me?" So the girl that took me back there, she said, so if I get her vitals will you do everything else? And she was like, "OK." I guess she didn't know how to do all of that. So she was fumbling around trying to get my blood pressure, and she kept working. (Kimberly) Yeah, Let's see, I had it on Friday, and probably the first day, I was tired, I was really tired on Saturday. Sunday, I really felt bad. And by the middle of that

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
			week, I started feeling a lot better, but that's when your white counts start going down. And then, this week, I had to go out of town on work, which was really hard. So Wednesday, Thursday, Friday I wasn't feeling too good. At all (Kimberly) So, you know, something else I'd to look into is the dense breast issue. I read where Christina Applegate was told that she has dense breasts. And a lot of times, um, supposedly, breast cancer isn't necessarily picked up in a mammogram with dense breasts, so much is it's easier to see with a MRI. And she's a big advocate of using MRIs for women with dense breasts. And I was never told I have dense breasts until like, after I found something. It took the second mammogram to confirm that there was something there. And the lady said, "you have dense breasts." And I was like, "Why is the first time I'm hearing this?" And, if I'd have known and I'd been a little bit more aware, I would have said, "Well, why haven't we been doing MRI more periodically?" Or, you know--It's probably a more expensive diagnostic--- (Rebecca) Oh, yes it's been--I had to go back in December to do the biopsy, the first biopsy because there's all that, which it kinda, it always, it scared me to death because my husband had numerous biopsies and he always talked about the needle was, and I was

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
			kinda like, "Oh no." So the biopsy was not that bad, except I ended up getting a hematoma. Biggest hematoma I think they said they'd seen, all the little techs. (Shirley) It was 90-95% clear, so I lobbied for two extra rounds. So I'm not gonna get 100% clear, but I think it was worth it. (Lori) I actually had a knot in 2006. I had a mammogram done, the health department sent me. And then the year after that, I had another one. And they told me that it was nothing. And it kept getting bigger, and it would hurt. So I went to my OB/GYN this time in Georgetown, and she said because of the way it felt and it was really big, she sent me to a surgeon. To biopsy it. And the woman who did the surgery said it probably was benign. She said most doctors can tell by how it feels. So when she took it out and it came back as cancerous, the woman behind the desk told me to come in early. And she said, "Girl, let me know when you're ready to come out. I want to talk to you." And her girl goes to school with my daughter, and she was devastated. And uh, I went back there and she said, "It's cancer. I just don't know any other way to tell you but it came back cancerous." (Denise)
Post traumatic	Being vigilant about genetic link	All	Um, when we went, we went to the lake on Sunday,

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
growth of child (6 codes)	Child having more empathy Child learning medical procedures Child more independent Child wanting to be in a medical profession Doing self exams		and he and I ended up getting in the water, and she was in for a little bit, but then she got cold and so they went and sat under the tree. And he kept asking me, "Is this your bad arm, is this your bad?" Because we were towing around. And I said, "Yeah, you have to get on my other arm." And he can't come up behind me and jump on me. (Lori) [on self exams] I mean, I've told my girls, I've even showed them how to check. I even told them I was gonna schedule them for their doctor to keep updates on them. Make them feel positive. (Denise) He was, he was really good. It was kind of a good experience for him because he saw what it was like to see somebody that was sick and not be able to help themself. And so it was kinda good for him. (Melissa)
Post traumatic growth of mother (12 codes)	Anything's possible Being assertive Being forthright Builds character Cancer advocacy I'm bent but not broken Participating in cancer organizations Proactive Role model for daughter		I mean, I've literally, I've been through hell and back, and I believe that if I can overcome this, I can overcome anything. (Ellen) [on being assertive] No, this is definitely, having cancer has taught me to be. Because you have to. Normally, I guess I'm not real outspoken because Kelsey was real surprised when I said something. (Kimberly)

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	Setting an example Sharing with others importance of self exams Talking to new patients		It's just kind of something you have to go through. It's just like my dad said, it builds character. So I should have a lot of character after all of this is over with [laughs] (Kimberly) I actually did the Susan G Koman Race for the Cure. [laughs]. It was so funny because I did that, it was a Saturday, and the very next day I was getting chemo. [laughs] (Ellen) Yeah, so I've learned a lot, I've learned a lot from being sick and being hospitalized multiple times, and I've learned to ask for reports and um the best piece of advice I could give to any patient battling cancer and anything else is, not only do you need to be proactive and know your body and ask as many questions as possible, and keep on top of everything (Ellen) Yes, so I've always pushed harder because I, I think about what kind of example I want to set for him. I want to, to, be the kind of mother and the kind of parent that says, "You may have so many challenges and obstacles in your life, but you can persevere, you can accomplish anything you set your mind to." And that's what I want to teach him. And, um, and really I think that more than anything, not just for him, but for everyone else

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
			around me to just so, just to inspire people to be better than where they are now. Because anything's possible. (Ellen) And then I talked to the undergrad sorority group, and they were doing breast cancer awareness in October, and the young lady is trying to get into our program, and we started talking… And she said, "I just knew God led me here." And she said, "would you like to speak to my sorority?" And I said sure, because they do breast cancer awareness, and I said sure. Gosh we probably had 30 or 40 and there were guys there too, one of the young men I know from church. And I talked to them, and they had other people give their stories, and it was so sweet. (Shirley)
Routines and organization (6 codes)	Adapted schedule Keeping a planner Keeping on working Making lists Being organized Routines	All	I started wearing my watch again. Because I used to not need it, but now it works because I'll go, OK, What time it is? So it helps to wear a watch again. I know a lot of people had stopped. Um, reminders, you know, I just keep this big calendar [shows calendar, large size]. I keep it with me at all times and I just have to keep looking at it. I mean, if you weren't here I would probably just open it up and look at it and review the whole week, and do that a lot, because I just can't remember where I'm supposed to be and what I'm supposed to be doing. (Sarah)

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
			I really think [kids have adjusted well], I think it's because I keep the schedule. I mean I just don't, even like last time when they were in volleyball and soccer and basketball, and I went to everything, because I thought that was important. (Shannon) And that didn't, um, my big thing was just keeping a routine and keeping things as normal as possible, and I think that was, kinda, "Oh yeah, I didn't even think about, you know, this, mom having this, going through this and going through that. … What I'd recommend to people is keeping a schedule and being organized. That really gives you peace. I think it's really important. And I think it's important for kids too. I really do. (Shannon) That's what we did. Don't change anything. If you change anything, it's just gonna downfall them. It's gonna mess with their work. Just keep the same routine. We do, we don't change anything. (Denise)
Side effects of treatment that interfere with life (outside the clinic) (27 codes)	Anxiety Bedridden Changing taste preferences Chemo brain Chemotherapy induced menopause	All	I go to work, and I feel, I start getting really tired. And then I started feeling better. And then when I get home I am just exhausted. (Kimberly) I was pretty much stuck in the bed a lot. (Ellen)

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	Exhausted Fainting Fatigue Feeling better Food aversion Hair loss Hematoma High blood pressure Infections Losing weight Low counts Lymphedema Nausea Not feeling like doing anything On going effects Pain Passed out Reaching for things Sitting posture Sleep Vision changes Vomiting		Because after that surgery I developed an infection. I had cellulitis, which is incredibly painful. It was an open wound; it was a hole in my belly button. And it just wouldn't go away. (Ellen) And I do have permanent [hearing] loss, and I'm overcoming that. And you know, hearing aids aren't so bad. You can't even tell, they're great. So far so good. It's stabilized, so if it does not change again the next time I go in in November, um, for a hearing exam, then the audiologist believes that um, it has done all of the damage it's going to do. That I just have to protect the hearing that I have left. Which is good. (Ellen) So, and the chemo's messed with my brain. I have a hard time, I could go read a book that I've read and not even know that I've read it before, or not remember the ending, or whatever. I remember all last year I didn't, I couldn't even hardly flip through a magazine. And I used to read. And I don't take baths much anymore. That used to be my thing I'd get a magazine and get in the tub. (Lori) But I would just be so tired from that 30 minutes that I would literally cry on the way home. And I mean, we went straight from school, and we would still want to run through McDonald's on the way home because my child was starving. So it, it just

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
			takes, um, time to figure out what your limitations are. (Lori)
			I couldn't do anything during chemo. I threw up all of the time… By that third one, I was in the bed. And I could barely make it to the bathroom to throw up… So I mean, for the entire summer, the kids, I couldn't take him anywhere, I couldn't you know, with his friends… I still get sick. I just felt so week, and it was just non-stop. And I would drink water and throw it up. I was so sick. I had to go get fluids I don't know how many times. I was that dehydrated. (Melissa)
			But I don't do any of that now. [working in the yard] I'm just tired. I'm, like, exhausted. I could sleep four or five hours and wake up and feel energized, and the second I sit on the couch, I'm exhausted. From the walk to my bed to the couch, I'm exhausted. (Denise)
			I can't raise my arm to a certain length because it shoots pain through my underarms. (Denise)
			I don't sleep at all. Like, 2 or 3 o'clock in the morning I'm up, and I'll lay down and then get up when he gets ready, and then I'll go back to sleep and then I'll get up. (Denise)

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
Support that is helpful (28 codes)	Daughter not wanting to return to college to help mom Flexibility of employer Fundraising Giving spouse a break Help cooking Help cleaning Help from child Help from ex-husband Help from family Help from friends Help from moms at school Help from in-laws Help from neighbors Help from parents Help from spouse Help paying for children' activities Help with childcare Online support groups Support from family Support from church Support from family Support from family abroad Support from friends Support from school Support from work Support groups Support network	All	I sent an email to all her teachers, and let them know when I was diagnosed, and I said, "please let me know if you notice any behavioral changes, or if there's any problem, so we might be able to get her help on days when I can't help." and they were so great, responsive and supportive. (Rebecca) And other people I wrote, I, really surprised me. People, like some people came out of the woodwork and still, I have one woman that every week sends flowers and cards, you know, I'll never forget. You know, she's stuck, I mean, she was, and it's always. And I know she's so busy with her own life. And she still. She goes to the grocery store and buys me a funny card. And somebody I wasn't even close to. (Sarah) I'm a big diehard Louisville fan, I'm a traitor [laughs], when they won the NCAA, that got me through, you know, sitting at home and you know watching, you know that was so exciting. And so Meryl and her husband came down, and they had taken up donations from the faculty and everybody, and they had bought me a TV, a flat screen. (Shirley) Yeah, my church, oh yeah, they brought me everything, and "if you need any help around the house" and this and that and the other thing.

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	Unexpected support		Everybody is wonderful. (Shirley)
	v		
Support that is unhelpful (7 codes)	Guarding the gate from unwanted help Help leaves while in remission More help than she needs Not wanting help Not wanting to ask for help Privacy Unhelpful	Kimberly, Ellen, Sarah, Shirley, Shannon, Lori, Cheryl, Denise	Yeah, and there's a lot of, you know recovery. Even I didn't realize, I mean, people say, you have cancer have surgery, and somebody brought me dinner. And I thought well that's really nice, but I wish you would do something else for me [laughs] That was last year. I mean this is, I hate to be selfish, but, like, it would have been nice. There were a lot of people I expected to call or I expected to be, help more and didn't help, and it was kind, do you not know that I'm really sick for a long time? It's just, I know they have their own lives, but, just that I thought there some people I thought were closer. That didn't. (Sarah) Right, people give you help and you don't want it. Or it's like, don't clean my house [laughs] cause, I'll clean it when I'm on Decadron [laughs]. Or just get a grip. I don't know, just enjoy every day. (Sarah) I just don't want, I never wanted to be a burden on anybody. And it's, it's hard for me, even with my mom. And it's kinda like, so now, she's just kinda like yesterday, "It's like, no, you know, I'm just having this test, and you'll just have to wait in the waiting room." And she was just like, "No, no. I'm coming anyway." So sometimes she's like that after

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
			I put her off. Because I don't want her to have to take off work and just sit there in the waiting room. (Shannon) The best thing that she was good at, I didn't want my parents there, or one of my other sisters. It's just, there's just too much drama. She was the dragon… And she guarded the gate. In fact, literally she would meet them at the gate. (Lori) It was hard for me to accept help. Because I think, I don't know that I think of it as a sign of weakness or if I just want to prove that I can do it, because I can do it. You know, and my mom says, you're just, if you don't let people help, you're depriving them of blessings, so I try to keep that in mind, but sometimes it gets a little difficult because I feel like I don't want to be a handicap. (Cheryl)
Taking care of children during chemotherapy (28 codes)	Bathing Bonding Breastfeeding Carrying child Catching things from children Child being rough with mom Communication with child Couldn’t take care of baby Diapering Discipline	All	He ran to me and jumped on me, and his knee hit me in my ribs and broke three ribs. Which was really hard, and it took probably a year for them to grow back. It took forever. But he didn't know what he was doing. He was just wanting to play and love on me, which is fun. (Kimberly) I would try [to change diapers]. I tried, and if he were up there, I would try to change him, and I did, and I tried to change him, but I felt miserable so

Major Category	Corresponding Codes	Participants Who Mentioned	Significant Supporting Quotations
	Dressing children Feeding children Getting child in and out of car seat Getting up in the morning with children Helping child get homework done Keeping child safe Love and affection from child Male vs. female roles Picking up child Playing with child Potty training Providing entertainment Reading Rough and tumble play Single parenting Teenage rebellion Telling children about cancer Toileting for child		much that caring for him was really hard. There was just no way. The smell of food, and it was just oooof. (Ellen) Yes, I can't spank. Not that spanking works. It hurts my arm if I do it. And um, you know, I could get my slipper, and somebody suggested a ping pong paddle, but then I don't like not having that contact because I don't know how hard it is. And because of the hormone and the lack of sleep, I'm a lot more short, so I'm, I'm gonna have to change. I don't really know. He's five, he sneaks out his window if you put him in his room. Oh, but, you know when he's quiet, he's snuck the cat into the bathroom. They're outdoor cats from the barn. (Lori) But I do have a hard time bathing them, so my husband still bathes them, and he actually, we have a kneeling pad and everybody gets down on their knees and bathes them right? I can't do that. I have to stand up and bend over because I can't bend over, I don't have any feeling here [points to underarm]. (Lori)

Total Open Codes: 318

Axial Coding. After development of the 21 major categories, I completed a Conditional Relationship Guide (Table 4.19) in order to understand the relationship among these categories; thereby completing what Corbin and Strauss (1998) describe as axial coding. In this table, I described what, when, where, why, how, and with what consequences this category exists in the data. According to Scott (2004), each of these headings on the Conditional Relationship Guide ask the following questions:

> What is [the category]? (Using a participant's words helps avoid bias)
>
> When does [the category] occur? (Using "during . . ." helps form the answer)
>
> Where does [the category] occur? (Using "in . . ." helps form the answer)
>
> Why does [the category] occur? (Using "because . . ." helps form the answer)
>
> How does [the category] occur? (Using "by . . ." helps form the answer)
>
> With what consequence does [the category] occur or is [the category] understood? (Scott, 2004, p. 204).

I will describe the process of creating the Conditional Relationship Guide for the same category described above, being a mom comes first. This category, which encompasses 25 codes, was mentioned by nine of 10 interviewees. In the Conditional Relationship Guide, the first question I asked was what is the category. I defined this category, as "even though mothers are facing difficult medical treatments and side effects, their first priority is to care for their children." I then asked when does this category occur, which was during making treatment decisions, pushing through when feeling side effects, and taking care of children day to day. For where does the category occur, I answered at home, in the clinic, and in the community during a mother's day-to-day life. I answered why does this category occur by stating because mothers feel a responsibility to care and that it is her job to be the mom. I answered the how question by stating that the mothers put the mothering role above her own health, often pushing herself past the point of fatigue. The ultimate consequence of this category was that the mother puts the child ahead of herself and chooses treatment that bests the mothering role.

Another example of a category from the Conditional Relationship Guide was taking care of children during chemotherapy, which was mentioned by all participants. I answered what this category is by defining it as taking care of children, including discipline, dressing, bathing and feeding children, taking them to activities, and helping with school work. This category occurs all day every day, except when the mother is too sick to provide care. It occurs in the family's social context, within the home and in the community. This category occurs because, according to interviewees, it's a mom's job to care for the child, children need their mother, and mom does it best. The mother getting help for physically difficult tasks, and doing things even when she is feeling bad are methods mothers carry out these activities. This leads to the consequence of pushing herself too hard, and adapting by changing the way she takes care of her children.

Table 4.19. *Conditional Relationship Guide Explaining the Process of Mothering During Chemotherapy*

Category	What (Collective Definition)	When (During)	Where (In)	Why (Because)	How (By)	Consequence (With what consequence)
Being a mom comes first	Even though mothers are facing difficult medical treatments and side effects, their first priority is to care for their children.	• Making treatment decisions • Pushing through when feeling side effects • Taking care of children day to day	• At home • Clinic • Community such as ballgames	• Feel responsibility to care • It is her job to be mom	By putting mothering role above her own health, often pushing herself past the point of fatigue	Putting child ahead of herself Choosing treatment that best fits mothering role
Characteristics of child that impact the child's reaction to mother's cancer	Demographics and unique characteristics of the child impact the child's ability to cope with and adapt to mother's cancer	• Reacting to being told mom has cancer	• In the relationship between mom and child	• Level of maturity impacts acceptance of mom's cancer	• Learning about cancer • Helping mom • Pretending like life is the same	Accepting mother's cancer diagnosis
Coping strategies used by the mother	Mothers try to minimize the difficulty of the situation by stating potential	• Dealing with side effects • Feeling down	• In personal relationships	• They need to push fears and negative thoughts to	• By stating all of the ways that her life	Hanging in there Dealing with it

Category	What (Collective Definition)	When (During)	Where (In)	Why (Because)	How (By)	Consequence (With what consequence)
	positive benefits of cancer treatments. Mothers often compare their situation with far worse situations.			the side in order to keep life normal for the children • Living up to society's image of a brave cancer patient	could be worse	
Dealing with low energy	Strategies that mothers use in order to still participate in mothering activities during periods of low energy	• After chemo-therapy • When blood counts are low • When push too hard	• At home • At work • In community • Within social relationships	• Because the role of mothering is so important, mothers learn to carry out mothering even when energy levels are low.	• Taking rest breaks • Finding lower energy ways of doing things • Planning higher energy demand activities for days when rested.	Adapting the way mom does daily activities
Dealing with side effects	Chemotherapy, surgery and	• During diagnosis	• At home • In family	• Side effects can be	• Taking medications	Still being the mom even if

Category	What (Collective Definition)	When (During)	Where (In)	Why (Because)	How (By)	Consequence (With what consequence)
	radiation cause many side effects, such as nausea, fatigue, pain, chemo brain, and mood swings.	(pain from surgery and tests) • During treatment • After treatment	context • In the community	debilitating • Mothers want to provide as much care for their children as possible in spite of these side effects.	• Resting when needed • Working with medical staff	feeling bad
Financial impact of cancer	Strain on the family due to the expensive nature of diagnostic procedures, surgery, chemotherapy and radiation.	• Active phase of treatment • After treatment has concluded	• At work • Within the relationship between mom and spouse	• Cancer treatment costs not completely covered by insurance. • Some have no insurance at all. • Mothers may not be able to continue working due to illness	• Needing to have a payment plan • Spouse working more • Cutting back on non-essential expenses	Prioritizing family resources

Category	What (Collective Definition)	When (During)	Where (In)	Why (Because)	How (By)	Consequence (With what consequence)
Having fun in spite of cancer	Mothers use humor, hobbies and games to have a good time even though they are going through a hard time.	• Active phase of treatment • During day to day interactions with family	• Within family relationships • At home, in the community and in the clinic	• Levity and humor allow the family to relieve stress and still have a good quality of life during treatment	• Laughing • Making jokes about cancer • Playing board games • Going on vacation	Improving relationship among mother, spouse and children Alleviating the stress of dealing with cancer
Helping child cope	Mothers' attempts to make the child not worry about her cancer, and helping them accept the ill	• When child exhibits distress from cancer diagnosis	• Relationship between child and mother	• Because children rely on mother to provide care and support • Children worry	• Hiding how mom really feels so children don't worry • Keeping life normal • Communication	Child accepting mother's illness
Household activities	Activities around the house such as cooking, cleaning, and laundry	• After surgery • During treatment • After treatment	• At home	• Because surgery and chemotherapy may cause pain, nausea and fatigue, the	• Getting help for difficult tasks • Giving children chores • Using the	Everyone pitching in

Category	What (Collective Definition)	When (During)	Where (In)	Why (Because)	How (By)	Consequence (With what consequence)
				mother may need to adapt how she does these or ask for help.	chemo recovery routine to get things done	
Life before cancer	The mother's description of what life was like before she was diagnosed with cancer, including childcare activities, work, and household activities	• During day to day life before being diagnosed with breast cancer	• In various contexts, including home, work, and community and social relationships.	• Because it is important to understand how life was before cancer as a point of comparison	• By reflecting on previous experiences	Comparing how difficult life is now to before. Keeping life the same now as before cancer.
Mother's reaction to cancer	The mother's process of responding to and internalizing the breast cancer diagnosis. This includes her emotional reaction her	• During the time of diagnosis, including diagnostic tests, surgery and beginning chemo-	• Personal context	• Because each mother has a different way of accepting her illness.	• Working through it • Talking to others who have gone through it • Deciding to fight	Accepting illness

Category	What (Collective Definition)	When (During)	Where (In)	Why (Because)	How (By)	Consequence (With what consequence)
	communication of the diagnosis to others.	therapy				
Mother's relationship with spouse	How the mother interacts with and receives support from her spouse.	• During daily life at home	• In social relationship between mom and spouse • At home • Community	• Mom relies more on spouse	• Asking for help from spouse • Communi-cating with spouse	Spouse supporting mom Strain on relationship with spouse
Mother's relationships with others	How the mother interacts with family other than children and spouse, medical staff, and community members.	• During diagnosis, treatment and recovery	• At home • At work • In the community • At child's school	• Because cancer changes the nature of individual relationships	• Keeping lines of communication open • Being honest	Connection between mother and community
Navigating the medical world	The process of the mother finding her way through the medical establishment. This includes	• Time at the clinic (diagnosis, treatment and recovery)	• At the clinic	• Because the mother is coming into a different world than she is used	• Asking physicians and clinic staff for information • Looking up	Finding her way through the medical aspects of cancer

Category	What (Collective Definition)	When (During)	Where (In)	Why (Because)	How (By)	Consequence (With what consequence)
	understanding the diagnosis, choosing treatment, understanding medications and spending time at the clinic.			to, she needs to learn the language and routines of breast cancer care.	information online • Having someone come to the clinic • Planning around chemo recovery cycle • Bringing items to pass time at the clinic, such as books, movies or an iPad.	
Post traumatic growth of child—“It was kinda good for him.”	The experience of having to deal with a mother who is sick helps the child become more independent, more resilient, and more	• During interactions with mother • When hanging out with friends	• In social relationships • At home • In the community	• Because the child sees what it is like to have a serious illness • Because child has to	• Taking care of self • Taking care of siblings • Helping with household tasks • Providing	Child is more caring Child is more independent Helping child grow

Category	What (Collective Definition)	When (During)	Where (In)	Why (Because)	How (By)	Consequence (With what consequence)
	empathetic.			learn to do things that mom can’t do	care for mother	Being stronger
Post traumatic growth of mother—“It builds character.”	The experience of going through a serious illness helps the mother to realize what is important in life and she is more assertive in seeking cancer care. She also may participate in cancer advocacy, peer education, fundraising and overall awareness.	• During temporal context of diagnosis, treatment and recovery	• In community • In social relationships	• Mothers feel a connection with others in the cancer community • Mothers are assertive because they want to be there for their children	• Raising money for cancer • Speaking to groups about breast self exams • Giving support to new patients • Sticking up for self more	Being part of the cancer community Advocating for self and others Being stronger
Routines and organization	Mothers organizing their day in familiar patterns, including	• During daily home activities	• At home • In family context	• Because children are more secure with familiar routines	• Keeping life predictable for children • Compensating for cancer	Keeping life the same as before cancer

Category	What (Collective Definition)	When (During)	Where (In)	Why (Because)	How (By)	Consequence (With what consequence)
	keeping calendars and writing lists.			• Because organizers and lists are helpful for dealing with chemo brain side effects	side effects deficits	
Support that is helpful	Support from spouse, children, friends, family and community, such as helping with household tasks, bringing in food and taking children to activities.	• During interactions with supporters during diagnosis, treatment and recovery.	• Within social context	• Many friends and family members are generous with their time and provide support during cancer treatments	• Bringing food • Providing babysitting • Helping with household tasks • Giving money • Coming to clinic • Entertaining mother	Taking some of the burdens off the mother so she can rest and heal.
Support that is unhelpful	Support from others that is not needed, wanted or helpful as judged by the	• During interactions with supporters during	• Within social context	• Because those who are not supportive don’t	• Telling mothers about their own problems	Strained relationships Decrease in privacy

Category	What (Collective Definition)	When (During)	Where (In)	Why (Because)	How (By)	Consequence (With what consequence)
	mother. Examples include having too many people wanting to help, and people being negative.	diagnosis, treatment and recovery.		understand what helpful support is like. • Because supporters are feeling upset or unsure about how to act	• Giving criticisms to mother • Being too pushy with help	
Taking care of children during chemo-therapy	Taking care of children, including discipline, dressing, bathing and feeding children, taking them to activities, and helping with school work	• All day, every day except when too sick to provide care • When child is younger, these tasks are more physical in nature	• In family's social context • Within the home • In the community	• It's mom's job to care for the child • Children need their mother • Mom does it best	• Getting help for physically difficult tasks • Doing things even if feeling bad	Pushing self too hard Changing the way she takes care of children

Selection of the Central Category. As I did for the categories described above, I completed the Conditional Relationship Guide for each of the 21 categories. From this Conditional Relationship Guide, I was able to identify the major processes or actions that occurred for the mothers with breast cancer. These processes were derived from the "with what consequences" column of the Conditional Relationship Guide and are listed below.

- Finding her way through the medical aspects of cancer
- Finding new ways of taking care of children
- Seeking and taking help from others
- Bring stronger in the face of cancer
- Keeping life the same as before cancer

I then analyzed the relationship among these processes in order to develop the core category by using a Reflective Coding Matrix (Table 4.20). I placed each of these five processes in a column, and developed the properties (characteristics of the category), dimensions (property location on a continuum), contexts, and modes for understanding the consequences.

From these consequences, I further reduced the processes into the following major properties or characteristics of the category:

1. ***Navigating***: Encompassing major categories of navigating the medical world, relationships with clinic staff, side effects of treatment impacting daily functioning, financial impact of cancer.

2. ***Adapting***: Encompassing major categories of being a mom comes first, household activities, dealing with low energy, taking care of children, dealing with it, and avoiding support that is unhelpful.
3. ***Accepting support***: Encompassing major categories of relationship with spouse, relationship with others (friends and family), and support that is helpful.
4. ***Growing***: Encompassing major categories of post-traumatic growth of the mother (including assertiveness, anything's possible, being a role model, speaking to others about cancer, and cancer fundraising) and post-traumatic growth of the child (more empathy and more independence).
5. ***Keeping life normal***: Encompassing major categories of life before cancer, mother's reaction to cancer, helping children cope, having fun in spite of cancer, characteristics of child impact reaction to cancer, and routines and organization.

When I first created the Reflective Coding Matrix, I placed the processes in a different order. As you read the Reflective Coding Matrix from left to right, it should represent the development of the storyline. In other words, the first step in the story line would be the first column, the second step would be the second column, and so forth. At first, I had placed "being stronger in the face of cancer" in the final far right column, meaning that this is the end result of process I was trying to develop a theory to describe. However, after consulting with my mentor Dr. Howell and returning to the data, I realized that the end step of the storyline is "keeping her life the same as before cancer" which I truncated as "keeping life normal." The way that the Reflective Coding Matrix is set up, if follows the steps of the storyline, leading to the core category. From going back and forth to between the data and my analysis, I generated a core category of "keeping her life the same while weathering breast cancer treatments." The image of "weathering" came from Shirley, who, after showing me a picture of a tree in her front yard, said,

> That's my 27 year old tree. My husband and I got that when we got married… Same tree. I have posted it on Facebook. And I said, what did I say? "This is my 27 year old tree. It's a lot like me. It's bent but not broken.

This powerful metaphor became the metaphor that resonated with me throughout the entire analytic process. I began to think of the ways that a tree can withstand changes in the weather, year after year, and how it adapts to different wind patterns, weather and diseases. I will further discuss this metaphor when I discuss the theoretical model that emerged from the data in Chapter 5: Interpretation of Results.

Table 4.20. *Reflective Coding Matrix*

Core Category	Keeping her life the same while weathering the breast cancer treatment process				
Processes (Action/ interaction)	Finding her way through the medical aspects of cancer	Finding new ways of taking care of her children	Seeking and taking help from others	Being stronger in the face of cancer	Keeping her life the same as before cancer
Properties—Characteristics of Category)	Navigating	Adapting	Accepting support	Growing	Keeping life normal
Dimensions (Property location on a continuum)	• Navigating the medical world • Relationship with others (clinic staff) • Side effects impact daily functioning • Financial impact of cancer	• Being a mom comes first • Household activities • Dealing with low energy • Taking care of children • Dealing with it • Avoiding support that is unhelpful	• Relationship with spouse • Relationship with others (friends and family) • Support that is helpful	• Mother ○ Assertive ○ Anything's possible ○ Role model ○ Speaking to others about cancer ○ Cancer fundraising • Child ○ Empathy ○ Independent	• Life before cancer • Mother's reaction to cancer • Helping children cope • Having fun in spite of cancer • Characteristics of child impact reaction to cancer • Routines and organization
Contexts	Patient role	Mothering role	Getting help	Personal beliefs	Daily routines
Modes for understanding consequences	Trust the treatment and recovery process	Still getting to be the mom	Being part of a caring community	Finding a silver lining	Children accept illness and feel secure

Development of the Storyline

Each step of the qualitative analysis thus far leads to the final phase of the development of the storyline of the interviewees' experiences. According to Corbin and Strauss (2008), the storyline is developed as one of the final steps to developing a theoretical explanation for the data. In previous editions of their work *Basics of Qualitative Research* (Strauss & Corbin, 1990, 1998) Strauss and Corbin describe two steps of the coding process: open coding and axial coding. However, in their revision in the third edition, Corbin and Strauss (2008) describe how the two steps are not distinct entities. Therefore, in order to aid in the coding process and the development of the theoretical underpinnings of being a mother with breast cancer, I followed Scott's (2004) and Scott and Howell's (2008) notion of the Reflective Coding Matrix in order to develop the storyline of the study as described above. In this part of the study, data interpretation is revised and refined in order to lead a storyline that explains the process of keeping her life the same while weathering breast cancer treatments.

I will now describe each column of the Reflective Coding Matrix in order to further develop the storyline of the data with excerpts of interviews supporting each step. From left to right in the Reflective Coding Matrix, I will consider navigating, adapting, accepting support, growing, and keeping life normal in order.

Navigating

For the process of navigating, mothers described in great detail about medical details of diagnosis, treatment, and recovery, even when they do not have medical training. This need to navigate the medical world, learn about how treatments affected her, manage side effects, communicate with clinic staff, and manage the financial strain of expensive treatments was something that all interviewees discussed as one of the first hurdles they had to get over.

One mother, Ellen, age 35, described how she found a lump in her breast just after giving birth to her son. She stated,

> I had actually always been very diligent about self-exams, and I actually found it when I was the hospital. I had just given birth to him. And I had this tiny little spot, and thought, "Well, that's odd. What is that?"

Ellen, like other interviewees, described how her physician assured her that it was nothing to worry about, delaying the diagnostic process. She waited another two months, and, after noticing a drop-off in her milk production and an enlargement of the lump, finally called her general practice physician who got her into a mammogram.

Another mother, Shannon, age 39, also described having to be assertive with her medical practitioners in order to get diagnosed properly. After her first mammogram looked normal, she pushed for an ultrasound, and then a biopsy to further rule out breast cancer. She stated, "Yeah, they said, 'It looks like it's benign.' But unless you do a biopsy, you never know. So I pushed them to do the biopsy that day."

Other mothers described needing to be assertive with medical practitioners to get diagnosed properly. One participant, Denise, age 29, talked about being concerned about a lump for eight years.

> I actually had a knot in 2006. I had a mammogram done, the health department sent me. And then the year after that, I had another one. And they told me that it was nothing. And it kept getting bigger, and it would hurt. So I went to my

> OB/GYN this time in Georgetown, and she said because of the way it felt and it was really big, she sent me to a surgeon. To biopsy it. And the woman who did the surgery said it probably was benign… I went back there and she said, "It's cancer. I just don't know any other way to tell you but it came back cancerous." And I was just like, I didn't know what to say. And she said, "if you need time," And I was like, No, I want to go home. She said, "Are you sure you don't want to stay for a while?" And I said, "No, I got five kids to raise." So my daughter's friend, um, my daughter's friend's mom came back there and she said she was so puzzled when it came back cancer, because it didn't look like it, it didn't feel like it. But it was one that triple negative, so it was aggressive.

Like other mothers in the study, needing to be there for their children caused them to pursue the diagnosis and be more assertive than in their daily life. This theme will be further developed when I discuss the major category of adapting in the next section.

One mom, who was diagnosed with the rare condition of two different types of breast cancer at once, went into great detail about the cell type, the staging, and even gave precise dates for each step in the diagnostic process. This degree of detail about her diagnosis exemplifies the full immersion into the cancer world that happens with such a diagnosis.

> Yes, I had ductal carcinoma *in situ* and the other one was the adenocystic carcinoma, the rapidly growing one. And everything, it was rapidly growing, both of the tumors. So it took us about a week or a little over a week before we actually knew what type of cancer because um, Lexington Clinic had no idea what

> they were dealing with. So they had to send it off to Mayo Clinic. And Mayo Clinic was trying to see what they were dealing with. (Ellen, age 35)

This quote exemplifies how adept these participants were when dealing with medical terms. According to Ellen, her first experience in the oncology world was to find out that she had a very rare form of breast cancer that required a lot of research for her to understand. She needed to get information, learn about different treatments, and make choices based on this information.

Overall, participants had positive experiences with the clinic staff, often forming close relationships with nurses and physicians. However, Kimberly, age 45, describes an especially difficult experience with her first chemotherapy after a recurrence.

> I had a really bad chemo experience this time. I was really upset. It was very specific what happened. And this never happened before so I was really surprised. But when I went in for first chemo treatment they didn't know I was supposed to be there. And you know how stressful it is going for your first chemo treatment anyway, and she was like, I don't think you have an appointment, and I was like, "Uh, yeah, I think I do!" I wasn't on the list. And they kept lookin' and lookin' and went upstairs to see what they say. So when the nurse was calling [the doctor], the other nurse was like, "Oh, here, I found your name." And I was like, OK, great. So I was supposed to be here today. So she took me back to get all my vitals done, and the nurse said, "well I'm on lunch break." And I was just like, "Are you kiddin' me?" So the girl that took me back there, she said, so if I get her vitals will you do everything else? And she was like, "OK." I guess she didn't

> know how to do all of that. So she was fumbling around trying to get my blood pressure, and she kept working.

In spite of Kimberly's negative experience with the chemotherapy infusion staff, most participants described having a positive relationship and experience with Cancer Center staff, especially those in the Comprehensive Breast Cancer Center. According to Denise, her relationship with her oncologist is very close, and she and her husband often joke around with him, especially about her husband's baldness.

> He's nice. But of course my husband had to ask a question. "If I unhook her IV and hook it into me, will my hair grow back?" and [the doctor] said, "No, sorry, once it's gone, it's gone." And today he had to tell him there's not hope for his hear [laughs]. Just sayin'…. Yeah, well, we like him.

Most participants discussed learning to deal with the routine of chemotherapy treatments, often planning work around the chemotherapy recovery cycle. According to Kimberly,

> Yeah, Let's see, I had it on Friday, and probably the first day, I was tired, I was really tired on Saturday. Sunday, I really felt bad. And by the middle of that week, I started feeling a lot better, but that's when your white counts start going down. And then, this week, I had to go out of town on work, which was really hard. So Wednesday, Thursday, Friday I wasn't feeling too good. At all.

One of the most difficult aspects that mothers had to deal with when going through diagnosis and treatment was the financial stress of the cost of cancer treatments. Of the ten interviewees, only four were able to continue working fulltime during treatment (Rebecca, Kimberly, Shannon and Cheryl), all of who were the sole financial providers for the family. Two participants were able to work at the beginning of chemotherapy, but had to cut back on hours due to side effects (Shirley, Melissa). Three participants, Ellen, Sarah and Lori, were stay at home mothers when they were diagnosed and could not go back to work due to fatigue. One participant, Denise, was actually laid off her job due to not being able to fulfill job duties of working in a factory. She said, "Uh, I actually lost my job because of this. They had to replace me. They couldn't leave a spot open."

Because of this financial pressure, spouses of the participants had to work more hours in order to make up for the missed income. Lori, age 47, described a family vacation to visit family overseas for a month of which her husband will have to miss part. "I'm gonna miss, my husband's not going until the last week. We couldn't afford for him to be off work." Another mother, Denise, talked about how her husband needs to pick up extra shifts at the factory in order to make up for her missed income. Here is an excerpt of our interview (I am JAB):

JAB: So are finances tough?

Denise: Oh yeah. Oh yeah it puts a burden on him.

JAB So is he picking up the slack with that?

Denise Yeah. Everyday. Seven days a week.

Another mother, Sarah, discussed the difficulty of paying off medical bills for her many procedures and treatments. She stated, "You know, It's just financially devastating to have to pay for the insurance, pay for the deductible, and go really significantly in debt and we might have to, we might have to sell our house." Up to this point, she has paid for services by cashing in her retirement when she worked as an attorney.

In summary, for the major category of "navigating," mothers had to learn about their medical condition, advocate for diagnostic procedures, and deal with the financial pressures of medical expenses. This navigation was greatly facilitated by a good relationship with clinic staff and oncologists, which were overall positive interactions.

Adapting

The next major process I will discuss is "adapting." This category encompasses the major categories of being a mom comes first, household activities, dealing with low energy, taking care of children, dealing with it, and avoiding support that is unhelpful. Nine of the 10 interviewees described how their first concern when hearing the news that they had breast cancer was for their children. According to Rebecca,

> Well, your first concern as a mother, and even as a single mother is for your child. OK, worst case scenario, something happens to me, and I don't make it. And who's gonna take care of my baby? [cries].

Another mother, Ellen, described how her approach to dealing with breast cancer was always focused on how it would ultimately affect her son. She said,

> Everything I have done from the get go, it's not, "Oh my gosh, I've got cancer." It's, "OK, I've got cancer, what do I do now because I've got to think about living and being his mother for years and years and years."

In response to this desire to be there for her young son for "years and years and years," she decided that she needed to put her medical care and her recovery first, which caused her to prioritize where she used her energy.

> My job now is to survive. I have to do everything I can to survive. I have to take care of my body, I have to rest when I need to rest. I have people who are helping me, I need to let them do it because all I could think was long term. I can't think short term. Short term, disciplining him. But that's not, that may not have helped me. I had to think, I want to be with him for 5, 10, 15, 20 years. He needs a mother. He wants someone with him while he's growing up. And if I don't do everything I can now, I may not get that chance.

For Ellen, taking care of herself in the short term will result in being there for her son in the future.

In contrast, another mother, Sarah, who did not have as much help with childcare as Ellen, described how she chose surgical and treatment options that would take her away from her son the least amount of time. She said,

> And even my surgery, I just did the outpatient. And one reason that I did that is you can have a lumpectomy or a mastectomy, it's your choice. I could not, I had to have the least possible surgery because I have to take care of my son.

Another mother, Shirley, described how fighting for her daughters and her new grandchild gave her strength when side effects were difficult. Because her husband had just passed away two months before her cancer diagnosis, she felt the need to fight as much as she could so that her daughters could have a parent.

> The only thing, I mean, that's what really gave me a lot of strength was fighting for my daughters and the new grandbaby, because I knew that I was they had since I had lost my husband.

Lori, who is the mother of an 18 month old daughter and a 4 year old son, said that she made choices overall on how it would affect them. She said,

> You know, my everything is what's gonna, you know, what's best for them, what's gonna, how it's gonna impact them. You know, it just, it's so, they're gonna have, the choices, you're gonna have to make choices. And, you know, so they're gonna have to clean house, and they're probably not gonna get to go to Disney, but you can't put a price on it.

Lori realized that having a mother in the future was going to be more important than having an extravagant lifestyle.

Another major category under "adapting" is household activities. Since part of my interview guide addressed how breast cancer treatments impacted their ability to do household activities, such as cleaning, cooking, housework and laundry, all participants discussed this. Several of the mothers described how they learned new ways to do things or incorporate new routines into their household activities.

Sarah described how she limited the amount of laundry that she does in order to conserve her energy. She said,

> I'm sort of down to two loads a week. I've told my husband he's on his own. Just I'm gonna do a load of colors and a load of white. And I can remember that. And I do it on the weekend, and I know my son has clothes… I can barely do his. Because you gotta walk up and down the steps.

Again, her child's needs came before those of her husband's and her own in terms of clean laundry.

Kimberly described how her older daughter helped with cooking and cleaning while she was home for the summer. She said, "And Kelsey has been really good about helping to fix dinner and take care of things and do the dishes and clean house." Another mother, Cheryl, described having someone come in to clean her house, although she still cooks and straightens the house on her own.

In terms of dealing with low energy, nine out of 10 interviewees described adaptations to daily occupations in order to take care of the household activities. Strategies interviewees used included getting take-out food, doing difficult tasks during the most alert time of day, getting children to help out by giving them chores, and resting when needed. Many of the mothers described having lifting limitations due to mastectomies, lymph node dissections and reconstruction expanders, which impacted activities such as vacuuming, laundry and overhead tasks such as putting away dishes. Lori described a strategy to deal with not being able to move her heavy vacuum around the floor by getting a child-friendly vacuum for her children to use.

> But they would, we bought them a little broom, if I could find them a little mop. They fought, the best thing ever, $20 Dustbuster on a stick. They fight over who's

> gonna vacuum. I did have to get a different vacuum. I had an Oreck, and we had gotten a new one. And it wasn't an Oreck. I'd gotten some Hoover, and it was too heavy and I couldn't use it. As soon as I brought it home, they were fighting over it. They still fight over it. And actually the boy will get it out the closet and sweep his room if he's made a mess.

Lori also described that she deals with a lot of memory deficits secondary to chemotherapy and fatigue, and one of her household jobs is to do the bills. Due to her bad memory, she had some missteps with paying bills until she made adaptations to her routine. Now, she uses the strategy of finding her best time of the day to focus on paying bills, reducing distractions and having coffee to keep her focused. She said, “When I have to do the bills, I usually get a cup of coffee and I try to do it in the morning and there cannot be any kids.”

Sarah described using her treatment side effects to her best advantage in order to clean her house, stating, “And I would try, you know, when I was on chemo, I would have the Decadron, the steroids. And I would clean the house on steroid day.” She described not being comfortable with an outside person cleaning her house, so she waited until she had the energetic side effects of steroids.

Other strategies mothers described using were doing less, exercising to keep fatigue at bay, finding low energy activities to do with children, resting while children were at school, getting children in activities in order to get a break, and overall letting go of high standards for household cleanliness.

Interviewees also described difficulties of taking care of children during chemotherapy. Rough and tumble play was especially hard for interviewees with younger children due to fatigue and being more fragile. Kimberly described how, during her first occurrence of breast cancer, her son, two years old at the time, jumped on her and injured her. She said,

> He ran to me and jumped on me, and his knee hit me in my ribs and broke three ribs. Which was really hard, and it took probably a year for them to grow back. It took forever. But he didn't know what he was doing. He was just wanting to play and love on me, which is fun.

In this situation, Kimberly needed help from her husband and her in-laws in order to provide care for her son, especially while her ribs were healing. After this event, her son stayed overnight at her in-laws' home on a frequent basis since it was difficult for her to provide care.

Ellen also described difficulties with providing care during the worst side effects of treatment. She said,

> I would try [to change diapers]. I tried, and if he were up there, I would try to change him, and I did, and I tried to change him, but I felt miserable so much that caring for him was really hard. There was just no way. The smell of food, and it was just oooof.

Instead of changing diapers, Ellen found other ways of bonding with her son, doing a lot of snuggling, reading and other low-energy activities with him.

Lori described changing her disciplinary practices due to lymphedema pain in her dominant arm.

> Yes, I can't spank. Not that spanking works. It hurts my arm if I do it. And um, you know, I could get my slipper, and somebody suggested a ping pong paddle, but then I don't like not having that contact because I don't know how hard it is. And because of the hormone and the lack of sleep, I'm a lot more short, so I'm, I'm gonna have to change.

In this case, Lori was able to step back and realize that her long term hormone blocking treatment Tamoxofen was causing her to have less patience with her son, so she was able to change her disciplinary practices, focusing more on positive reinforcement.

Interviewees also described using cognitive strategies to help them deal with breast cancer and chemotherapy. Interviewees talked about being positive, how it wasn’t all that bad, and letting go of expectations of how life “should” be. Shannon described how keeping a positive attitude helped her through treatment.

> Um, I just think it's so important keeping a positive attitude. And just not getting discouraged and depressed. And down. Um, which I thrive more on just doing things, you know, keeping the routine and doing things by myself. And I think that just kinda helps me mentally and physically. Because I've seen, I've seen people that are just so negative, and I just really think that affects your health. I really just do. And just being positive.

Other mothers described how comparing their own situation with others who are worse off helped them deal with it. Cheryl, who works at a neurology clinic, said,

> I look at it as, this is what it is, you can't change it, you can help it, maybe if it works out that way, but it could always be worse. It could always be worse. I can walk down the hallway at work every day, and I will see somebody that is in worse shape than I am in.

Sarah also made a comparison of her life to others, albeit a more extreme comparison. She said,

> But, you know, it's like, we're alive, we have all our limbs, we could have been in a car accident. Our son's healthy. It's not that bad, really. We don't have to live in a concentration camp.

In addition, several interviewees described how religion played a large part in their ability to cope with breast cancer. According to Cheryl, “Well, let me tell you what it is, God is a huge part of this. OK, probably the biggest part of anything in my life.”

Six of ten participants described the strategy of avoiding people who were not helpful to them during their chemotherapy experience. Sarah described not wanting to take help and wanting to take care of her home herself. She said,

> People give you help and you don’t want it. Or it’s like, don’t clean my house cause, I’ll clean it when I’m on Decadron [laughs].

Later in the interview, when asked what last thing she would like to add, she said,

> People always tell you ask for help, but I hated that advice because [sigh], you can't always take, I mean, you can't always take it. And people tell you to rest and, you can't always rest.

Denise echoed Sarah's comments by describing how sometimes others' words of concern were especially unhelpful.

> Right, and that's something I can't stand is for someone to come up to me and be like, "Are you alright? Are you OK?" "Dude, I just had both of my breasts removed and my hair fell out, and I take chemo. Why are you asking? It's not OK. It's just something that I have to do."

For Cheryl, the need for privacy and not wanting to be labeled as a cancer patient kept her from asking for help.

> It was just hard just dealing with the ramification of it. Cause, like, oh gosh, I just told everybody and now everybody wants to talk about it, and I don't really wanna, like, be the person with cancer.

Shannon described really wanting to do things for herself rather than have help. She said,

> So even last time, and that was my biggest struggle is that I just don't ask for help. And even when my oncologist said, "you have to ask for help," and I'm like, I'm fine. She's just like, "Really, you're not?" And I'm like, I really am. I mean, I just don't, even if I need it, I don't like to….I'm just super independent.

Lori described how her sister protected her by not letting unhelpful people in the home for very long periods of time.

> The best thing that she was good at, I didn't want my parents there, or one of my other sisters. It's just, there's just too much drama. She was the dragon. And she guarded the gate. In fact, she would literally meet them at the gate.

In summary, mothers adapted to their breast cancer treatments by finding new ways of doing household and childcare activities, prioritizing activities, remaining positive and avoiding negative people.

Accepting Support

The next process in the storyline is accepting support, which is the process of seeking and taking support from others. Interviewees described support from spouses, family members, friends, co-workers, church members, and even strangers. As Shannon and Sarah described above, it was not always easy for mothers to accept help from others. However, interviewees found it necessary to accept the help when their adaptation strategies weren't enough to meet their or their children's needs.

For most married interviewees, their spouses were the first source of support. Ellen talked about the support she received from her husband by saying,

> He's been fantastic and supportive throughout. I mean, I can't begin to imagine what this has been like for him, to have to, you know, take on so much

> responsibility and have in the back of his mind of, if I'm not going to be around. Is he gonna lose me? I can't imagine thoughts like that. Um, that has to be the most painful thing, um, and it did, it affected him. It was hard for him to sleep. For me, all I could think was I, I am going to win. When you hear you know they give you the chemo and they try to push you as close to death as possible without actually killing you, and it's really true.

Lori talked about how her husband helped with the children, let her take naps, and was tolerant of the house not being clean.

> But he's really good about me taking a nap, he's really good about the house being dirty, and the clothes not being folded--they're clean, they're just not necessarily folded and put away.

Denise described how her husband helped with the discipline with her five children.

> Let me tell you something. There's a difference between me and his voice. I can say it on some things, and they know I mean it, and some things he says, when his voice gets deep, it's shutdown. They all, know, seriously. They all go to their rooms and you hear the doors slam, and you don't hear another word. It is the peacefulest house you have ever heard with five kids in it. It's wonderful.

Kimberly described how helpful her mother-in-law was during the toughest part of her chemotherapy during her first occurrence, often with her son living with her in-laws in a separate home.

> It was really hard, really hard, and um, but my mother in law really stepped up and did a lot to help because I was really sick once I started chemo, and um, probably for about three months I was really sick. She pretty much raised [my son] for three months… It was hard, because I wanted him home. I don't guess [my husband] could take care of me and the baby at the same time.

Several months later, however, her husband had a hard time with dealing with cancer, and this ended up impacting the help she received from her in-laws.

JAB	So did you have a lot of help other than your mother in law?
Kimberly	Um, well, my husband, at least until, from February until July, and then he left. But up until then I had a lot of help.
JAB	So he left and moved away from the home, is that right?
Kimberly	Uh hum. Well, he decided he was unhappy so he moved out.

Not only did Kimberly lose the support of her spouse after her separation, she lost the support of her in-laws, who had been very active in caring for her young son. At that point, Kimberly received more support from close friends.

Unmarried interviewees tended to find support from friends, family members, support groups and the community at large. Rebecca described using a time bank support group to help her with household activities when she was feeling ill.

> Even though I'm a single mom, I've got a really good support network, and part of it I've developed over time, you know, myself. And then I had a friend refer me to a single parents' group online through MeetUp.com, and I have established

> friendships and some resources through there. And then time banks that I've signed up for that where you trade work for hours, not money. And so I signed up for time banks since I might need some help with cleaning the house in a month or two. I might need someone to bring meals, and some of the people from that system would come and bring meals, and I would go on the computer and give them time credit for their commute and cooking. And it was really great.

In summary, although interviewees didn't always feel comfortable accepting help, support from others was necessary in order to have their children's needs met while feeling fatigued or nauseated from cancer side effects. This support ranged from spouses, co-workers, friends, family members, and community members.

Growing

The next step in the storyline was growing, which can be described as being stronger in the face of cancer. Interviewees described growth of themselves and their children from dealing with the difficult experience of breast cancer. Growth for mothers manifested in being more assertive, more forthright, feeling more confident in her abilities, participating in cancer advocacy groups, and being a role model to others.

Ellen described how getting through breast cancer surgery and treatments gave her a confidence that she can do anything. In fact, after she was in remission after her recurrence, she joined a running group and ran a marathon to raise money for cancer research.

> I mean, I've literally, I've been through hell and back, and I believe that if I can overcome this, I can overcome anything.

Kimberly echoed this sentiment by talking about cancer as character building, although not by choice.

> It's just kind of something you have to go through. It's just like my dad said, it builds character. So I should have a lot of character after all of this is over with [laughs].

Kimberly also described being more assertive than she normally would be when things weren't going well during her chemotherapy session, which surprised her daughter. When I asked if she has always been assertive, she stated,

> No, this is definitely, having cancer has taught me to be. Because you have to. Normally, I guess I'm not real outspoken because [my daughter] was real surprised when I said something.

Ellen described needing to be proactive in order to deal with the medical world and be knowledgeable about all aspects of care and communicate with medical staff.

> Yeah, so I've learned a lot, I've learned a lot from being sick and being hospitalized multiple times, and I've learned to ask for reports and um the best piece of advice I could give to any patient battling cancer and anything else is, not only do you need to be proactive and know your body and ask as many questions as possible, and keep on top of everything.

Ellen also described wanting to be a good role model for her son by being able to handle difficult challenges with grace.

> Yes, so I've always pushed harder because I, I think about what kind of example I want to set for him. I want to, to, be the kind of mother and the kind of parent that says, "You may have so many challenges and obstacles in your life, but you can persevere, you can accomplish anything you set your mind to." And that's what I want to teach him. And, um, and really I think that more than anything, not just for him, but for everyone else around me to just so, just to inspire people to be better than where they are now. Because anything's possible.

Shirley discussed being asked to speak with a university sorority on breast cancer awareness, and this inspired her to think of herself as a cancer advocate.

> And then I talked to the undergrad sorority group, and they were doing breast cancer awareness in October, and the young lady is trying to get into our program, and we started talking… And she said, "would you like to speak to my sorority?" And I said sure, because they do breast cancer awareness, and I said sure. Gosh we probably had 30 or 40 and there were guys there too, one of the young men I know from church. And I talked to them, and they had other people give their stories, and it was so sweet. (Shirley)

Denise demonstrated growth by being a good example for her daughters and demonstrating breast self exams to be vigilant about their risk of breast cancer.

> I mean, I've told my girls, I've even showed them how to check. I even told them I was gonna schedule them for their doctor to keep updates on them. Make them feel positive.

Lori noted how her four-year-old son learned empathy by understanding that her mastectomy and lymph node dissection left her with activity limitations on one arm.

> Um, when we went, we went to the lake on Sunday, and he and I ended up getting in the water, and [my daughter] was in for a little bit, but then she got cold and so they went and sat under the tree. And he kept asking me, "Is this your bad arm, is this your bad?" Because we were towing around. And I said, "Yeah, you have to get on my other arm." And he can't come up behind me and jump on me.

Melissa described how her 15-year-old son, who normally didn't provide care for others, stepped up and helped her when she was bedridden with nausea during chemotherapy.

> He was, he was really good. It was kind of a good experience for him because he saw what it was like to see somebody that was sick and not be able to help themself. And so it was kinda good for him.

Despite this focus on positivity, I found that some mothers made comparisons of their lives to catastrophic situations, such as the Holocaust, death, dismemberment and homelessness. For example, Sarah stated,

> But, you know, it's like, we're alive, we have all our limbs, we could have been in a car accident. Our son's healthy. It's not that bad, really. We don't have to live in a concentration camp.

Another participant of the study, Shannon, described a casual acquaintance with the same type and stage of breast cancer as she did, but that she was really negative and died in the end. To Shannon, being positive helped her survive and help her children cope with her illness.

In summary, although going through very difficult times in terms of side effects and painful surgery, interviewees identified growth in themselves and their children. These findings will be further discussed in the next chapter, Interpretation of Findings.

Keeping Life Normal

The final step in the storyline is the keeping life normal, or keeping life the same as before cancer, incorporating categories of life before cancer, mother's reaction to cancer, helping children cope, characteristics of child impact reaction to cancer, having fun in spite of cancer, and routines and organization. For all participants, keeping a sense of normalcy for themselves and their children was the ultimate goal of getting through breast cancer treatments. I placed the categories of life before cancer, mother's reaction to cancer, and characteristics of child impact reaction to cancer because these were all discussed in terms of bringing life back to some sense of normalcy as before mothers were diagnosed.

When asked about life before cancer, all interviewees described as being independent in daily activities and having more energy than after cancer treatments.

According to Sarah, who had great difficulty with nausea and fatigue during her chemotherapy, stated,

> I was one of these people who went from daylight ‘til dark. And I helped with everything under the sun. I just went constantly.

Sarah described how, before her diagnosis, she never had health problems. “Yeah, just, yeah, I was healthy, I've never been sick.”

When diagnosed, the upheaval to interviewees’ lives was immediate. Kimberly described the emotional upheaval that was caused by her breast cancer diagnosis.

> It was very traumatizing. When you hear the word "Cancer," you think you're gonna die, with two small children. So it was really hard, really hard.

Sarah described how her first reaction to breast cancer was that it didn’t fit into her busy life.

> And then I got diagnosed. So it was, look, I've got to work, and everything… I think most moms or anybody with families think, “I just don't have time for this.”

The children’s reaction to their mother’s diagnosis of breast cancer was varied, from denial, to jumping in and taking care of household tasks and care of siblings. Ellen described how her 18-month-old son intuitively knew that she wasn’t able to do things for him that others could.

Yes, he's always been such a smart, intuitive little boy. I mean, he knew from the get go, he was like, "Ah, she can barely pick me up. She's gonna drop me!"

Rebecca described how her daughter seemed to accept the breast cancer diagnosis well, but that her grades dropped as a result.

> You know, she did pretty well behavior wise, um, but I think the biggest thing that I noticed later, and even late late, was the drop in her grades.

Although four of Denise's five children accepted her diagnosis, one daughter didn't acknowledge that the breast cancer was real.

> She, for two weeks, she was real quiet. And I told the other kids to help with the housework, and she wasn't really listening. So I went to school and I had her by herself. And I was like, "You know, Addie, it's real. It's not going anywhere." And she was like, "No it's not." She was in denial big time. Then so I pulled the school counselor to the side, which is good because she's her aunt. And I was like, "Amy, you're gonna have to talk to her, because she's really in denial. She really believes I'm lying, that it's not gonna happen, that my hair's not gonna fall out. The whole nine yards." And it took the counselor two weeks to get it into her head that it was there.

After helping the children come to terms with her breast cancer, another part of keeping life as normal as possible was helping children cope, which often resulted in mothers hiding feeling ill and acting like everything's fine. Kimberly described hiding how ill she felt not just to her children but also to her co-workers.

> You know, when I went in to work on Friday, she said, you don't look good. Are you feeling bad? And I said, I've felt bad this whole week, and she said, well you sure didn't let on that you felt bad. But I was like, "well, I try not to."

Shirley described putting on a brave face so she wouldn't worry her daughters, especially since her husband had just passed away,

> And I had to not show fear. And I didn't really feel a lot of fear, I guess because of my faith, I was just like, what's gonna be is going to be. Sometimes I get discouraged, but it's not, you know, in front of them. And I think that helped me a lot.

Denise reassured her children by keeping life the same as before breast cancer treatments. She said,

> But of course I told them, "Nothing changes." Day to day, everything they do, nothing changes. They go to school, they make good grades, they do this, they do that, nothing changes.

One strategy that interviewees used to keep life as normal as possible for their children was to keep routines and improve organization. Shannon, who was always very organized, described how keeping routines in placed helped all of them cope.

> I really think [kids have adjusted well], I think it's because I keep the schedule. I mean I just don't, even like last time when they were in volleyball and soccer and basketball, and I went to everything, because I thought that was important.

Shannon also described how keeping routines and a sense of normalcy helped keep anxiety at bay.

> And that didn't, um, my big thing was just keeping a routine and keeping things as normal as possible, and I think that was, kinda, "Oh yeah, I didn't even think about, you know, this, mom having this, going through this and going through that." … What I'd recommend to people is keeping a schedule and being organized. That really gives you peace. I think it's really important. And I think it's important for kids too. I really do.

Denise echoed Shannon's adherence to routines as being good for their children by stating,

> That's what we did. Don't change anything. If you change anything, it's just gonna downfall them. It's gonna mess with their work. Just keep the same routine. We do, we don't change anything.

Sarah described using routines and organizers to help compensate for her memory problems secondary to chemotherapy and fatigue.

> I started wearing my watch again. Because I used to not need it, but now it works because I'll go, OK, What time it is? So it helps to wear a watch again. I know a lot of people had stopped. Um, reminders, you know, I just keep this big calendar [shows calendar, large size]. I keep it with me at all times and I just have to keep looking at it. I mean, if you weren't here I would probably just open it up and

> look at it and review the whole week, and do that a lot, because I just can't remember where I'm supposed to be and what I'm supposed to be doing.

Another strategy that all interviewees mentioned was having fun in spite of cancer. In all of the interviews, mothers laughed and made jokes out of the situation. Sarah described how her son joked with her about using cancer to his advantage to get more time with the tablet computer.

> I think we're better now and also we can joke about, you know, “Mommy, you can go rest now.” [laughs] “Oh, you, I know what you are trying to do. You are trying to get more screen, right? Right. So why don't you just tell me.” So we're able to joke about it.

Shirley described using humor as a way to bond with her teenage daughter and helping them keep a close relationship.

> They were at their New Year's Day party, and she said, [in English accent] “Cheerio, mother.” And we were talking in this British accent. And I said, “Hello chap chap. What are you blah blah blah.” I said you had me on speakerphone? [laughs] And then, they said, they looked at her and said, “My mother would never act like that,” and their mothers are ***way*** younger than me, because I'm an old one. And [my daughter] said, “Oh yeah, we act like that all of the time.” And was just like, we do that all the time. And she said, they were just laughing and my mother would never act like that. Yes, enjoy life. And we act crazy, and make up silly songs, and do all that kind of stuff.

Denise described how her leisure activities revolve around her children, such as taking pictures of them and going to play baseball, which was her preference before her breast cancer diagnosis.

> I like to do pictures. I like to stay at the house with the kids. If they gotta go someplace, I like going with them. I like doing things with the kids. If it consists of getting up in the morning and getting dressed and going to the ball field and playing with our family, that's where I want to be. Otherwise I don't want to go.

Denise also described still having fun activities to do with the children, especially when the children had to do most of the physical activity and she could rest and watch.

> We do all kinds of goofy things. We fill balloons full of, what did we put in, shaving cream? The kids got older, and they got tired of playing tag, so I took some balloons and I filled shaving cream in them and I only filled them up so far, so they would be harder to bust. Then I tied a string to the end of them and the string to their leg. They chased each other all over the yard, and the last one to have the balloon won.

In summary, keeping life normal was a process that all mothers interviewed as a strategy to help their children cope with their breast cancer diagnosis and treatment. They described wanting to keep life as similar to before the breast cancer diagnosis as possible, often by keeping to the same routines and keeping children in their activities. Some mothers used organizers and routines as a means of compensating for memory deficits and fatigue. And overall, mothers retained a sense of humor and a need to have fun with their children, even during difficult times.

Mixed Methods Research Questions

The qualitative and the quantitative data in the study served to provide further information to understand the experience of going through chemotherapy for mothers with breast cancer. For each participant, the interviews, which were conducted between 1 month and six months after collection of quantitative data, confirmed what they responded on the quantitative measures. I will discuss each of the two research questions for mixed methods, and I will further interpret these results in Chapter 5: Interpretation of Results.

MM 1 How do parent disability, CRF and QOL relate to the experience of mothering during chemotherapy treatments for breast cancer?

Parent disability, CRF and low QOL serve as challenges for mothers, and those who were interviewed confirmed these difficulties through their interview statements. The quantitative data from the study was consistent with the interviews. For example, Ellen rated her fatigue interference on the FSI-TT as an extreme interference with her daily activities, and her ratings on the PDI were "unable to do" for all items except the items "keeping your child out of unsafe situations" and "getting up with your child," to which she responded the she had a lot of difficulty doing those tasks, which was echoed by her statements in the interview:

> I really couldn't [take care of him]. I had a lot of help. We had friends that stepped up and helped. Not, my husband, uh, was able to adjust his schedule. His boss…was fantastic. And let him adjust his schedule so he could be home when some people had to, a friend of ours had to, could only come from 9:30 until about 2, so he would go in a little bit later and come home earlier. And did that,

> and we had another friend who would stay. She was doing M, W, F, and we had basically, we had friends who could help everyday…There was no physical way. I was pretty much stuck in the bed a lot.

For Cheryl, who has recurrent metastatic breast cancer, she reported having no difficulty with any parenting tasks and reported no fatigue and high quality of life. She said,

> I think the best thing to do is not change anything. Don't quit work, don't cut back on work, if you can go to work, go to work. Keep your life as normal as you can. When I had my bilateral tran flap a year after my chemo, I actually left the hospital and went straight to the ball park. I didn't get out, but I did go to the ball park… So I just, I didn't, I would stick those drains wherever I could stick them, and I couldn't drive for a while, I so would have somebody pick me up and drop me off at the ball park, and then I'd get a ride home… I do have somebody come in and clean the house. I have somebody who comes in every other week. Um, but, I do all the, 90% of the cooking and the straightening, which is a chore when you have three teenagers, they consider their space as everywhere. So they, you know, they don't, I did mow my yard myself, but, and then, my neighbor friend, the little guy next door, wanted to do it kinda like for his summer job. You know, I did, I just started letting him do it because you know, It was just to kinda help him out. I'm capable of mowing my own yard.

Another mother, Lori, rated having a lot of difficulty on the PDI item on maintaining discipline. She also brought up in the interview how she has a hard time with disciplining her four-year old son.

> Yes, I can't spank. Not that spanking works. It hurts my arm if I do it. And um, you know, I could get my slipper, and somebody suggested a Ping-Pong paddle, but then I don't like not having that contact because I don't know how hard it is. And because of the hormone and the lack of sleep, I'm a lot more short, so I'm, I'm gonna have to change. I don't really know. He's five. He sneaks out his window if you put him in his room. Oh, but, you know when he's quiet; he's snuck the cat into the bathroom. They're outdoor cats from the barn.

There were multiple examples when both the interview data and the quantitative data confirmed each other, which further added to the trustworthiness of the study, which will be discussed in Chapter Five: Interpretation of Results.

The only example where there was a discrepancy between the qualitative and the quantitative data was with Melissa (44), which may be due to the delay between the quantitative data collection and the qualitative data collection. At the time of taking the inventories, Melissa rated on the FACT-G “very much” to the questions “I am able to work” and “My work is fulfilling.” She completed the quantitative inventories just after her second chemotherapy session and was interviewed three months later, just after the completion of her chemotherapy. Melissa described how her nausea got worse and worse with each subsequent treatment. Fortunately she is a teacher and had the summer months to rest and recover during the most difficult times of her treatment, but she stated,

> I got to the end of the year, and thank goodness it was summertime. Because I

> could have never done it. By that third one, I was in the bed. And I could barely make it to the bathroom to throw up… They tried every kind of anti nausea thing, and nothing seemed to work. So I mean, for the entire summer, the kids, I couldn't take him anywhere, I couldn't you know, with his friends.

There were also instances in which the qualitative added to the overall picture of the mothers' experiences. For example, the concept of unhelpful support was not measured in the quantitative data collection process but was mentioned by eight of ten of the interviewees. Unhelpful support is help given by family members or friends that actually makes the lives of the mothers actually more difficulty. For example, Ellen described how her sister in law was not easy to have around during her chemotherapy. She said,

> My sister in law, was, she helped once or twice, but she, God love her heart, she is not the most stable person anyway. She is kind of a Negative Nancy, and when you're sick and you, you don't need that. You need positive energy around you. You don't need something who makes you feel like you have one foot in the grave. So I just kind of pushed that away and tried to um um not deal with her as much as possible [laughs]

Without the addition of the qualitative data, I may have overlooked this important aspect of mothering during breast cancer treatments.

MM 2 How do age of mother, marital status, socioeconomic status, number of children, and age of children impact the experience of being a mother undergoing chemotherapy for breast cancer?

Age of mother, marital status, number of children and age of children increased the challenges placed upon mothers. Single mothers reported having to take care of everything within the home, and they reported needing to keep working in order to have an income and to keep life more normal. Cheryl, age 48, said,

> I think the best thing to do is not change anything. Don't quit work, don't cut back on work, if you can go to work, go to work. Keep your life as normal as you can.

Since her husband died only two months before her diagnosis, Shirley tried downplaying the seriousness of her illness so her children wouldn’t worry.

> The only thing, I mean, that's what really gave me a lot of strength was fighting for my daughters and the new grandbaby, because I knew that I was they had since I had lost my husband. And I had to not show fear. And I didn't really feel a lot of fear, I guess because of my faith, I was just like, what's gonna be is going to be. Sometimes I get discouraged, but it's not, you know, in front of them. And I think that helped me a lot.

For socioeconomic status, mothers reported having difficulty in paying medical bills and having reduced work hours or having to quit work all together. One mother, Denise, age 29, rated her income as $15,000 to $24,999, which is a decrease from her income before she was diagnosed with breast cancer and was able to work full time. She stated,

> Uh, I actually lost my job because of this. They had to replace me. They couldn't leave a spot open.

Additionally, she rated for “I am forced to spend time in bed” as “quite a bit,” which further reinforced the physical impact of cancer on her ability to work and complete household activities.

Although there was concordance between income and what participants said about their financial status, the quantitative data alone did not fully represent the trajectory of the story of the interviewees’ financial status. Denise above lost her job because she could not work at her physically demanding job. However, only after interviewing her did I understand that, because of her being laid off, her husband had to pick up extra shifts at work, causing him to work most weeks seven days a week.

I originally hypothesized that mothers with multiple children would describe having difficulty with parenting tasks. However, I found that mothers with multiple child got help and support from their older children, especially in caring for the younger children and doing household chores. Shirley described how her older daughter would drive her younger daughter to basketball games when Shirley was feeling too tired. She said,

> I did OK with it [driving her to basketball practice]. And if I couldn't, [my older daughter] would help out. Jessica was really helpful. She was the one, she took me to all of my doctor's appointment. And she was very helpful fixing me some food, and blah blah.

For mothers with younger children, the physical aspect of care was described as more difficult. However, in my sample of interviewees, only two had children younger than six years old at the time of completing the quantitative inventories (Shirley's daughter had a baby just after she completed chemotherapy). However, one participant, Kimberly, had her first occurrence of breast cancer when her son was one year old, and she dealt with a lot of difficulty in caring for him during that time, which resulted in her getting injured.

> You know, he was a year old at that point. He was sitting on the floor and I couldn't pick him up or anything of course, and he ran to me and jumped on me, and his knee hit me in my ribs and broke three ribs.

Another mother, Ellen, whose son was an infant when she was diagnosed and who is now two years old, described how, although she could not provide for his day to day care due to her side effects of treatment, she was still able to bond with him.

> We would, we did a lot of snuggling, even with the radiation, so luckily the burn was over on this side so I had always kept him on this side. But even during everything else, I would put him on the floor and I always, I would always try to hug him and kiss him and love on him, and play with him, like I said on the floor. And when he would try to climb on me, just tell him, "OK, be really gentle with mommy. Mommy's a little broken right now." Uh, so be gentle. Uh, but I always tried to find some way to interact and bond and just hold him and love on him so that he, he got that from me.

In summary, there was a great deal of concordance between the interviews and the quantitative data.

Summary of Results

In this study, I collected both qualitative and quantitative data. Several of my hypotheses concerning demographic trends were not confirmed due to the failure to reject the null hypothesis of no difference between participants to the level of significance. The qualitative analysis led to a storyline with five processes (*navigating, adapting, accepting support, growing and keeping life normal*), all of which culminated in the central category of *keeping life the same while weathering breast cancer treatments.* The quantitative results informed the analysis of the qualitative data in that areas of difficulty in carrying out parenting tasks, such as fatigue and poorer physical wellbeing, represented challenges to carrying out the mothering role. In addition, the qualitative and the quantitative results served to confirm each other, which further enhances the trustworthiness of the study, which will be discussed in Chapter Five: Interpretation of Results.

CHAPTER FIVE: INTERPRETATION OF RESULTS

This study gives valuable information for rehabilitation professionals working with women with breast cancer. In this chapter, I will describe the meaning of the results in relation to the literature and the unique contribution this information will provide for occupational therapy practice with women with breast cancer. Since this is a mixed methods study, I will provide an interpretation of qualitative, quantitative, and mixed methods results in order to obtain a better picture of issues pertaining to mothers undergoing chemotherapy for breast cancer. I have organized this chapter in the following manner:

I. Interpretation of quantitative results, including an interpretation for significant and non-significant correlations and the magnitude of effect sizes.

II. Interpretation of qualitative results, including a description of the theoretical model arising from the data and comparison with the literature.

III. Interpretation of mixed methods results in relation to the literature.

IV. Trustworthiness, including member checks, triangulation of data, audit trail, and confirmation from the literature.

V. Limitations of the study.

VI. Implications for future occupational therapy practice, including interventions to address fatigue, adaptations to parenting, cognitive functions after chemotherapy (“chemobrain”), assertiveness, and return to work.

VII. Future research

Interpretation of Qualitative Results

After completion of the Reflective Coding Matrix (Table 4.20), I created a diagram reflecting all of the major processes created through the analytics process. According to Corbin and Strauss (2008), the last step in grounded theory analysis is final integration, leading to theory development. This phase requires working through data, reordering processes, and developing relationships among categories. I will outline below the theoretical model developed from the data, followed by an analysis linking the literature to better understand the results of this study.

Theoretical Model Emerging from the Data

In this study, I conceived a tree metaphor that was based on what one participant, Shirley, age 55 and mother to two daughters, ages 15 and 20, and grandmother to one granddaughter, age 6 months, described during her interview. She stated, "I'm like this tree: I'm bent but not broken." This metaphor remained with me throughout the entire analysis. It was important that I not mold the data to fit this metaphor. Instead, I set this metaphor aside and kept going back to the data. However, after all of the data were analyzed and I returned to the metaphor of the tree, I realized that it still fit the interpretations of the results for all participants. I will describe each element of the theoretical model by each part of the diagram, with examples from the data, both qualitative and quantitative, in order to present a logical and comprehensive model that describe the data.

The overall central figure of the model, the tree, is a representation of the mother. The point in time that we are looking at in the tree's journey is after treatment has resumed and the challenges are experienced. On the left hand side of the diagram (Figure

5.1), the various challenges that the participants faced are listed. These challenges were identified in the interviews (side effects, financial difficulties, unhelpful support) and the quantitative portion of the study (CRF, QOL, Parent Disability, younger children and stage of disease). These can be visualized as strong winds that put pressure on the tree. The first step is navigating, which is represented by the tree's ability to grow upward and away from the wind in order to find its way to growth. The second step is adapting, which is visualized by the tree growing new branches in the opposite direction of the wind. The third step is accepting support, which is represented by a support line to keep the tree upright. The fourth step is growing, which is represented by an arrow pointing upwards, symbolizing the mother's post-traumatic growth. And finally, the ultimate step is keeping life normal, which is represented by the root system of the tree in order to keep the mother's life "grounded." All five of these stages lead to the overall central category of keeping life the same while weathering cancer treatments.

The challenges to the mother undergoing chemotherapy for breast cancer were pulled from the quantitative data as areas that were significantly correlated with higher scores of parent disability on the PDI, such as lower QOL scores on the FACT-G, higher scores on the FSI-TT, and demographics such as stage of cancer, and age of the children. For QOL ratings, mothers demonstrating difficulty in specific parenting tasks also had significantly lower total quality of life, physical wellbeing, social wellbeing, and functional wellbeing. For example, in Table 4.6, I summarize correlations between PDI older children items and FACT-G QOL data. This analysis found a significant correlation between total quality of life and being able to do various parenting tasks, such as being involved in the child's school functions. Therefore, poorer QOL served as a challenge to mothers, as did fatigue. In addition, statements from interviews also provided insight into challenges. These included negative support (or support that was unhelpful to the mothers), financial strain of cancer treatments, side effects, and having younger children. Note that having younger children was a challenge that emerged from interviews rather than the quantitative data. That is, although the surveys did not demonstrate significant correlations between parent disability and age of children, mothers interviewed described the challenges of caring for younger children. A possible explanation for this discrepancy is that the sample of participants was small (N=6), therefore there was not adequate statistical power for this group in order to demonstrate a significant relationship between parent disability and age of child.

Challenges are summarized in Table 5.1. In the theoretical model diagram, challenges were conceptualized as the wind putting pressure on the tree to knock it over.

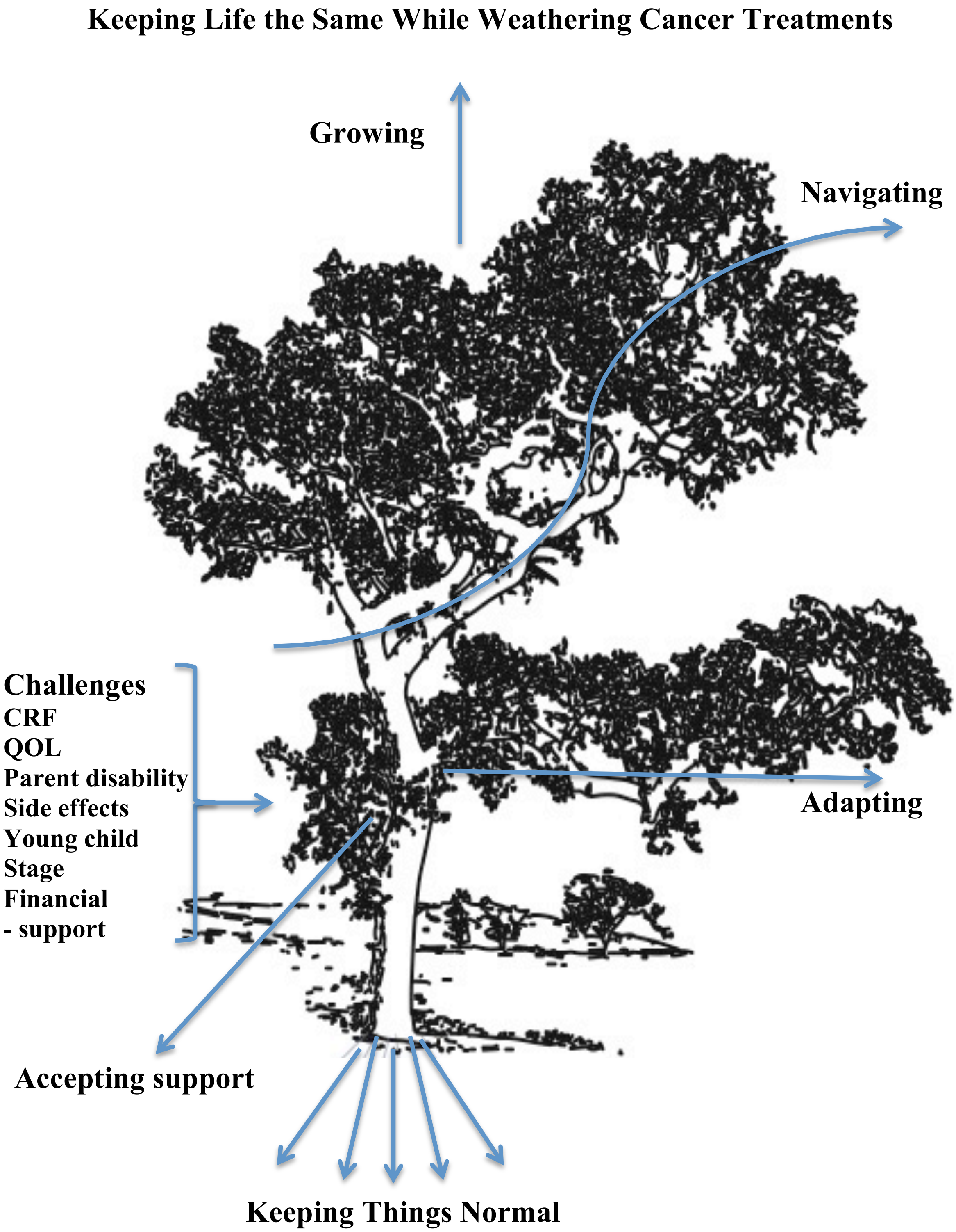
Table 5.1. *Challenges from quantitative and qualitative data sources*

Quantitative	Qualitative
• Parent disability	• Negative support
• Cancer-related fatigue	• Financial strain
• QOL: Physical, functional, social and emotional wellbeing	• Side effects
• Stage of cancer	• Younger children

Next, the storyline is represented in each aspect of the diagram in order to help the tree resist the challenges of the wind. The first step, navigating, represents the mother's ability to find her way through the medical world and accept her diagnosis. In the tree diagram, the tree growing up and away from the wind represents navigating. In the second step, adapting, the mother finds new ways of fulfilling her mothering role, even when she is feeling ill. The tree growing a stronger trunk on the wind side and growing foliage away from the wind represents adapting. In the third step, accepting support, mothers come to terms with being able to accept support from others, which is very difficult for some mothers who are very independent. The support lines for the tree that keep it upright represent accepting support. In the fourth step, growing, the mother and the child experience post-traumatic growth, which means that they find some benefit from going through such a difficult experience. The tree vertical growth and having a thicker trunk over time represent growing. And finally, the ultimate goal of the mothers was to maintain normalcy by keeping life normal. This meant keeping previous routines, keeping children in their afterschool activities, and upholding family traditions such as birthday parties. The root system of the tree, which gives the tree strength and stability, represents keeping life normal. For the mother, this normalcy keeps her grounded and helps the children have stability. All interviewees described having difficult times when they felt off balance, but they retained their footing and were able to recover. In the same way, the tree may experience a strong wind and may lose some leaves and branches, but it eventually grows back.

As mentioned previously, this metaphor came directly from a participant, Shirley, who had added significance because the tree of which she spoke was planted the year she was married, and her husband had passed away just before she was diagnosed with breast cancer. When asked how she felt about this being the major metaphor describing the findings of the study, she said, “I’m honored.”

Figure 5.1. *Theoretical model to explain the experience of chemotherapy for mothers with breast cancer.*



Analysis of Theoretical Model and Link to the Literature

The theory that emerged to describe the core category of *keeping life the same while weathering breast cancer treatments*, describes how mothers with breast cancer handle the upheaval in their daily lives and continue to participate in the mothering role. Many of the concepts and processes that emerged in this study have been demonstrated in other research studies. I will go through each major process and compare and contrast my results with these studies.

Navigating. When mothers are thrown into a whole new world of biopsies, radiological tests, surgeries, second opinions, and chemotherapy, they have to assume a new role of patient. This can be a frightening process, and can cause great distress in a mother’s life. According to Morse et al. (2014), women going through the diagnostic process “rapidly transitioned from wellness to frightening phases of facing terror during the testing phase” (p. 350). Interviewees also described the difficulties of this early phase of their experience with breast cancer, which was magnified by worrying about their children. Kimberly stated,

> It was very traumatizing. When you hear the word "Cancer," you think you're gonna die, with two small children. So it was really hard, really hard.

Some women in this study reported being delayed in their diagnosis because their doctors dismissed their concerns. Each of these three interviewees, who were under who were under 40 years old at the time of diagnosis (Ellen, Shannon and Denise) all described finding a lump and having their concerns dismissed by medical staff. Likewise, Ruddy et al. (2014) found that for women under 40 years old, 12% of 585 participants reported a delay in diagnosis due to their healthcare practitioners downplaying their concerns.

Mothers also talked a great deal about the financial impact of breast cancer. Medical costs, copays, missed work time, and spouses' time off work meant that mothers had less disposable income and more debt. Sharp, Carsin and Timmons (2013) found that anxiety, depression and distress were more common for women who reported increased financial stress related to cancer treatments. Single mothers in the study discussed needing to stay working in order to make ends meet, which added to the burden of trying keep on a schedule. According to Shannon,

> Yeah. I try to plan things, and with third [shift], it's so hard because I'll be up all night, get off work, go down to UK, and sometimes I'll, I mean, with radiation, I'd just get off work and go down there, and sometimes I'd have to see the Dr. afterwards. And if they weren't running on schedule, which they were great, they were a wonderful team down there, but I'd just be so tired when I'd get home, and I'd have to go back to work that night.

Mothers who were married were able to depend on their spouses to make up for missed income when she was unable to work, although this caused strain on the spouse.

Accepting Support. Many of the mothers described difficulty in accepting support from others during treatment. Other studies of mothers with breast cancer conducted internationally did not have this finding (Elmberger et al., 2000; Elmberger et al., 2008; Fisher & O'Connor, 2012; Player, Mackenzie, Willis, & Loh, 2014). One possible explanation is that Americans tend to be independent and have difficulty accepting help. Additionally, in Western countries, mothers are encouraged to be "super-moms." In their article titled, "Supermum, Superwife, Supereverything: Performing Femininity in the Transition to Motherhood," Choi, Henshaw, Baker and Tree (2005) describe how mothers felt immense pressure to live up to the ideal in their roles of mothers and wives. Larson (2000a) also described the pressure from cultural images of ideal mothering to which mothers have difficulty attaining.

In this study, the most successful instances of accepting help were those situations in which the mother gave very specific boundaries for which tasks she needed help. For example Rebecca described using a local, online parent support group to help with specific tasks. She said,

> And so, I, even though I'm a single mom, I've got a really good support network, and part of it I've developed over time, you know, myself. And then I had a friend refer me to a single parents' group online through Meet Up.com, and I have a, established friendships and some resources through there, and then time banks that I've signed up for that, where you trade work for hours, not money. And so I signed up for time banks since I might need some help with cleaning the house in a month or two, I might need someone to bring meals, and some of the people from that system would come and bring meals, and I would go on the computer and give them time credit for their commute and for cooking. And it was really great.

In this quote, Rebecca describes the specific tasks she asked others with which to help. Unsuccessful instances of getting help from others often involved helpers focusing on the emotional difficulty of the mother’s cancer. Mothers reacted by limiting the exposure to these unhelpful family members. Lori said about family members coming to her house to help,

> But they just, they would just get into, well, I don't know why you had to get cancer. You know. Just why does this happen to good people, and just blah blah blah. So it got to the point where, I would let them come over, but I was really strict. I was like, "You can come over, you can bring lunch. This is what I think sounds good, and you need to leave in an hour because I'm taking a nap."

Similarly, Ellen described having a family member that wasn’t helpful to her in spite of the helper’s good intentions.

> My brother and his wife, my brother was working and my sister in law, was, she helped once or twice, but she, God love her heart, she is not the most stable person anyway. She is kind of a Negative Nancy, and when you're sick and you, you don't need that. You need positive energy around you. You don't need something who makes you feel like you have one foot in the grave. So I just kind of pushed that away and tried to um um not deal with her as much as possible [laughs]. You need positive people when you're fighting for your life [laughs]. If you don't have that, you're up a creek.

Again, mothers needed to use assertiveness skills to control the environment around them so that they could cope with their treatments while still being a mother.

Lori described one difficulty of post treatment breast cancer is that her support network disappeared after chemotherapy was over. Similarly, Salonen et al. (2013) found, in their longitudinal study of social support for women with breast cancer, that received social support decreased within 6-months after treatment ended, leading to decreases in QOL measures. Leung, Pachana and McLaughlin (2014) also found a link between QOL and social support, although they found in their sample that support remained steady over a 3-year period.

Adapting. I found that mothers used adaptive methods of continuing to participate in the mothering role. In my study, mothers adapted the task—such as using a lighter vacuum, delegated the task to another—such as having the spouse give the children baths, or stopped the task all together—such as not having other children over in the home. Elmberger, Bolund, Magnusson, Lutzen and Andershed (2008) found, in their study of mothers with breast cancer and lymphoma, found that mothers' priority was to participate in the mothering role as much as possible, stating they still wanted to be a good mother in the face of cancer. One participant in this study described adapting her family routine for when her nausea was the worst after chemotherapy by sending her child to stay with a friend so he could get help with homework.   A mother in my study, Sarah, described having to lessen standards in terms of the amount of screen time her child used so that she could rest.

Growing. Mothers in this study described positive changes in their lives due to their experience with cancer. One mother, Lori, described how her children helped out a lot more around the house and displayed a lot more empathy. Another mother, Ellen, described participating in a variety of cancer advocacy organizations, such as the

Leukemia Lymphoma Society, the Kentucky Pink Connection, and the American Cancer Society. Another mother, Shirley, described speaking to a local university's sorority about the importance of breast cancer screenings. These findings are consistent with literature pertaining to post-traumatic growth, which describe the cancer experience as providing positive benefits to patients (Boyer & Cantor, 2005; Brix et al., 2013; Fallah, Keshmir, Lotfi Kashani, Azargashb, & Akbari, 2012; Lelorain, Tessier, Florin, & Bonnaud-Antignac, 2012; Mosher, Danoff-Burg, & Brunker, 2006; Ruini, Vescovelli, & Albieri, 2013).

Many of the interviewees described being more assertive than prior to cancer treatments, especially about health-related issues. When asked why this was so, most mothers responded that they pursued the best treatment so they could be there for their children in the future. Similarly, Elmberger, Bolund and Lutzen (2005) found that mothers with cancer felt a moral obligation to provide care for their children. Sarah in my study described this moral responsibility by stating, "It's my job to be the mom."

Urcyo, Boyers, Carver and Antoni (2005) found that breast cancer patients in their study found positive benefits from cancer (or benefit finding) related to better coping and inversely related with distress. Remaining positive was heralded by many of my interviewees as a way to cope with breast cancer. As was described in the previous chapter, I found that some mothers made comparisons of their lives to catastrophic situations, such as being in a concentration camp of being in a car accident. This comparison to the worst possible situation imaginable helped mothers in the study to realize their lives weren't so bad after all. The statement about the concentration camp and the car accident stood out to me as a rather extreme comparison to pretty horrific life struggles as a way to comfort her in a difficult situation. Other stories participants described included women whose personal reactions were negative during breast cancer treatments, which was in part responsible for their deaths. Such stories put a great deal of pressure on mothers with breast cancer to remain cheerful and optimistic. Since this is a qualitative study and I am valuing the voices of the individuals, I won't overanalyze this method of mothers reframing their situations, but it warrants investigation in the future.

However, there is some debate in the popular culture about the possible detriment of this over-cheerfulness about cancer. Barbara Ehrenreich (2009), in her book *Bright-sided: How Positive Thinking is Undermining America*, describes how this over-emphasis on positivity made her breast cancer experience much more difficult. In her chapter "Smile or Die: The Bright Side of Cancer," she describes how she was chastised by members of online breast cancer support groups for posting feelings of anger and dislike for the pink ribbons that are so ubiquitous in our culture. She makes the case that this over-positivity as a means of beating cancer can lead to shaming women who do not get better. As a well educated woman and accomplished writer, Ehrenreich felt infantilized by ads for pink breast cancer teddy bears. "I didn't mind dying," she writes, "but the idea that I should do so while clutching a teddy and with a sweet little smile on my face—well, no amount of philosophy had prepared me for that" (p. 17). In my study, Cheryl, the interviewee who will need to stay on chemotherapy indefinitely, shared Ehrenreich's dislike of the pink ribbon culture, saying that she doesn't want to be labeled as being a cancer patient as her entire identity.

Sulik (2011), in her work *Pink Ribbon Blues: How Breast Cancer Culture Undermines Women's Health*, describes how corporations are making money on breast cancer pink ribbon merchandise, with little money actually going to breast cancer research. She posits that this positive breast cancer culture does little to honor those who have negative experiences and even die from breast cancer. This “pink ribbon culture” warrants further research in relation to mothering during cancer.

Keeping Life Normal. Several studies of parents with cancer have found that parents strive for normalcy in order to help children cope (Elmberger et al., 2008; Fisher & O'Connor, 2012; Helseth & Ulfsaet, 2003, 2005b). This normalcy involved keeping organized and keeping to typical family routines. In the occupational therapy literature, routines are described a way to save time and energy, and to bring a sense of security and order to family life, especially in times of difficulty such as the mother experiencing breast cancer treatments (Buchbinder, Longhofer, & McCue, 2009; Oswald, 2002). This need for normalcy and keeping family traditions was described by all of the interviewees. When I asked Denise what advice she would give to other mothers with breast cancer, she said, “Don’t change a thing. Keep everything the same.” However, mothers in this study have described taking risks with their health and pushing too hard in order to keep things normal. When I asked Shannon if she stayed home from her daughter’s basketball games when her counts were low, she replied that she didn’t, although she should have. In this case, her needs of being a mother superseded her needs as a patient. Overall, I found that keeping routines and having as much normalcy as possible helped mothers and children cope with the frightening experience of breast cancer treatments.

Interpretation of Quantitative Results

When interpreting quantitative data, I found that there were greater effect sizes and more significant correlations for PDI items for older child items but not for younger child items. In other words, I found more significant correlations between PDI items and certain demographics, fatigue and QOL domains for older children than for younger children. From these data, I may draw the conclusion that mothers of older children had more difficulty in carrying out childcare activities and experienced more fatigue and lower QOL. However, due to the small sample size of mothers of children under age 6 in my study (N=7, and one participant had missing data), I am unable to definitively make this assertion.

Although level of significance is useful for determining whether or not to reject the null hypothesis, the magnitude of the correlation coefficient determines the effect size. Huck (2008) recommends using the following criteria when evaluating effect sizes of correlations: A small effect size is a Spearman's rho correlation coefficient of at least .1. A medium effect size is a Spearman's rho of at least .3. A large effect size is a Spearman's rho of .5 or larger. However, in the case of the PDI Younger Child Items, which had a small sample size (N=7), a large Spearman's rho may not lead to a strong effect size.

There were several correlations that had a large effect size, especially for older child PDI items. For example, in Table 4.10, I summarize Spearman rho correlations between PDI item groupings and domains of wellbeing on the FACT-G. For older children, physical wellbeing was negatively correlated with the grouping of PDI items relating to home routines with the effect size of -.673 ($P<.001$). Likewise, significant correlations with high effect size were found for older children between physical wellbeing and community items ($\rho=-.669$, $P<.001$), and physical items ($\rho=-.669$, $P<.001$). There were also significant correlations between older child items on the PDI and functional wellbeing and emotional wellbeing for all groupings, with large effect sizes and P<.005. However, there were not significant correlations between younger child PDI item groupings and FACT-G QOL domains. As mentioned earlier, this may be due to the small sample size of participants with younger children (N=7, although some items had N=6 due to some missing data). Due to this small sample size for this subset of mothers, I am unable to draw a conclusion about the relationship between FACT-G QOL domains and parent disability as measured by the PDI.

PDI Items and Demographics. There were very few items on the PDI that correlated significantly with demographics, which is a surprising finding. I had hypothesized that women with more children, younger children, higher stage, lower income and less education would have more parent disability, lower QOL and more fatigue. In this section, I will discuss possible reasons for significance or lack of significance in correlations between items.

For mothers of younger children, there was a significant correlation between stage and taking care of the child's hygiene, feeding the child, picking up or carrying the child, taking care of the child outside the house, and getting up and down to the floor to play with the child (see Table 4.15). One major limitation of the younger children data is that there are only seven participants with children under six years old in the study, and one of those had missing data. However, it is reasonable that the higher the stage and therefore the more aggressive the chemotherapy treatment regimen and surgical interventions, the more difficulty the mother would have with these physical tasks.

I was surprised that there was no difference among groups of mothers with younger children in age of the mother, age of the children and income for PDI tasks. I found that there was a significant correlation between the number of children and a number of the PDI younger children items. The higher the number of children, the less difficulty mothers rated with taking care of the child's hygiene needs (ρ=-.892, P=.007), taking the child out in the car (ρ=-.794, P=.033), playing with the child outdoors (ρ=-.764, P=.046), and taking the child to social events or recreational activities (ρ=-.775, P=.041). This was actually the opposite of what I had hypothesized since I thought that having more children would result in greater parenting difficulties. However, in casual discussions with participants, they told me that the older children helped provide care for the younger children. Therefore, a reasonable explanation for this result is that mothers with more children had more help around the house and with younger children. However, this was not discussed in-depth during interviews with women with multiple children except for older children helping with providing younger children with transportation. Since having more children made certain parenting tasks easier for women with breast cancer, older children may be serving as a source of positive social support for mothers.

Looking at the literature, there is support for the notion that older children can serve as support for parents undergoing cancer treatments. Kennedy and Lloyd-Williams (2009a), in their qualitative study of parents with cancer and their children conducted in the United Kingdom, found that children helped out around the house and with siblings more often after the parent's diagnosis. This finding is echoed by my study's major category of *growing*, in which mothers reported that their children were more empathetic and more independent as a result of their mothers having breast cancer. Therefore, older children may have helped more with bathing, outdoor play, taking the child to social or recreational activities, so mothers perceived having less difficulty with these tasks. This would be an interesting finding to research in the future, especially since it was contrary to my hypothesis and I did not address it in-depth in the interviews.

I found that mothers with more education had significantly more difficulty in playing with her younger child outdoors. One possible reason for this difference is that, according to Sayer, Gauthier and Furstenberg (2004), more educated mothers tend to spend more time with children than less educated mothers. Additionally, this time is typically filled with more helping and playing activities than less educated parents. Therefore, higher educated mothers may see a greater discrepancy between the amounts of time spent playing with children before their breast cancer diagnosis than after the diagnosis. The mothers in my study who had higher level of education had significantly higher incomes, which may lead to them participating in more activities in the community before cancer. After cancer, due to fatigue and infection risks, getting out into the community may be more difficult for them. However, I cannot generalize these results since my sample size of mothers with younger children was so small (N=7), but this may be an interesting area for future research.

For mothers of older children, the only significant correlations were between cancer stage and getting up with the child (ρ=-.487, P=.010), and rural and playing with the child outdoors (ρ=.390, P=.036). Mothers in my study with a higher cancer stage reported having less difficulty in getting up with their child, which doesn't make sense to me. For mothers with a higher cancer stage, participants may have had more radical surgery or more aggressive chemotherapy, which could lead to difficulty in getting up in the morning with children. One possible reason for this discrepancy is that perhaps mothers with a higher cancer stage are delegating the task of getting up with children to other family members, or their children may be more self-sufficient due to their needing to “step up” and take more responsibility for their own sleep-wake routines. Indeed, in the interviews, mothers described their children becoming more independent and asking for less help for completing daily tasks. Another possible explanation for this result is that mothers with higher stage and therefore more treatments are more fatigued and do not respond as well to the child’s request for the mother while she is asleep. Several interviewees mentioned that their sleep was impacted by chemotherapy. This anecdotal finding is echoed by Dickerson, Connors, Fayad, and Dean (2014) who, in their systematic review of sleep-wake disturbances in cancer patients, found a high prevalence of sleep problems in 18 studies reviewed. Or perhaps mothers with higher stages of cancer do not want their children to worry so they push themselves to keep typical family routines, such as getting up with children. I would be interested in further investigating this issue in future studies. Again, the reason for these deviation from my hypothesis is unclear and warrants future research.

Mothers in rural counties reported having more difficulty with playing with children outdoors, which may be a result of an increased need for surveillance since they lived in a more remote location and had more acreage for children to wander outdoors. This was echoed in interview findings in which Kimberly described who, since she lives on a working farm, she worries that her two young children could get hurt on machinery or other hazards such as the creek near her house. Mothers of children in urban areas may have fenced in yards or more protected play spaces for children, thereby decreasing the difficulty in playing outdoors.

PDI Items and Fatigue. As described in Chapter 4, there were few PDI items that correlated significantly with fatigue interference as measured by the FSI-TT. For mothers of younger children, fatigue was associated with difficulty in using a stroller (ρ=.833, P=.039). For mothers of older children, fatigue interfered with taking her child to all the places s/he needs to go (ρ=.419, P=.024), being involved in school functions (ρ=.396, P=.033), helping the child with homework (ρ=.398, P=.032), playing outdoors with the child (ρ=.536, P=.003), getting up with the child (ρ=.386, P=.046), and doing household chores and shopping (ρ=.377, P=.041).

Not all mothers reported fatigue interference. Several studies of CRF describe how its incidence varies, and a small portion of breast cancer patients experience significant CRF. Indeed, three participants rated having no fatigue whatsoever in spite of having multiple chemotherapy treatments. One of the interviewees, who had the most chemotherapy cycles in the entire study, said that she was always an energetic person, and that fatigue has never been a problem for her. So it may be that prior level of performance and tolerance of fatigue, pain and nausea could have a protective effect. However, for some women, fatigue can greatly impair participation in daily activities (Andrykowski, Curran, & Lightner, 1998; Andrykowski et al., 2009; Andrykowski, Schmidt, Salsman, Beacham, & Jacobsen, 2005; Bower et al., 2006; Bower et al., 2000). In the interviews, some mothers described the extreme and debilitating impact of fatigue on caring for children, especially outside of the typical family routine (e.g. taking the child to social events or having other children in the home). An interesting intervention study could be to examine the effect of energy conservation strategy education and training on the level of fatigue and parent disability.

PDI and QOL. The PDI younger and older child items correlated significantly with domains and total QOL as measured by the FACT-G (Table 4.13). Many of the activities that were difficult for mothers related to their inability to complete physical tasks such as diapering and dressing the child for younger children, and many tasks in the older child version of the PDI. Many of the interviewees described one barrier to participation in these activities was upper extremity pain, decreased range of motion, and weakness. Possible reasons for these side effects could be sentinel node biopsies, lymphedema, mastectomies, radiation, hormonal treatment, and breast reconstruction. Hidding, Beurskens, van der Wees, van Laarhoven and Nijhuis-van der Sanden (2014) found that in multiple studies of arm and shoulder impairments in breast cancer, many patients have difficulties with functional activities secondary to pain, reduced joint mobility, lymphedema, and reduced strength. Therefore, treatment of upper extremity problems is an area of needed intervention for many women with breast cancer, as I will discuss in the section on clinical implications.

One area of the FACT-G that did not have significant correlations with parent disability was social wellbeing. One would assume that there would be a negative correlation between difficulty in carrying out parenting tasks and an increase social support (more support, less difficulty with parenting tasks). However, I did not find these significant relationships despite mothers describing in great detail the impact of support during the interviews. In these interviews, mothers described two types of support: helpful (or positive support) and unhelpful (or negative support). Positive support make mothers' lives easier in caring for children and getting through medical treatments.

Negative support made life more difficult (see Lori's description of her sister-in-law who was a "negative Nancy" in Chapter 4). However, there was no such distinction evident using the FACT-G. One explanation is that the specificity of the social wellbeing items of the FACT-G were not adequate to fully explore the complexity of social support during breast cancer treatments. As mentioned below, there are other measures of social support that may have been more appropriate such as the Social Support Questionnaire (Sarason, Levine, Basham, & Sarason, 1983). Another limitation of the use of the FACT-G is that I used the general version of this questionnaire instead of the version specifically written for breast cancer, the FACT-B. The reason I chose the FACT-G is that I initially thought that I was going to use multiple diagnoses in my study, but I later decided to focus on breast cancer. Perhaps if I had used the FACT-B, I would have found slightly different information.

Trustworthiness

Trustworthiness was ensured for the qualitative portion of the study by member checks, multiple data sources (quantitative measures and observations in addition to the interviews), and confirmation from the extant literature.

Member checks. For member checks, all ten interviewees were contacted, although I only received responses from three participants. I presented these final five themes and the central category was presented to interviewees via telephone or email. Member checks confirmed my interpretation of the data, with a small addition by Ellen. According to Ellen, in terms of growth for her son, she stated, "He's more outgoing." When we discussed the idea of keeping to a routine and keeping life normal, she talked about keeping a bedtime routine.

> We tried to keep things as close to, well, for him, that was normal. Unfortunately, for him, his normal was mommy being sick. If things were different now, because I guess the lucky thing is he was too little to know. Reading was a huge thing for him. I was able to take him to bed. I always managed to put him to bed. No matter what, no matter how yucky I felt. We became very, very close.… A couple of weeks without chemo meant that I got to give him a first year birthday party.

Shirley wrote, “I’m no expert, but it sounds great. I forgot I told you about my old Christmas tree. I believe you have captured everything with this metaphor.”

Shannon wrote, “I think it sounds great. You did a wonderful job conveying the issues and struggles.”

Triangulation of data. For multiple data sources, I confirmed results of the qualitative portion of the study with interviewees’ quantitative data. I found a good concordance between qualitative and quantitative data. For example, Ellen described in her interview how she was unable to provide any care for her son during chemotherapy, and she rated “Unable to do” for all PDI younger child items.

Confirmation of findings by comparison to the literature. The major finding of the qualitative portion of the study was the extent to which mothers attempted to keep their daily lives as normal as possible for themselves and for their children. This result is echoed by findings of Fisher and O’Connor (2012). In this qualitative study of women with breast cancer in Western Australia, the authors found four themes: Diagnosis and disruption, maintaining normality, continuing the mothering role, and experiencing survivorship. These themes are similar to core categories discovered in this study of navigating (similar to diagnosis and disruption), adapting and accepting support (similar to continuing the mothering role), growing (experiencing survivorship), and keeping her life normal. When comparing the findings of this study to the literature, I found studies conducted internationally that echoed my findings. In Western Australia, Fisher and O’Connor (Fisher & O'Connor, 2012) interviewed eight women with breast cancer and dependent children living in the home. The major themes that emerged from the study were “diagnosis as disruption,” “maintaining normality,” “continuing the mothering role,” and “experiencing survivorship.” The theme diagnosis as disruption describes the mother’s reaction to breast cancer diagnosis and the “disruption to the biographies of the women” (p. 160). This is similar to my theme of navigating the medical world in that they both describe needing to learn new terms, make decisions and cope with the uncertainty and fear around breast cancer. The theme accepting support from my study was not described in this study. One possible reason for this theme of having difficulty accepting support is that in Australia where the study was conducted, there may be different socially accepted norms about accepting support. One mother in my study, Shannon, describes not liking to take help from others.

> I'm just super independent. You don't like the idea of someone coming in and taking care of your kids and taking care of your kids. I just don't want, I never wanted to be a burden on anybody. And it's, it's hard for me, even with my mom. And it's kinda like, so now, she's just kinda like yesterday, "It's like, no, you know, I'm just having this test, and you'll just have to wait in the waiting room."

> And she was just like, "No, no. I'm coming anyway." So sometimes she's like that after I put her off. Because I don't want her to have to take off work and just sit there in the waiting room.

This difficulty in accepting support was not mentioned at all in the Fisher and O'Connor study.

For the theme of maintaining normality, Fisher and O'Connor (2012) describe the same need to keep routines and a sense of normalcy in order to help the children adjust. In my study, all mothers described keeping life normal as the ideal that they strived for in dealing with breast cancer.

Fisher and O'Connor's theme of continuing the mothering role was similar to my theme of adapting. In both studies, mothers described wanting to still have the identity as a mother and take care of her children. Mothers in my study continued to participate in the mothering role by finding new ways of taking care of children, including enfolding children into daily routines and having children pitch in with age-appropriate chores.

Fisher and O'Connor's theme of experiencing survivorship is similar to my study's theme of growing, in which mothers put life into perspective and focus on what is important. The one difference is that mothers in my study discussed participating in cancer advocacy groups such as the Susan G. Komen Foundation and the Relay for Life, which may also be a cross-cultural difference.

These four sources of trustworthiness, member checks, multiple data sources, an audit trail, and comparison with the literature, all suggest that my interpretation of the data was appropriate. However, there were limitations that impacted this study, which I will discuss next.

Limitations

The first major limitation of this study was the small sample size. I recruited 32 participants, and two had missing data, and one participant had to be eliminated due failure to meet selection criteria (her children living with her sister for five days a week). This number of participants was inadequate to make a general statement about the population of women with breast cancer overall. The number of qualitative interview participants was adequate in that I reached saturation with new information at about the eighth interview. Although the power analysis I conducted said that I needed 28 participants for adequate statistical power, I only had seven participants who had younger children in my study, which may be the reason that very few of the correlations for data from mothers of younger children were significant. Since this was a sample of convenience and I recruited most of the eligible participants from the clinic in a 15-month time period, it was difficult for me to predict the specific demographics of participants.

Another limitation of the study when comparing the qualitative and the quantitative results was the demographic differences between the entire sample of participants and the interviewees. The interviewees skewed more urban than the entire sample. This may be due to participants who were willing to be interviewed lived closer, and ones who lived further away were worried that it was too far for me to drive for the interview.

Unfortunately, I did not put marital status or employment status on the demographic sheet, so I did not have that data to analyze. I did have that information for interviewees, however.

Missing data was a limitation. After the first day of participant accrual, however, I began checking for completeness of data and did not have this problem for subsequent data collection. However, this missing data decreases the power of my overall analysis.

Another limitation was that my quantitative measures were not specific enough to provide clearer explanations of relationships among variables. For example, in order to understand social wellbeing, I used the FACT-G. The FACT-G is a global measure of QOL, and has a very brief section (7-items in total) assessing social wellbeing. Since these are quite general (e.g. “I feel close to my friends”), this assessment does not provide enough information to draw adequate conclusions about the relationship between social support and parent disability. A possible better assessment for social support is the Social Support Questionnaire (Sarason et al., 1983), which has been used in a number of different studies of various health conditions.

Finally, as mentioned in Chapter 1, since I am a cancer survivor who is a mother, there were times during the interview in which I may have asked leading questions of the participants to confirm my own interpretation. I continued writing in my reflective journal and kept mindful of stepping back from overly identifying with mothers. As mentioned in Chapter Three: Methods, I conducted an autoethography of my experience as a mother with cancer in order to help me understand my own assumptions and biases about my experience so they wouldn’t overly influence the results and interpretation. I chose to disclose that I went through a similar experience as they did since being a cancer survivor is an entrenched characteristic of my identity. One benefit of disclosure is that participants identified with me right away and I got the insider's perspective of their experience. One problem was that I may have led the interview to fit my own experience, but I believe this concern was mitigated by my adherence with the interview guide and a process of self-reflection that allowed me to bracket my own experiences.

Clinical Implications

The results of this study provide information about a number of different areas of occupational therapy intervention for mothers with breast cancer. Coming back to the *Occupational Therapy Practice Framework* (3rd Edition) ("the *Framework,*" American Occupational Therapy Association, 2014), occupational therapy interventions fall under different categories. These categories are occupation and activities, preparatory methods and tasks, education and training, advocacy, and group interventions. Occupations are the highest level of participation and are meaningful everyday activities. The occupational therapist may use occupation as a therapeutic tool, or as a goal for treatment. An example is a mother with cancer playing a game with her child or getting the child ready for school. The occupational therapist can work with the mother to adapt a play activity with her child that fits her energy level, such as choosing seated activities. Activities are "actions designed and selected to support the development of performance skills and performance patterns to enhance occupational engagement" (p. S29). One example of using an activity as OT intervention is a mother buttoning her child's clothing during dressing. Preparatory methods are actions that "prepare the client for occupational performance" (American Occupational Therapy Association, 2014, p. S29). An example of this would be providing manual lymph drainage for lymphedema. Education and training is imparting knowledge and information to the client and working on specific skills for completing a task, respectively. For example, the therapist may educate the mother about the typical progression of fatigue throughout cancer treatment (education), and teach her specific assertiveness skills through role play (training). Advocacy is the process of empowering the client to seek out and meet her own needs. For example, the therapist could work with the mother to communicate more effectively and assertively with her caregivers in order to get the support she needs. And lastly, group interventions are a type of therapy session that involves a group of participants. For example, the occupational therapist could run an energy conservation group for cancer patients since fatigue is a common side effect of treatment.

A description of occupational therapy intervention recommendations by study finding, and its linkage to the *Framework,* may be found in Table 5.1. Like the reflective coding matrix in Table 4.20, this table is read sequentially with less occupation-based and more preparatory interventions falling under navigating and more occupation based and higher level of participation activities occurring in growing. For example, under the process of navigating, treatment of fatigue through exercise and increase in endurance falls under the intervention category of preparatory methods. Then under adapting, recommended interventions move more toward performance patterns, then performance skills and finally engagement in occupation. Education and training are consistent throughout the recommendations since this occurs at all levels of treatment. However, these are not meant to be discrete quantum leaps from one type of treatment to another. Instead, there should be a fluidity of treatments based on the needs of the mother on a given day.

Treatment of many of the challenges described by the mothers, particularly client factors, may be accomplished via , preparatory methods, as described in the *Framework*. For example, if the mother is experiencing upper extremity edema, pain and weakness, the occupational therapist could work to remediate those symptoms. Preparatory interventions serve to prepare the client to participate in higher level and more occupation-based and meaningful activities. Therefore, the goal of treatment is not just to improve physical functions but rather to enhance the client's participation in occupation.

I will now discuss findings of my study as they relate to previously studied and more traditional occupational therapy interventions for breast cancer patients. First, Lattanzi et al. (2010), based on their qualitative exploration of physical and occupational therapy needs for breast cancer patients, recommend an increase in pre-surgical consultations with therapists, treatment focusing on functional daily activities that are important to the participant, emotional support to the patient, and creation of a supportive and inviting clinical environment. Such treatment could occur in a variety of settings, such as outpatient clinics, breast cancer centers, home care settings, and acute care. I will now describe specific treatment recommendations that emerged from the findings of this study, with a summary in Table 5.1.

Upper extremity treatment and lymphedema management. A traditional area of occupational therapy intervention for women with breast cancer is treatment of the upper extremities, lymphedema management and manual lymph drainage. Upper extremity dysfunction such as lymphedema can cause a great deal of difficulties in activities of daily living for women with breast cancer (Hidding et al., 2014). Therefore, it is important for a rehabilitation program to include management of lymphedema. McClure, McClure, Day and Brufky (2010) conducted a randomized controlled trial for a treatment program for lymphedema, and found that participants in the program had increased QOL, better mood and increased arm flexibility. Having better upper extremity function would allow mothers to participate more fully in mothering occupations, such as bathing, lifting, dressing and playing outdoors with children. However, occupational therapy intervention for mothers should not end here, as has often been the case in current clinical practice.

Routines. Keeping life normal was the overarching goal for participants of this study, both for themselves and their children. One strategy to keep normalcy in daily life is to develop and maintain routines. According to Segal (2004) routines are an important part of the daily lives of families to give life order. One strategy to help families keep routines is to use organizers. Several study participants described how they relied on organizers and other external memory aids, to keep daily routines in place. With the added burden of keeping scheduled doctor’s and treatment appointments, not to mention children’s activities and other obligations, keeping an organized schedule and daily routines would be an excellent occupational therapy intervention to help the mother continue to participate in meaningful occupations.

Another strategy to establish and maintain routines even when the mother is feeling ill is to designate a family member or other social support to have the responsibility for specific parenting tasks. For example, Melissa described how her father helped out by taking her son to all of his sports and social activities so that she could rest. Having this one person complete these activities created a greater bond between the child and the grandfather, and allowed the mother to not worry that her son was missing out on activities due to her breast cancer.

It may be necessary to establish completely new routines in order to accommodate changes from breast cancer. For example, Lori described how she used to give her children baths daily, but, because of pain and decreased shoulder range of motion due to surgery and radiation, she now has her husband complete this part of the daily routine.

Adaptations to mothering tasks. Occupational therapists are skilled at analyzing activities and finding adaptations for participation in those activities (Creighton, 1992). Many of the mothers in this study described finding new ways of carrying out mothering tasks. For example, Ellen described how, when her nausea didn't make it too difficult for her to change diapers, she changed her son on a diaper pad on the floor rather than lifting him to a changing table, which was difficult due to pain and limited range of motion. The occupational therapist could help the mother make modifications to the mothering task to fit her current abilities. For example, when playing with children, the mother could choose lower energy activities such as reading to children, playing board games, telling stories, and doing activities while the mother is lying down. One mother, Lori, described being on a walk with her children and needing to rest, so she had them all lie down on the grass and tell stories about shapes in the clouds. Another strategy is to modify the tools used to complete daily activities. The same mother, Lori, described buying a stick vacuum because her previous upright was too heavy for her.

Other adaptations mentioned were having the children help out with daily chores. Denise described how she was not able to lift laundry baskets due to expanders in her breast, so she delegated this task to her daughter, and they worked on laundry side-by-side. Another mother, Sarah, described only doing two loads of laundry a week—one load of darks and one load of lights, and her husband and son were responsible for bringing the laundry items down to the laundry room.

Assertiveness training. Several mothers in this study described needing to be assertive with medical practitioners and social support members in order to get the care needed for her optimal recovery. Occupational therapists can provide strategies for learning assertiveness through education and role playing situations that may arise.

Participation in cancer survivorship groups. Many study participants described the benefit of participating in cancer survivorship groups and services for women with breast cancer such as the Look Good Feel Better program through the American Cancer Society and exercise classes tailored to the needs of women with breast cancer. The occupational therapist can provide resources for the patient so that she may benefit from these organizations and services.

Fatigue management. Cancer-related fatigue can greatly interfere with daily occupations. Occupational therapists can provide intervention in energy conservation strategies (Barsevick, Whitmer, Sweeney, & Nail, 2002) such as sitting during tasks, using the best time of day to do more difficult activities, and using larger muscle groups to complete activities. Another strategy to conserve energy is prioritizing activities and spending energy on the most important activities. Exercise has been demonstrated to reduce fatigue as well (Berger et al., 2009; Kangas, Bovbjerg, & Montgomery, 2008).

Accepting support. Occupational therapists can work with patients in improving communication skills when interacting with social support members. Again, assertiveness training and role playing interactions with caregivers can be useful treatment strategies.

Cognitive impact of chemotherapy. An emerging role for occupational therapists in working with women with breast cancer is to address the cognitive impact of treatment, or chemobrain. Player, Mackenzie, Willis and Loh (Player et al., 2014), in their phenomenological study of women with chemobrain, found that women needed adaptive strategies to deal with the cognitive impact of breast cancer treatments. They recommend that occupational therapists begin to address these issues through providing awareness of chemobrain, and helping women problem solve strategies for dealing with memory deficits. Strategies that occupational therapists may use are providing training in use of planners and organizers (such as iPad apps).

Table 5.2. *Occupational Therapy Treatment Recommendations from Study Findings with Relevant Links to the Occupational Therapy Practice Framework 3rd Edition*

Study Finding	Occupational Therapy Treatment Recommendation	*Framework* Link
Navigating	• Assertiveness training • Education on treatment and recovery • Being an advocate for patient • Pain management; energy conservation strategies; lymphedema management; interventions to treat cognitive limitations.	• Social interaction skills • Education and training • Advocacy • Client factors
Adapting	• Establishment of and adaptation to family routines • Activity analysis of daily tasks and modifications • Help find best time of day for specific tasks • Provide adaptive equipment • Modify household environment	• Performance patterns • Activity demands • Performance patterns and temporal context • Physical environment
Accepting support	• Role play assertive communication skills and boundary setting • Train caregivers	• Social interaction skills • Social interaction skills • Education and training
Growing	• Provide information about breast cancer advocacy groups • Provide opportunity to develop new skills and interests • Encourage participation in support groups	• Education and training; Occupation: volunteer exploration and participation • Occupation; values and interests • Occupation: Social participation
Quality of life	• Help to continue meaningful activities and hobbies through adaptations and modifications to task and materials • Provide treatment to improve upper extremity function	• Occupation; values and interests • Occupation: Social participation

Future research

From this study, I have a number of directions I could go in terms of future research about mothers with breast cancer. First, I would like to further explore the family structure for mothers with breast cancer and how this impacts her ability to participate in the mothering role. For example, I was surprised to find mothers with more children had less difficulty with certain parenting tasks. As discussed earlier, this may be due to the older children helping provide care for the younger children. However, this is a link that has not previously been explored in the occupational therapy in oncology literature. I would also like to further explore the impact of social support on the mothers' ability to care for her children. As mentioned previously, I did not find significant correlations between social wellbeing and parent disability, which may be due to the lack of specificity of the FACT-G in measuring social support. Another study using the PDI and the Social Support Questionnaire (Sarason et al., 1983) would better elucidate this relationship.

Since I did not find many significant correlations between parent disability and fatigue, QOL and demographics for younger children, I would like to conduct a study specifically focusing on mothers of younger children in order to determine if the lack of significant results were indeed due to the small sample size of mothers of younger children. This may be a challenge since I had difficulty finding participants with younger children. I will need to cast a wider net in order to find participants by expanding my study to more treatment centers or take a longer time to recruit participants.

Another area of future research is to investigate the experiences of family members of breast cancer patients. I am particularly interested in the perspectives of the spouse or significant other, and children.

In terms of intervention research, I would like to evaluate an energy conservation program for women with cancer. I would also like to conduct future research about occupational therapy interventions for chemobrain since many of my study participants described how difficult it is to perform higher level activities with poorer cognitive functioning.

In terms of the clinical utility of assessments used in this study, the most useful for future interventions with mothers with breast cancer would be the PDI since it bears so much resemblance to similar occupational therapy criterion referenced assessments. This assessment is a comprehensive view of many of the important parenting tasks with which a mother with breast cancer might have difficulty. I would need to conduct future research to determine if there is a clinically measurable difference in PDI scores between pre- and post-treatment measures. Another assessment that would be useful as a measure of treatment effectiveness is the FSI-TT. The FSI-TT measures fatigue both retrospectively and concurrently. If used prospectively at different time points during treatment for fatigue, I could determine how effective my treatments are in addressing fatigue. The FACT-G is too general to be used in a clinically meaningful way with this population since it gives little in-depth information about QOL domains, specifically social wellbeing. A perhaps better assessment of social support would be the Social Support Questionnaire (Sarason et al., 1983), which has been used in many studies relating to social support when dealing with medical diagnoses.

Summary

This study provides information about how mothers with breast cancer continue to participate in the mothering role during chemotherapy. I collected quantitative data on quality of life, cancer related fatigue, parent disability, and demographics. These data demonstrated a correlation among fatigue and poor quality of life and specific parenting tasks. The only demographic characteristics that correlated significantly with parent disability were number of children (more children resulted in less parent disability), and education of mother (the higher education of the mother, the more difficulty she reports in playing with her children). In the qualitative part of the study, I interviewed ten mothers and analyzed the data using a grounded theory approach. From this analysis, I came up with the overarching theme of "keeping life the same while weathering breast cancer treatments." After open and axial coding, I discovered five processes that allowed mothers to keep their lives the same during cancer treatments. These five processes were navigating, adapting, accepting support, growing, and keeping life the same. The ultimate goal for mothers was to keep their lives as normal as possible for their children. These mothers found a way to incorporate former routines and rituals while adapting them in order to find a new normal.

One mother, Lori, summed up being a mother with breast cancer in the following way:

> You know, my everything is what's gonna, you know, what's best for them. What's gonna, how it's gonna impact them. You know, it just, it's so, they're gonna have, the choices, you're gonna have to make choices. And, you know, so

they're gonna have to clean house, and they're probably not gonna get to go to Disney, but you can't put a price on it [having a mom].

APPENDICES

Appendix A : Demographic Survey of Study Subjects

Study Participant Information Form

Participant #__________Willingness to participate in interviews (initial) __________

First Cancer Diagnosis (type)_______Date of Diagnosis__________Stage________

Recurrences (if any)____

County of residence__________________________________State_______________

Highest level of education (check) ☐ some HS ☐ HS diploma ☐ some college

☐ college degree ☐ graduate school

Race/ethnicity (check) ☐ American Indian or Alaskan Native ☐ Asian

☐ Black or African American ☐ Hawaiian or Pacific Islander

☐ Hispanic or Latino ☐ White

Annual family income (check) ☐ less than $15,000 ☐ $15,000 - $24,999

☐ $25,000 - $39,999 ☐ $40,000 - $54,999 ☐ $55,000 - $69,999

☐ $70,000 - $84,999 ☐ $85,000 to $99,999 ☐ over $100,000

Other health conditions:____

____

Number of children living at home_______________Ages_____________________

Date of first chemotherapy session_______________

Total # chemotherapy sessions_________________________

Appendix B: Proposed Interview Guide

A. Before you were diagnosed with cancer:

1. How were you able to provide for the physical care of your child(ren) such as bathing, dressing, feeding, diapering, etc.?
2. How were you able to provide for the enrichment of your child(ren) such as through
   a. Reading to the child(ren)
   b. Playing with the child(ren)
   c. Helping the child(ren) with school work?
3. How were you able to teach the child(ren) to behave appropriately?
   a. Manners?
   b. Discipline?
   c. Chores?
4. What are the things in your life that supported your ability to care for your child(ren) before diagnosis?
5. What are the things in your life that hindered your ability to care for your children before diagnosis?

B. During diagnosis and treatment:

1. Tell me about when you were diagnosed with cancer.
2. How did your children, spouse and other family react when you were diagnosed?
3. How were you able to care for your children when you were diagnosed? Dressing, bathing, diapering, feeding, etc.

    4. What was the impact of fatigue on the ability to care for your children?
    5. How were you able to provide enrichment such as reading books, playing with and helping with schoolwork for your children around the time you were diagnosed?
    6. How were you able to manage the children's behavior during the time they were diagnosed? How did you manage discipline during this time?
    7. What are the things in your life that supported your ability to care for your children during diagnosis and treatment?
    8. What are the things in your life that hindered your ability to care for your children during diagnosis and treatment?

C. After treatment/today:
    1. Tell me about how you are able to provide care for your children today.
    2. How are you able to provide for the enrichment of your children today, such as reading books, helping with homework, and playing with your kids?
    3. How are you able to manage the behavior your children today? How has this changed from when you were first diagnosed and undergoing treatments?
    4. What are the things in your life that support your ability to care for your child(ren) today?
    5. What are the things that hinder your ability to care for your children today?

What else would you like to add about your story as a mother with cancer?

Appendix C: Recruitment Flyer

UNIVERSITY OF KENTUCKY

Research Study for Mothers Receiving Chemotherapy

Are you a woman who is undergoing chemotherapy who has one or more child living in the home who is under the age of 18?

Is so, volunteers are being sought to help researchers in the Department of Rehabilitation Sciences at UK understand how chemotherapy affects your ability to care for your child or children.

The study will involve filling out surveys and, for some women, being interviewed. You will be rewarded with a $25 gift card for completing the surveys and another $25 gift card for the interview. Cards will be prorated for early withdrawal from the study. Please call Julie Baltisberger, MS, OTR/L at (859) 582-3169 for more information.

Mothers receiving
chemotherapy study
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Appendix D: Parent Disability Index (PDI)

Did you have any trouble or difficulty with the following?
(Response options include: no difficulty, some difficulty, unable to do, did not do for reasons others than cancer.

Young child(ren) (ages 0–5 years)
For each of these items, rate whether you had any trouble or difficulty with the following. Also, check "yes" if you do this activity less frequently because of your cancer.

Parenting Task	Level of Difficulty—Choose one					Did less because of cancer?
Diapering, dressing, or helping your child with dressing	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Taking care of your child's hygiene needs; for example, bathing or helping with bathing, brushing teeth or hair, or cutting nails	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Feeding your child; for example, preparing formula or bottles, holding your child for feeding, cutting food for child, using utensils to feed your child, or preparing food	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Picking up or carrying your child	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No

Parenting Task	Level of Difficulty—Choose one					Did less because of cancer?
Taking care of your child while out of the house; for example, carrying things you might need, changing diapers, feeding	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Taking your child out in the car; for example, getting child in and out of car, using car seat	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Getting up and down to the floor to play with your child	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Keeping your child out of unsafe situations; for example, away from stairs or the street, running after them, or keeping track of them outdoors or in stores	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Getting up with your child, either during the night or early in the morning	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Playing with your child outdoors; for example, going to the playground, throwing balls, or practicing sports	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No

Parenting Task	Level of Difficulty—Choose one					Did less because of cancer?
Having other children in your home; for example, having birthday parties or having other children over to play	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Taking your child to social events or recreational activities; for example, taking your child to play groups or other children's birthday parties, or going to family events, museums, or swimming pools	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Taking care of your child when s/he is sick; for example, giving medicine, using a thermometer	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Maintaining discipline with your child; for example, managing tantrums or setting and enforcing limits	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Doing household chores or shopping; for example, cleaning, vacuuming, laundry, ironing, shopping, or errands	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Using a stroller	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No

Parenting Task	Level of Difficulty—Choose one					Did less because of cancer?
Using a car seat	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Opening safety latches or locks	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No
Opening medicine or childproof containers	No difficulty ☐	Some difficulty ☐	A lot of difficulty ☐	Unable to do ☐	Did not do this for reasons other than cancer ☐	☐ Yes ☐ No

Appendix E: FACT-G (Version 4)

Below is a list of statements that other people with your illness have said are important**. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.**

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy……………………....	0	1	2	3	4
GP2	I have nausea……………………………..	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family…….	0	1	2	3	4
GP4	I have pain………………………………..	0	1	2	3	4
GP5	I am bothered by side effects of treatment….	0	1	2	3	4
GP6	I feel ill…………………………………...	0	1	2	3	4
GP7	I am forced to spend time in bed…………..	0	1	2	3	4

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends	0	1	2	3	4
GS2	I get emotional support from my family	0	1	2	3	4
GS3	I get support from my friends..........................	0	1	2	3	4
GS4	My family has accepted my illness	0	1	2	3	4
GS5	I am satisfied with family communication about my illness...	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support)..	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please mark this box* ☐ *and go to the next section.*					
GS7	I am satisfied with my sex life.........................	0	1	2	3	4

Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GE1	I feel sad	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness	0	1	2	3	4
GE3	I am losing hope in the fight against my illness	0	1	2	3	4
GE4	I feel nervous	0	1	2	3	4
GE5	I worry about dying	0	1	2	3	4
GE6	I worry that my condition will get worse	0	1	2	3	4

	FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GF1	I am able to work (include work at home)	0	1	2	3	4
GF2	My work (include work at home) is fulfilling	0	1	2	3	4
GF3	I am able to enjoy life	0	1	2	3	4
GF4	I have accepted my illness	0	1	2	3	4
GF5	I am sleeping well	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun	0	1	2	3	4
GF7	I am content with the quality of my life right now	0	1	2	3	4

Appendix F: FACT-G Scoring Guidelines (Version 4)

Instructions:*
1. Record answers in "item response" column. If missing, mark with an X
2. Perform reversals as indicated, and sum individual items to obtain a score.
3. Multiply the sum of the item scores by the number of items in the subscale, then divide by the number of items answered. This produces the subscale score.
4. Add subscale scores to derive total FACT-G score. ***The higher the score, the better the QOL.***

Subscale	Item Code	Reverse item?	Item response	Item Score
PHYSICAL	GP1	4 -	________	=________
WELL-BEING	GP2	4 -	________	=________
(PWB)	GP3	4 -	________	=________
	GP4	4 -	________	=________
Score range: 0-28	GP5	4 -	________	=________
	GP6	4 -	________	=________
	GP7	4 -	________	=________

Sum individual item scores: ________

Multiply by 7: ________

Divide by number of items answered: ________=**PWB subscale score**

SOCIAL/FAMILY	GS1	0 +	________	=________
WELL-BEING	GS2	0 +	________	=________
(SWB)	GS3	0 +	________	=________
	GS4	0 +	________	=________
Score range: 0-28	GS5	0 +	________	=________
	GS6	0 +	________	=________
	GS7	0 +	________	=________

Sum individual item scores: ________

Multiply by 7: ________

Divide by number of items answered: ________=**SWB subscale score**

EMOTIONAL WELL-BEING (EWB)	GE1	4	-	________	=________
	GE2	0	+	________	=________
	GE3	4	-	________	=________
Score range: 0-24	GE4	4	-	________	=________
	GE5	4	-	________	=________
	GE6	4	-	________	=________

Sum individual item scores: ________

Multiply by 6: ________

Divide by number of items answered: ________=**EWB subscale score**

FUNCTIONAL WELL-BEING (FWB)	GF1	0	+	________	=________
	GF2	0	+	________	=________
	GF3	0	+	________	=________
	GF4	0	+	________	=________
Score range: 0-28	GF5	0	+	________	=________
	GF6	0	+	________	=________
	GF7	0	+	________	=________

Sum individual item scores: ________

Multiply by 7: ________

Divide by number of items answered: ________=**FWB subscale score**

TOTAL SCORE:

Score range: 0-108

__________ + __________ + __________ + __________ =________=**FACT-G Total score**

(**PWB** score) (**SWB** score) (**EWB** score) (**FWB** score)

*For additional guidelines please refer to the Administration and Scoring Guidelines in the manual or at www.facit.org.

Appendix G: FSI-TT

For each of the following, circle the one number that best indicates how that item applies to you.

1. Rate your level of fatigue on the day you felt **most** fatigued during the week before you started cancer treatment:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Not at all fatigued										**As fatigued as I could be**

2. Rate your level of fatigue on the day you felt **least** fatigued during the past week:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Not at all fatigued										**As fatigued as I could be**

3. Rate your level of fatigue on the **average** during the week before you started cancer treatment:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Not at all fatigued										**As fatigued as I could be**

4. Rate your level of fatigue **right now**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
Not at all fatigued										**As fatigued as I could be**

5. Rate how much, in the past week, fatigue interfered with your **general level of activity**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No interference										**Extreme interference**

6. Rate how much, in the past week, fatigue interfered with your **ability to bathe and dress yourself**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No interference										**Extreme interference**

7. Rate how much, in the past week, fatigue interfered with your **normal work activity (includes both work outside the home and housework)**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No interference										**Extreme interference**

For each of the following, circle the one number that best indicates how that item applies to you.

8. Rate how much, in the past week, fatigue interfered with your **ability to concentrate**:

0	*1*	*2*	*3*	*4*	*5*	*6*	*7*	*8*	*9*	*10*
No interference										**Extreme interference**

9. Rate how much, in the past week, fatigue interfered with your **relations with other people**:

0 1 2 3 4 5 6 7 8 9 10

No interference **Extreme interference**

10. Rate how much, in the past week, fatigue interfered with your **enjoyment of life**:

0 1 2 3 4 5 6 7 8 9 10

No interference **Extreme interference**

11. Rate how much, in the past week, fatigue interfered with your **mood**:

0 1 2 3 4 5 6 7 8 9 10

No interference **Extreme interference**

12. Indicate **how many days**, in the past week, you felt fatigued for any part of the day:

0 1 2 3 4 5 6 7

Days **Days**

13. Rate **how much of the day**, on average, you felt fatigued in the past week:

0 1 2 3 4 5 6 7 8 9 10

None of the day **The entire day**

14. Indicate which of the following best describes the **daily pattern** of your fatigue in the past week:

0	*1*	*2*	*3*	*4*
Not at all	**Worse in the morning**	**Worse in the afternoon**	**Worse in the evening**	**No consistent pattern of fatigue**

Fatigue Symptom Inventory, Moffitt Cancer Center and University of South Florida, Tampa, FL ©1998
Modified for Then-Test, Andrykowski, et al., 2009

CURRICULUM VITAE

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EDUCATION

8/2006 - 12/2014 ***Ph.D., Rehabilitation Sciences***
Department of Rehabilitation Sciences
University of Kentucky, Lexington, KY. G.P.A. 4.0/4.0
Doctor of Philosophy Candidate, 8/2010
Dissertation Title: I'm Bent but not Broken: A Mixed Methods Study of Mothering during Chemotherapy for Breast Cancer.

1/1998 – 6/2005 ***M.S., Occupational Therapy***
Eastern Kentucky University, Richmond, KY. G.P.A. 3.9/4.0
Thesis: Factors That Relate to Handwriting Performance in Children

8/1995 - 12/1998 ***Post-baccalaureate Certificate, Occupational Therapy***
Eastern Kentucky University, Richmond, KY. G.P.A. 4.0/4.0
Kentucky license # R2158

8/1988 - 12/1992 ***B.A., Biochemistry and Molecular Biology***
University of California, Berkeley, CA. G.P.A. 3.3/4.0

WORK EXPERIENCE

8/2010 to present ***Assistant Professor***
Department of Occupational Therapy
Eastern Kentucky University, Richmond, KY
Chair: Colleen Schneck, Sc.D., OTR/L, FAOTA

8/2005 to 5/2010 ***Adjunct Professor***
Eastern Kentucky University, Dept. of Occupational Therapy, Richmond, KY
Supervisor: Colleen Schneck, Sc.D., OTR/L, FAOTA
Courses taught: Practicum in Occupational Science (OTS 301), Self as an Occupational Being (OTS 311), Health Sciences Orientation (HSO 100), Professional Dynamics (OTS 335), Level I Fieldwork (OTS 831), Early Childhood Sensorimotor Development (OTS 515/715), and Professional Seminar II (OTS 871).

8/2007 to 5/2010	***Academic Fieldwork Coordinator Assistant*** Eastern Kentucky University, Dept. of Occupational Therapy, Richmond, KY Supervisor: Colleen Schneck, Sc.D., OTR/L, FAOTA Prepared students for Level II fieldwork; collaborated with the Academic Fieldwork Coordinator in fieldwork site preparation; supervised and advised students and therapists on Level II fieldwork sites visits.
3/2006 to 8/2007	***Research Coordinator*** Eastern Kentucky University, Dept. of Occupational Therapy, Richmond, KY Supervisor: Doris Pierce, Ph.D., OTR/L, FAOTA Duties included providing research support, conducting and analyzing qualitative research, planning and implementing informal research gatherings and supervising a Graduate Assistant.
7/1999 – 8/2001	***Occupational Therapist*** Lifespan Therapy Services, Mt. Sterling, KY Supervisor: Carol Rushing-Carr, MOT, OTR/L Provided home health services to children under First Steps and EPSDT programs. Provided OT services in the school in Menifee and Montgomery Counties, KY. Provided OT services in a sensory integration summer camp.
8/1999 – 5/2001	***Instructor*** Eastern Kentucky University, Dept. of Occupational Therapy, Richmond, KY Supervisor: Onda Bennett, Ph.D., OTR/L Taught OT for Infants and Children (OTS 352), Early Childhood Sensorimotor Development (OTS 515) and Level I Fieldwork (OTS 341).
6/1999	***Occupational Therapist*** Putting It Together Sensory Integration Camp Early Child Development Center, Winchester, KY Supervisor: Ruth Lowe, M.A., OTR/L Provided OT services to pre-school children in a day camp setting.
1/1999 – 5/1999	***Graduate Assistant*** Eastern Kentucky University, Dept. of Occupational Therapy, Richmond, KY Supervisor: Shirley P. O’Brien, M.S., OTR/L, FAOTA Instructed portions of courses Occupational Therapy for Infants and Children and Level I Fieldwork; guest lectured; assisted faculty with research, including a school safety program at the Fayette School.

8/1995 - 5/1997	***Laboratory Instructor*** Eastern Kentucky University, Dept. of Chemistry, Richmond, KY Supervisors: Harry Smiley, Ph.D. and John Davidson, Ph.D. Instructed Chemistry 101/105 (General Chemistry) laboratory.
9/1993 - 6/1995	***Principal Laboratory Technician*** University of Kentucky, Dept. of Biochemistry, Lexington, KY Supervisor: Robert Dickson, Ph.D. Conducted research on yeast lipids; supervised undergraduate workers.
6/1992 - 6/1993	***Laboratory Technician*** (under previous name Julie Duckart) University of California, Dept. of Neurology, San Francisco, CA Supervisor: William Mobley, M.D., Ph.D. Conducted research on Alzheimer's Disease; synthesized and purified peptides; trained post-doctoral fellows and graduate students in peptide synthesis.

PUBLICATIONS

Baltisberger, J. A. (in preparation). The impact of chemotherapy on mothering occupations for women with breast cancer. Dissertation for Doctor of Philosophy degree, Department of Rehabilitation Sciences, University of Kentucky.

Baltisberger, J. A. (in revision). Reflexive bracketing through autoethnography. *International Journal of Qualitative Methods*.

Hunter, E. G., Baltisberger, J. A. (2012). Functional outcomes by age for inpatient cancer rehabilitation: A retrospective chart review. *Journal of Applied Gerontology, XX(X), 1-*.

Marken, D., Pierce, D, & Baltisberger, J. (2010). Grandmothers' use of routines to manage custodial care of young children. *Physical & Occupational Therapy in Geriatrics, 28*(4), 360-375. doi:10.3109/02703181.2010.535119

Schoenberg, N., Baltisberger, J., Bardach, S., & Dignan, M. (2010). Perspectives on pap test follow up care among rural Appalachian women. *Women & Health, 50*(6).

Pierce, D., Atler, K., Baltisberger, J., Fehringer, E., Hunter, E., Malkawi, S., & Parr, T. (2010). Occupational science: A data-based American perspective. *Journal of Occupational Science, 18*(1).

Nagiec, M. M., Baltisberger, J. A., Wells, G. B., Lester, R. L. and Dickson, R. C. (1994). The *LCB2* gene of *Saccharomyce*s and the related *LCB1* gene encode subunits of serine palmitoyltransferase, the initial enzyme in sphingolipid synthesis. *The Proceedings of the National Academy of Sciences. 91*, 7899-7902.

Nagiec, M. M., Nagiec, E. E., Baltisberger, J. A., Wells, G. B., Lester, R. L., & Dickson, R. C. (1997). Sphingolipid synthesis as a target for antifungal drugs. Complementation of the inositol phosphorylceramide synthase defect in a mutant strain of *Saccharomyces cerevisiae* by the *AUR1* gene. *Journal of Biological Chemistry. 272*, 9809-9817.

Qie, L.,Nagiec, M. M., Baltisberger, J. A., Lester, R. L. & Dickson, Robert C. (1997). Identification of a *Saccharomyces* gene, *LCB3*, necessary for incorporation of exogenous long chain bases into sphingolipids. *Journal of Biological Chemistry. 272,* 16110-16117.

AWARDS AND SCHOLARSHIPS

- University of Kentucky Woman's Club Fellowship, November, 2013
- Related Services Scholarship, Kentucky Dept. of Education, November, 1997
- Pi Theta Epsilon Occupational Therapy Honor Society, January, 1997
- Appalachian Traineeship Award for Occupational Therapy, December, 1996

PROFESSIONAL ORGANIZATIONS

- American Occupational Therapy Association (AOTA)
- Kentucky Occupational Therapy Association (KOTA)
- Society for the Study of Occupation, USA (SSO-USA)
- World Federation of Occupational Therapy (WFOT)
- Pi Theta Epsilon

PRESENTATIONS

Baltisberger, J. A. (2014, October). Bent but not broken: A mixed method study of mothers with breast cancer. Paper presented at the Twentieth Annual Qualitative Health Research Conference, Victoria, British Columbia.

Baltisberger, J. A. (2011, October). Autoethnography of a Mother with Cancer as a Means of Reflexive Bracketing. Paper presented at the Tenth Annual Conference of the Study for the Study of Occupation: USA, Park City, UT.

Baltisberger, J. A. (2009, October). The use of computer-assisted qualitative data analysis software in occupational science research. Poster presented at the Eighth Annual Conference of the Society for the Study of Occupation: USA, New Haven, CT.

Marken, D., & Baltisberger, J. A. (2007, March). *Highlight the positive: What grandmothers can do to create a safe home environment.* Paper presented at the Grandparents and Relatives Raising Children Conference, Lexington, KY.

Atler, K., Baltisberger, J. A., Malkawi, S., Parr, T. D. (2007, October). *The first five years: A thematic analysis of presentation abstracts of the SSO: USA*. Paper presented at the Sixth Annual Conference of the Society for the Study of

Occupation: USA, Albuquerque, NM.

Baltisberger, J. A., Marken, D., & Pierce, D. (2006, October). *Strategies and challenges of custodial grandmothers raising grandchildren.* Paper presented at the Fifth Annual Conference of the Society for the Study of Occupation: USA, St. Louis, MO.

INVITED PRESENTATIONS

Baltisberger, J. A. (2014, August). Fine motor skills and sensory integration for physical therapists. Guest lecture for DPT students, University of Kentucky.

Baltisberger, J. A. (2014, April). Play in occupational therapy, physical therapy, and communication disorders. Guest lecture for the PRePARE program, University of Kentucky

Baltisberger, J. A. (2014, March). An occupational science perspective of play. Guest lecture for EKU undergraduate Occupational Science program, OTS 421: Occupations across the Lifespan.

Baltisberger, J. A.   (2014, March). Sensory processing disorders in children. Presentation at Kentucky SEED New Community Gathering, Lexington, KY.

Baltisberger, J. A. (2014, February). There's an app for that: The use of iPads in occupational therapy practice. Presentation at the Kentucky Occupational Therapy Association Eastern District Meeting, Richmond, KY

Myers, C. M., & Baltisberger, J. A. (2012, October). Sensory processing in children. Presentation at Kentucky SEED New Community Gathering, Lexington, KY.

Baltisberger, J. A. (2012, August). Fine motor skills and sensory integration for physical therapists. Guest lecture for DPT students, University of Kentucky.

Baltisberger, J. A. (2012, April). The therapeutic use of play in occupational therapy, physical therapy, and communication disorders. Guest lecture for the PRePARE program, University of Kentucky

Baltisberger, J. A., (2012, March). The Use of iPads in Rehabilitation. Presentation at the Kentucky Occupational Therapy Association Eastern District Meeting, Richmond, KY.

Baltisberger, J. A. (2011, September). SGA grant assistive technology devices. In-service at Model Lab School for special educators.

Baltisberger, J. A. (2011, August). Fine motor skill and sensory integration for physical therapists. Guest lecture for DPT students, University of Kentucky.

Baltisberger, J. A. (2011, April). The therapeutic use of play in occupational therapy practice. Lecture presented to KOTA Student Conference.

Baltisberger, J. A. (2010, November). The use of the iPad in education. In-service presented at Model Lab School to special educators.

Baltisberger, J. A. (2010, October). Assistive technology use across the lifespan. Guest lecture presented for Mixon Ware in CDF 441 Family Dynamics in Adulthood and Aging.

Baltisberger, J. A. (2010, October). The use of play in early intervention. Guest lecture for Christine Myers in OTS 864 Early Childhood Practice.

Baltisberger, J. A. (2010, September). The role of occupational therapy as a related service in special education. Guest lecture for Dusty Columbia Embury in SED 104 Special Education Introduction.

Baltisberger, J. A. (2010, September). The therapeutic use of play in rehabilitation. Guest lecture for the PRePARE program, University of Kentucky

Baltisberger, J. A. (2010, August). Fine motor skills, sensory integration, and play development in children. Guest lecture for Susan Effgen, Doctor of Physical Therapy Program, University of Kentucky.

Baltisberger, J. A. (2009, October). The use of qualitative research software in occupational therapy research. Guest lecture for Lynnda Emery, Eastern Kentucky University.

Baltisberger, J. A. (2009, September). Play as a therapeutic modality of occupational therapy, physical therapy, and communication disorders. Guest lecture for PRePARE program, University of Kentucky.

Baltisberger, J. A. (2009, August). Physical therapists' role in fine motor skill development in children. Guest lecture for Susan Effgen, Doctor of Physical Therapy Program, University of Kentucky.

Baltisberger, J. A. (2009, July). The use of play in the therapeutic process. Guest lecture for Leslie Mattacola, Communication Disorders Program, University of Kentucky.

Baltisberger, J. A. (2008, August). Fine motor skill development in children. Guest lecture for Susan Effgen, Doctor of Physical Therapy Program, University of Kentucky.

Baltisberger, J. A. (2008, April). Computer Assisted Qualitative Research Software: A comparison of four commonly used programs. Guest lecture for Dana Howell and

Peggy Wittman, OTS 875, Eastern Kentucky University.

Baltisberger, J. A. (2007, August). Fine motor skills in children. Guest lecture for Susan Effgen, Physical Therapy Program, University of Kentucky.

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