A Narrative Analysis of the Stories of Mothers who have Parented a Child Diagnosed with Hodgkin's Disease and is Currently in Early Survivorship

Jennifer Marie Darcy
This research was completed as part of the degree requirements for the Nursing Department at Molloy College.

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Molloy College

The Division of Nursing

PhD in Nursing Program

A NARRATIVE ANALYSIS OF THE STORIES OF MOTHERS WHO HAVE PARENTED A CHILD DIAGNOSED WITH HODGKIN’S DISEASE AND IS CURRENTLY IN EARLY SURVIVORSHIP

A dissertation

By

JENNIFER MARIE D ARCY

Submitted in Partial Fulfillment

of the Requirements for the Degree

Doctor of Philosophy

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MOLLOY COLLEGE
DIVISION OF NURSING

The dissertation of Jennifer Darcy entitled A NARRATIVE ANALYSIS OF THE STORIES OF MOTHERS WHO HAVE PARENTEO A CHILD DIAGNOSED WITH HODGKIN'S DISEASE AND IS CURRENTLY IN EARLY SURVIVORSHIP in partial fulfillment of the requirements for the degree of Doctor of Philosophy in the Division of Nursing has been read and approved by the committee:

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Abstract

With the growing number of survivors of childhood cancer in the United States, it has been essential for research to look more closely at the challenges these “children” and their families face later in life as they live to adulthood. While much has been written about childhood cancer survivors and their parents independently, there are unique struggles that a mother and a childhood cancer survivor face as a dyad. A diagnosis of cancer falling on one’s child is undoubtedly a life altering event. Examining the dyadic relationship over time offers a unique perspective to understanding the parenting experience with a child whose fate is uncertain. Utilizing the methodology of Narrative Inquiry, this research explored the bonds the mother has with her child before he or she is diagnosed with cancer, the relationship during treatment, and the subsequent relationship when the child has entered survivorship. Most specifically, the research explored the attachment of the mother to her child as it relates to the Caregiving System. An initial sample of 4 mothers representing a child from each birth order category (youngest child, middle child, oldest child and only child) was chosen. Based upon the results of the interviews the sample was increased in rounds of 3 for saturation to a sample of 13. The participants were interviewed one time. The interviews were analyzed through thematic analysis and 4 core themes were identified. A metastory was then compiled. The research shows activation of the Caregiving Behavioral Response System as it relates as a reciprocal to Attachment Theory. The stories add to what is known about how the relationship between a mother and her child evolves during the treatment of Hodgkin’s disease into survivorship.
Dedication

I dedicate this dissertation to my family most especially James and Cate whose unyielding smiles and constant enthusiasm added a unique richness to this experience that will stay with me always and to Phil. Without your support and understanding I would never have been able to dedicate the time and effort needed to complete this research. I thank my committee for their encouragement and support. Finally, this is dedicated to the families who graciously offered their stories to help the lives of others. Without all of you this work could never have been possible.
# Table of Contents

CHAPTER 1 BACKGROUND AND IMPORTANCE ............................................................................. 1

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>INTRODUCTION</td>
<td>1</td>
</tr>
<tr>
<td>CONCEPTUAL DEFINITIONS FOR THE STUDY</td>
<td>3</td>
</tr>
<tr>
<td>ATTACHMENT</td>
<td>3</td>
</tr>
<tr>
<td>BIRTH ORDER</td>
<td>6</td>
</tr>
<tr>
<td>Youngest Child</td>
<td>7</td>
</tr>
<tr>
<td>Middle Child</td>
<td>8</td>
</tr>
<tr>
<td>Oldest Child</td>
<td>8</td>
</tr>
<tr>
<td>Only Child</td>
<td>9</td>
</tr>
<tr>
<td>CHILDHOOD CANCER</td>
<td>9</td>
</tr>
<tr>
<td>SURVIVORSHIP MEDICINE</td>
<td>10</td>
</tr>
<tr>
<td>HODGKIN LYMPHOMA</td>
<td>11</td>
</tr>
<tr>
<td>Incidence, Causes and Risk Factors</td>
<td>12</td>
</tr>
<tr>
<td>Signs, Symptoms, and Diagnosis</td>
<td>13</td>
</tr>
<tr>
<td>Subtypes of Hodgkin Lymphoma</td>
<td>14</td>
</tr>
<tr>
<td>Staging</td>
<td>15</td>
</tr>
<tr>
<td>Treatment</td>
<td>17</td>
</tr>
<tr>
<td>Treatment Side Effects</td>
<td>19</td>
</tr>
<tr>
<td>Survival Rates</td>
<td>20</td>
</tr>
<tr>
<td>Long Term Sequelae and Follow up Care</td>
<td>21</td>
</tr>
<tr>
<td>THEORETICAL FRAMEWORK</td>
<td>22</td>
</tr>
<tr>
<td>SPECIFIC AIMS</td>
<td>23</td>
</tr>
<tr>
<td>SUMMARY</td>
<td>24</td>
</tr>
</tbody>
</table>

CHAPTER 2 REVIEW OF LITERATURE ....................................................................................... 25
CHAPTER 3 METHODS

INTRODUCTION ............................................................................................................... 49

SPECIFIC AIMS ............................................................................................................. 49

NARRATIVE INQUIRY METHODOLOGY ...................................................................... 49

History and Foundations .............................................................................................. 50

Contemporary Narrative Inquiry .................................................................................. 51

Sampling in Narrative Inquiry ....................................................................................... 55

SAMPLE ....................................................................................................................... 56

SETTING ....................................................................................................................... 58

DATA COLLECTION .................................................................................................... 58
# CHAPTER 4 FINDINGS

## INTRODUCTION

## YOUNGEST CHILD

*Research Participants*

- Lyn .................................................. 68
- Lena .................................................. 75
- Ellen .................................................. 82

**SUMMARY - YOUNGEST CHILD** .................................................. 87

## MIDDLE CHILD

*Research Participants*

- Diane .................................................. 88
- Katherine ............................................. 93
- Anna ................................................... 100

**Summary - Middle Child** .................................................. 105

## OLDEST CHILD

*Research Participants*

- Patricia .............................................. 106
- Terry .................................................. 117
- Maria .................................................. 125
Dina ...................................................................................................................... 171
Liz ......................................................................................................................... 172

Shifting Priorities ................................................................................................. 172
Terry ....................................................................................................................... 172
Katherine .............................................................................................................. 173
Diane ...................................................................................................................... 173
Dina ......................................................................................................................... 173
Lyn .......................................................................................................................... 174
Tina .......................................................................................................................... 174

Unique Bond ........................................................................................................... 175
Ellen ........................................................................................................................ 175
Katherine .............................................................................................................. 175
Diane ...................................................................................................................... 176
Lyn .......................................................................................................................... 176
Tina .......................................................................................................................... 177
Patricia ...................................................................................................... 177

Lost Innocence ...................................................................................................... 177
Katherine.............................................................................................................. 178
Diane ...................................................................................................................... 178
Dina ......................................................................................................................... 178
Tina .......................................................................................................................... 178
Patricia ................................................................................................................... 179

SUMMARY ............................................................................................................ 180

CHAPTER 5 DISCUSSION ....................................................................................... 181

INTRODUCTION .................................................................................................. 181

CONNECTIONS TO ATTACHMENT AND CAREGIVING .................................. 181

SIMILARITIES AND DIFFERENCES AMONG BIRTH ORDERS ................................. 184
REFERENCES .............................................................................................................. 192

APPENDIX A EXEMPLARS OF NARRATIVE INQUIRY ................................................. 204

ANALYSIS IN NARRATIVE INQUIRY ....................................................................... 204

Thematic Analysis .................................................................................................... 204
Williams .................................................................................................................. 204
Ewick and Silbey ..................................................................................................... 205
Tamboukou ........................................................................................................... 206
Cain ....................................................................................................................... 207

Structural Analysis .................................................................................................. 208
Labov .................................................................................................................... 208
Robichaux .............................................................................................................. 209
Gee ......................................................................................................................... 209
Riessman ............................................................................................................... 210

Dialogue/Performance Analysis ............................................................................. 210
Riessman ............................................................................................................... 211
Brown ..................................................................................................................... 212
Gallas ...................................................................................................................... 213

Visual Analysis ....................................................................................................... 213
Creef ....................................................................................................................... 214
Bell ......................................................................................................................... 215
Tamboukou ........................................................................................................... 215
Luttrell .................................................................................................................... 216
List of Figures

Figure 1 - Childhood Cancer Incidence Rates................................................................. 10
List of Tables

Table 1 Staging of Hodgkin Lymphoma .......................................................... 16
Table 2 Survival Rates for Hodgkin Lymphoma ........................................... 20
Table 3 Participants by Birth Order .................................................................. 66
Chapter 1 Background and Importance

Introduction

American families face many challenges and obstacles even in the best of times. No family is without its share of hardships and tribulations. The focus of a family is no longer on its members but on the condition of the family as a whole. There are certain needs that a family has over time in its developmental trajectory and certain shared behaviors that it has to maintain in order to support its members. When a member of a family is under stress the entire family feels the stress. As nurses, it is our responsibility to foster and support family unity and health to the best of our ability.

One of the most stressful times for a family as a unit is when a member receives the diagnosis of cancer. The burden becomes seemingly more unbearable when the diagnosis falls on a child. The parents and siblings are thrown into a whirlwind of emotion. They often are overcome by grief, anger, and resentment, and left with a unique vulnerability.

In the family without hardships, children and parents share a close bond. In particular, mothers and new babies experience an intense and unique relationship early in the infant’s life. This bond has been described and studied as the concept of attachment. Bowlby (1979) conceptualized attachment as a profound connection between children and their parents. In normal parenting, attachment serves a constructive purpose to keep mother and child close to benefit both in their new and developing mother-child relationship. When parenting a child with cancer, a mother’s attachment may become intensified or altered over the course of the illness to cope with the uncertainty of the condition and logistics of the health care treatments.
Parents of hospitalized children often face long periods of time away from home to visit or care for their sick child. They may be physically far from their spouse and/or other children. The caregiver, many times the mother, may become detached and isolated from other family members during hospital stays and treatments for her sick child (Harding, 1996). This separation causes strain and perhaps alters her innate attachment drives. A review of the literature will reveal ways in which attachment is normally fostered and practices that may strain the connection or become altered with the presence of a sick child. Additionally, the mother-child relationship may be influenced when there are other children in the family presenting her with competing demands that have an impact on the mother’s ability to give attention focused on the sick child. Thus, birth order of the sick child may contribute to the stress and strain of maternal attachment. Adler (1927) discusses personality as it relates to family position and both actual and perceived birth order, and an altered attachment mechanism may be influenced by birth order. The purpose of this research is to explore what it is like to be the mother of a child diagnosed with cancer, specifically Hodgkin Lymphoma, and how parenting behaviors are related to attachment theory as defined by Bowlby (1979) as well as examine these experiences according to the child’s birth order.

Chapter one will detail the significance and life altering nature of parenting a child with cancer. It will begin with operational definitions. The chapter will explore normal parental attachment as well as traditional findings on birth order. It will discuss childhood cancer survival statistics and detail specifically Hodgkin Lymphoma, a highly curable cancer that carries many long term sequelae (Horning, 2010). The chapter concludes with the research aims and summary.
Conceptual Definitions for the Study

This study will focus on the mother’s experiences with her child who has Hodgkin lymphoma and has survived. It is predicated on the attachment relationship and potentially influenced by the child’s birth order. The following definitions will serve to refine the research question:

**Attachment**

A special type of affectional bond between individuals. “An affectional bond: (1) is persistent; (2) involves a specific person who is not interchangeable with anyone else; (3) is emotionally significant; (4) produces a desire to maintain proximity; and (5) results in distress from involuntary separation” (Edwards, 2002, p. 390).

**Birth Order**

The order in which a child enters a family (Adler, 1927).

**Hodgkin Lymphoma**

A type of malignancy involving the lymphatic system. The disease was discovered by Thomas Hodgkin in 1832. It is characterized by hallmark swelling of lymph nodes in the neck, axilla, or groin. Hodgkin lymphoma has a high survival rate (85%) for all stages. The long term effects of treatment are significant and include secondary cancers, heart disease, thyroid disease, and infertility (Horning, 2010). For the purposes of this study, Hodgkin lymphoma, Hodgkin’s and Hodgkin’s disease will be interchangeable.

**Survivorship**

The period of time 2 years and beyond after treatment has ended for cancer without relapse (American Cancer Society, 2013).

**Attachment**

Attachment, as defined by Bowlby (1979) and Ainsworth (1989), is a special type of affectional bond between individuals. “An affectional bond: (1) is persistent [in the mother
infant relationship]; (2) involves a specific person who is not interchangeable with anyone else, [generally the mother unless there is a situation where a maternal substitute is in the relationship]; (3) is emotionally significant [for the mother and at some level for the infant]; (4) produces a desire to maintain proximity [that is marked by intentional behavior]; and (5) results in distress from involuntary separation [that can be expressed by both mother and infant]. An attachment bond involves all five of these criteria, and also involves seeking security and comfort in the relationship with that person” (Edwards, 2002, p. 390).

Cassidy (1994) describes successful or secure attachment as when children are provided with a sense of basic trust in their caregiver as well as safety in their environment. An insecure attachment results in a lack of feelings of trust. This bond is established through parents reading and responding to their infant’s physical and emotional needs. From these basic interactions the relationship is further strengthened as the bond develops and matures.

In the 1930s, John Bowlby worked as a psychiatrist in a child guidance clinic in London where he treated many emotionally disturbed children. It was during this time that Bowlby recognized the importance of the child’s connection to the mother in their social, emotional, and cognitive development. Specifically, Bowlby noted a link between early infant separations from mothers and maladjustments later in life. This work led to the development of Attachment Theory as we know it today. According to Bowlby, infants have a universal need to seek close proximity with their caregiver when under stress or threatened (Prior & Glaser, 2006). Bowlby relates attachment to an evolutionary context in that the caregiver provides safety and security for the infant.
Attachment Theory, according to Bowlby, suggests that upon birth children have a need and instinct to form attachments to help them survive. Smiling, crying, cooing, and other engaging behaviors are produced by the infant to stimulate the caregiving response from adults. He concluded that the determinant of attachment is care and responsiveness.

The mother typically serves as the first main bond formed by the infant. This attachment figure serves as a secure base for the infant and ultimately the child and adult to explore the world. This attachment relationship serves as a prototype for all future social relationships. According to Bowlby, the disruption of the mother infant attachment has severe developmental consequences, possibly including decreased intelligence and increased aggression (Bowlby, 1958).

The attachment relationship is a critical foundation toward helping the child achieve interdependence. Guiding toward interdependence entails helping children to overcome their natural egocentricity and begin to see themselves as part of a community, not any better nor any worse than anyone else, and to live cooperatively with others. To fully develop interdependence the child must develop four critical capacities. These are affect regulation, empathy, moral code, and prosocial behavior (Edwards, 2002).

Affect regulation is the ability to use one’s affect well. For example, in a secure attachment a positive affect may be used to invite or encourage another, while negative affect could be used to signal the need for problem solving (Edwards, 2002). Affect regulation is imperative in developing cooperative relationships. “Empathy draws a person out of the self into the sphere of others, allowing them to influence his feelings, thoughts, and behaviors” (Edwards, 2002, p. 396). Empathy and self regulation complement each other. If a person
has not developed affect regulation, seeing someone in distress is likely to elicit feelings of personal discomfort rather than empathy (Edwards, 2002). Moral code is described as “the capacity for morality that guides both one’s goals as well as the behaviors chosen for enactment” (Edwards, 2002, p. 396). The guide to developing a moral code is achieved through parental modeling and the development of emotions such as guilt, shame, and pride. Prosocial behaviors such as helping, sharing, comforting, and acting altruistically help develop interdependence. The foundation of prosocial behavior is the attachment relationship and, indeed, many empirical relationships have been demonstrated between parent infant attachment and children’s social competence and cooperation in preschool. In addition to the moral and social development of the infant, the mother gains the satisfaction and fulfillment of an interpersonal, mutually beneficial relationship with their child.

Many factors influence the parent child attachment. Influences can include illness on the part of the mother or child, traumatic events, societal demands, or physiologic factors. In addition to these situations or events, there are also inherent characteristics that may have an impact on the parent child relationship such as birth order. The order in which children enter a family (birth order) may influence their attachment to their mothers in ways unique to that particular birth order category.

**Birth Order**

Birth order can be explored to understand a person’s behavior in certain circumstances. Birth order can be referred to as actual birth order or psychological birth order. “Actual birth order (ABO) refers to the numerical rank order in which siblings are born into or entered the family of origin” (Stewart, 2012, p. 76). Alfred Adler, the long time
researcher on birth order and personality, believed that because everyone seeks a unique way to belong, the order in which a person enters a family might influence the way siblings interact and find a way to belong (Stewart, 2012). Psychological birth order (PBO) refers to a person’s self-perceived place in the family, as this “contributes to ways the child approaches the tasks of completion and belonging” (Stewart, 2012, p. 77). Adler explains this phenomenon: “What the child feels need not actually be the case. It does not matter what really has happened, whether an individual is really inferior or not. What is important is his interpretation of his situation” (Adler, 1927, p. 150). Members of a family assume the roles they perceive to be fitting for themselves. “The development and engagement of such roles embodies the person’s journey to fulfill the basic human needs to belong and to play a meaningful part in family, work, and community groups” (Stewart, 2012, p. 77).

There is an abundance of research on birth order with Alfred Adler having led much of the conceptualizations. He describes first born, youngest child, middle child, and only child. He identifies that there is not one determinant of one’s perceived position but rather, it is influenced by family dynamics, actual birth order, and atmosphere (Stewart, 2012).

**Youngest Child**

Those in the youngest child role may feel they are at a disadvantage as opposed to their siblings. Their older siblings have established their own roles in the family and the youngest may perceive themselves as unable to measure up. This may result in others perceiving them to be less capable as well. The youngest may develop the ability to charm or coax people to do tasks for them and provide for them. This may contribute to an image of popularity and outgoing nature (Stewart, 2012). Adler points out that, conversely, some
youngest children are discouraged and do not seek out a socially useful role both inside and outside the family dynamic. Some may seek significance through their inadequacies or failures. However, Adler also points out that those that excel in the youngest role may welcome opportunities in their families that promote their significance (Adler, 1927).

**Middle Child**

The middle child differs from youngest and oldest in several ways. It is possible for those in the middle child role to feel there is nothing unique or special about them. They lack the attention seeking and dependency of the youngest and the authority of the first born. These characteristics may contribute to feelings of perceived rejection (Stewart, 2012). However, Adler identifies that those who actually thrive in the middle child role may have enhanced self-worth and well developed interpersonal skills (Adler, 1927). This can be referred to as a sense of achievement in that they have found meaning in their role by developing certain characteristics of both their older and younger siblings and creating a specific sense of self.

**Oldest Child**

According to Adler, those who are in the first born or oldest child role may gravitate toward leadership in the family. They are comfortable taking authority and look for order. They obey rules and expect others to do so. First borns tend to be goal oriented and have high achievement standards for themselves and others (Stewart, 2012).
**Only Child**

Several authors in the literature (Adler, 1927, 1937; Mellor, 1990) cite that those in the only child role experience perceptions of feeling smothered or family relationships that are too close as a result of parental overprotection and over-involvement (Stewart, 2012). However, those in the only child role may appreciate the attention and experience feelings of entitlement outside the family. Falbo (2012) found that those in the only child role possess a number of adaptive characteristics making only children amenable to change and challenging circumstances, thus proving the only child to be a diverse birth order category.

**Childhood Cancer**

Overall, childhood cancer is a relatively rare disease, with approximately 1 in 300 children developing cancer before the age of 20. The most common types of childhood cancer are Leukemia, central nervous system malignancies, and Hodgkin lymphoma (American Cancer Society, 2013) (see Figure 1). However, with the recent advances in the treatment of these cancers, there is a marked increase in the number of young childhood cancer survivors. Leukemia, the most common form of childhood cancer, currently has a greater than 80% cure rate (American Cancer Society, 2013. Hodgkin lymphoma has a 90% cure rate when treated in early stages (Horning, 2010). However, with these successes come the use of potentially toxic drugs and intensive treatment regimens, and the long term physical, psychosocial, and familial effects on this population of children and families is still being determined (McCubbin, Balling, Possin, Friedich, & Bryne, 2002). Approximately one quarter of survivors face a late-effect from treatment that is classified as severe or life-threatening (Oeffinger, Mertens, & Sklar, 2006). Due to the fact that the children are treated
during a time of rapid development and growth, they face late effects such as heart and lung damage, infertility, cognitive delays, and even secondary cancers (Oeffinger et al., 2006). The extent to which these late – effects impact the survivors may vary greatly.

Figure 1- Childhood Cancer Incidence Rates
American Cancer Society, 2013

Survivorship Medicine

It is estimated that there are 388,500 survivors of childhood cancer living in the United States. This equates to approximately 1 in 530 young adults between the ages 20 to 39 being a survivor of a childhood malignancy (Howlander et al., 2013). Survivorship medicine has become a rapidly growing and evolving field of practice.
The Institute of Medicine recommends a survivorship care plan (Keene, Hobbie, & Ruccione, 2006). The American Cancer Society recommends treatment with a survivorship program after treatment has ended and into adulthood. Survivorship programs today focus on the patient as a whole. They encompass the prior treatment regimen, family dynamics, current health conditions, and co-morbidities, as well as follow up treatments and medical considerations (Keene et al., 2006).

It is of particular importance for those treated for Hodgkin lymphoma to be followed into survivorship. The disease is frequently diagnosed in the adolescent years, a time of rapid growth, both emotionally and physically (Horning, 2010). The strains on the family are real and may be felt for years to come.

**Hodgkin Lymphoma**

Hodgkin lymphoma (also referred to as Hodgkins or Hodgkin’s disease) was named for Thomas Hodgkin, a British pathologist. In 1832, Hodgkin described several cases of people with cancer that involved the lymph nodes. This came to be known as Hodgkin’s disease for about 170 years. In the 20th Century, when the etiology became clear, the disease was renamed Hodgkin Lymphoma (Horning, 2010).

Hodgkin lymphoma results from an injury to the DNA of a lymphocyte. The damage is acquired, or rather, not inherited. The altered DNA in the lymphocyte will produce an uncontrolled growth of cancerous lymphocytes. The accumulation of the cancerous lymphocytes results in masses found throughout the lymphatic system and may eventually affect other organs such as liver, lungs, and bone marrow (Horning, 2010).
Hodgkin lymphoma is distinguished from other types of lymphoma by the presence of Reed-Sternberg cells (RS). Reed-Sternberg cells are giant multi nucleated cells that derive mainly from B cells. The number of cells found and the variations in distribution help to stage or classify Hodgkin lymphoma (Horning, 2010).

**Incidence, Causes and Risk Factors**

Hodgkin lymphoma has a annual incidence of three cases per 100,000 individuals. It is one of the most frequently diagnosed lymphomas in the western world. The disease has its highest incidence in adolescents and young adults ages 15-40 years. Each year 9,190 individuals are diagnosed with Hodgkin’s lymphoma with 10%-15% of these individuals being children and adolescents (Howlander et al., 2013). Hodgkin’s accounts for 50% of lymphomas in children. There is a bimodal distribution of the incidence with peaks from 15-34 years and then again greater than 55 years (Horning, 2010). Children younger than 5 years of age account for only 3% of cases, and among children younger than 10 years of age; boys are 3-4 times more likely to be affected than girls. However, in older children, adolescents, and adults, males and females are affected equally (American Cancer Society, 2013).

Several risk factors place a person at an increased risk for Hodgkin lymphoma. People who have had an Epstein-Barr virus infection have an increased risk for developing Hodgkin lymphoma (approximately 3-4 times greater than an unaffected individual). The reason for the connection has not been determined. Having a sibling with Hodgkin’s places an individual at a 3-7 times greater risk for developing the disease. This risk is more elevated in monozygote twins. Those persons with HIV/AIDS have a significantly higher incidence
than the general population. Other risk factors include: family history; Leukemia in a first degree relative; Caucasian race or Jewish ancestry; and organ transplantation. It is also noted living in a rental home, attending daycare or nursery school, and early parity have been shown to decrease the risk of developing Hodgkin Lymphoma (Horning, 2010).

**Signs, Symptoms, and Diagnosis**

The hallmark, early sign of Hodgkin lymphoma is a painless enlarged lymph node mainly found on the axilla, groin, or neck. The swelling may be nonspecific and generalized to the affected area. Other symptoms include fever, persistent fatigue, drenching sweats at night, weight loss, and puritis. These are referred to as systemic signs and often project a less positive prognosis (Armitage, 2010). Of particular interest is pain in the lymph node after drinking alcohol. This is uncommon but very specific to the disease (Leukemia and Lymphoma Society, 2012).

A diagnosis of Hodgkin lymphoma is made through several tests. Initially, a provider may order imaging such as a chest x ray or CT scan to identify enlarged lymph nodes or lymphoma related abnormalities to internal organs. A complete blood count with differential may reveal low hemoglobin, hematocrit, red blood cells, platelets, and lymphocytes and elevated levels of neutrophils, eosinophils, and erythrocyte sedimentation rate (ESR). The degree of sedimentation rate elevation correlates to an increased risk (Horning, 2010). Serum chemistry analysis may reveal increased levels of glucose, lactic dehydrogenase, alkaline phosphatase, liver enzyme, blood urea nitrogen (BUN), and creatinine levels (Leukemia and Lymphoma Society, 2012). A lymph node biopsy will likely be performed and cytohistologic analysis of the specimen may reveal Reed-Sternberg cells and identify the
type and stage of disease. A Galium-67 scan and fluorodeoxyglucose positive emission tomography (FDG-PET) can identify Hodgkin lymphoma stage and detect bone marrow and other abnormalities not visible on CT scan (Horning, 2010).

**Subtypes of Hodgkin Lymphoma**

There are two main subtypes of Hodgkin lymphoma: classic Hodgkin lymphoma and nodular lymphocyte-predominant Hodgkin lymphoma. The subtype will affect the treatment regime. Approximately 95% of Hodgkin lymphoma patients have the classic subtype. Classic Hodgkin’s is further divided into four major subtypes: nodular sclerosis, mixed cellularity, lymphocyte-depleted, and lymphocyte-rich classic (Horning, 2010).

Nodular sclerosis is the most common form of Hodgkin lymphoma representing approximately 70% of all cases. It is the most common type in young adults ages 15-34 years. The nodes initially affected are those in the mediastinum. The distinguishing characteristic is fibrous tissue found under microscope among the Hodgkin cells. This subtype is highly curable. Mixed cellularity occurs in about 25% of patients and is the second most common subtype. It is most common in the older (55-74 years) and younger (0-14 years) populations and those with immune disorders. It is also highly curable but is a more aggressive subtype. Lymphocyte-depleted Hodgkin lymphoma may be mistaken for Non- Hodgkin lymphoma and has a poor prognosis. It occurs almost exclusively in the older population and is more common in those with HIV (Horning, 2010). It is found in only 4% of patients (American Cancer Society, 2013). Lymphocyte-rich classic is common to nodular lymphocyte predominant Hodgkin lymphoma in terms of histopathology. However, its clinical characteristics are more in line with classic Hodgkin lymphoma and those affected...
with lymphocyte-rich tend to be older than those with nodular lymphocyte predominant (Horning, 2010).

The second main subtype, nodular lymphocyte predominant Hodgkin lymphoma (NLP HL) occurs in approximately 5% of all patients. The cells found in NLP HL are known as histolytic or lymphocytic and differ from classic Reed Sternberg B cells. Patients diagnosed with NLP HL are often asymptomatic and the disease is non-aggressive (Horning, 2010). It is most common in young men and the subtype is associated with long term survival. There is a 3% chance that NLP HL can convert to Non- Hodgkin Lymphoma (American Cancer Society, 2013).

**Staging**

Staging is used for the healthcare team to summarize the extent of the cancer disease. The Cotswold Staging System is a modified version of the older Diane Arbor system and is used to stage Hodgkin lymphoma (see Table 1). There are four stages numbered I-IV. If the cancer is found in an organ outside the lymph system the letter E is added after the stage (for example IE or IIE). If it involves the spleen the letter S may be added. Bulky disease is used to describe tumors in the chest that are at least 1/3 as wide as the chest or if in another area, measure at least 10 cm across. Bulky disease is noted by adding an X to the stage (Horning, 2010).

Stage I is indicated by the following: Hodgkin disease is found in only one lymph node area or lymphoid organ such as the thymus (I) or the cancer is found only in one area of a single organ outside the lymph system (IE). Either of the following means that the disease is Stage II: Hodgkin disease is found in two or more lymph node areas on the same side of
(above or below) the diaphragm (II) or the cancer extends locally from one lymph node area into a nearby organ (IIE). Either of the following means that the disease is stage III: Hodgkin disease is found on both sides of the diaphragm (III) or Hodgkin disease is in lymph nodes above and below the diaphragm and has also spread to a nearby organ (IIIE), to the spleen (IIIS), or to both IIIES.

Table 1 Staging of Hodgkin Lymphoma

<table>
<thead>
<tr>
<th>Stage</th>
<th>Extent of Disease</th>
</tr>
</thead>
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<tr>
<td>I</td>
<td>Apparent involvement of a single lymph node region or a single organ, such as bone.</td>
</tr>
<tr>
<td>II</td>
<td>Involvement of two or three lymph node regions that are close to each other; for example, all in the neck and chest, or all in the abdomen and on the same side of the diaphragm (a thin muscle below the lungs).</td>
</tr>
<tr>
<td>III</td>
<td>Involvement of several lymph node regions in the neck, chest and abdomen (on both sides of the diaphragm).</td>
</tr>
<tr>
<td>IV</td>
<td>Widespread involvement of lymph nodes on both sides of the diaphragm and in other organs, such as the lungs, liver, and bones.</td>
</tr>
</tbody>
</table>

**Categories A and B**

The four stages of Hodgkin Lymphoma can be divided into A and B categories.

- The A category indicates the absence of fever, exaggerated sweating and weight loss.
- The B category indicates that patients have fever, excessive sweating and weight loss. For example, stage IIB indicates that the patient has
  - Two lymph node sites near each other with disease involvement (for example, enlarged lymph nodes in the neck and near the collarbone or in the neck and the armpit)
  - Fever, excessive sweating and weight loss.

Patients in the B category often require more aggressive treatment.

American Cancer Society, 2013

Either of the following means the disease is stage IV: Hodgkin disease has spread widely through one or more organs outside the lymph system; cancer cells may or may not be found in nearby lymph nodes; Hodgkin disease is found in organs in two distant parts of the body and not in nearby lymph nodes; or Hodgkin disease is in the liver, bone marrow, lungs (other than growing there directly from another site), or cerebrospinal fluid (Horning, 2010).
Each stage may also be assigned a letter A or B. A “B” is added to the stage (i.e., IB ) if the person has any of the following symptoms: loss of more than 10% of body weight over six months without dieting; unexplained fever of at least 100.4 degrees Fahrenheit; or drenching night sweats. Any of these symptoms generally means the disease is more advanced. If none of these symptoms are present, the letter A is added to the stage (Horning, 2010).

**Treatment**

The treatment for Hodgkin lymphoma varies depending on the stage and severity of the disease. Treatment consists of chemotherapy, radiation therapy, monoclonal antibodies, high dose chemotherapy, and stem cell transplantation. The treatment modalities can be used independently or in conjunction depending on the severity of the disease (Horning, 2010).

The chemotherapy regime for Hodgkin lymphoma combines several different drugs to attack the disease from various angles. The combinations are referred to by abbreviations. The most common regime in the United States is ABVD (Adriamycin, Bleomycin, Vinblastine, and Dacarbazine), which decreased mortality figures by 60% in the decade following its introduction (Horning, 2010). Other regimes include the Stanford V and the BEACOPP (bleomycin, etoposide, doxorubicin, cyclophosphamide, vincristine, prednisone, procarbazine). Radiation therapy is given after the Stanford V regime but is only sometimes given after ABVD and BEACOPP. Of the alternative chemotherapy agents, BEACOPP demonstrates superior cure rates (Horning, 2010).

Radiation therapy is most useful when Hodgkin lymphoma is in only one part of the body or if bulky disease is present, and is typically given after a course of chemotherapy.
Radiation is generally given five days a week for several weeks. Involved field radiation is used. This is when only the areas that are actually involved are targeted. In the past, extended field was also used, where large areas of involved and surrounding “clean” lymph nodes were treated. This is seldom seen anymore as it has been shown to increase morbidity and mortality in later years (Horning, 2010).

Stem cell transplants are sometimes used to treat Hodgkin lymphoma. It is not normally the initial treatment but it is sometimes useful for relapsed disease. “Fewer than 10% of patients respond only briefly or do not respond to ABVD and experience disease progression” (American Cancer Society, 2013, p. 22). These patients require treatment consisting of high dose chemotherapy with stem cell transplantation (Horning, 2010). “Cure rates from transplantation range from 40-60 % with transplant related mortality at 5%” (Horning, 2010, p. 19).

There are two main types of stem cell transplants: autologous and allogenic. In autologous stem cell transplants the patient’s own blood cells are harvested and frozen and stored while the patient receives high dose chemotherapy and or radiation. They are then reinfused to the patient. In allogeneic transplants the blood cells are harvested from someone with a matching human leukocyte antigen (HLA) type. Allogeneic transplants are more likely to rid the body of the Hodgkin disease but are also more likely to be rejected (American Cancer Society, 2013). Allogenic are the first line stem cell transplants for Hodgkin disease.
Treatment Side Effects

With the promise of the Hodgkin lymphoma treatments, there are both long term and short term treatment side effects. Chemotherapy, radiation, and stem cell transplant all carry individual risks. Precautions are taken for each treatment to help decrease the potential of side effects.

Chemotherapy targets cells that divide quickly, both cancerous and non-cancerous and therefore, as well as targeting and destroying cancer cells, they also target other cells that divide quickly such as hair follicles, bone marrow cells, and cells that line the mouth and intestines. Side effects will depend on the type and dose of chemotherapy used (Oeffinger, et al., 2006). Short term effects typically include such symptoms as hair loss, mouth sores, anorexia, nausea and vomiting, diarrhea, neutropenia, thrombocytopenia, and fatigue. Long term side effects can occur six months to many years after treatment has ended. They include heart damage (doxorubicin), lung damage (Bleomycin), increased risk of secondary cancers, and infertility (Horning, 2010).

Radiation therapy side effects are both short term and long term. Immediate side effects include skin changes similar to sunburn and fatigue, dry mouth, nausea, or diarrhea. The long term side effects of radiation are of particular interest. Long term effects include the development of secondary cancers including Leukemia. Radiation to the neck can damage the thyroid gland, which can cause hypothyroidism and contribute to strokes later in life. Treatment to the chest may also cause heart and lung disease. Radiation that reaches the bones may slow growth and may result in deformities. Doses are calculated to be the
minimal necessary to achieve the desired results, and shields may be used to protect nearby body parts from the radiation (Oeffinger, Hudson, & Landier, 2009).

**Survival Rates**

Survival rates for Hodgkin Lymphoma are based on the stage when the cancer was diagnosed. The rates vary from 65-90%. Table 2 outlines the current survival rates for stage I-IV.

**Table 2 Survival Rates for Hodgkin Lymphoma**

<table>
<thead>
<tr>
<th>Stage</th>
<th>Survival Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>90%</td>
</tr>
<tr>
<td>II</td>
<td>90%</td>
</tr>
<tr>
<td>III</td>
<td>80%</td>
</tr>
<tr>
<td>IV</td>
<td>65%</td>
</tr>
</tbody>
</table>

American Cancer Society 2013

Other prognostic factors affect survivorship (Horning, 2010). The disease is likely to be more serious if the patient has B symptoms (weight loss, fever, and night sweats), is older than 45 years, is male, has a white blood cell count above 15,000, has a hemoglobin count below 10.5, has a blood lymphocyte count below 600, or has a blood albumin level below 4. An erythrocyte sedimentation rate (ESR) over 30 with the presence of B symptoms or over 50 without the presence of B symptoms also increases the severity of the disease (Horning, 2010 and American Cancer Society, 2013).
Long Term Sequela and Follow up Care

Treatment for Hodgkin lymphoma carries significant long term effects, the most serious of which is developing secondary cancers. However, the treatment has changed very much over the last few decades and continues to evolve. ABVD, the most common Hodgkin treatment, does not pose a significant risk for leukemia or infertility as compared to previous treatments.

“The degree of risk for developing a second cancer is related to both the extent and the dosage of the radiation treatment. Second cancers, including cancer of the breast, lung, stomach, bone, and soft tissues, have been reported as soon as 5 years and as late as 30 years after treatment” (Leukemia and Lymphoma Society, 2012, p. 23). Females under the age of 30 treated with radiation to the breast to treat the disease are at an increased risk for developing breast cancer 15 to 20 years later. Although male survivors are at an increased risk to develop second cancers as well, their risk for developing breast cancer is not increased (Oeffinger et al., 2009). When given with Bleomycin, chest radiation increases the risk of developing lung cancer. Survivors treated 10 to 20 years ago who do not smoke have a four times greater risk of developing lung cancer than the general public. Survivors who smoke have as much as a 49 times greater risk than the general public (Horning, 2010). Radiation to the chest is also linked to heart disease and myocardial infarctions (Horning, 2010). Radiation to the neck may cause hypothyroidism (Oeffinger et al., 2009).

Patients treated with chemotherapy in the 1970s and 1980s were treated with combination chemotherapy consisting of mechlorethamine, Oncovin (vincristine), procarbazine, and prednisone (MOPP). This treatment has an increased risk of leukemia. As
mentioned above, the chemotherapy used today, namely ABVD, is not associated with an increased risk (Horning, 2010).

The Leukemia and Lymphoma Society recommends that survivors keep a record of all treatments given. If the patient was treated with chest radiation, blood tests every 5 years to monitor cholesterol levels are recommended as well as regular heart disease screening. Females treated with chest radiation also need regular breast self exams and a baseline mammography within 10 years of treatment or by age 25 and repeat mammograms every two to three years. Further, if treated with chest radiation, lung cancer screenings are recommended. All survivors are recommended to have regular thyroid function tests and seek medical and psychosocial support for late effects as needed (Oeffinger et al., 2009).

Although survival of Hodgkin lymphoma today is likely, it is nonetheless a traumatic diagnosis to hear from the pediatric oncologist. Parents whose children are diagnosed with Hodgkin lymphoma are undeniably shocked when confronted with the situation and inevitably experience profound sadness and feelings of uncertainty. The mother whose child has cancer faces major strains on her maternal role in the ensuing hospital and treatment regimen, and may endure serious stresses on her relationship with her child, spouse, and the rest of the family. The bond between her and her child may seem under attack by the situation and the health care system. Her experiences in this situation will be the focus of this study.

**Theoretical Framework**

Although traditional qualitative research does not generally warrant extensive theoretical background, for the purposes of this research the author will utilize Attachment
Theory and its related concept of the caregiving system as the theoretical framework for this study. The framework will serve as a foundation for the research questions and subsequent analysis.

Bowlby (1982) discusses caregiving as a behavior reciprocal to attachment. Solomon and George (1996) worked on defining caregiving as a system under the premises of Bowlby’s work (1982). They define the goal of the caregiving system, as with attachment, as protection of the young. They write, “The goal of the caregiving system is to keep the infant or child close to the caregiver under conditions of threat or danger” (Solomon & George, 1996, p. 186).

It has been found in related literature, that in some cases, a diagnosis of a life threatening illness or trauma to a family may result in an alteration in the caregiving system (Solomon & George, 1996). This research plans to embrace this phenomenon and explore it using a semi structured interview guide in an effort to ascertain a more complete understanding of the relationships forged between mothers and their Hodgkin Lymphoma survivor children through their experiences as they recount them. Specifically, the caregiving system and Attachment Theory will be applied to examine more deeply the attachments forged between the mother and her survivor child while taking into account the consideration of birth order of the child.

**Specific Aims**

The specific aims of this study were (1) to explore the life experience of a mother of a Hodgkin lymphoma disease survivor prior to her child’s diagnosis, through treatment, and after treatment has ended as she has lived it and in her own words; (2) to relate her
experiences to her attachment to this child who is now cancer free; and (3) to discuss the self-reported experiences in the context of the theoretical propositions of Attachment Theory and birth order as it applies to the mother child dyad with this life experience.

**Summary**

It is imperative to study childhood cancer survivors, namely Hodgkin lymphoma survivors, to promote the quality of life during and after treatment for the child and his or her family. There is a multitude of research on the childhood survivors themselves. However, there appears to be a gap in the literature regarding the effects on the parents of these survivors. Most especially, there is a lack of research on the well-being of the parents after the child has entered survivorship. The mother-child relationship continues to evolve and develop in conjunction with and despite this traumatic event in the life of the family. Zebrack, Chesler, Orbuch, and Parry (2002) and Van Dongen-Melman, Van Zuuren, and Verhulst (1998) have done work in this area and found lasting changes in the family dynamic, but further research is necessary to specifically explore the attachment of the mothers to their children in the periods after the child has been deemed cured. The information gained will influence those facing chronic illness, various cancers, and traumatic events in adolescents and the nurses that care for them.
Chapter 2 Review of Literature

Introduction

Various research has been done concerning Attachment Theory and its many applications. In applying this perspective to childhood cancer survivors and their parents, there must be an understanding of the underlying components of initial attachment of an infant to its mother and then an understanding of how that connection is strengthened into a lasting bond. The components of the cancer process must be understood and explored such as the diagnosis, treatment aspects, and survivorship. In exploring all of these facets the researcher gained a deeper understanding for the unique attachment abilities of the ill child and his or her mother.

Attachment

Relationships are often strained and even tested when a life threatening illness is experienced. A secure mother-child bond may help to ease the strain within a family when a child is diagnosed with cancer. The relationships between the child and the mother, the mother and her other children, and the mother and her partner can all be affected by this pivotal bond, often formed many years before diagnosis.

Bonds are formed in early infancy, and while there is great difference between a human and a monkey, Harlow’s (1958) monkeys present an interesting and intriguing look into the basics for forming an emotional attachment. Harlow conducted a study consisting of wire monkey mother surrogates and a surrogate wrapped in warm terry cloth. Both surrogates were able to provide milk through the same type of nipple device. The monkeys were placed in a cage with only the two surrogates. The monkeys consistently went to the cloth covered
surrogate. The researchers also introduced frightening stimuli to the monkeys and time and again the monkeys clung to the cloth mother. “The frightened or ailing child clings to its mother…and this selective responsiveness in times of distress, disturbance, or danger may be used as a measure of the strength of affectional bonds” (Harlow, 1958, p. 678). Based on these findings, one may argue that the bond between a mother and her infant are invaluable and are primitive in nature, aiding to the survival of the child.

Bowlby (1958) discusses five responses related to the child’s positive tie to its mother. These are sucking, clinging, following, crying, and smiling. “Sucking, clinging and following achieve their end, in the one case food and in the other close proximity to the mother with only a limited reciprocal response being necessary on the mother’s part. Crying and smiling, on the other hand, depend for their results their effect on maternal behavior” (Bowlby, 1958, p. 364). The successful attainment of these instinctual characteristics helps establish and secure the bond between the infant and mother.

Edwards (2002) wrote regarding the relationship between mother and child. First, she sought to “focus on how parents help expand their child’s relatedness to ever-widening circles of families and friends and community and to share with others the responsibility for developing and maintaining these relationships and to live cooperatively with others” (p. 389). The second point in the article presents a Parenting Process Model.

The attachment relationship formed from the initial interactions between mothers and their infants leads to the development of secure feelings or understanding that their (the infants) needs will be met. In turn, accordingly the infant has the ability to focus its attention on exploring the environment. As the child explores the environment, there may be times of
struggle. It may be difficult for parents to witness this struggle. Lending help prematurely, however, can limit the child’s ability to develop coping mechanisms and accept failure and loss. These tendencies and either successes or failures can present themselves as the mother and child are threatened in a situation such as cancer.

In *The Making and Breaking of Affectional Bonds*, Bowlby (1979) discusses the magnitude of the ability of human beings to make strong affectional bonds with each other. The book details the many forms of emotional distress and personality disturbance, including anxiety, anger, depression, and emotional detachment, to which unwilling separation and loss give rise.

Murray (2000) used Attachment Theory to investigate if the adjustment difficulties of siblings of children with cancer are related to the loss of, or separation from the attachment figure (the mother) who may be preoccupied caring for the ill child. He concluded that the feelings of emotional distress and personality changes may be seen. Changes include anxiety, anger, depression and emotional detachment. The symptomatology could be symptoms of mourning as a result of the unwilling separation from their loved attachment figure (the mother). The urgent need of siblings to restore the family dynamic to the way it was before illness can be seen in fits of anger directed toward the attachment figure or to themselves.

Joubert and colleagues (2001) conducted a study of 97 adult childhood cancer survivors. They found that survivors with functional sequelae in adulthood describe themselves as more insecure in their relationships and more ambivalent in their relationships with their parents. Joubert and colleagues (2001) also concluded, based on their study population, that the developmental stage at the time of onset and duration of the functional
deficit is an important variable in the individual’s ability for developing and maintaining secure intimate relationships.

Ainsworth (1989) examined several types of affectional bonds. Among these bonds were the caregiving system that underlies parents’ bonds to their children, and a comparison of these bonds with children’s attachments to their parents. She focuses on the maintenance of the bond between the mother and infant beyond infancy. Her research suggests there are occurrences or instances in the life of the child and the mother that will engage this system again and in a sense reactivate the bonding. She notes little research has been done in this area.

In conclusion, attachment between the mother and infant is initiated immediately to shortly after birth. This initial and often first bond establishes a basis for all subsequent relationships. When the bond is compromised or threatened both the mother and infant initiate behaviors to maintain the bond. When a child is diagnosed with cancer, the mother and child relationship is threatened both for the mother and ill child and the mother and well children.

**Caregiving**

The caregiving system has been referred to as the reciprocal act of attachment (Solomon & George, 1996). In a time of threat, the system is engaged and the instinct to protect is engaged in the mother. Throughout the cancer treatment and into survivorship the caregiving system remains active.
Cassidy (2000) provides an overview of the caregiving system as it relates to Bowlby’s Attachment Theory. She begins by describing that the caregiving system is thought to have evolved because “during the time when humans and other primates were evolving, parents who provided protective care to their offspring were more likely to have offspring survive and pass on the genes of this caregiving behavior” (p.87). Cassidy further describes that there are multiple internal and external factors that stimulate the caregiving system. Internal factors consist of the parent’s state of mind, hormones, and cultural beliefs. External cues can be the state of the infant (healthy or sick) and the conditions of the environment. The author summarizes by stressing the importance of keeping the caregiving system in the context of Attachment Theory and to further develop the system and enhance the developing theory with further research of the system.

In 1996, Solomon and George defined the caregiving system. They write, “The set goal of the system is to keep the dependent close or safe; its adaptive function is to protect the young. The caregiving system is designed to provide changing levels and forms of protection depending upon the development and individual requirements of the young” (p. 183). Solomon and George further explain that if a “mother’s own attachment system is aroused she would look to her attachment figures but a situation that evokes feelings of helplessness in the mother may both initiate and cause disruption in the caregiving system” (p.183).

Pianta and colleagues (1996) conducted a study of 91 mothers who received a diagnosis of cerebral palsy or epilepsy for their children (ages 15-50 months). The authors used interviews and a classification system consisting of resolved or unresolved acceptance
with respect to their child’s diagnosis. The authors found that approximately half the mothers were grouped as unresolved. Diagnosis type, severity of condition, developmental age, and time since receiving diagnosis were all unrelated to the distribution of resolved/unresolved classifications.

Klassen and colleagues (2007) developed a literature review of the caregiving process as it relates to parents caring for their children with cancer. The authors compiled and reviewed 57 articles. They concluded that certain child characteristics such as child behavior and time since diagnosis and indicators of coping such as family cohesion, social support, and stress management are related to parental psychological health. They note that other aspects of the caregiving process such as parental self-perception, family-centered care, and physical health have received less research attention.

In conclusion, as parents are engaged in the cancer process, the caregiving system is activated. They may struggle with feelings of helplessness or uncertainty that may alter their approach to coping with the situation at hand. The need to protect and keep the ill child close may also have an impact on other members of the family including spouses and other children.

**Birth Order**

Birth order can be studied to understand a person’s individual lifestyle or preferences. Multiple studies have been conducted to examine actual birth order and psychological birth order. Alfred Adler pioneered much of the birth order research and Alan Stewart provided a thorough review of the theory behind birth order and recommendations for future birth order research.
Adler (1927, 1937) researched birth order and developed the most widely referenced theoretical background for personality development. He acknowledged the importance of actual birth order but took more interest in how an individual developed a meaning for the particular ordinal position and how certain life events and external variables shaped one’s personality and how one chooses to approach life.

Levy-Wasser and Katz (2004) studied birth order as it relates to siblings of children with mental retardation (MR). The authors concluded that the presence of a child with MR in the family does not negatively affect sibling adjustment or attachment style. Birth order of the child with MR and siblings did influence attachment style. The study supported that the presence of MR in the family does not necessarily influence the siblings, either older or younger, negatively but may have a positive influence on the overall adjustment of these children.

Stewart (2012) reviewed recent birth order research. He begins with the fundamentals of Adler and actual birth order and then discusses perceived birth order. The last section of this article contains recommendations and suggestions for conducting birth order research. He states, “for actual birth order research to be meaningful and informative, especially within the studies of individual psychology, investigators must also incorporate additional variables, such as sibling gender and age spacing, and other aspects of family constellation and family atmosphere” (p. 76). The inclusion of the additional variables allows for the individual’s experience to be noted and taken in the appropriate context.

Both actual and perceived birth order are vital in understanding development in children and adolescents. For the purposes of this research actual birth order was used. The
author explored the perspective as it relates to the mother’s attachment to her survivor child and the life event of surviving Hodgkin Disease.

**The Hospitalized Child**

Having a child hospitalized can have a range of effects on the family unit. The situation is further compounded when there is a life threatening diagnosis such as cancer. Much research has been conducted in this regard. The Platt report (Ministry of Health 1959) recommended that hospitals provide for parents to stay with sick children. Of mention, Kearney and Byrne (2011), Priddis and Shields (2011), and Cleary, Gray, Hall, Rowlandson, Sainsbury, and Davies (1986) expand on this subject.

For parents of children with a life threatening or terminal illness, the engagement can be that much more challenging. Kearney and Byrne (2011), discuss their preliminary results of the development of the parental engagement scale. Using attachment and caregiving as a framework, Kearney and Byrne systematically analyzed literature and pediatric palliative care consultations to create a measure for parental engagement. As a result, a 9 point Parental Engagement Scale was created focusing on three dimensions: (1) Information–Centered Dialogue, (2) Insightful Participation, and (3) Achievement of a Collaboratively Agreed-Upon Plan. Psychometric testing continues on the tool. However, the research revealed a need for a structured approach to assist parents in their caregiving function as well as move inquiry forward in understanding parental needs.

Priddis and Shields (2011) looked to the literature to see if parents who wished to be close to their child during hospitalization were welcomed to do so. Their research found that although parents are found on pediatric units, their presence is not routinely encouraged or
facilitated by staff. However, they point out that recent advances in family-centered care and education in communication between families and staff is encouraging.

Cleary and colleagues took parental proximity to the next level. They conducted a study consisting of 26 caregiver (parent) / child dyads to investigate if having a parent provide the majority of care (including medical) to their child while in the hospital had an effect on the hospitalized child. They referred to the outline of care as a scheme. Ten children did not have a resident parent at the bedside, nine did but were not included in the caregiving scheme and nine were in the scheme. The results showed that children in the scheme spent much less time awake alone, had significantly more social interaction with a smaller group of adults, cried less, and slept less. The children who had a resident parent but were not included in the scheme had a somewhat intermediate response to these criteria. They concluded having a parent reside at the bedside was beneficial to the emotional welfare of the child and in fact may contribute to an improved medical outcome. The study shows promise particularly for children who are chronically sick or disabled in that there is the prospect of fewer and shorter hospital admissions.

The hospitalized child is a unique entity. The child is particularly vulnerable to stressors as are his or her parents. In the case of the child with cancer, the situation becomes even more complex. The parents are away from their home and other children often for extended periods of time, and the strain on all family members is significant.

**Cancer Diagnosis**

Families go through a range of emotions upon receiving the devastating diagnosis of cancer. The parents are unable to protect their children from the inevitable pain of testing
and procedures, which can lead to feelings of helplessness or anger. In some cases, parents and children grow to have increased bonding and enhanced relationships through the cancer treatment. How the children and the family accept and deal with the diagnosis often may influence how they deal with treatment and subsequent survivorship.

Clarke-Steffen (1997) conducted a longitudinal, prospective, grounded theory study of 32 members of seven families who had a child recently diagnosed with cancer. They included all family members 5 years old and older. The study was conducted with three semi-structured home interviews. Constant comparative analysis was used. The families engaged in a core process consisting of managing the flow of information, reorganizing roles, evaluating and shifting priorities, changing the future orientation, assigning meaning to the illness, and managing the therapeutic regimen.

Ramini, Brown, and Buckner (2008) used the Roy Adaptation Model (RAM) to examine adaptive strategies of adolescents with cancer. A convenience sample of four adolescents that met the inclusion criteria was obtained. The participants were interviewed using open-ended questions based on the four adaptive modes (physiological, self-concept, role function, and interdependence). The participants reported creatively managing changes to their body, keeping positive attitudes, and demonstrating psychosocial maturation.

Woodgate and Degner (2011) conducted a longitudinal qualitative study guided by the philosophy of interpretive interactionalism to gain an understanding of childhood cancer from the children’s and families’ perspectives. A purposive sample of 39 families was recruited and participated. The families included the child with cancer, siblings, and parents. Formal and informal interviews took place as well as participant observation. The children
and their families could not easily differentiate the experience of the cancer symptoms and the cancer experience as a whole. The authors developed a substantive theory of “keeping the spirit alive - the spirit within” describing how the families coped with the cancer diagnosis and subsequent treatment. There were two main components of the process. The first was getting through (not over) the rough spots. The participants expressed that cancer would be with them always even after completion of treatment. They often described the enormity of cancer and how difficult it was to express how much pain and suffering it caused the entire family. The second component is what was referred to as “keeping the spirit alive.” The spirit, as described by the participants, is what got the child and family through the rough spots. It was their individual will to live and “fight” as a family.

Receiving the diagnosis of cancer forever changes a life. The same is true if it is one’s child or sibling diagnosed with the disease. How parents handle the initial diagnosis and demands of treatment while supporting their child is a daunting task. As the research indicates, often times parents who cope well initially will cope well when the child enters survivorship, and those that have difficulty initially may continue to have difficulty.

**Survivorship**

With 1 in 530 young adults between the ages 20 to 39 years being a survivor of childhood malignancy, the need to study the nuances of survivorship are increasingly more important. It is imperative that the ferocious toll of cancer treatment and the lifetime of potential psychological and physical sequelae that follow be acknowledged and appreciated. The current research points to the majority of survivors with no major long term effects.
However, in many cases the long term effects can be severe. Survivorship medicine is currently on the rise in many fellowship programs throughout the country.

Peck (2008) formulated a concept analysis on survivorship. She reviewed literature related to cancer survivors, heart attack survivors, earthquake survivors, and accident survivors among others. She concluded: “survivors have faced their mortality and altered their future memories as well as their self–identities in response to a life altering event” (p. 100). There are commonalities noted across the various diseases or conditions from which the survivor emerges. Among these commonalities are the altered self–identities, a feeling of vulnerability, and, in contradiction, a feeling of strength. Using care methods that include these commonalities enables nursing to have insight into the behaviors of this unique population.

Zeltzer and colleagues (2009) reviewed psychological quality of life (QOL), health related quality of life (HRQOL), and life satisfaction outcomes and their associated risk factors for the large cohort of survivors and siblings in the Childhood Cancer Survivor Study (CCSS). The review is based on previous data focused on psychological outcome measures, including the Brief Symptom Inventory (BSI-18), the Medical Outcomes Survey Short Form – 36 (SF-36), the Cantril Ladder of Life, and other self-report questionnaires. The results reveal that survivors report more symptoms of global distress and poorer physical, but not not emotional, domains of HRQOL. Most survivors report good present and future life satisfaction. Brain tumor, bone tumor, and sarcoma survivors reported higher rates of impaired physical health, while leukemia and lymphoma survivors reported higher rates of impaired psychological health.
Oeffinger, Hudson, and Landier (2009) detailed the various types of follow-up care for long term pediatric cancer survivors. They outline those survivors that fall into a low, intermediate, and high risk group and the importance of understanding the late effects of chemotherapy. They discuss the importance of including a primary care physician into the care model. They go on to outline many of the risk factors associated with each cancer and suggest the importance of long term follow-up programs in congruence with the Institute of Medicine.

Ruccione’s (2009) research highlights the need for nurses to take the lead in conducting research in survivorship medicine. She outlines the major contributions already made by the oncology community including nurses. She discusses the evolution of survivorship programs with roots in the 1970s. The Institute of Medicine (IOM) recommends nursing participation and leadership in evidenced-based guidelines for follow-up care, standards, and models of care (with the U.S. birthplace of survivorship care being at the Children’s Hospital of Philadelphia), increasing awareness of late effects and follow-up care, improving training and professional education, improving access to care for survivors, and increasing research to prevent or manage late effects. She looks to the future to enhance and improve survivorship care by sustaining and improving cure rates, addressing workforce issues to meet the needs of the survivors (pediatric nurse practitioners [PNPs], family nurse practitioners [FNPs]), and securing funding for increased research in the area of survivorship.

When entering into survivorship the road is not defined. There are commonalities among all survivors regardless of their previous conditions. However, the path each person takes is uniquely prescribed as a product of their precursor diagnosis. Long term follow-up
for children with cancer is a necessity that does not always seem evident in the early stages. When they become a survivor, they have formed an identity that forever remains a large part of their identity.

**Returning to the Community after the Child’s Treatment**

The period of time following treatment is a time of great change and transition. Rivero-Vergne, Berrios, and Romero (2011) explored this transition. They described a “re-entrance” into a world that continued to move while these families were faced with a life threatening diagnosis and treatment, and undoubtedly became removed. The return to the community can be a complex process with competing priorities on the parts of the survivor, the parents and the family.

Rivero-Vergne and colleagues (2011) used a phenomenological approach with flexible interviewing to allow participants to narrate their experiences as they wished. The sample consisted of a total of 18 participants (7 mothers, 7 childhood acute lymphocytic leukemia (ALL) survivors, 2 hematology-oncology nurses, and 2 hematology-oncology physicians). The results of the study revealed financial hardships, the burden of responsibility on the parent, and the transition to school as key difficulties upon returning to the community. The study was limited in its sample, but the need for support in the time following treatment for successfully treated patients and their families was evident.

In investigating the experiences of mothers of children who have been successfully treated for Hodgkin disease, the reintegration process is crucial. The late school age period into adolescence carries with it great change for those without cancer. The challenges are that much greater for the cancer survivors and their families. By studying this population and
understanding the needs of the mothers and their children, the healthcare community is afforded the ability to ease the transition.

**Parental Fears**

Having a child survive cancer can elicit strong emotions in a parent. The uncertainty that follows extensive treatment may bring with it the fear of the unknown. Long term complications from side effects may not present themselves until many years have passed. There may be a sense of relief coupled with a sense of simultaneous fear.

Zebrack and colleagues (2002) explored the realities of mothers of survivors of childhood cancer. In the study, 167 mothers completed questionnaires, and follow-up intensive interviews were conducted with 29 of the parents. The results were analyzed and the authors concluded that mothers’ worries were significantly related to their own perceptions of their child’s worries and the meanings they attached to their own experience with cancer and the experience they perceived their child to have.

Wallace, Reiter, and Pendergrass (1987) examined the needs and concerns of parents of long term survivors of childhood cancer. The participants were 93 parents of survivors of childhood cancer whose children were 2-15 years from diagnosis and not receiving any cancer treatment. The participants completed self-report questionnaires. The concerns of the group were the child’s ability to marry and have children, risk of other or recurrent disease, the child’s emotional development, relationship with the child’s siblings, and communication among family members. The group expressed the need for continued medical support and written information on survivorship to be the most helpful.
Van Dongen-Melman, Van Zuuren, and Verhulst (1998) conducted 85 interviews of parents who had children that survived cancer. The time off treatment ranged from 6 months to 7 years and 9 months. The authors concluded that the parents sustained definite and long lasting changes as a result of cancer in their child. Despite the child’s survival, feelings of loss of previous life and perseveration of problems related to the cancer prevailed. The parents reported feelings of loss of their healthy child and depression. Although their child was cured, the physical and lasting effects of the cancer caused the parents to mourn for life before cancer. Worthy of note, they also expressed guilt for having these feelings and difficulty with expressing this to others.

Hobbe and colleagues (2010) conducted a study to determine the educational needs of parents as their children completed cancer treatment and assessed the feasibility of measuring parental educational needs, anxiety, and family management styles as treatment ends. The researchers conducted focus groups with 10 parents (7 mothers and 3 fathers) who had children off treatment for 11-15 months. The parents expressed a desire to receive information to distinguish which symptoms are cause for concern and which are not. They also expressed a desire and importance to remain connected to their child’s primary oncologist in the period after treatment has ended. The parents also expressed concern regarding late effects but did not wish to receive that information yet.

Ozona and colleagues (2010) conducted a study measuring psychological distress in families of Japanese childhood cancer survivors. The sample consisted of 88 adolescent cancer survivors, 87 mothers and 72 fathers. All participants completed a questionnaire. The Family Relationships Index (cohesiveness, expressiveness, and conflict) was used to assess
family functioning. The participants were divided into three groups based on the results. The groups were supportive type, conflictive type, and intermediate type. An analysis of variance revealed that conflictive type members had the highest level of post traumatic stress symptoms, depression, and state-trait anxiety. The authors concluded that perceptions of family functioning are related to psychological distress in family members of childhood cancer survivors.

In conclusion, parents of childhood cancer survivors report many fears and concerns after treatment. Most immediately after treatment has ended is the fear of separation from the oncologist. As time progresses, parents report concerns related to their perceived worries of their children. The loss of what life was like before cancer is a real fear and may lead to depression. In looking at mothers and their survivor children from the perspective of attachment, based on previous findings, one can see that the caregiving system may become engaged and remain engaged throughout the illness into survivorship in an effort to protect the child.

**Post-Traumatic Stress**

Current literature has suggested the presence of Posttraumatic Stress Symptoms (PTSS) and Posttraumatic Stress Disorder (PTSD) in parents who have had children survive cancer. According to the DSM-V (American Psychiatric Association, 2013) the stressful event must elicit a strong sense of fear, helplessness, or horror. Certainly a diagnosis of cancer for one’s child is life threatening and leaves the parents with a sense of helplessness and intense fear.
Alderfer and colleagues (2005) applied a cluster analysis to the Post Traumatic Stress Disorder (PTS) Reaction Index scores of 98 couples parenting adolescent childhood cancer survivors to describe patterns of post-traumatic stress in families. The results revealed 5 clusters: Minimal PTS, Mothers Elevated, Disengaged, Fathers Elevated, and Elevated PTS. The authors concluded that the majority of families had at least one parent with PTS symptoms.

Fuemmeler and colleagues (2005) compared levels of PTS in parents of childhood cancer survivors with the levels in parents of children with Type I diabetes mellitus (DMI). Participants included 47 parents of childhood cancer survivors and 31 parents of children with DMI. All parents completed self-report measures of post-traumatic stress, general psychological distress, coping strategies, social network size, and perceived illness uncertainty. The authors concluded that parents of children surviving cancer reported higher levels of PTSS and general distress compared with parents who had children with DMI.

In his 2006 article, “A systematic and conceptual review of posttraumatic stress in childhood cancer survivors and their parents,” Matt Bruce argues that the research indicates that parents of cancer survivors are prone to post traumatic stress disorder. However, he also brings to light that in many situations the stress of the cancer is ongoing and that the parents are continuously strained despite the status of being disease free.

It can be concluded from the literature that PTSD is a reality for parents of children who survive cancer. Although the majority of parents do not have major long term sequela, those that do may find it crippling (Alderfer et al., 2005). The symptoms of PTSD such as severe anxiety and avoidance can impair the relationship between parents and their survivor.
children. Implementation of interventions during treatment may help to alleviate the symptoms seen in PTSD after treatment has ended.

Post-traumatic growth, as discussed by Barakat, Alderfer, and Kazak (2005), is also a potential result from the cancer experience. The illness is warranted as traumatic, however, the authors found that many adolescents (84.7%) reported at least one positive response to having survived cancer and 90% of mothers of adolescents who have survived cancer reported at least one positive response to having been through this traumatic experience.

**Vulnerable Child Syndrome**

Although it is normal and routine to protect one’s child from the dangers of the outside world, overprotection results in behaviors that go beyond what other parents would do in similar situations. Overprotective parenting can result from a host of different psychosocial roots. However, a traumatic event such as surviving cancer can contribute to a parent feeling as if the child is more vulnerable than others. Green and Solnit’s landmark 1964 study as well as Thomasgard (1998) and Vrijmoet-Wiersma and colleagues (2010) explored this phenomenon and described this vulnerability.

Green and Solnit (1964) investigated a group of parents of 25 children who had survived a diagnosis with an illness or trauma that would likely result in death. They found that there are instances of depression after the initial diagnosis that did not necessarily dissipate upon recovery. The parents reported nightmares of their child’s death and reported difficulty with separation from the child, as well as difficulty with discipline. The authors concluded that parents who have had a child faced with a life threatening condition often demonstrate a continued, irrational fear that the child is destined to die prematurely; and as
the child became more independent, the parents found it difficult to set limits on their behavior, which led to guilt and anxiety on the part of the parents.

Thomasgard (1998) conducted a study entitled “Parental perceptions of child vulnerability, overprotection, and parental psychological characteristics.” The parents of 871 children ages 22-72 months were recruited from 5 pediatric primary care sites in the greater Columbus metropolitan area between March and August of 1994. The respondents were mainly white (65%), married (59%) mothers (89%). All participants completed the Child Vulnerability Scale (CVS) (1996) to measure the parent’s perceived vulnerability of their child. From the 871 participants, 111 of the parents had a child who had a previous life threatening condition. The findings of the study illustrate that perceived child vulnerability is independent of parental overprotective behavior (Thomasgard, 1998).

Vrijmoet-Wiersma and colleagues (2010) also conducted a study exploring parental stress and child vulnerability following a life threatening illness. Seventy-three parents of children that underwent stem cell transplant either 5 years or 10 years prior completed the general health questionnaire, Pediatric Inventory-short form (2001), and the Child Vulnerability Scale (1996). Ninety-six percent of parents of children who were 5 years since transplant and 76% of 10-year survivors scored above the cutoff point set as a reference by the authors. They write: “Although most parents of SCT (stem cell transplant) survivors are resilient, the majority of parents perceive their child to be much more vulnerable as compared with parents of healthy children. This perception is associated with disease–related stress and may induce overprotective parenting” (p. 1102). The overprotective
parenting may lead to impaired relationships between the parents and their children or in the interpersonal relationships yet to be forged by the survivor or his parent.

As evidenced by Green and Solnit (1964), Thomasgard (1998), and Vrijmoet-Wiersma et al. (2010), there is often still vulnerability and concerns with parental attachment regardless of the time since the illness. Increased perceived or actual vulnerability by the parent predisposes the survivor to a sense of vulnerability. This altered dynamic may lead to a strained parent child relationship as the survivor matures.

**Parent Child Relationships**

All parent child relationships have a dynamic unique to that family complete with individual nuances directly attributed to each child and parent within the family. The cause for one child to feel a greater bond than a sibling to a parent is often unknown and can be attributed to many different factors. In looking at the relationships forged between parents of childhood cancer survivors and the survivor children, Orbuch and colleagues (2005) found that certain family strengths promoted more positive outcomes for the children in the adverse situation.

Oorbuch and colleagues (2005) conducted a study of 190 long term survivors of childhood cancer. Long term was defined as three years or greater since treatment. The survivors completed self report questionnaires. The findings indicated that survivors who reported better relationships with their mothers and fathers consistently report a greater quality of life especially in the psychological domain. The sample from this study reported better relationships with their mothers than their fathers.
Linking a favorable relationship with one’s parents to a favorable quality of life is useful in studying children who have survived any traumatic event. In the case of adolescents who have survived Hodgkin disease, this is of particular interest because adolescence is traditionally a time to seek independence and experience natural separation. In contrast, a strained relationship with a parent may cause significant angst within the adolescent.

**Chronic Illness**

The disease of cancer does not dissipate upon completion of treatment. As previously discussed, the long term side effects, both physically and emotionally, can last a lifetime. It is reasonable to consider cancer, in many ways, a chronic condition. There has been much research on how families with children with chronic illness adapt and normalize in their situation. Mercer (2000) and Knafl and Deatrick (2002) have done research in this area.

Mercer (2000) discussed the application of the life span development model (Baltes, Reese, & Lipsitt, 1980) to families with chronically ill members. She does not limit the application to those with children but rather she discusses the implications for various family models. The authors proposed that the older the family, the less disequilibrium caused by the illness. The author uses a family with a young child diagnosed with leukemia as a model. The parents’ stage of development will affect the life goal reorganization process. There may be added stressors from an interruption in the marriage relationship. Overall, there are biological and environmental factors across the life span that will affect each family in a different manner as they attempt to achieve normalization with chronic illness.
Knafl and Deatrick (2002), researched and described the challenges of normalization for families of children with chronic conditions. The authors identified 38 families from a previous study that had difficulty achieving normalization (Knafl, Breitmayer, Gallo, & Zoeller, 1996). The original study consisted of 54 families interviewed 12 months apart to highlight successful normalization techniques. Of the 54 families, 38 families had difficulty achieving normalization. Twenty-four did not achieve normalization. They described the illness as a burden and a source of conflict within the family. The authors described another group of 14 who had a change in normalization between the first and second interview. Eight of the families experienced a change toward normalization while 6 were not able to sustain normalization. This group discussed the ever changing demands of chronic illness and how those demands ultimately influence the ability of a family to achieve and sustain normalization.

Achieving a sense of normalcy for a family with a child with a chronic illness is both difficult and fragile to maintain. Chronic conditions are variable and adaptation is influenced by biological and environmental demands along with the disease process itself. In viewing cancer as a chronic condition, a family can hope to achieve normalization after treatment has ended.

**Gap in the Literature**

According to Attachment Theory, the relationship a mother and child have developed is often the result of many influences including the interactions of the mother and infant as well as environmental stimuli. In reviewing the literature surrounding children with cancer, their parents and the relationships between them, it is clear there is a gap in research on
mothers and their attachment to their survivor child particularly. Additionally, birth order is a variable that has not been studied as it relates to this concept.

Summary

In conclusion, the researcher identified an understudied phenomenon in attachment of mothers to their survivor children as it relates to birth order. The extent with which a mother attaches to and subsequently remains bonded with her child are often the result of a complex series of occurrences. The research was conducted to evaluate this concept and is detailed in Chapter 3.
Chapter 3 Methods

Introduction

Chapter three presents a discussion of the research method and design used in the study. The chapter begins with the aims of the research and a detailed discussion of the methodology of narrative inquiry. The descriptions of the sample and setting follow. The means for data collection, management, and analysis are then discussed. The chapter concludes with the risks and benefits and the protection of human subjects.

Specific Aims

The specific aims of this study were (1) to explore the life experience of a mother of a Hodgkin’s disease survivor prior to her child’s diagnosis, through treatment, and after treatment has ended as she has lived it and in her own words; (2) to relate her experiences to her attachment to this child who is now cancer free; and (3) to discuss the self-reported experiences in the context of the theoretical propositions of Attachment Theory and birth order as it applies to the mother child dyad with this life experience. As these aims focus on the mother’s self-report of personal and deep emotional or social experiences, a qualitative approach is needed.

Narrative Inquiry Methodology

Narrative Inquiry (NI) delves into experiences as told by individuals. These accounts may come in the form of written narrative, oral interviews, or images (Appendix A details exemplars in NI). The common theme product of Narrative Inquiry that is present throughout all narratives is that a story is told and it is told in essence by the person who lived it.
History and Foundations

Chase (2005) describes several key terms in the evolution and description of the method known as Narrative Inquiry (NI). The first key term she describes is a narrative itself: “A narrative may be oral or written and may be elicited or heard during fieldwork, an interview, or a naturally occurring conversation” (Chase, 2005, p. 652). Narratives may cover a brief aspect of the participant’s life or cover a complex engagement or process occurring in the participant’s life. The term “life history is the more specific term that researchers use to describe an extensive autobiographical narrative, in either oral or written form, that covers all or most of the life” (Chase, 2005, p. 652). Riessman (2002) uses the term personal narrative to describe a type of life story that hinges on a particular topic or life moment. In step with Riessman’s description of personal narrative, Chase describes oral history as a way that historians focus on what events mean to those who have lived through them.

The roots of modern day NI date back to the Chicago School sociologists. They collected personal stories and life documents during the 1920s and 1930s. Thomas and Znaniecki’s (1927) The Polish Peasant is often cited as the first significant work of life history in sociology. They write: “Personal life records, as complete as possible, constitute the perfect type of sociological material” (p. 1833). Narrative research gained recognition and grew in popularity greatly through the work of William Labov and Joshua Waletsky of 1967.

Labov and Waletzky’s 1967 article “Narrative Analysis: Oral Versions of Personal Experience” (reprinted in 1997) has been used as a foundation for many works of Narrative
Inquiry. In this groundbreaking work the research focuses on the everyday stories of everyday people. They stress that this is grounds for research itself rather than the formal life stories of historians (Chase, 2005). Labov and Waletsky (1967) outline six elements that constitute a complete narrative: an abstract; orientation; complicating action; evaluation; resolution; and a coda. The abstract is a synopsis or “point of the story.” The orientation sets the scene. It establishes the time, place, characters, and situation. The complicating action is the main body of the narrative. It is the plot or turning point. The evaluation is when the narrator steps out of the narrative and comments on the emotion or gives reflection. Riessman (2008) describes this as the “soul of the narrative” (p. 84). The resolution describes the outcome of the plot and finally the coda brings the interviewer back to the present. Not all narratives contain all six points and not all occur in the chronological order presented. However, Labov and Waletzky’s outline for narratives has laid the foundation for what has become contemporary Narrative Inquiry (Chase, 2005).

**Contemporary Narrative Inquiry**

Contemporary Narrative Inquiry is not so far removed from the historical foundations outlined above. Narrative analysis is used by multiple disciplines and carries with it caveats unique to those disciplines. Chase (2005) outlines five major approaches used in contemporary narrative research. In the field of psychology, some take the approach to focus on the connection between the narrator’s story and the quality of their lives. McAdams and Bowman (2001) found that those participants who score high on conventional measures of psychological well-being are likely to construct their narratives with an essence of optimism and focus on the beneficial effects of negative events.
Sociologists focus on the self-development that the story tellers engage in as they construct their narratives (Chase, 2005). They construct their narratives in the context of a particular institution, culture, or group. Sociologists are most concerned with and find value in the individual’s telling of the story and how one describes him or herself in the story and setting. Chase references Loseke’s 2001 study of support groups for women who have experienced domestic violence. She found that often group facilitators try to have the women tell their story in a rigid format. The women often do not view themselves as battered women and in this format the researcher is missing the lived experience of the individual woman (Chase, 2005).

Sociologists also take another approach. This approach focuses mainly on in-depth conversations or narratives about a particular aspect of a person’s life. It integrates the story with specific cultural and historical contexts (Chase, 2005). The researcher is not as concerned with the typical flow of a narrative but in the interweaving responses and dialogue between the researcher and the participant. An example of this type of approach is Riessman’s 1990 study of divorced men and women and marital discourse.

The fourth approach originates with anthropologists. It combines ethnography with life history methods. “Like traditional ethnography, this approach involves long term involvement in a culture or community; like life history it focuses heavily on one individual or on a small number of individuals” (Chase, 2005, p. 659). There is large emphasis on the human interaction between the researcher and the researched. An example of this type of ethnography narrative is the Myerhoff 1978 study entitled Number Our Days. In this story Myerhoff highlights the life of an elderly Jewish tailor and describes his life story as told by
him. She details her interactions with the subject and how her questions or probes contribute to the reactions and story told by the participant. “A major goal of narrative ethnography is moving to the center of empirical anthropological work the issues of voice, intersubjectivity, interpretive authority, and representation” (Chase, 2005, p. 659).

A final approach to contemporary narrative inquiry is autoethnography. Here researchers are often the focus of the narrative. They write, interpret, and perform their own narratives on societal, cultural, or historically significant experiences. The research may be independent or in collaboration with another researcher. In 1992 Bochner and Ellis narrated joint and separate accounts of Ellis’ unwanted pregnancy and the abortion that ultimately resulted. The stories paralleled each other in time but reported very different views.

The importance of narratives is that “the stories people tell constitutes the empirical material that interviewers need if they are to understand how people create meaning out of events in their lives” (Chase, 2005, p. 660). This shift in the research paradigm has consequences in the data collection process. The researcher holds a responsibility to embrace the stories the interviewee happens to tell, but also invites stories to be told. The researcher uses probes and questions to both follow the interviewee down the path they create and to create paths for the interviewee to follow. All of this is done while allowing interviewees to navigate through their experiences in a way that they feel best illustrates it.

There are three main “voices” for the narrator to hold in the context of contemporary narrative inquiry. These are authoritative, supportive, and interactive. All of the “voices” refer to the way a researcher interprets and analyzes the narration (Chase, 2005).
When using the authoritative voice the researcher “speaks differently from, but not disrespectfully of, the narrator’s voice” (Chase, 2005, p. 664). It is based on the narrator and researcher having different interests. While the narrator is focusing on making sense of an experience perhaps through cultural or societal context, the researcher is looking for the “what” and “how” he or she is actually speaking about. The narrator frequently takes this for granted.

The supportive voice is best represented when the researcher is in the background or rather, muted in a sense. The focus is on the narrator’s story. This is most evident in the telling of oral histories and life stories. The researcher still makes decisions on how to translate and transcribe the stories but it is secondary to the narrator. The researcher highlights the actual story told. Chase (2005) describes the theatrical performance of the personal narratives of two cafeteria workers who led the movement for better pay and working conditions at the University of North Carolina in 1968. The performance took place 25 years later. The “researcher’s voice as interviewer and editor of the women’s narratives was muted; the performance highlighted the women’s voices” (Chase, 2005, p. 665).

The third voice is the interactive. Chase describes this strategy as one that “displays the complex interaction—the intersubjectivity—between researchers’ and narrators’ voices” (Chase, 2005, p. 666). Here, the narrator often makes comments or reflections on his or her own personal experiences or interpretations. This voice is most often used in ethnographies and autoethnographies.
Sampling in Narrative Inquiry

Although there are many different approaches and techniques present in contemporary narrative research, there is a general consensus regarding sampling. Qualitative research is detailed and devotes much attention to each participant. However, the narrative approach tends to elaborate and expand on each participant’s narration with even more detail than other forms of qualitative research. Entire books have been written on an individual’s life story or ethnography of a small population. It is not uncommon for a small number of narratives to be the focus of chapters, articles, or books (Chase, 2005). The majority of samples are purposive and relatively small in size. Subjects are chosen because they represent a particular aspect of society or have encountered a life experience sought after by the researcher (Riessman, 2008).

The true question or concern is if or how narrative inquiry, using a small sample, represents a population. A detailed account of a life story has been used for an entire work such as in the *Polish Peasant* by Thomas and Znaniecki (1927). The authors felt that this was generalizable to society because their subject, Wiszniewski, represented the commoner that represents a typical member of society. Contemporary narrative researchers have interest in the specifics of society and contexts of the narratives they research and by nature of this interest, they tend to reject the idea or notion that all research must be generalizable to the population. Chase writes, “From this perspective, any narrative is significant because it embodies and gives us insight into what is possible and intelligible within a specific social context” (p. 667).
For the purpose of this study, the researcher actively selected participants to serve as a common representative to give “voice” to the experiences of others who share a common experience in an uncommon situation, i.e., parenting a child with Hodgkin Lymphoma. Their representativeness was strategically selected (affected child is youngest, middle, oldest or only) so that the experience of birth order, a potential confounding influence on the shared common parenting experience, could be elucidated in the stories evoked by the parents and perhaps help clarify the stories along different configurations of family.

Sample

A purposive sample was used for the study. An initial sample of 12 mothers of children treated for Hodgkin lymphoma diagnosed between the ages of 8-19 years and off treatment for 2-10 years was chosen from a tertiary care center’s childhood cancer survivor database. Selection of these eligible participants was in three cycles of four representative of mothers who have survivor children that fall into different birth order: first born, middle child, youngest, and only. A goal of three from each birth order group in the population was achieved with intentional selection and invitation and snowball sampling, with a final configuration of 3 mothers of survivor youngest children, 3 mothers of survivor middle children, 4 mothers of survivor oldest children and 3 mothers of survivor only children.

The final sample consisted of 12 white, non-Hispanic mothers and 1 African American mother. The average age of the mothers at the time of diagnosis was 36-40. The average annual household income was $91,000-$150,000 and 11 of the mothers were married at the time of treatment and 2 were divorced. The majority (10) of the mothers were not
working or on a leave of absence during their child’s treatment and 3 mothers worked at least part time.

The inclusion criteria were (1) The mother must have a child who was diagnosed with Hodgkin lymphoma between the ages of 8-19 years; (2) The child must be off treatment for between 2-10 years; (3) The mother must be able to speak and read English; (4) The child must have only had Hodgkin lymphoma with no secondary cancers; and (5) the child must not have relapsed. The exclusion criteria consisted of (1) failing to meet any of the inclusion criteria and (2) the participant having had a personal situation that the clinic director deems not suitable or able to participate. All participants were voluntary and able to refuse or withdraw at any time.

An initial screening of the cancer survivors’ database at the tertiary care center took place. The clinic director assisted the researcher in identifying appropriate contacts from the database. The parents who met the inclusion criteria were identified. Those potential participants were approached via email by the researcher and clinic director to request participation. The email contained a description of what participating in the study entailed (Appendix B). A sufficient sample was not achieved through the emails, and a follow-up telephone invitation was made. Those that agreed to participate from each birth order category were invited to participate in an effort to obtain sufficient sampling. There were three rounds of contacting participants within the initial sample of birth order as described above. For the final round, snowball sampling was used. The identified participants were then formally consented in accordance with the Molloy College IRB and tertiary care center’s IRB (Appendix C) and completed a brief demographic questionnaire (Appendix E).
The sampling in this study was an iterative process, or rather, the objective was achieved by repeating multiple rounds in the selection process to achieve saturation. As convenient, the interviews were scheduled by rounds. The adequacy and rich descriptions were assessed. When saturation was achieved subsequent rounds ceased.

Setting

The setting for the interviews was a mutually agreed upon location for the participant and researcher. The goal for the chosen setting was that it was a place each participant felt comfortable, relaxed, and able to share her story free from any distractions. The settings consisted of seven in the participant’s home, five in the conference room at the survivorship clinic, and one in a quiet restaurant.

Data Collection

Responsive interviewing lends itself greatly to the narrative method for it allows for freedom on the part of the participant to tell her own story and not be limited to the confines of structured interview questions. This study used a responsive interview approach.

Responsive interviews are less formal than traditional interview styles. The focus of the responsive interview is to build trust between the researcher and participant. The interview begins with an introduction between the researcher and the participant. In an effort to help each participant be comfortable to tell her story and answer the questions or prompts with great detail it is imperative that trust be established between the researcher and the participant. As stated by Rubin and Rubin (2012), this can be achieved in several ways. The most common way to establish a good rapport with the interviewee who will be sharing very personal information with the researcher is for the researcher to share something personal
about herself. This may be why the research interests her, an experience she has had with interviews in the past, or something relevant to both the interviewee and researcher. Careful attention must be paid not to share too personal information and not to lead the interview with the information shared.

As the interview begins, questioning is gentle and basically friendly with little or no confrontation. Strong probes are not present in this type of interview, rather, subsequent questions are adjusted based on the response of prior ones. It is imperative that the researcher does not focus on contradictions or on the truthfulness of a story but rather allows the research participant to tell the story the participant wishes to tell. If the researcher seeks clarification or wishes to understand the source of information, he or she will ask for it in a non-threatening manner or consult with other sources. Through formulating the initial questions broadly, the researcher allows the interviewees the ability to answer as personally or globally as they like. “Low key and open ended questions encourage the conversational partners to raise issues that are important to them” (Rubin & Rubin, 2012, p. 37).

Responsive interviews are defined by four key components as outlined by Rubin and Rubin (2012, p. 38). These concepts are:

1) Responsive interviewing emphasizes searching for context and richness while accepting the complexity and ambiguity of real life;

2) The personalities of both researcher and participant impact the questioning;

3) Interviewing is an exchange that occurs within a meaningful relationship between the interviewer and interviewee. The interviewee is treated not as a research subject but as a partner in the research whose ideas impact subsequent questioning; and

4) In responsive interviewing, the design remains flexible. In response to the participant’s answer, the interviewer can change the questions, the people to talk to and the concepts or themes emerging. The issues that are explored in depth evolve as there is more evidence for one or another of the themes or sets of themes.
All participants in this study completed a demographic questionnaire (Appendix E). The researcher conducted oral interviews with each participant privately. The mothers were interviewed using the responsive interview approach, focusing on their experiences with their child prior to diagnosis, during treatment and now several years off treatment. Although there was a semistructured interview guide (Appendix D), the researcher adapted the interview and followed the lead of the participant. Each interview was recorded digitally using two recorders to assure the success. The researcher kept field notes and memos from each interview. The information was obtained in one meeting. Subsequent meetings for interviews were offered but not requested by the participant or indicated by the researcher.

**Data Management**

All interviews were transcribed verbatim. A coding system was instituted on all data resources and de-identified. Codes were password protected and kept in a separate area. The recordings were kept by the researcher on a secure external drive. The written transcriptions were kept in a secured cabinet throughout the research process. An outside transcriptionist was commissioned at a rate of $1.30 per recorded minute and only had access to the coded resources.

**Data Analysis**

Thematic analysis (Riessman, 2008) was used in the study, focusing greatly on “what” was actually said by the participants. Williams’ perspective of “reconstruction” as it relates to the story of the evolving attachment of the mother to her child was also used.

To interpret the interviews, the researcher used the listening guide of Brown and Gilligan (1992). The guide includes listening to an interview four times to gain a full
understanding of its meaning. The first time, the researcher listened for the overall story or the plot. The goal was “to get a sense of what is happening, to follow the unfolding of events, to listen to the drama (the who, what, when, where and why of the narrative)” (Brown & Gilligan, 1992, p. 27). This first reading also required that the listener reflect on the meaning of interpreting someone else’s words and the magnitude of such a task. With the second reading the researcher listened for “self,” in other words, for the “I” in the voice of the speaker. This allowed for the participant to enter into the psyche of the researcher (Brown & Gilligan, 1992). The third and fourth times the researcher listened, she was listening for the ways people form and maintain relationships or, how they experience themselves with others. While listening to the interviews, the researcher identified emerging core themes that were noted across the birth orders.

In an effort to identify the emerging themes, the researcher used the approach developed by Van Manen (cited in Polit & Tatano Beck, 2012). Van Manen stresses that experiences can be uncovered from the participants’ words in several different manners. The first is the holistic approach where the information is viewed as a whole and the researcher tries to capture its overall meaning. The second approach is the selective method. In this approach the researcher may pull out sections or statements that seem essential to the experience. The third approach is the detailed approach. In this approach the researcher analyzes every sentence (Polit & Tatano Beck, 2012). The researcher then develops codes. “Coding is the process of identifying and indexing recurring words, themes or concepts within the data” (Polit & Tatano Beck, 2012, p. 722). NVivo computer software (version 10)
was used to organize and facilitate management of the transcribed data and executing the coding strategies.

The research in this study used a blend of Van Manen’s three approaches. The initial coding was in vivo coding, which is defined by Polit and Tatano Beck as “codes derived directly from the language of the substantive area and have vivid imagery” (2012, p. 570). The researcher continuously compared new level I codes with previously identified ones. From there, the basic codes were condensed into broader codes known as level II codes. From these codes general themes and patterns were identified. The researcher formulated generalities from the individuals and group as a whole. The researcher performed member checks by sending the verbatim transcripts and portions of interpretative statements to assure accuracy and was available to re-interview the participants. However, no participant requested a second interview and the researcher did not deem it necessary to conduct a second interview with any participant. The researcher used her field notes and memos to enhance the experience and recall nonverbal or informal communication from the participant regarding the experience.

Themes were identified as well as individual distinctions that make the narrative unique. In congruence with Williams’ method, the themes were identified and passages excerpted to create or symbolize the account of the parent’s experience. A metastory was then constructed and written by the researcher connecting the stories chronologically while keeping their individual stories intact. Riessman refers to creating a metastory as “telling what the interview narratives signify, editing and reshaping what was told and turning it into a hybrid story” (Riessman, 1993, p. 13).
Risks and Inconveniences

The main risk to the participant involved in this research was emotional distress. The researcher has extensive experience dealing with families of critically ill children including children with oncologic conditions and used this in making an earnest effort to protect the participants in this case by providing access to counseling services within the survivorship clinic if requested or if the researcher, based on her education and assessment, felt they may be indicated. At the conclusion of the interviews, the researcher did not assess that counseling was indicated based on her nursing experience with oncology patients and mother and no participant requested services.

Potential Benefits

The benefits of the participant’s enrollment in the study were clearly disclosed as well as the risks. The benefits to the participants included the ability to discuss their experiences with an outside party not involved in their child’s care, access to counseling services through the research if needed, and the fact that they would make a contribution to the welfare of other parents in similar situations.

Protection of Human Subjects

Human subjects in the research were protected in accordance with the Molloy College and North Shore LIJ Health System Institutional Review Boards (IRBs). All participants received and signed informed consents and participated freely. They had the opportunity to ask questions and to exit the study at any time. Counseling was available to all participants through the survivorship clinic of the tertiary care facility.
Methods to Ensure Rigor

In qualitative research the scientific adequacy or merit is defined as trustworthiness. Trustworthiness is comprised of several different categories. These are dependability, confirmability, credibility, and transferability.

“Dependability refers to evidence that is consistent and stable” (Polit & Tatano Beck, 2012, p. 175). By reaching saturation, the study demonstrated dependability. Dependability was also be achieved by using respected and known methods described by Riessman, Williams, and Van Manen. Using the constant comparative analysis, the researcher identified the consistent, recurring, common themes. For this study, at least four planned readings were done per the description by Brown and Gilligan (1992). Confirmability is “the degree to which study results are derived from characteristics of participants and not from the researcher’s biases” (Polit & Tatano Beck, 2012, p. 175). Confirmability was assured by offering all subjects the opportunity to review transcripts for accuracy and credibility was maintained by using subjects that have experienced the actual phenomenon under study and had given consent. A confirmability audit was developed by the researcher with the committee chair, a pediatric nurse researcher, and was provided to members of the dissertation committee to review sampled summary briefs and comments along the process.

“Credibility is achieved to the extent that the research methods engender confidence in the truth of the data and researchers’ interpretations” (Polit & Tatano Beck, 2012, p. 175). Credibility is enhanced through triangulation. Triangulation is the idea of drawing conclusions by using multiple sources and referents about what constitutes the truth (Polit & Tatano Beck, 2012). In the study described, the researcher used sampling representative of various birth orders to enhance triangulation. In addition, the researcher used field notes and
memos from the interviews to complete the experience described by the participant.

Transferability is the concept that the research may be applicable to other populations. As Polit and Tatano Beck (2012) discuss, it is a combined effort. The researcher must “provide detailed descriptive information that allows the reader to offer inferences about extrapolating the findings to another setting” (p. 525). In addition, the reader carries the responsibility of deciding whether or not these conceptualizations transfer to other situations. As mentioned earlier, the research gained from examining the experiences of childhood cancer survivor parents and their children as they relate to attachment carries much weight in other areas of research such as various chronic illnesses and acute episodes for children and adults.

Summary

In conclusion, this research study was conducted using the thematic analysis approach of Narrative Inquiry. A purposive sample representative of varying birth order was obtained and participants were formally consented and informed of all risks and benefits. The participants were interviewed using the responsive interviewing technique and all transcripts were analyzed and themes identified. A metastory was constructed. The study was conducted according to the appropriate IRB guidelines.
Chapter 4 Findings

Introduction

Chapter four describes the characteristics of the participants and the analysis of their narratives. The narratives are grouped according to the birth order of the participants’ survivor child and connected to Attachment Theory and traditional birth order research as grounds to interpret and understand the mother child dyad. All names of all mothers and children were changed using pseudonyms when compiling the narratives in an effort to maintain confidentiality. Table 3 outlines the names of the participants according to birth order. A synthesis of the narratives follows in the form of a metastory. The chapter concludes with identification of emergent themes.

Table 3 Participants by Birth Order

<table>
<thead>
<tr>
<th>Birth order</th>
<th>Mother/ Child</th>
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<tr>
<td>Youngest</td>
<td>Lyn/ Mark</td>
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<td>Lena/ Rick</td>
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<td></td>
<td>Ellen/ Bobby</td>
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<td>Middle</td>
<td>Diane/ Liz</td>
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<td>Katherine/ Christine</td>
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<td>Anna /Courtney</td>
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<td>Oldest</td>
<td>Patricia/ Paul</td>
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<td>Terry/ Allyson</td>
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<td>Sheila/ Matt</td>
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<td>Dina/ Melissa</td>
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Youngest Child

The youngest of the family or last born’s intrinsic personality is to charm the world. In contrast, some last borns take this to the extreme and grapple to get attention in any way possible, like making a mess or being a nag or rebelling. A typical last born will exhibit both of these sides, by being endearing one minute and difficult the next (Wilson & Edington, 1981). In researching the experiences of mothers and their youngest child, these traits become evident in the narratives they tell.

Research Participants

The sample was selected from a tertiary care center’s survivorship clinic according to the standards described in chapter 3. The first of the three participants in the youngest child category was Lyn. Lyn had two children. She had one son older than her survivor child. Her survivor child was also male and his name is Mark. He was diagnosed at 15. She was married and her husband had two children from a previous marriage. She was a nursing student at the time of her son’s diagnosis. The second participant was Lena. Lena was married and also had one son older than her survivor child. Her survivor child was also male and his name is Rick. He was diagnosed at 16. Lena worked part time at the time of her son’s diagnosis. The third participant was Ellen. She, too, is the mother of two boys with one older than the survivor child. Her survivor son’s name is Bobby and he was diagnosed at 16. At the time of her son’s diagnosis she was working freelance and was doing grant writing. She is married.
Lyn

Lyn gave an in depth and vivid description of the entire span of her son’s illness. She began by describing her son Mark as a “mushy” or loving and gentle, sweet child growing up, and that he was “very attached always.” She described that when her children were young she could bring them to her mother’s and her oldest would be fine, but not Mark, as he preferred to be with her. It was a problem to leave him. However, he was also a very happy baby and child. “Always smiling,” she notes and stated, “I think everyone liked that about him because he has kind of like an infectious laugh.” Leman (1998) writes, “Youngest children in the family are typically the outgoing charmers, the personable manipulators” (p. 168). As he grew she notes he was nervous or stressed, which was in contrast to her older son who had a “laid back” demeanor. Despite his tendency to worry, he was happy and projected his happiness on others.

Mark had just completed his first year of high school at a private Catholic school in the area and his older brother Matthew was preparing to leave for college. Mark had been experiencing respiratory symptoms. There were several weeks of back and forth to the doctor. Mark was originally treated for pneumonia, which appeared to help at first, but after a week the symptoms returned. Prior to leaving on a summer vacation, Lyn returned with Mark to the pediatrician and insisted something was wrong. A blood test was taken and his white cells were 18,000. She described a telephone call to the pediatrician after the results of the blood test. She asked the pediatrician, “What is wrong? You know what I’m thinking.” She stated she never said the word cancer nor did he, but she was reassured after x-rays as she was told they did not show signs of cancer but rather pneumonia. Despite being a
nursing student, she was at the beginning of her schooling and had limited medical knowledge. She tells of her fears “I just, I was just a mother and I thought something is telling me this is – it’s wrong.” The literature shows a common theme among parents of child cancer patients is either a perceived or actual delay in treatment. Sloper (1996) found that 57% of parents in her study perceived a delay in diagnosis. He had multiple x-rays over the following weeks and was ultimately sent to the tertiary care center for CT scan and further work up.

Lyn, her husband, and Mark came to the emergency room when he was just not improving and Lyn vividly recalls Mark saying, “You know- there’s something wrong. Don’t lie to me. Tell me the truth.” She states she thought, “You know?” She had a feeling of what was happening and what the working diagnosis was but the official diagnosis came days later. The doctor had told Lyn initially what the suspicions were and she told Mark and her husband. She recalls, “Maybe he trusted me because I was honest with him.” As a couple, Lyn and her husband decided to always be honest with Mark, no matter what lay ahead, with regard to treatment or procedures because they believed he would always want to know the truth. He was admitted to the Pediatric Intensive Care Unit (PICU) as a result of severe fluid accumulation in his lungs. Chest tubes were placed and Mark remained under close watch. In the PICU, parents are not permitted to sleep at the bedside of their child. Parents may go to a lounge or stay by the bedside next to their child as long as they (the parents) remain awake. Lyn described her nights there, where she was getting little to no sleep. Finally, one nurse said, “You need rest, go to the lounge and I will come and get you if he needs you.” Lyn reluctantly went to the lounge and found all the chairs taken with other
parents attempting to do the same thing. She returned to Mark’s bedside and proceeded to sit with him night after night without sleep, functioning on one hour or less most nights. She recalls, the cool dark nights inside the PICU with the drone of the monitors, “I felt like I was all by myself in a tunnel.”

Mark was transferred to the oncology floor after a few days and it was there that the official diagnosis and treatment plan were established. Mark was diagnosed on August 21, which was also Lyn’s 40th birthday. Mark and his parents returned to the floor from a test, and Mark was taken back to his room while his parents were taken to meet with the social worker and oncologist. She remembers Mark looking back at her and looking like “something is wrong, why are they taking you in there?” She recalls, “I was trying to take everything in but all I could do was worry about him in there alone worrying.” She said, “I felt like it was unreal, is this happening? I can’t believe this is happening.” When they returned to Mark they shared the diagnosis and the treatment plan that was shared with them as they had promised him they would. Lyn recalls the diagnosis,

*It was, it was so much of a relief, and that is so ironic because they just told me my son has Hodgkin’s and I’m relieved. Like okay, thank God because they seemed so positive. It seemed like okay, this is really bad, but you can get through this. The most horrific thing was now better.*

Sloper (1996) found that “in some cases the actual diagnosis itself marked the end of a period of frustration and the feeling that at least something was being done” (p. 193).

Mark began treatment and his chest tubes were removed and he was discharged. He returned to the hospital shortly after to have a mediport placed and there were complications.
Mark’s lung had collapsed. Ambulatory surgery was scheduled, but due to the complications, a chest tube needed to be placed. Thus, he was again hospitalized. Lyn recalls feelings of disbelief, anger, resentment, and overall frustration. However, as with the previous hospital stay, the parent-child bonds were strengthened. She said they were a unit, Lyn, her husband, and Mark. They spent a total of 10 weeks in the hospital and they were always together. She recalls,

“You have a house, and you think you need the house, and there is never enough space. Then the three of us, we were in this tiny little room for months and we were happy. We laughed so much all the time, I mean the first two weeks were horrible, waiting to be diagnosed but then we had a plan and all three of us knew what we needed to do.

The fact that Lyn’s family grew closer during the treatment is in keeping with current literature. It is not uncommon for parents to grow closer to each other or for the family as a unit to bond during the treatment time. Sloper (1996) found 70% of parents felt that family members had become closer since the illness; similar to Lyn’s narrative, the majority commented that they were already close and that coping with the illness made them closer.

Lyn and her husband stayed at the hospital the entire day with Mark and then they alternated who slept there with him. The parent leaving would stay as late as possible and then go home. She recalls how she hated to go home,

“I used to ask my husband why he cared so much, why he wanted to be there too. I would go home as late as possible and literally go straight to bed and return as soon
as I opened my eyes. We wanted to be here (hospital) all of the time, which was weird, too, ‘cause we didn’t want to be home ‘cause he was here (hospital).

She worried Mark felt like she was deserting him, “Why do I get to go and he has to stay?” Normally, a teenager left alone would not be cause for concern or worry in a parent. However, as the caregiving system is activated, the parent is drawn to stay close to the child. The mother may feel more intense worry or concern regarding leaving the child for periods of time that would not normally cause concern (Solomon & George, 1996).

At home there was an outpouring of support. There were always gift baskets, meals, and flowers at home when she returned from the hospital. However, despite her gratitude she describes not being able to enjoy or even look at them. Trying to write thank you notes brought her to tears. Lyn recalls the only other times she and her husband would leave Mark were to see her older son play football. He was in his first year of college playing ball and her mother would come stay with Mark in the hospital so they could be there for his brother. She notes it was not often but a few times.

A major stressor for parents of children with cancer is revealing the diagnosis to the other children (Sloper 1996). When speaking of her oldest son Matthew, she recalls a sense of relief that he was away and settled. She remembers not feeling as concerned for him because she knew he was safe and “protected” from what was occurring at home. She tells of him learning of the diagnosis, “He was away at football camp for school and when I told him he already knew. He had heard things from family friends at home. The diagnosis wasn’t official but the likelihood was strong.” Lyn notes it was with good intention that friends told him, thinking he already knew and wanting to help. She regretted she hadn’t told
him sooner because he mentioned to her, “I have to hear things from other people.” She said, “He was always such a laid back kind of kid, reserved. He’s not an emotional person but he has mentioned it a few times. I can’t imagine how he felt when the first person said something to him.” He came home from college for a week and stayed with Mark for a while. She recalls watching them sleep, Mark in the bed and her older son in the chair next to him, their relationship was unchanged. McCue and Bonn (2003) make note that although children need to hear the truth they don’t necessarily need to hear everything. The important factor is for the honest communication to build a base of trust for both the child being treated and the sibling.

The chemotherapy ended and the radiation treatment began. Lyn recalls the mold for the radiation and the fear she felt on the first day. She also recalls the calming words of the radiation physician, “It’s one down.” She said he could see the terror in her eyes and, despite the simplicity of his statement, it allowed her to focus and help Mark move through. Again, Lyn, her husband, and Mark all traveled to radiation together. Treatment ended and Mark returned to school. They all wanted to put the ordeal behind them.

Spring of 2009 marked the swine flu pandemic in the United States. Mark returned to high school and within a few days, Lyn received a call from the school nurse regarding an unprecedented amount of absences and her concern for Mark. Lyn chose not to take him home from school because he so desperately wanted to be normal. It was later discovered that the school had a swine flu outbreak. The school closed for a period of time and when it reopened, Mark returned. Shortly thereafter, Mark showed his mother a rash on his side and complained of severe pain there. She knew immediately it was shingles and he was once
again admitted to the hospital. After the treatment for shingles, life returned as much as possible to normal. Lyn stresses again how he was always so respectful and never got into trouble. In his senior year of high school he made a comment on Facebook to which a classmate took offense. The complaint was escalated and Mark was almost expelled. This was extremely uncharacteristic of him and Lyn wondered if he was seeking attention.

Mark expressed interest in going away to college, and so he went to school in Connecticut. In *First Child, Second Child* (1981), Wilson and Edington discuss the frequently displayed, less positive aspects of a youngest child: “If you are a typical last born, you have a fair share of both the charmer and the rebel in your makeup, and other people are often caught off guard by the fact that you can be endearing one minute and hard to deal with the next” (p.109). He purchased a BB gun while on a trip with friends and brought it with him to school. He was made to leave campus for bringing the gun on the grounds. Again, this was very uncharacteristic. He was expelled from the college when he participated in buying alcohol with friends and bringing it to campus. He returned home to live with his parents. Lyn adds she thinks he has regret about college:

*I just have a feeling that he felt more secure at home, I do. I don’t know if that has anything to do with the illness, because he was always like a little mush when he was younger and he was always very attached.*

When discussing concerns for her son now, she worries for his fertility. She describes that he is involved in his care and attends the survivorship clinic, at times alone and at times with his parents. She feels less worried regarding the cardiac or pulmonary complications from the treatment. Her main concern is that he will not be able to have children. She states
that when he was initially diagnosed, a friend who works with pediatric oncology patients told her about the option to bank Mark’s sperm. They chose not to pursue it at the time but she has concern now. She says, “I should’ve been clear enough to say this is it, this is his, his life. You know? Because now he’s getting older and those things that seemed so far off are not far off and his options may not be there.” The caregiving system supports this notion as Solomon and George (1996) explain, “Although the child ultimately must protect his or her own survival and reproductive fitness, the mother’s fitness depends on the fitness of all her offspring” (p. 186). Lyn concluded her narrative,

You have no idea how this follows you, you know? Like it follows you through life. It follows you every day, like, for, for a year I couldn’t even think for a year. It affects that you, you know, you kinda get through that initial six months, and then your life, and I, we jumped right back into normal life. But you…it’s just not possible. Like it’s not, it, it changes you forever and you can never change that.

**Lena**

Lena began her narrative describing life before Rick received his diagnosis. They were “a typical family.” They vacationed in Greece to see grandparents and they enjoyed day trips to Six Flags (a theme park). Rick had just entered high school and things were progressing normally. Upon routine examination, his pediatrician found a lump in his clavicle area. Rick was sent immediately to the hospital. Lena recalls thinking, “Oh no, this is the worst possible thing.” Although, at the time she didn’t know exactly what that was.

On Christmas Eve, a biopsy was performed, which confirmed the diagnosis of Hodgkin Lymphoma. Lena searched the Internet to gather information regarding his
diagnosis. She noted good survival rates and positive comments. Simultaneously she struggled because despite the information given to them from the doctors and items she had gathered; her husband very much believed this was the most horrific diagnosis possible. She notes a cultural variance as her husband is not originally from the United States. She struggled with her husband’s anxiety throughout Rick’s entire course as she describes in her narrative.

Rick received his diagnosis with his mother and father together. He was diagnosed as early stage 4. It was Christmas Eve and they still celebrated as they had done every other year. They had their family members to their home and Rick was upbeat and positive.

The treatment began and was intense initially. Rick developed a fever and required hospitalization. Lena describes the admission:

David Wright was here visiting patients and he (Rick) didn’t care about baseball so I followed him. Rick’s roommate had a wish to meet David Wright so for that reason he came into our room special. My husband was patting him on the back like he was his best friend.

Rick recovered, staying three days in the hospital. He had an increased appetite secondary to the medications and he was always hungry. Lena’s husband expressed concern that he was gaining weight. The nurses and doctors felt it was good for him to eat, that often times many children lost weight. She remembers having to sneak him food, “Dad’s not here, have a ham sandwich.”
Her husband expressed significant concern after Rick’s diagnosis as to what the cause was. He felt that it was related to dust. She recalls him telling her there wasn’t enough airflow in Rick’s bedroom and that there was a lot of dust. He insisted they change the bedding, mattress, rugs, and curtains. She states it was very difficult for her son because her husband was going to such extremes. She quietly cries and acknowledges how difficult her husband’s behavior was for her and her son. It is not uncommon for marital tension to be found in families with a child with cancer. While not all discourse ends with a separation or divorce, Sloper (1996) found that 30% of all couples in a situation where their child was being treated for cancer reported increase marital tension as a result of the illness.

She recalls the treatment days, playing video games and board games with Rick and passing the time. They met two other families from their neighborhood that had children with cancer and found support talking with them. Treatment took place in the winter and they needed to drive to the hospital in 12 inches of snow. She stated, “They (the hospital) were open, so we came.” Lena does not drive and relies on her husband to drive her and Rick to the appointments. The home medication regime was particularly daunting. She recalls being instructed the first day: “I’m surprised I actually got the medicines because that was the rough part. There are so many other things you need to go to do besides coming to the hospital. We do the other medicines. But I got through it.” Granek and colleagues (2012) point out that with the growing trend to keep children with illnesses such as cancer treated outside the hospital as much as possible, the parents are taking on more responsibility and “ownership” over their children’s health trajectory than ever. Parents are faced with the
daunting task of managing many medications, their side effects, potential complications, and providing much needed emotional and physical support to their child.

Lena talks of a particularly difficult time, when Rick lost his hair. She states he said it didn’t bother him and he would go out with a hat on. He would want to come home and take the hat off and her husband would say, “No leave it on.” She points out that this upset her because Rick had an illness and this was a consequence. It was out of Rick’s control and she wanted him to be comfortable. Her son has told her recently how difficult it was for him when he lost his hair but at the time, did not share his feelings. He always pretended everything was alright, that he wasn’t bothered or upset by what was happening.

The family had been assigned a social worker, and he was replaced by a woman of Greek culture, Lena recalls, because it was good for her husband. She appreciated and liked both social workers but found the first to be more of a “pusher” to her son. He pushed for school and didn’t let him slide if he didn’t meet his commitments. Lena felt that was good for him. Rick had a tutor to keep current in high school. He took frequent breaks and “went to the bathroom a lot” she remembers with a chuckle. Currently, at college Rick tutors and Lena talks of his frustration that the “kids don’t want to learn” and she reminds him “he was one of those kids!”

“Friends, both home based and friends with cancer, are also valued, with the former providing important links to the child’s non cancer self” (Mitchell, Clarke, & Sloper, 2005, p. 806). During his treatment Rick still remained social and kept many of his friends. Lena was always concerned for infection and complications from the treatment, but allowed him to be as free as possible.
As the medications decreased, Lena would track them. She remembers thinking, “OK he is only on one now that is good.” Rick completed his chemotherapy and his radiation protocol and returned to high school. Over the summer he was granted a “make a wish” and they sent the entire family to Greece. “It was once he was better and was able to enjoy it. We stayed another month because he has grandparents there.”

After high school, Rick was accepted into a college specializing in culinary arts. The week prior to his leaving for college, Lena received a phone call that he had received a full scholarship, including everything—tuition, room and board and fees. She remembers she couldn’t even speak. She was shocked. It was a donation from someone originally from her area and the stipulation was that the recipient be from that area. He went to college and was excited to go but Lena had lingering concerns regarding infection. She worried he wouldn’t take good care of himself. This fear is common in parents of childhood cancer survivors. The perception that the child is more vulnerable may lead to overprotective parenting, overindulgence or over intrusive parenting (Thomasgard, 1998). Lena struggles with the demands of letting Rick go and grow, and her concerns for his well-being and ability to care for himself. Solomon and George (1996) describe the internal conflict of a mother in this position: “The mother has two alternative strategies available—she can protect the child from a distance, requiring greater child autonomy; or she can keep the child close, permitting greater child dependence” (p. 187).

Rick confides in Lena now that he gets anxious sometimes and she is confused. She asks him, “Why do you get anxious now and not then?” She has been reassured by the nurses and physicians in the survivorship clinic that this is within the normal process for a
patient who has undergone such extensive treatment. However, she is adamant: “I don’t want him on any other medication.” She would prefer for him to handle the anxiety with non-pharmacologic strategies. She states he goes to a counselor at college once or twice a week. She worries if the anxiety is related to the Hodgkin’s or if it has just developed separately.

Rick says that he likes college but he is not sure he wants to cook all the time. He has been having gastrointestinal symptoms and has had a previous work up. However, due to his history and the fact that symptoms are not responding, he is scheduled for more procedures to determine a cause. The doctors believe at this point it is likely reflux. However, Lena still feels concern and worry. Rick also has high cholesterol, so he is monitored for that. Parents often fear that complications will arise and medical conditions will develop despite being cancer free (Zebrack et al., 2002).

Lena talks of her older son:

*I guess back then, he may have been, not jealous but we paid way more attention to Rick obviously, and then he was 18 at the time. He was focusing on college and submitting applications. “The only word I could say is jealous, he didn’t say it then, but it affected him. If I say, ‘Oh Rick is doing this,’ he says, ‘Oh yeah?’ So I’m like maybe deep down he still regrets that we paid more attention to him, you know at the time and maybe still a little bit now, but it’s okay ‘cause he’s 23 so he needs to be able to handle it.*
Feelings of jealousy on the part of the well sibling toward his brother or sister with cancer are a real potential consequence. In fact, jealousy is frequently seen and parents report a lack of appropriate services available to siblings (Mitchell et al., 2005).

Lena goes on to describe how her older son was in Japan during the tsunami and earthquake. She recalls talking to him via Skype and seeing lights flickering and furniture shaking. She asked him to leave and he refused. He finally left with his friends when they saw black smoke, signaling radiation. He returned to Japan again a few years later for work.

She talks of visiting her older son and how it was like staying in a dorm.

*Rick was probably like a year or so off treatment. So he was fine and everything and I could tell when I talked to him on the phone that he just wanted to get off. I know he probably was jealous that I was on a trip without him or jealous I was spending time with my older son. I’m not sure which one it was.*

Youngest children often have difficulty stepping out of the limelight and giving attention to others, as Leman (1998) describes.

Lena concludes:

*When I talk to him he seems to have more anxiety but when he comes down here he seems more relaxed. He likes being away but at the same time maybe has some anxiety being up there and not being home all the time...He is nervous about what he may get next...I wish he wasn’t so anxious but he says I’m helping him...so I guess that is good.*
Ellen’s narrative gives an overall depiction of the diagnosis, treatment, and life thereafter. However, she makes particular frequent mention of worry that she made the right decisions regarding her son’s care, especially in the area of radiation therapy. Ellen begins with her life before diagnosis:

*My life before was good. Um, I had two really healthy children. Other than the annual wellness visit they never saw the doctor. Um, Bobby had a couple of stitches and John had an ear infection. But seriously, we never went to the doctors.*

She talks of a charmed life with a doting husband, bright boys, and wonderful career.

At Bobby’s 17th annual exam his white cells were elevated. The physician told Ellen “not to panic” and they would repeat the test in 10 days. At that point, the number of white cells had doubled. Bobby was referred immediately to the emergency room. Further examination revealed a lump (points to neck clavicle area), which was biopsied. The doctor came out of the procedure and revealed to her that it looked like Hodgkin’s, but the oncology group would meet with them tomorrow. She chose not to discuss this with Bobby, as she felt that if he had questions she would not be able to answer them and that it would be better to let the team discuss it with him. On Friday, the diagnosis of stage IIA Hodgkin’s lymphoma was made. Ellen’s husband was away in California the week of the diagnosis. Ellen’s brother in law is a dermatologist and he became very involved in Bobby’s care from the beginning. He was there with Ellen while her husband was away.
We go into this meeting and sit down with this team, and I think my son just wanted to get out of there and see his buddies. I just—I think that he felt I was there, my brother-in-law was there and so if there was anything he needed to know we would tell him later because we got in the car to drive home and I said to him, ‘Okay so now you are going to back to school (because therapy was starting in two weeks and he had finals) and people are going to be all freaked out because you have cancer.’ He looked at me and said ‘I have cancer?’

She went on, “I was like ‘Oh my God this is amazing, he totally didn’t get it.’ He got it after that. So that is where it happened, in the car. He found out he had cancer in the car.” She recalls the shock of the diagnosis:

We came out of the meeting with the oncologist, his PA, sociologist, and some other people and on the way home I said to my son, ‘We have a job to do. We are just going to do this job. If we do this job you’ll be done with it and you’ll be able to go on with your life.’

She remembers not knowing that for sure, but that was what she was being told and that was what she was going on. Sloper (1996) found it imperative that physicians provide parents with realistic, honest information in a timely manner and that the parents and physicians communicate this information to the patient. Ellen went on, “I told him, ‘this is, this is our job and your job is to tell me what you’re feeling and be there for all your medications.’”

She recalls that car trip as one of the hardest times throughout the illness.
I was shocked, but then again I shouldn’t have been. That was so like my son: ‘This is boring, talking to my parents. If I need to know something they will tell me later.’ Again, when you never go and see a doctor all your life you are really not expecting something like that.

The car trip to and from the hospital proved to be meaningful for them on more than one occasion. “We caught up on the 30 minute car trip on the way to treatment, so I appreciated that.” Ellen describes how these times or trips became their time together with no interruptions and served as an outlet for both of them. This is true of many families going through cancer treatment. Families frequently describe increased bonding, participation in activities they would not normally be doing and enjoying the little things in life such as a car ride (Clarke-Steffen, 1997).

She recalls the treatment time. The hospital was undergoing a massive renovation and the clinic appeared to be in turmoil with patients receiving treatment in chairs. She remembers the nursing staff and how wonderful they were in the time of flux and how the care was so consistent regardless of the environment. She recalls the receptionist:

_I gave her a little gift and card at Christmas and she practically started crying, you know, because you come in there and you don’t know what you are doing. You are just looking for someone to give you a little direction and she was the first person you would see and she was just wonderful the whole time._

Having a positive relationship with the staff has been found to have noticeable impact on families (Mitchell et al., 2005).
Ellen recalls seeing mothers with toddlers and infants and bringing other small children with them to the clinic. She couldn’t imagine the pain for those mothers. She recalls one of the nurses pulling her aside and saying, “You don’t know how lucky you are. Sometimes these teenage boys refuse to come. They are just so angry and it makes the treatment take so much longer.” Ellen describes her son as being very cooperative and willing. They bonded over everyday things during the treatment days. Whether it was a board game, video game, or their mutual dislike of the clowns, it was something they shared and found humor in. Typically, Bobby slept during the treatment. Ellen attended every treatment session and did not leave him often. She notes, “I went away for one weekend and stayed with a friend; it made my husband really appreciate what I was doing with all the medicines and still doing dishes and all the household things.” Parents face many strains during the treatment time including maintaining domestic responsibilities. There can be serious financial implications and parents are often in need of guidance (Mitchell et al., 2005). Fortunately, Ellen was completing a grant proposal when Bobby was diagnosed, and when she completed the proposal she declined to take on another so she was able to be focused on the treatment plan. Bobby wasn’t driving and she accompanied him to all treatments. She notes that he still does not drive. Ellen points out that she is glad he doesn’t drive. She laughs that it is something less to worry about. She had her notebook and wrote everything down. “I wrote everything they told me here. Writing it helped me to remember it.”

The ride home from treatment was not as interactive as the ride there in that Bobby would often sleep during the ride home, feeling the repercussions of the therapy quickly. He
would go on to sleep 18 hours after that first day each cycle. Ellen recalls thinking, “Is this normal? Who can I ask? Is he ok?”

One of the next most difficult times during the treatment process was the decision to use radiation. Bobby was considered borderline and the family along with their physicians consulted for a second opinion. The decision was to complete the course of radiation therapy, which proved to be costly. Bobby lost his thyroid immediately after the therapy. However, the recommendation for radiation was based on the fact that if they had not completely cured the Hodgkin’s without the radiation and if it returned, the disease and subsequent treatment would likely be significantly worse. She poignantly states, “We’ll never know if it was the right decision.” As a result, also, of the decision to complete the radiation course, Bobby was unable to attend a paintball event with his friends. Ellen points out that this seems trivial, but it meant the world to him. It was one of the few times she saw him cry. His treatment was without any major side effects or hospital stays.

As Bobby went into recovery, he was granted a “Make a wish.” He asked to go to a paintball event and meet the stars of “paintball.” His wish was granted and he went to California for an event. Recovery came with costs as well; entering the survivorship clinic and learning of all the possible side effects and concerns from the treatment was terrifying. Ellen recalls, “I must have been told before but I didn’t hear it.” Sitting in the office it became real. “The survivorship clinic is wonderful,” Ellen notes. She hopes Bobby can stay in it for life. She still worries about his diet and health habits. She feels he doesn’t eat healthy or take care of himself in that way. Ellen points out,
It’s like you are living in a parallel universe while you are going through this. You know, you’d see other people with their children- their healthy children and I would feel I can’t relate to you at all. You really suddenly feel like you’re totally separated from mothers and their healthy children [chuckle]. So I was kind of in this bubble I think. So afraid I was going to do something wrong...When treatment ended, that was awful because you start to mourn. I didn’t realize that would happen. You’re so busy; you know when you are taking care of him, and so worried and so busy. And then, all of a sudden you don’t have that to do and you’re just like oh my gosh! So yeah, and that took a long time for me to get past. You really are mourning, even though it’s not a loss. It’s the loss of a perfectly healthy child. He will never be perfectly healthy to me. I’ll always be worried about him whereas the older- had the same prior- same and still healthy as can be.

Summary- Youngest Child

The youngest child in a family carries certain traits and characteristics that lend it to be protected. A diagnosis of cancer falling on this child places a unique hardship, especially when the siblings are past childhood, or not living full-time at home. The relationship with the siblings evolves and may change, and the mother is faced with an atypical situation where she must protect her ill child and allow her healthy children to be growing normally and establishing independence. As the ill child enters survivorship this once “protected” child must gain independence and begin to enter the normal realm of society.
Middle Child

“When a second–born child enters the family, his lifestyle is determined by his perception of his older sibling” (Leman, 1998, p. 152). The middle child is a term that refers to the child that is not born first, not born last but rather somewhere in-between. Middle children develop their personalities based on many different pressures including those placed on them by older and younger siblings as well as parents. They may step into a leader role especially when the older sibling does not fulfill this role in the family such as in times of illness or they may prefer to follow an older sibling.

Research Participants

The mothers of middle children included in the study were from diverse backgrounds. Diane was the mother of seven children and worked full-time. Her daughter Liz was diagnosed at age 19. Anna was a divorced mother of three when her daughter Courtney was diagnosed. Courtney was 15 at the time. Katherine was married and had four children when her daughter Christine was diagnosed. Christine was also 15.

Diane

Diane began her narrative discussing her daughter Liz’s diagnosis. She described that Liz came home from school during Easter Break and complained of a painful lump on her neck. Diane brought her to an urgent care center and they suggested she see an otolaryngologist. The next day they immediately went to the pediatrician. He started her on antibiotics to see if that would ease the pain and swelling. She returned home from college for the year and the swelling was slightly better but still remained. She was referred for an MRI. Diane notes her husband taking Liz since she was at work. The MRI was completed
and she was sent to another doctor. Diane points out “we didn’t know at that time it was an oncologist.” Her father had taken her again. Diane recalls getting the call at work and a friend driving her to the hospital to be with her husband and daughter.

She describes the diagnosis as a little easier to handle based on how organized and structured everything seemed to be at the hospital. “The team had everything, a whole schedule and all the next steps planned within an hour.” The treatment took place over the summer months, which helped Diane as she was a teacher. Sloper (1996) found that parents who received information in an organized way pertaining to the diagnosis and were able to understand it, reported lower malaise scores than parents who were unable to understand the information. She remembers making many decisions in a short period.

As you are offered options of different treatment types it’s very, it’s very hard to make a choice for someone else. You know it’s just amazing to think. It’s one thing if it’s yourself and you have to make a choice. It’s like ‘Okay I’m gonna take this choice or that choice and I know what the risks and benefits are,’ but um, you know she was entered into a study where they didn’t do radiation and, you know, you always think was that the right decision?

Diane notes that the decision to withhold radiation came based on doctors’ reports and the fact that the radiation carried a high increase of a secondary cancer. “We know many people who are in their 40s who have had full courses of radiation and are now having mastectomies and breast cancer. When you go through something like this you are just looking for the lesser evil.” She goes on to say that each year when Liz has follow-up she
does need to have extra testing and Diane wonders if they had chosen the radiation would the testing be less extensive in follow-up but notes there is no way to know.

The treatment time went smoothly. Immediately after her diagnosis a port was placed and she began chemotherapy. Liz volunteered at a camp each summer and the summer of her treatment she still wanted to go. Diane recalls having a hard time letting her go. She felt that based on her treatment progress she would likely be losing her hair there. Liz did go and was able just to be with everyone. It was a camp for deaf children. Liz knew the same children for many years as they would always return on the same week. As Diane had speculated, it was at the camp that she lost her hair. Diane notes,

> When she lost her hair there the kids just gathered around her and started singing to her that she still looked beautiful. I felt bad though, that she had to go through that without me that I couldn’t be there for her but it was a time she made a decision that she was going to do something and it was important to her.

Liz had several siblings. She was a middle child of seven. Her siblings all took a vested interest in her treatment and well-being. All would rotate going for treatments with her. The age range of her siblings went from 13 to 24. Diane notes, “They weren’t babies. They didn’t need me directly. They all understood because they were old enough to understand. They were all just really good and supportive.” Liz’s siblings all rallied around her and Diane points out that as the treatment took place over the summer months, they chose things to do together that Liz could participate in. She recalls that they all painted the house together and that they found places that had shade to vacation in so that Liz could join them. Sloper (1996) found that 81% of parents who had a child treated for cancer reported closer
relationships between parents, siblings, and the survivor child. Included in the description was spending more time together. However, when the treatment times were long, Diane would go with Liz. She recalls spending time talking with Liz and enjoying her company. It has had an effect on their relationship that remains today. While Diane sought to protect her daughter, they developed a bond that was strengthened throughout the experience. Diane’s greatest fear for Liz when she was sick was that she would be afraid. She was always so strong and patient, even when tests were delayed for hours because of new equipment or training.

I didn’t want her to be afraid of what was happening and then not to be afraid of the future. There were times she was in pain and feeling awful and she never complained. Actually, she was the one that kept us all going because she had such a great attitude, you know, like she was always concerned about everybody else.

There’s always one in the family that kind of keeps everybody- that everybody rallies around. Well, she was that one.

Going back to school, Liz remained strong. Diane recalls driving her back to school after her tests were clear. Diane notes that Liz never wore a wig. “She was honestly just bald all the time.” Upon arriving at the dorm Liz just ran out of the car. Diane recalls saying “wait wait do they all know and she chuckles as she says if they didn’t know -they know now.”

Diane goes on to discuss life now for her and for Liz. She notes that right after graduation from college Liz went and volunteered at an orphanage in Chile. “I wonder if she would have done quite the same thing if she hadn’t had this experience. You know- I think it
made her want to really make a difference for other people.” Diane elaborates on how she feels the cancer affected Liz,

I think she is a little unsettled because of this experience and she wants to keep volunteering and doesn’t seem to have settled down. I wonder if her outlook on life would’ve been different if she didn’t have this experience. Not that it is bad. It is just different.

Diane notes that the cancer has changed her perspective as well.

There’s just x amount of time you have to make decisions about how to spend your time and I think it’s made me – um make better choices in spending time. You know, people are important and you know, enjoy the now. Like think of the future also but really appreciate what’s going on now.

As the time since treatment increases, Diane struggles to maintain balance. She notes there is more of a need to let Liz make her own decisions now and not interfere. She notes, “I try not to phrase things in a way that seems as if I am judging her because she was so dependent at an age where you really don’t want to be dependent that I try to give her freedom.” She elaborates further, “I think the cancer has taken away some of her freedom to make decisions. A job with good health benefits is a very high priority.” Diane notes the importance of having a job with benefits for the annual testing and in case she has long term effects. Woodgate (2009) found that parents reported the cancer “never really leaving” the child and the family. Decisions and actions are continually influenced by the experience of having battled cancer.
Diane concludes by describing her relationship with Liz,

*There is another whole level of closeness, but then on the other hand, I feel like after you have had that much intensity you need to step back a little, because I didn’t have that experience with my other daughters. I feel like everything is more on an even keel now but it was like so intense I needed to take a step back so I wasn’t overbearing.*

**Katherine**

Katherine starts her narrative by describing life before the diagnosis. She was working part-time from home as a medical transcriber. Her husband was a lieutenant in the fire department. She refers to her situation as the average American family.

Christine was diagnosed the summer before her sophomore year in high school. She had just turned 15. She was out shopping with friends and a friend’s mother. She tried on a necklace and felt a lump in her neck. When she returned home she showed it to her mother. Katherine reassured her it was nothing and that they would go see the pediatrician tomorrow. Katherine recalls, “*When Christine left I turned to my husband and said, ‘she has lymphoma.’ He asked why I would think that and I replied I just feel it.*”

The pediatrician started her on a 10-day course of antibiotics. Katherine had to take her son to a baseball tournament in Hershey, Pennsylvania so Christine stayed with a friend for a few days. Katherine called daily to confirm she was taking the medication. After 10 days they returned to the pediatrician and he suggested a biopsy. The pediatrician called the next day and wanted to speak to Katherine without Christine present. Katherine recalls the
conversation with the pediatrician, “I knew right away, 'you think it’s lymphoma don’t you?’ I asked. I was aware because I had been transcribing for so many years.”

Katherine and Christine met with a surgeon and at first he was going to perform a sonogram in the next week or so and then a biopsy if needed. Katherine recalled demanding,

Can you 100% guarantee me that my daughter doesn’t have cancer? He asked why I would think that and I told him, my pediatrician is concerned and I feel it. He returned with the chief of surgery and a biopsy was set for 5 days from then.

Prior to the biopsy, Katherine recalls telling Christine what the suspicion was. Katherine describes the morning,

I had to wake her up and I’ll never forget. I just like tapped her foot and she sat up. I said to her ‘they think it’s cancer’ and she immediately said ‘okay’ and asked if she would lose her hair? I had no idea and I told her that but I told her we would find everything out.

The biopsy was performed as planned and when they completed it the surgeons spoke with them immediately. Katherine recalls vividly,

They took us into a room and told us they didn’t need to see her again, that she needed to get to an oncologist. So I knew the answer that day and at that moment, you don’t know how to handle it. You just do. You don’t even- I think it was an out of body experience for me. I didn’t cry, I held it together. I just – I knew I had to- I had one focus and that was to take care of Christine.
They met with the oncologist the next day and they were given a clear plan. Katherine recalls asking about the treatment effects on Christine’s fertility. The doctor had told her she was too young to have her eggs frozen and that they considered it a very low risk for her to have fertility issues. Katherine recalls taking Christine for test after test in the two weeks after meeting with the oncologist. The tests included PET scans and CT scans.

Katherine describes telling her other children of the diagnosis. 

*She has an older brother, younger brother, and younger sister. My oldest flipped; he wanted it to be him. He wanted to be the protector. They are only one year apart in school. Her younger sister knew because she was in the room with her when I told Christine. We didn’t tell the third one for a while because he is so sensitive.*

Christine began her treatment and things were going well. She was tired, would rest a little and then want to go out. Katherine would beg her to stay in but she would insist on going out. After the first round she got very sick and wound up in the hospital for five days and needed a blood transfusion. Socialization with their peers and children who are well is a strong consideration for children with cancer (Mitchell et al., 2005). Katherine points out that after that she didn’t really push as hard to go out.

Katherine describes Christine’s relationship with her friends. She notes they were all there in the beginning and they all went wig shopping with her. They all showed up for her first chemo treatment and when she was hospitalized but then school started and they just weren’t around as much. Katherine comments, “*I have a very, very, very good relationship*
with my daughter and her friends, and always have. My house is always a house they come to and to this day it still is. They all like to hang out with me and talk to me.”

Katherine recalls when Christine began to lose her hair. She had gone to a wedding for her cousin in Atlantic City and while she was there she received a call from Christine that her hair was starting to fall out. Katherine’s mother-in-law was staying with the children but was at church with the other children when Christine’s hair began to fall out. Katherine asked Christine if she wanted her to come home and she told her not to. She told Katherine that she would be over it by the time she could get home. “So again, against my better judgment I had left her and I don’t know if it was a good thing, a bad thing, because she learned to deal with it and she did. So I stayed at the wedding and cried for the rest of the night.” Orbuch and colleagues (2005) found children with cancer develop a sense of resilience, which is noted long into survival. Upon Katherine’s return she had her friend who is a hairdresser come over to shave the rest of Christine’s hair. The hair was just falling out in clumps. Katherine recalls Christine’s reaction:

My husband was watching, my friend was watching and my oldest son was watching and Christine got up and walked over to the mirror. She looked at herself and starts hysterical crying, and my husband starts crying, and my son starts crying and my friend starts crying. So I went over to Christine and I grabbed her and I looked her in the face and I said, ‘we knew this was happening, this is part of the cure; you’re going to be okay, I need you to go upstairs and take a shower, wash it all away. You’re going to be fine.’
Katherine recalls assuring her friend (who felt guilty) that she did what Christine needed her to do and her husband that he needed to be strong and that, “this was happening to her and not to us.” Katherine remembers her oldest son being devastated that he couldn’t help her and that night he was so upset he kicked and punched the wall. Siblings of the affected child may feel guilty, angry, scared, and jealous as a result of the changing family dynamic and fear of losing their sibling (Murray, 2000). Christine returned downstairs 20 minutes later with the wig on with a bow in it and said “see you later” and went out. Katherine notes that Christine always had the wig on. She would never let anyone see her without it, even when she was sick in bed the wig was on.

The treatments continued and she needed blood transfusions on occasion. She was getting progressively sicker with each treatment in terms of vomiting and lethargy. Katherine went to all treatments with Christine.

*I went with her every single day, like it was me. She only wanted me. She didn’t want anybody else. My mother came every day with me or would meet me there and she was okay with that. My husband would come and bring us lunch but she didn’t want him there the whole time, like it was only me and when we would come home it was only me. I would have to lay in bed with her. I think she slept with me for four months straight. My husband slept in her bed.*

Life at home continued. Katherine’s three other children were in school and as Katherine put everything into Christine, her husband had to take over things with the other children. Katherine notes, “The other children were basically ignored by me, not willfully ignored but even when I was with them my head wasn’t there.” She recalls trying to explain
to them everything as it was going on but was faced with great difficulty because it was hard
to explain such a serious thing to children. She recalls always being worried about Christine
and felt she was fortunate that her husband was able to handle everything else. However, she
notes her relationship with Christine wasn’t always easy for her husband. It is not
uncommon for fathers to struggle with their role in the treatment of a child with cancer. As
more often the mother assumes the role of caring for the ill child and the father assumes the
role of caring for the well siblings (Sloper, 1996), the fathers struggle during treatment and
afterward to provide support (Brody & Simmons, 2007).

He wanted to be more a part of Christine and her healing and her treatment and
everything and she wanted nothing to do with it, and I think I prevented it too because
I had to be in charge because I understood what they were saying. I never felt
confident that it would come back to me the same way and there was nobody stopping
me.

After the chemotherapy, Christine began radiation and Katherine notes that was hard
because she couldn’t be with Christine. Her treatment ended and was deemed to be
successful and no other treatment was indicated. Christine returned to school and struggled.
Katherine notes:

She hated school; I think I called her every Monday because she just couldn’t make it
to her first couple of classes. Things I wouldn’t let the other kids slide with I let her.
Now she’s in college and she loves it. She’s thinking about becoming a nurse.
The time after treatment continued to be difficult for the family. Katherine’s oldest son continued to struggle and fell into a depression. He began to act out and was getting into trouble. He suffered from dyslexia and it was very hard for him. Murray (2000) describes the intense anger and resentment siblings often feel at the unwilling separation from their attachment figure as well as an urgency to return the family to the state prior to the cancer diagnosis.

All through his years of schooling I was always there and now come like the important times and I’m gone. I’m not there and my husband did the best he could but didn’t know what I did. He never saw any of the signs and I think my son really felt abandoned by me and he felt he couldn’t save her. He felt it should have been him and not her. He couldn’t protect her but he lost me in the process. He had a pretty big break at one point and we got him help. He is doing much better now. He got a tattoo that said ‘my sister, my hero’. He did it for Christine and I really don’t know if she ever fully appreciated or understood it.

For Christine, one of her biggest struggles was her hair. It was taking a long time to grow back in and she wanted to get extensions. Katherine brought her to a woman who someone had referred to them. The woman’s name was Kirsten. She was from California and Katherine notes, “she was a beautiful girl, petite and doll like with the most beautiful long blond hair.” Katherine admits she was hesitant with how Kirsten would react to Christine but she looked at her hair and told how quickly her hair would grow and when she could return for the extensions. This went on a few times and then in June she had the extensions done. It wasn’t exactly what Christine was expecting but she was happy. What
they also weren’t expecting was the generosity and good nature shown to them by Kirsten, who was essentially a stranger to them. She would not take any money from them toward the extensions and she treated Christine with complete respect and kindness. The family still uses Kirsten as their hairdresser because as Katherine states, “Because I could never leave her because somebody who did that much to help Christine just will always be part of my life.”

Katherine talks of her difficulties after treatment,

Christine went off to school and my husband was working more regularly and I’m trying to work but I couldn’t because my brain is scattered and I’m thinking I’m used to being with her every second of every day. I kept wondering what she was doing and worrying what if she got a cold…what if this, what if that…I felt like I was floating. My whole being had changed. My friends had noticed it, my family had noticed it. I would talk to my mother a lot. I would cry to her a lot. I had a hard time sleeping. I tried to work outside the house but found that difficult at first. My husband suggested I take time off to get my thoughts together because I was so scattered and then I got a job working with children and adults with developmental disabilities, which is where I am now and I absolutely love it. I feel like I’m me again. But I’m not the me I was before. I’m definitely a different person and I’m definitely stronger and more focused on everything.

Anna

Anna began her narrative by explaining her family dynamic at the time of her daughter Courtney’s diagnosis. Anna and her husband Ken had divorced several years prior
and Ken was engaged to another woman who had children younger than Courtney. They had an amenable relationship but Anna struggled at times, working full time, raising the three children and taking care of the household with limited financial means. Her narrative reflects these stressors.

Courtney was diagnosed at 17. It was early June. She had a lump in her neck and had shown her mother a few times. They went for a routine Gardasil injection and they showed the physician. In a few weeks when they went for the follow up injection the physician sent Courtney for a sonogram. “Those girls there must have known so much but they were so, - they didn’t- you never knew anything was wrong.” The doctor called the next day and asked Anna to come to the office. The doctor suspected lymphoma based on the sonogram results and wanted to have a biopsy done. Anna came straight home and went to her friend from down the block and her ex-husband came over and they all sat outside and talked. Courtney was away on a Girl Scout trip. They had the biopsy done and on June 19th they met with the oncologist who told them the likely diagnosis. Anna notes she will never forget that day; it was her son’s graduation and her ex-husband’s birthday. The only question Courtney asked was if she was going to lose her hair.

Courtney had a port placed and June 30th was her first chemotherapy treatment. Shortly after the treatment was initiated Courtney turned blue. She had a severe reaction to the medication. She was immediately treated and Anna recalls that day being so long in the hospital. She had to have all medication flushed from her system, hydration and then receive the chemotherapy. Anna notes she was not there when the reaction occurred but was there for the later part of the day. Courtney’s dad was there during the reaction.
The port that was placed became infected and Courtney had a PICC line placed. She completed the remainder of her treatments through the PICC line. Anna notes that Courtney’s dad was very present during her treatment.

*He would never leave her side when the meds were coming. He would never, that’s why for me, when I was back at work, it didn’t matter. I could only come for when the flush was; when she received the hydration after the medication. Her father was always watching the medication and telling the nurses when it was time for something.*

Courtney was hospitalized twice during the course of her treatment. The first time was a long hospitalization because they could not determine the source of the infection and the second was shorter, when they removed the port. Anna points out that “*from day one Courtney said she would kick cancer and I hope she did. She was just the best patient ever. Courtney never complained, not once. It just wasn’t her.*” Anna recalls her fear during treatment:

*I was scared to death and I remember saying to myself, would you trade places with her and I was too afraid to say yeah. Isn’t that sad? Because Courtney was so brave and I couldn’t be that brave. That’s a terrible thing but I could never say I was scared because who’s supposed to be scared? She’s supposed to be scared.*

Anna and Courtney’s relationship continued to develop over the course of the hospitalization as well. She acknowledges good times that were shared.
I don’t want to say we had fun but we got to hang out. Whether it was playing cards or watching television, or – I don’t know- eating? We passed the time. We would watch the parking lot. One day I saw a car take off with no one in it and the valets were chasing it. They were such fun those valets. I felt like we were on a little adventure, hanging out at the hospital- ‘cause I used to work in a hospital I sort of enjoyed the hospital. It’s weird though right, to enjoy that?

Anna refers to her ex-husband when discussing Courtney’s care:

I was helping him ‘cause he was the boss, because that’s just the way it is, because that’s his little girl, and if I messed it up, I’d be in big trouble. [chuckle] No, because, also, you know what? Uh I’m not gonna fight with him about it because it would- it’s not – it didn’t make a difference. He was there. He loves her more than anybody, so it’s not like I’m leaving her nobody good’s hands, you know?

Courtney donated her hair routinely (prior to her diagnosis). When she lost her hair she inquired about a wig from that organization. Anna notes they replied that they did not provide wigs to cancer patients. They were referred to another organization and that organization only used adhesive strips of hair not an actual wig. Anna noted it was difficult to obtain, more difficult than one would think. Locating available resources is not an easy task. Parents, especially single parents who have limited financial means, find it difficult to identify opportunities at low or minimal cost for their children (Granek et al., 2012).

Anna goes on to describe interactions with other patients in the hospital:
There was a little girl there whose prognosis was that she would die and the little girl she was just happy and many other parents would talk of their child’s cancer spreading and then I knew that we were so much luckier. My daughter had a good life and I had 17 good years with her and these little children didn’t even know enough to fight.

Throughout treatment they kept a notebook. Anna notes it was her ex-husband’s idea. He wrote down when medications were given, what her vital signs were, and anything that was happening at the time. Anna recalls and takes out the book and reads excerpts aloud.

Courtney was granted a Make a Wish and it was to see the Rangers. This came after she had turned down the wish several times. “You must take the wish before your 21st birthday and she requested this 4 days before her 21st birthday.” Anna motions to pictures of the event and points out that Courtney now has season tickets for the Rangers.

Courtney’s chemotherapy ended and she began her radiation. The radiation was quick and both Anna and Courtney’s dad alternated taking her to the treatment. It ended late November. She returned to school in February and she was able to graduate with her class. She went on to attend an honors college and is currently in graduate school. Anna describes her relationship with her daughter now, “You want – well you just want your kid to get back on track. You want, you want you know the things to be back to what they call normal. And for me, you know, luckily it did go back to normal.”
Anna ends her narrative discussing her fears for Courtney. She has fears regarding the treatment and possible side effects. She recalls how she didn’t pay much attention to the possible side effects at the time of diagnosis because it was just part of the protocol and it was what they needed to do to treat her. She notes that you hear stories of people who do well and have no residual effects and people who are suffering from secondary cancers.

Anna describes their current relationship,

...we hang out a lot together but it’s not like it is on TV where everyone is always having fun. We fight like cats and dogs [laughter]. So you know we have a good relationship but it’s...I feel like I work hard and I’m trying to run a house and kids are so much work, my God. They- but I love them. Courtney was fearless, and that’s what, what I would really like to be- I was the most proud of as a parent, you could never let on, so- whether they know or not. God knows, so that’s all that matters in a way. You can never let on (your fear). You just can never let on.

Summary- Middle Child

The experience of mothering a middle child with cancer shares threads with both the mothers of oldest and youngest children as well. The mother has the added strain of caring for other children while caring for her sick child. As when the oldest or youngest is affected, the siblings may react with strong emotion and may be involved in the treatment process. This can prove to be a support for the parents or add increasing demands on an already stressful time.
**Oldest Child**

The first born sets the precedent for all future offspring in the family. First borns tend to be organized, list makers, and perfectionists. How the parents engage with these first borns is often influential on how these traits develop and mature. Their scholarly nature may contribute to making them eager to please their parents. Only children take on the leadership role either in the formal or informal manner (Leman, 1998).

**Research Participants**

There were four research participants that had a survivor child that was the first born. In recruiting for the sample, one participant was listed as having a survivor middle child. Upon interview it was found that it was their first born that was affected. The researcher chose to include this participant, increasing the sample size to 4 for mothers of oldest children.

The first participant was Patricia. Patricia was a married mother of five who did not work outside the home when her oldest child, Paul was diagnosed. At the time of diagnosis Paul was 16. Terry was a married working mother of three when her oldest daughter Allyson was diagnosed. Allyson was diagnosed at the age of 11. Maria was a married, working mother of three when her oldest son, Len was diagnosed. Len was 13 years old when he was diagnosed. Sheila was a working mother of two when her oldest son Matt was diagnosed. Matt was 16 when he was diagnosed.
Patricia begins her story talking about her children. She had three boys and two girls. She tells of how Paul was 16, Sam was 15, Mary was 13, Irena was 11, and Alex was 2. She laughs noting that the youngest was a big surprise for the whole family and "that's why I have an odd number not an even number of children. He was a great surprise, a beautiful surprise." She also takes time to mention that when they had Alex, they thought "why did God send us this child? But when Paul got sick then we realized how much the little one helped us, uh, get over the hard times. It was much easier having the little one."

She recalls Paul being the healthiest of her children and what a shock it was when he got sick. He was involved in all sorts of activities and sports. She notes her fourth child was dramatic and would say "I'm so sick" over minor things and Paul would "give strength to the rest." He would say "why you acting like that? It's nothing."

She recalls the time of diagnosis, "we were planning our trip to Greece, as we do every year, because we are from Greece. Every year when school lets out we have our tickets and we go to Greece." She remembers that year, she was going first with the three younger children and then her husband would follow with the two older boys because they were working at the family owned pizza shop.

She recalls:

It was a week before, a Tuesday morning and he woke up with a big lump on the right side of his neck. I know he likes to keep the air conditioner very low and sleep with a lot of pillows so I thought maybe it is just the way he slept. He had no other
symptoms. I waited 2 days and took him to the pediatrician on Thursday because it had not gone away.

Patricia and Paul were sent immediately to the radiology office for a sonogram. She recalls waiting for so long in the waiting room and wondering ‘why is this taking so long?’ She recalls knocking on the door and saying “I want to come in.” She entered the room and saw Paul lying on a bed, “like the ones the doctor’s use for operations and it was so cold and he looked so stressed.” She remembers so many people standing around him, looking at things on the screen and talking and she noted a ball on the screen with what appeared to be blood and nerves all around it.

It wasn’t easy. My pediatrician told me go there (to the radiologist) and they will tell you what is going on but we were there for 2 hours and no one told me anything. They gave me a big yellow envelope and sent me back to my pediatrician. They said go there – he will tell you everything.

The car ride was described as the worst ride of Patricia’s life. She recalls:

We were so quiet in the car and when we got close to the pediatrician’s office Paul asked me what was in the lump and I told him I really didn’t know. I knew it was not good but I really didn’t know what it was. We prayed in the car together.

Patricia notes that her religion is great strength for her.

She describes her relationship with the pediatrician: “He is a family doctor. He has known Paul since the day he was born. It is more than a doctor-patient relationship. It is –
we are close with that person.” The doctor went on to tell them that he had bad news but he also had good news. He said “Paul has cancer. But I have to tell you it’s curable. -98 percent. Don’t worry everything is going to be okay.” Patricia recalls her reaction, “But I felt…..my body had collapsed. It wasn’t easy. It wasn’t easy. And yet you feel so bad for your child [crying] you want to understand, why…has this happened to my child and not to me?” She notes that Paul was quiet at first. He wasn’t crying or yelling. They called her husband from the car; no one knew how to react.

They returned home and it is of interest that Patricia remembers exactly how her other children were and how they handled the situation. She touches upon each of them:

Irena, my 11 year old had a pool party at a friend’s house (it was the end of the school year). She was upset and wanted to know why I was late. I told her I couldn’t hear anything right now. I wanted to absorb this before I told them. It was good though, because I drove her there and she stayed there all day and we had time to think. Mary was in school. Mary is quiet….she has a different feeling. I mean you don’t have to tell things to Mary she feels the way you are.

She pauses as she recalls her second oldest, Sam. “They’re so close. They’re so close. They have one year apart, and they are very close, do everything together.” She smiles as she says “Paul was always the boss. From character and from being the oldest and Sam was always following with happiness. He wanted to follow him. Paul was a good leader I guess.”
She recalls that Sam was in school and that the youngest, Alex was with a babysitter that was like “a family member.” As she talks of each child she speaks of them as if they are there and gives a vivid description to help gain an understanding of who they are as individuals. Clarke- Steffen (1997) found that parents of adolescents are more likely to share information than those with school age or preschool age children. Patricia’s children were in the range of adolescence and as she described, they seemed to understand the situation. She notes her children’s ages eased the burden slightly on her and her husband.

Once Patricia was home she was able to start to process the situation. She received a call from the pediatrician and he told her he had notified the hospital and that she needed to go to an appointment on Friday (the next day). Paul went for a biopsy on Monday and they were able to tell while he was still in the operating room that it was Hodgkin’s and that it was aggressive- Stage IV. They informed her he needed a mediport placed and to start chemotherapy the next day.

The two girls went to Greece at the recommendation of her daughter Irena and stayed there for the summer with their grandparents. Her son Sam was scheduled to attend a camp for three weeks in Greece with Paul. When Paul couldn’t go, Sam did not want to go alone. However, Patricia recalls, “we told him it was better if he went and he should go.” She goes on, “We only had Paul and Alex, the baby. It was much easier like that. We had to focus only on Paul. I have a good babysitter, like my mother. I was completely calm to leave the baby with her all day and all night if needed.”

The chemotherapy began and Paul developed a fever. Patricia recalls being in the hospital for one month, until the 20th or 22nd of July she notes. They tried everything to
break the fever and nothing worked. She recalls that she did not often give her children medication and it seemed as if Paul’s body was reacting badly. She remembers, “They brought in a mattress. It was ice. It didn’t work [crying]. He went through so much. It’s very hard....” Nothing brought the fever down. Finally, the mediport was removed and replaced on the other side. “He had so much hair and it started to fall out in large pieces,” she notes “not a few today and some more tomorrow. I mean a lot.” He did not want to see his teachers or friends. He was embarrassed. Patricia struggled,

...how do I tell people who only love you not to come. Everyone asks so many questions and they know something from someone and all they want to do is help. But I couldn’t talk anymore. I didn’t want to explain. My husband and I were just sitting there watching our son and there was nothing we could do. We were so helpless. So helpless. And our other children....to have to explain...Thank God we have a supportive family and everyone was wonderful but it’s so tiring.

Mitchell and colleagues (2005) found that parents have intense feelings as their child is going through treatment regardless of the stage and that emotional support for the parents is limited. Feelings of confusion, fear, and helplessness are not uncommon.

After the mediport was replaced Paul began to tolerate the treatment without fever. However, he developed, as Patricia notes, “horrible mouth blisters. His mouth was full of blisters.” The chemotherapy was giving him a lot of reactions. Every time they started to improve, he needed another dose of chemotherapy.
He was there for so long and he was so angry. I had to have a lot of patience. I always am patient but this was much more. He was constantly fighting all day against the treatments and didn’t want to talk to the nurses and tell his story over and over again.

Patricia stresses how he was such a sweet and caring boy and that this was so out of character for him. Granek and colleagues (2012) found emotional tasks in terms of dealing with the reactions either to pain or other stressors of their ill child to be a particular concern for parents and difficult to handle. “I stayed all day with him and sometimes the night or I would come home and my husband would go be with him at night. Paul needed that.” She mentions the joy having Alex brought her when she came home at night and how he helped her as a blessing during this time.

While in the hospital Paul had a roommate, a young girl about 4 years old with an amputated right leg. She used a wheelchair and Paul would play with her every day. The child had no family or parents and Patricia and her husband talked of adopting her. She felt such sadness for the girl and was grateful that she had her family and so many people were there to support Paul.

Patricia recalls a particularly difficult day, August 3. They had a priest staying with them from Greece. All day Paul and the priest talked and played basketball. He planted a few rose bushes and seemed so happy to have the company. His other siblings were away and he was enjoying the company. They all went to church and the car ride made him nauseous. He went downstairs to bathroom and was vomiting with such force and such noise that Patricia thought he was going to die. She recalls, “We were so in a panic we didn’t
know what to do.” Patricia stayed with Paul while her husband informed the priest that they needed to leave and bring Paul to the emergency room. Patricia recalls how the priest would not stay without them and came along to help. He was praying for Paul in the car and laid his cross on Paul. Paul “had no color.” “I thought he was going to die right there.” Patricia describes with a joyful expression, “within minutes of the prayer and holding the cross, Paul had color and was sitting up talking asking to eat.” They could not believe what they were seeing. They returned home and ordered food and Paul felt good for the rest of the night. Patricia adds, “It was a miracle.”

The radiation treatment started shortly thereafter. Paul was fitted with the mold and received the radiation through “holes” in the mold to his lymph nodes. They went everyday Monday to Friday. Either Patricia or her husband took Paul to treatments. Paul shared that he was scared and was often uncomfortable under the mold and moved a tiny bit. She notes he sometimes tells her now he is afraid the radiation didn’t get to where it was supposed to because he was moving. Their time together was valued. Patricia notes:

_I have to say I was happy to be with him so much, because when you have teenagers, you don’t have – you don’t get to spend a lot of time with them anymore. They want to feel independent, and they want to do stuff without mom and dad anymore. It was nice to- I have to say I enjoyed my son. I enjoyed him. I enjoyed him a lot. It wasn’t easy but we were talking so much, not every day; it wasn’t everyday he wanted to talk. But when he was it was so beautiful. It was beautiful and I was thinking if Paul wasn’t sick and Paul was in school it wouldn’t be like this._
Parents especially mothers are reported to be one of the strongest and most common support for adolescents with cancer (Decker, 2007).

As treatment came to an end, they had visits with the doctors. First the visits were every other week and gradually were spaced out. Patricia remembers all of the physicians and nurses as friends. She recalls that it took a while for Paul to feel himself again. She notes, “He was more close to himself. He wasn’t opening up. He became very quiet. Very quiet.” She went on,

...the sickness made him changed in that area, the first two years I noticed he was depressed. We (my husband and I) were actually thinking of asking for help.
(Crying) Maybe they could use some medication or something. Thank God though we have a big family with lots of cousins and Paul is very close to all of them.

Patricia notes that he would ask her, “What do they think of me now? How do they talk to me regular? Can they think of me as regular and that I can do everything again or can I even still do everything?” She pauses, “Many times I didn’t know what he was thinking. He was very quiet and would want to stay in his room. We were trying to think the way he was and to understand him. We would push his brother Sam to talk with him and stay with him.” It was Sam that shared with his parents that Paul just wanted them to be there for him and be available. He told them “don’t push Paul if he wants to be in his room let him be in his room.” Patricia recalls listening to Sam’s guidance and although it was hard, gave Paul some space. She remembers Paul telling her, “I don’t need anything, just be there for me and if I need you I will come.”
Patricia talks of how hard it was for her to see Paul not be active because he was always so strong. He did not know his own strength. She remembers before he was sick, always when something needed to be done he could do it easily. Her husband or other son could be working and working and Paul would come along and just easily move or build something. "He is better now. He goes to the gym and he is always reading things to find out how to fight sickness and keep your body well."

He is Ok now. He is completely well. But his character changed in a way. He was never a kid anymore; never a kid anymore. And I see that sometimes when the other kids in the family are trying to be kids. He always has that- that look of what you see in a more- in an older person. I am sad for him. He stopped being a kid at 16. He didn’t enjoy being 17 or 18. He thought twice about everything he did.

She notes he would look at the other kids and probably think “wow, they can do all those things and when I was their age I wasn’t free at all.” Patricia pauses, “But he is thankful he is well now.”

Paul entered the survivorship clinic and Patricia recalls being so grateful. The time between completing the treatment and starting the survivorship clinic was a time of uncertainty. “I felt like we should have something telling what Paul went through, so many medications, and so many tests. He should have a paper saying he is Okay but we had nothing.” This feeling of uncertainty is not uncommon among parents of this population. Mitchell and colleagues (2005) noted that 43% of parents as a whole in their study felt an end of treatment meeting with a group of parents and staff members would be beneficial. Staff members especially integral in this meeting were nurses and social workers involved in the
child’s care. She remembers that at first Paul didn’t want to go to the clinic but he went and they were both glad they did. She makes note that she always goes and that Paul wants her to. She remembers him saying, “I want you to come but how does that look to the other patients and to the doctors with my mom there?” Regardless, they went together and that is their day together even today.

She tells a poignant story of their first interaction with the physician at the clinic. Patricia stayed in the room at Paul’s request while he spoke to the doctor. The doctor asked him, “Do you smoke?” Paul did smoke and knew that his parents were aware. The doctor then pulled his chair closer and spoke to him so nicely, “not like a doctor but like a father, a friend.” Patricia remembers:

I was crying because whatever I said it didn’t work and whatever Dad said it didn’t work but what this doctor said worked because Paul stopped that day. It was April 26. He did that (the doctor) (crying) because he talked to him with love. He loved….our kid…and he said…the words he said… (Crying) and everything came from God. I believe that. And now Paul has helped other kids stop as well.

Patricia closes the narrative discussing what her worries are and what she perceives Paul’s worries to be. She feels confident about his health but she worries whether he will meet the right girl. She says “sometimes I think he is too serious. He should have a little fun. We don’t say this to him just my husband and I talk. He only wants to bring home one girl. He talks very seriously when he meets girls.” She describes that he shares with her worries about his fertility.
He asks me ‘do you think I will be able to have children?’ I tell him we can use the sperm bank if you can’t (we banked his sperm). So don’t worry because even if that doesn’t work you are going to be a father. You can adopt a baby. I think deep down that worries him. I believe he is going to have children and I believe he is completely well now.

We had the hope from the first day that Paul’s going to be okay and especially when you have that and you have your faith to give you strength, you have good family to support you, it’s – you have everything. And its- it’s a good lesson- to go through that.

Terry

Terry begins her narrative discussing of life before her daughter’s diagnosis. She was a mother of three. Allyson, was the oldest, she had a son in kindergarten and another 2-year-old daughter. She was working Monday through Wednesday in the city and was with her children the other days. She starts by saying that she believes Allyson was diagnosed in an unconventional way in that everything happened so fast.

It was the Saturday before Mother’s Day and Allyson went clothes shopping with her grandmother (Terry’s mother-in-law). Allyson came out of the dressing room and she had a large lump on her neck. Her grandmother brought it to Terry’s attention and Terry admits she did not notice it prior. “At that age it is not like you are giving your child a bath or dress them. She was 11 and very modest about her body.” She decided to take Allyson to the emergency room, anticipating the need for an antibiotic. She did not want to wait for the
pediatrician until Monday given her work schedule. Upon arrival to the ER there were tests done, first an x-ray followed by a CT scan. Terry recalls:

...they kept coming and asking me questions and like- then I started to get concerned and think, you know I came here thinking we were going to put a Band-Aid on this, and we were going to be good and now I’m thinking this is not the way this is going.

The doctor returned to them and took Terry and her husband to an area away from Allyson’s bed and told them he thought this was a type of lymphoma, noting that Allyson had several other areas of concern in her chest. Terry adds in, “Before I could even ask him anymore questions, to give you a good indication of Allyson, she was off the bed and over by us and said, ‘if you are talking about me you can talk in front of me.’” Terry admits she did not know how to respond but quickly thought to tell Allyson “the doctor thinks this is something that needs to be treated and we don’t know what it is.” As she started to process and Allyson had returned to the bed, Terry asked the doctor, “That’s cancer?” He said “yes.” Terry describes the blow of the potential diagnosis, “Once you hear cancer you do not know how to process anything after that.” She goes on to describe the process, “We didn’t have the normal cycle of diagnosis (waiting). She was out, happy, fine, shopping buying clothes, and, and the next hour, we were being told she had cancer. It was like that fast, that whole thing spun out of control.”

They were transported to another hospital and it was now Mother’s Day. Terry was trying to think if she missed symptoms. Allyson had lost weight but she had been a little overweight so they had viewed it in a positive light and that it was the result of diet change and effort not disease. “Do I feel guilty I didn’t know sooner? Of course I do. But my
pediatrician did not notice either and there really were very little signs.” Terry recalls, people kept approaching and asking her to tell her story and she notes, “I was like I don’t have a story. I am here because she had a lump on her neck yesterday.” At this point the cancer was stage III. It was in her chest, lungs, and her spleen.

She recalls, sitting alone with her daughter in the hospital room (her husband went home to be with the other children) and thinking, “How do I wrap my brain around this? I’m sitting next to my daughter with cancer. How did this happen? How did we get to this point?” She does note she was slightly reassured as all of the physicians told her “If you have to have cancer this is the one to have.” She describes her daughter’s age:

She’s 11, not so young that she doesn’t understand what cancer is, not so old that, you know, she – that, that almost is like such a fragile age, because when they are really little- they are sick. They don’t know what cancer is. So she understood enough but was still a child and needed to be sheltered from some things. But I know my daughter and I know how strong she is and I know her spirit so I promised her, I will never lie to you. I promise you I will never lie to you. I wanted her to trust me when I said you are going to get better because I needed her to believe it.

She had her port placed and they received the details of the treatment. Terry went into “mom mode” and advocated for the immediate removal of her braces and had her prepared to start treatment. The doctors advised to take every precaution that she not get sick, in that would delay treatment. Terry recalls:
She was supposed to perform in her dance recital and I didn’t let her go. I kept her home. I didn’t want to take a chance of her getting sick and I selfishly couldn’t bear to listen to these other mothers. It took a little longer than this but I did get angry and bitter. I couldn’t sit there with these moms who would say ‘oh, don’t the girls look pretty,’ when I wanted to say who cares in a week my daughter will be in the hospital receiving her cancer treatment.

She began her treatment and very quickly she began to lose her hair. Terry recalls, “That was particularly hard for Dad. He didn’t know what to do with himself. He went out to buy her an iPod. I think that helped him.” Hill, Kondryn, Mackie, McNally, and Eden (2003) found that for parents whose children face severe illness, adjustment takes place in three stages. In the immediate stage the mother typically takes the lead where the need is to protect and nurture the sick child. It may be difficult for fathers to find and establish their role in this setting. The fathers’ role becomes more defined as the adjustment process progresses into the medium term in reestablishing relationships with family and peers and in the long term in assuring they assist their survivor child in forming social bonds and roles outside their family.

“She developed an infection halfway through her first round of chemotherapy and needed to have the port removed and a PICC line placed.” The placement was an ordeal. Terry was not allowed to stay in the room with Allyson. She recalls the experience:

So I’m in the hallway and my daughter is behind a door screaming and screaming. There’s my daughter, a wooden door and me. I’m hysterical outside, screaming through the door so she can hear me that I am there. Anyone with a badge that came
by I begged them to check on her, some did, some didn’t. She was screaming. I was hysterical and I had no idea what was going on in there. I almost lay down on the floor and looked under the door. I needed to be in that room in the worst way.

Mitchell and colleagues (2005) describe that 80% of parents in their study found that staff sought to make treatment more bearable and 90% of children felt it very important for parents to be able to stay with them during treatment.

From then on Terry stayed in the hospital during Allyson’s treatment. She had to rely on family for her other two children as she was basically living at the hospital.

I slept there, I showered there, and I stayed there. I lived with her at the hospital, to the point where at night I had a hard time sleeping but I was so exhausted I would pass out. If Allyson woke and I was asleep she would wake me up, ‘Mommy you need to keep your eyes open. You have to watch me, Okay?’ My husband would come almost every night and have dinner with us.

She went on to describe her relationship at home, “I tried to go home sometimes on the weekends but I felt horrible being home. I didn’t want to be there, and that was really bad, because I had my two other kids, but I just, I just didn’t want to be there. I wanted to be with her. I couldn’t not be there.” Sloper (1996) found that this feeling is common and that 82% of parents reported negative effects on siblings with the most common being the inability to provide enough attention to the well siblings. Terry describes keeping a notebook. She knew every blood count, every medication, every procedure and every test that occurred each day and recorded all of it. Terry recalls, “I needed to be there. She had an allergic reaction to one of the drugs, so I needed to be there to make sure they premedicated her for that.”
At the end of the first round the PICC line was removed. The doctors advised that Allyson should have a second round and so they placed another mediport. Terry’s husband had been missing a lot of work due to the treatment and so her mother went to the surgery with her. However, 30 minutes before the procedure Terry recalls, “Allyson said I want Daddy here. I want to see him.” Terry went on:

*How do I not tell him she wants to see him? If it was the other way around I would want him to tell me. And so I called him. He was there just in time and when she saw him she said ‘you better be here when I get out!’ When she came out of surgery we were all there in recovery. Allyson looked at her dad and said ‘okay now you can go back to work.’*

The port quickly became infected and was removed. Another PICC line was placed and Terry pleaded with the physicians to let her stay in the room this time. She recalls literally begging, “I will be good. I won’t get in the way. I will stay anywhere you tell me to. I just need to be there.” She was allowed to stay with Allyson during the procedure. Terry learned to care for the line and Allyson was able to receive the treatment as an outpatient.

Terry and Allyson started to fall back into “home” life. Terry recalls that she thinks her other children were young enough at that time that they were not too deeply affected by her absence. Still Terry feels guilty and wishes it was different but she remembers thinking “this is the one who needs me. I need to be with her.” At this point, all were together again and Terry was caring for the children at home. Allyson went for her last chemotherapy and Terry recalls the event:
It was a nurse we had never seen before and she attempted to get blood return from the PICC and she was unable. The poor woman, I said get out of the way and give me the gloves I will do it. Another nurse there who had treated Allyson many times said ‘just let her do it. Don’t even argue. She knows what she is doing.’ And I got blood return. I was so focused. That was the point when I had too much. There is no way on the day of her last treatment you are going to put another line in. My daughter had been through too much. I couldn’t handle anymore. She got her treatment and I said ‘I am not leaving here until you take this out.’

The line was removed and they went home. Radiation began and was uneventful.

Allyson’s treatment lasted from May until December and she returned to school after Christmas. Terry notes, “Most friends stayed, some left. The ones who left, parents also were not supportive. Did they think it was contagious?” She recalls the times she was home during the treatment and shortly thereafter when she would hear other mothers talking about Oprah or getting their nails done:

I wanted to smack every one of them. I wanted to say, ‘are you kidding me? I need to go home and make sure my daughter isn’t vomiting or that she doesn’t have a fever. I need to make sure she doesn’t have sores in her mouth and flush her PICC line.’ I felt like how dare somebody be happy in that way and I couldn’t be?

Norberg (2009) found that parents may find other parents’ complaints to be trivial, and while this often comes with an increase in value for the present day, it can make social relationships difficult with those unaffected by the cancer (2009).
She goes on to discuss her faith:

*I felt that anger, I was so angry at God for doing it to me. It took me a long time to go back to church. I feel very grateful to Him now but I was very angry that she was a child to burden this with. On the other hand when we went for treatments I would look around at the other children who did not have a good prognosis and I knew I was one of the very lucky ones. I knew that. Could such an oxymoron exist? My child has cancer and I am lucky?*

As time went on Allyson entered the survivorship clinic. Terry states:

*I actually carry around a list of her treatments that I received from Dr. Fess. I want to have it with me. She is not here. She is away at school but I have it with me. It’s my job to know, to know her background. I still think sometimes how we ever got through that as a family. But we did.*

In the time following treatment, Terry recalls missing the staff; the staff she “lived” with for 6 months. She recalls going to visit the floor after Allyson’s follow-up appointments. But then there came a point where she thought, as she looked around, “*this is so long ago for me. I really have moved on from this.*”

In discussing her daughter now, Terry notes, “*I think this changed her path in a positive way. She is fearless. I think she is who she is supposed to be. Right now she is in New Orleans building a house with Habitat for Humanity because she is about helping and giving back.*” She goes on, “*I don’t know if she gained some of that vibrancy for life because she saw so much or if she knows how grateful she should be. We don’t talk about it*
openly that much. She lives away at college.” Terry wonders, “Or when mommy said I was going to be okay was that the end of it? Did she just trust that what I said was going to happen would actually happen?”

When discussing her feelings now, Terry states, “I don’t forget but sometimes I forget just how hard it was. I handled it the best I could. I feel like I am whole still. I feel like as a family we came out of it okay.”

So you know, but I, I do believe- I don’t know if it’s true, but any cancer is- you hear that about your child and it’s the most devastating thing you could possibly hear, but you know, cancer doesn’t have to mean that you won’t survive. It doesn’t. I had to believe it, and I did, from day one. I tell everybody that, and that never crossed my mind, that I was going to lose her or that she wasn’t going to be home, never. I couldn’t allow myself to go there, and if I was delusional, or if it was whatever, it was what got me to help her get through it.

Maria

Maria begins her narrative with life prior to diagnosis. She had an eventful year leading up to her oldest son, Len’s diagnosis. Maria was the mother of three. Len was 12, her other son was 9 and her daughter was 6. She had broken her leg in October and was basically incapacitated through the winter into the spring. She was able to work from home and did so. Due to the ice and snow she delayed returning to work until March. They were putting an addition on their house and as she recalls it “we were living in a situation where the house was a mess.” She was back at work approximately one month when her son Len had a play date and came home with his neck enlarged and Maria immediately thought he
was having some sort of allergic reaction. They gave him Benadryl with no effect. The pediatrician advised them to come in on Monday. Prior to this, in approximately October or November Len had an episode of lymph node swelling in his neck and the doctors deemed it to be benign. The doctors sent him for tests and on Wednesday he had a CT scan. Maria recalls,

*My husband had taken him for the CT scan and I distinctly remember he picked me up from a train station I don’t usually go to. Still to this day every time I pass it I remember getting off the train, getting in the car and the look on his face. He had told me over the phone that the doctors wanted to talk to us. So we went in and she did not tell us definitively but more of it looks like this is what it could be. She had set us up with doctors and appointments at the hospital the following day. They needed to do a biopsy to know for sure.*

Maria goes on to describe the diagnosis:

*I remember sitting in the doctor’s office and there was this man sitting in the corner and didn’t say a word. I remember thinking ‘who is this stranger and why is he here?’ My initial reaction was like animosity or aggressive toward him. But I tell you something, he was a Godsend. He was the nicest person in the world.*

Afterward Maria learned he was the social worker. She recalls taking a liking to the physician as well and he told them to bring a notebook with them. Maria motions to the notebook on the table in front of her. The doctor told them the priority was to get the nodes down because there were two enlarged nodes pinching on Len’s trachea. She recalls
discussing the likelihood this was cancer: “I just felt like the floor opened up. Like this can’t be my kid. This is like; you know I had an out of body experience. This doesn’t just happen. How could this be happening?” The overwhelming feelings of stress and anxiety related to the diagnosis are often strongest at the initial time of diagnosis and when treatment begins. These feelings ease but do not disappear as time progresses (Sloper, 1996). Len knew something was wrong, that something could affect his breathing but he didn’t know about the cancer. He stayed the night and his dad stayed with him. Maria recalls, “I had a hair appointment the next day and I didn’t want to go and my husband said just go because you do not know what our life is going to be like from this point on. Just go and get it over with because you may not have another opportunity.” Maria describes her interaction with her hairdresser.

I have known her for many, many years and I went in and told her what had happened and her and I just started crying. She was trying to do my hair and be all professional but couldn’t help from crying. I remember leaving there with my hair all done up and thinking I’m going to see my kid with cancer. It was a crazy scenario.

Maria notes they hadn’t told anyone from the time they saw the swelling on the Saturday until they knew what was wrong on Thursday because they didn’t want to complicate things or alarm anyone unnecessarily. She recalls sitting outside the hospital making the calls to her family to tell them what was happening. “I mean imagine getting that call out of the blue? I kept repeating the same story over and over again. I didn’t want to involve them until then but on the other hand they had no expectation they were going to get that phone call.”
On Friday the biopsy confirmed the diagnosis and the physician gave them all the details. Maria remembers that she just looked at the doctor and asked how they would tell Len. He was only 12 years old. He replied “Right now. We will tell him now.” She recalls in detail telling Len:

*Len was in the bed already and he just, I sat on the bed and I’m looking at Len and he sat nearby and the doctor is basically telling him and the whole time Len is looking at me for reassurance. Like the whole time I’m looking at him positively and I’m saying yes we are going to lick this thing. It’s going to be fine. And the doctor is just telling him flat out in a way a kid could understand exactly what’s going on and he happened, my son happens to be a smart kid. And he just listened to it and the whole time I felt he was feeding off of me, just looking at me and, and saying, ‘is it really going to be alright? Is it?’ And I just reassured him the whole time and there was no reason for him to think otherwise. I mean the truth of the matter was I was feeding off the doctor because he told me he was going to get rid of this and I believed him.*

The first part of the treatment was to give blood thinners to get the lymph nodes to start to go down. Then he began the chemotherapy. He received five treatments with three weeks between each. So it was a total of 15 weeks. Maria recalls, “*We just started setting up schedules, who was going to sleep in the hospital with him and we were preparing for Passover. Your whole house has to be cleaned out and rid of certain product. I usually am the host family but I couldn’t that year.*” She goes on to describe the support from the community, “*When someone gets sick everyone is there to help. We had just finished with dinners from when I broke my leg and now boom! We were back.*” Maria recalls a strong
support system, with a few of her friends banding together to help. They came over with gloves and cleaning supplies and just cleaned everything out of her kitchen. Mitchell and colleagues note social and emotional support as an area of high priority for parents and a need that is not always met (2005). Maria recalls having Passover Seder in the hospital, joined by her in-laws. She remembers staying for a week because of the concern for Len’s trachea. She and her husband took turns sleeping there with Len. She recalls a funny story, “He’s 12 years old and he overhears me on the phone, someone must have asked where I was sleeping and I said there’s a lazy boy in the room that flips out. So, he thought he was going to be rooming with a lazy boy that would flip out on him.” She recalls taking turns with her husband but staying there for extended periods of time. “There was a pair of jeans, I wore them day in and day out, and I might have even slept in them for all I know.”

We were set up with the organization Chai Lifeline. We were introduced to Carrie in the beginning, she was the liaison. Then a young guy, barely in college, comes out of nowhere, introduces himself and starts- I was blown away by this kid, he’s part of the organization, one of the volunteers, and he’s just like you know, to make me feel better, to make Len feel better. He was the first of many, many, many that we were involved with. I wish I could talk to their mothers because they were just such good kids.

She went on to describe the huge amount of food that was given to them. In fact they had so much food they couldn’t possibly eat it all and began to have to give it away.

Somewhere in the middle of Passover they were able to leave and they went to spend the last few days with Maria’s brother in New Rochelle. After arriving and getting settled
they realized they had forgotten Len’s blood thinner. Her husband just got in the car and drove all the way home to get it. They were not going to miss that injection and they weren’t going to lose the opportunity to spend time with their family. “I remember making Excel spreadsheets of all the medications and shots and everything, and just did not want to miss any of them.” Families must administer medications, schedule and attend appointments, and attempt to maintain their “non cancer” lives (Clarke-Steffen, 1997).

Over the next five weeks, admittedly my husband did most of the leg work at the hospital, I couldn’t miss work, when I could go I would but he went most of the time. They had their routine, he and Len, like they would bring videos and they would bring entertainment. That all-encompassing video machine was a Godsend. My coworkers also pitched in and got him a Nintendo DS, which was new then.

…Early on we made the decision to shave his head or at least give him a crew cut. He looked so cute, you know, but we figured, why wait and watch long pieces of hair fall out. Most of the time he didn’t express anything negative but every so often he would be down on himself and ask ‘why is this happening why is it me?’

She goes on to touch upon Len’s character, “…we talk about the fact that if it was either of our two other kids, it would not have been the same experience, like they couldn’t handle it the way he did. He was just an amazing patient. He was always that way, even as a little kid getting shots, always very good.”

She recalls one time when all of his friends, a huge group, showed up at the door to see Len. They did let them in but it didn’t last more than 15 minutes when she admits, “My
husband lost it. ‘Everybody out everybody out you are crowding him.’ I don’t know if he was upset. I always felt bad we had to keep him from germs.” Maria does add that he was able to attend many events that Chai lifeline and others held like baseball games and activities where he got to meet players. She adds, “Things normal kids wouldn’t be able to do like go on the field.” There was a Camp Simcha that he attended but only for a few days because of where it fell in his cycle. He was able to go for three years after treatment and he did. He met incredible, close friends there.

Maria talks of her other children again:

My other son is a sensitive kid. He didn’t have outbursts or anything like that but he must have been internalizing it some way. The school had the school psychologist meet with him and meet with my daughter. It didn’t really do much with my daughter but my son started meeting with her on like a regular basis. He just loved it. It wasn’t even about the cancer. It was just about having someone to talk to, and he just really enjoyed it. He’s not the same kid now. He’s 18 and if I can get him to say two words (laughing). Then we found SIBS place. It’s basically for kids whose siblings have something like cancer and my kids loved it. It was the kind of program where you could show up or not show up. You didn’t have to reserve anything. It was all funded by donations. It was just such a wonderful thing to give these kids some of their own attention. To say, I know your family is going through something and, you know, you’re with kids that are just like that. They went a few nights a week. There were times we really just needed to have somewhere for them to go but they did love it. We tried to be conscious of giving them as much attention as we could when he was sick.
I don’t think my daughter remembers it really at all. In fact I don’t think Len remembers it entirely. It’s weird. I think we went through it more than he did. He was going through it physically but we were emotionally going through it. When you ask him about he doesn’t talk about it as being pivotal in his life or anything.

Spending time with the well siblings and providing attention to their needs proves to be difficult for families facing cancer. Having a safe place where the well siblings can go where they feel welcomed is pivotal (Mitchell et al, 2005).

Time passed and the treatments went well. Len graduated from 6th grade and Maria recalls, “We were able to get him there somehow and when they called his name for his diploma, and the kids were all chanting LEN, LEN. It was really nice to see.” He began radiation and also started 7th grade (in a new school). “I remember being annoyed in some way because people didn’t know him there the way they did in his previous school.” Schools having the appropriate amount of correct information prove to be helpful to parents and to their child when transitioning back to school. Education of teachers and those dealing with the affected child and siblings can be beneficial (Mitchell et al., 2005).

There was one teacher who did show such interest. Len had a test sometime in October related to the Hodgkin’s and the teacher said ‘I can’t wait until Monday for the results. Can you please call me over the weekend?’ And to this day we when we see him, my husband and I, we just love him. ...Len was able to celebrate his Bar Mitzvah later that year.

Maria touches on extended family:
I have a cousin in Cleveland and he has a son Len’s age. They really don’t know each other and are different types of kids but back then, whether the kid came up with it on his own or the idea was put in his head I don’t know but he organized through his class and through his teacher that every kid would make a square picture (she brings out the blanket) and make a blanket for Len. Some of the kids we have met over the years in social situations and when we hear the name, it’s like I know you – you made a square on the quilt. I think it may mean more to me than him. I don’t even know if he knows where I keep it.

She describes life now:

He volunteers at Camp Sunrise, which is a camp for kids with (or had) cancer and their siblings. He has done that for five years but now he needs to do something serious (laughter). He does offer to those kids though, the ability to say I know what you are going through, here this is my scar from my mediport.

Support from other children who have faced or are facing cancer has been found to be helpful. Mitchell and colleagues (2005) found that 71% of patients found this to be of benefit.

We transitioned to the survivor’s clinic and when we met with the doctor for the first time, he listed all these medications Len took and the side effects and what they watch for and I was just overcome. I was just balling and thinking where did this come from? Our life had gone back to normal and this just brought everything back. I hadn’t thought about it or cried about it in years and suddenly I was overcome. The
thought that he could, God forbid, have a secondary cancer after everything he went through...I just hate the thought of it.

She touches on the issue of fertility:

We talked about banking his sperm when he was first diagnosed but we decided it was something we would take the gamble on. Now, he, God willing will get married someday soon and is it something that will impact his future where a woman may not want to marry him if he can’t have kids? The doctor can’t guarantee 100% but they say it is not likely.

Maria concludes by describing her relationship with her husband and her feelings on how Len coped with his diagnosis.

I’m sure there are many people that had strains on their marriage or are very overprotective now but I don’t know the right way to put it. Maybe I had just had a great support system or maybe it’s that my husband and I are very well suited for each other but I don’t have scars from it. I have plenty of scars from breaking my ankle. Whether Len hid it or he just dealt with it, I don’t know. My husband and I talk about how, like I said initially he fed off my confidence, but we completely fed off of his dealing with it.

Sheila

Sheila begins her story with Matt’s diagnosis. She recalls the school nurse calling her and reporting that she had felt a lump in Matt’s neck. At that point she said, “My heart sank.” He was brought to his pediatrician who referred him to a pediatric oncologist. The biopsy was conducted and Sheila recalls: “When the surgeon came out and went straight to
the phone and I heard the word oncology, he didn’t even have to tell me.” Sheila goes on, “I knew the news was bad. We made the first appointment and met with the oncologist. It became surreal. I ran out of the room and called my father. I just kept thinking, I can’t lose my son.”

When faced with the impending treatment, Sheila and her husband discussed insurance coverage. She carried better insurance through her employer than her husband did. Based on this, she remained working full time and her husband took a leave of absence. She recalls the decision as difficult but she wanted Matt to have the most options for treatment. Clarke-Steffen (1997) found that parents often shared the burden of caring for the ill child and the siblings and processes at home. However, she found that fathers were more likely to take off of work than mothers to care for the ill child. Many mothers had difficulty if they worked to receive the amount of time off needed. Some families, similar to the situation of Sheila and Matt, shared responsibilities with one parent handling overnight visits and one handling outpatient treatments.

A mediport was placed, uneventfully. However, she notes, the port made her nervous. It caused her to worry about him lifting or straining. She described it as “the bane of my existence.” Matt began his chemotherapy treatment and as Sheila describes, “took a proactive approach.” She describes that he knew how to take his meds and took the initiative to hydrate himself before chemotherapy to make the process easier. “I didn’t want him to know how concerned I was, but, you know, from kind of a distance, a safe distance, I’d look at him to see if there was any change in his weight or his appetite.”
The treatment time was spent with Matt and his father at the hospital. She chuckles as she recalls the games and amusements they had to distract the patients, noting that she thinks her husband enjoyed it more than Matt.

*I would drop them at the hospital early in the morning and head to work. There were many times I would be distracted on the job- because you know, I’d be worrying about how he was doing today- how he’s feeling, is he eating, and I would get on the road and pick them up, maybe 5 or 6 in the evening.*

As with the majority of chemotherapy, Matt suffered side effects from his treatment. She describes Matt’s hair loss.

*He didn’t say anything to me. I’m not sure if he confided in his father, but it bothered him a great deal. I know one night, I got up to use the bathroom, and um, you know I went by his door, because I would check in on him at night, just to see if he was okay, and he would usually be asleep, but by the time I got to the door, I didn’t knock. I didn’t open it. I heard him crying, and I couldn’t bring myself to go into ask him why he was crying, because I had a good feeling it was because of his hair, and I didn’t really know how to comfort him, and to me that was like the worst of it, so I just got back into bed. Then I started crying. I didn’t want him, you know- I didn’t want to be around him, knowing that he was in such a state of depression. Then it would bring me down, and then I felt I wouldn’t be any good to him.*

She describes talking with him the next day, and he told her he was losing his hair and that people would look at him differently. She assured him that although it was
traumatic, this is what he needed to get well and that if people looked at him differently, “they were not people of substance.” She encouraged him to have faith in his friends and their ability to understand what he was going through. She notes that hair loss was probably the hardest hurdle to get over, as far as side effects go.

Sheila went on to discuss how hard it was to see Matt with the side effects, especially the vomiting. It was severe. They decided to give him his own bathroom and the rest of the family used another. She worried about the treatment being successful. She notes, “I couldn’t look into a crystal ball and say, it’s going to be okay. I’m not going to worry. I worried, um, I worried a great deal.”

She internalized her worry at times. She notes her husband internalized more than she did.

*I think that may have been for the best. Because I don’t know if I could have handled it. It was bad enough I was so concerned and worried. Then to have him talk about it, I’m sure we would’ve had the same anxieties and worries and concerns and stuff, and it probably would’ve compounded what I was feeling. I know that sounds very selfish but it’s the only way I could’ve seen myself getting through a situation like that.*

The internalizing of her fears and worries took a physical toll on Sheila. Sheila suffered from Crohn’s Disease and ultimately underwent several surgeries and multiple treatment regimens herself before finding relief. Caring for the ill child has been shown to have a negative physical effect on parents. They report increased stress and exhaustion and
mothers who did not have a supportive work environment reported higher overall malaise scores than those who did not work or those who had a supportive environment (Sloper, 1996). Sheila describes life at work while battling her own illness.

*There would be times where I would be on the job and then I’d be in the bathroom, and I would be doubled over, in so much pain, and I’m like ‘okay, you have to go through this.’ I couldn’t take a leave of absence. We were using my insurance.*

*People don’t know what other families are going through.*

Yet she points out there was very little time she needed to take off.

*The only conflict was being on the job, and your heart and mind are where your child is, you know what I mean? I worked with children as a librarian and I would see kids coming in but when they were healthy I would start crying. I mean you’d see them doing normal things that kids do and I’m like okay, thank God they are healthy, but, I have a child over here who’s not, and I have to be here with them.*

Sheila discussed her relationships at church and the strength it gave her and her family. She goes on to describe the personal anguish she experienced especially the intense emotions.

*Any act of kindness or concern has such an impact. It has no bearing on your child’s diagnosis but it helps a lot. You have good days and bad days. There were days I would have all this nervous energy, so I’d go home and I’d clean the house, and it’d be like 12:00, 1:00 in the morning and I would think I need to go to bed because I need to get up. Then there would be days, oh my God, I couldn’t cook dinner. I*
couldn’t even look at the mail. I have to just get into bed and go to sleep. That’s what I remember most about it, it’s like the different emotional changes that you go through- you know the highs, the lows, and the in- betweens.

Sheila goes on to discuss the treatment time. Matt completed chemotherapy and radiation a few days before 12th grade started. He returned to school without incident. She notes that “everyone was looking out for his well-being.” When he began college, he spent three semesters at a community school. She notes that his academics suffered. She acknowledges she and her husband gave him a pass after all he had been through. However, when he turned 21 she pushed harder.

“You’ve got, you’ve come through this. You’ve gotta reclaim your focus, get yourself together, and you know, you’ve gotta try and finish your education. He tried therapy but it didn’t work. I felt like things went down for him then. I’m hoping they start to pick up for him and he can have a family and be productive and make a living.

As Matt has grown her focus of worry has changed. She describes her worries now for Matt.

I believe in moving forward, and not looking back, but being young, you know I just want him to be aware of how ill he was to ensure that, you know his doctor’s appointments are always made and kept. You need to be diligent, constantly aware.

Sheila talks about the future. She acknowledges the great cost for all the services in the hospital and hopes that those who are able to make donations do so. “Cancer is something that has no borders. It can affect anyone, any age group, any ethnic group.” She
explains frustration with funding going to so many other areas when she believes that the highest priority is to save people’s lives.

*I know people see things differently, but in the end, I think, what else is there? - Your health and your life- What else is there? ‘Cause if you don’t have either one that other stuff’s not going to matter.*

**Summary- Oldest Child**

In conclusion, the oldest child has a position of authority in the family. Many of these children are the natural leaders of the family. With the initial attachment bond between a mother and her first born comes a unique relationship. The first born is the child that sets an expectation or influences what the mother will expect as she has future children. The diagnosis of cancer on this child presents the need for support for siblings including custodial care as well as emotional support. In addition, there is a unique struggle for the mother to care for this ill child and release him or her entering into survivorship.

**Only Child**

Only children have the social makeup to be perfectionists. The reason a child is an only child often contributes to their ultimate personality. Generally speaking, there are two main reasons a child is an only. The first is that the parents wanted more children and for some reason were not able to have them. Whether the cause is medical, financial, or otherwise, the parents will likely dote on and perhaps spoil this one treasure. The other main reason would be that the parents planned on only one child. The result is similar in that all of the attention is focused on that one child. However, in these cases, it is quite possible that the
parents were more rigid and disciplined as evidenced by their family plan. Regardless, typical only children tend to be perfectionists, organized, ambitious, logical, and scholarly (Leman, 1998). When the cancer diagnosis falls on an only child, they will not be afforded the support of a sibling. In turn, the parents are not afforded a “healthy” child to distract them from the treatments and medications. However, having the only child diagnosed allows parents to spend all their efforts on the one ill child. As with healthy only children, there is the possibility for overprotection, overindulgence, and intrusion into the life of the child as he or she is treated and enters survivorship (Stewart, 2012).

**Research Participants**

There were three research participants who were the mothers of only children. The first was Tina. Her daughter was Payton. Payton was diagnosed at the age of 8. Tina is a divorced mother who worked full-time in a job with flexible hours. The second is Betty, a married mother of Samantha who worked full-time at the time of Samantha’s diagnosis with the flexibility to work from home at times. At the time of Samantha’s diagnosis, Betty and Samantha’s father were not married. They were in the process of planning their wedding. Samantha was diagnosed at 14. The third participant is Dina. She is married and worked part-time when her daughter Mellissa was diagnosed. Mellissa was diagnosed at the age of 15.

**Tina**

Tina begins her story describing life before diagnosis as “an easy, consistent life.” She was a nurse and then went on to work in medical sales. She describes Payton as very active in sports, especially soccer, and school. She was working full-time but with very
flexible hours. She describes their family life as being without conflict. She notes, she and Payton’s dad were divorced when Payton was 2 ½ but remained friends. Payton’s dad is a pediatrician and is remarried. All of the members of the family get along well and she was happy as was Payton. Payton was diagnosed at 8 years old in the month of January. Tina recalls watching her play basketball and thinking she looked gray. She thought she looked weaker than the other children. Friends reassured her “it’s the middle of the winter.” She states, “I knew something was wrong for about 6-8 months but I didn’t know what. I couldn’t put my finger on it.” For the three days immediately prior to diagnosis she was persistent. Payton had a cough that wasn’t going away and she looked terrible. The pediatrician sent her for a chest x-ray and she remembers sitting outside radiology, with Payton crying and lying across her lap asking to go home. She asked if the radiologist could call the pediatrician with the results and she notes, “He didn’t have the heart to come out and tell me my daughter had cancer; he could see it on the x-ray.” The pediatrician called with the results and scheduled Payton for a 2:00 pm appointment with the oncologist. Tina couldn’t wait until 2:00 pm and went to the pediatrician immediately to obtain more details. He tried to reassure her but sent her to the oncologist at that point. Payton was questioning why she was so hysterical and Tina turned to her own mother for support and to help answer her questions. They met with the oncologist and Tina reports being in extreme denial: “There is no way this is cancer.” Then the oncologist asked Payton to turn her head and out popped a large mass from the side of her neck. It was then that it started to become real. She remembers, “I was literally basically hiding in the broom closet.” Payton went for scans that night, and the next day she was scheduled for surgery to place a port. The diagnosis was confirmed during that surgery when the surgeon called and said, “Yes it’s cancer; we are
putting in the port.” Tina lost it. She was devastated. She stared at her daughter on the stretcher and realized she needed to pull herself together because when her daughter woke up she would need her more than ever.

Payton was told she had cancer by the oncologist. This was one of the most poignant excerpts from Tina’s narrative as it truly pinpoints the agony a mother feels in such a state of helplessness.

He said, ‘you have lymphoma’; she didn’t know what that was. Then he said, ‘the other word for it is cancer.’ My daughter was hysterical. My mother and sister had to leave the building. They couldn’t handle that cry. It was a cry you’ve never heard. It’s not like a boo boo cry. It’s not like a falling down cry. It’s not a heartbreak cry. It’s a desperate cry I’ve never heard from her and she was terrified. She said, ‘I am so scared.’ And the two of us got in the elevator to go home that night and I will never forget her grabbing my hand and she said, ‘Mommy, do I have cancer?’ And I said, ‘Yes you do.’ And she said, ‘Am I going to die?’ I said ‘No, you have a good cancer and we are going to get through it.’ And you know seeing an eight year old having to face that fear…I almost wish she didn’t know.

She remembers thinking how Payton was so sweet and gentle and would never hurt a fly and that there would be no way she would be able to fight cancer and she was terrified. She notes Payton developed a blank stare and compares it to the St. Jude commercials. She relates it to seeing these children who have lost their hair and seem so old, yet they still have the face of a child. Their eyes are hard to look at. One could imagine the worry, fear, and grief they hold behind those eyes despite their age.
Because Payton is an only child, Tina feels that Payton was afforded everyone’s attention and devotion. Payton’s dad was remarried but did not have any other children. He and his wife were available to Payton at all times as well. In fact, when Payton needed to be given injections she asked for Jenna (her stepmother) to give them to her much to everyone’s surprise as Jenna was a teacher. Eventually, Tina took over but it demonstrated the cohesiveness of the family. “Everyone rallied around her and she felt that support.”

After the first round of chemotherapy, Payton needed to be hospitalized. Her counts were very low and she was admitted to the hospital for blood transfusions. The doctors attributed some of the side effects to her age, but it became a routine after each round of treatment she would grow anemic and require a transfusion and hospitalization. After the fourth round she had lost a large amount of weight and had sores in her mouth and down her throat. She had extreme nerve pain. She required morphine for the pain and was admitted to the PICU. Tina recalls Payton crying in pain and not eating at all and just being in so much discomfort during that hospitalization. She went to the desk and asked for more pain medicine because her daughter was in agony. “I was standing there in my pajamas screaming to give her more medicine.” This is a typical reaction when faced with a traumatic episode as the need to protect is triggered. The nurses were reluctant for fear Payton would need oxygen. “I said, ‘I don’t care if you need to knock her out, I do not want her in pain. I can handle anything, but not seeing her in pain.’” So they started her on (nasal) cannula, gave her more morphine, and she was able to eat. She knew then more than ever her mother would take care of her. She trusted her. Trust in a parent, especially the primary caretaker is imperative. As parents rely on the physicians to disclose truthful and impartial information,
so too does the child from the parent. Mitchell, Clarke, and Sloper (2005) found that over 80% of parents they studied felt it very important for the parents to be able to be present in the hospital with them and assist in their care, serving as an advocate or bridge between the child and the staff.

Chemotherapy continued and was followed by radiation. Payton did well and began to try to resume regular activities. Her hair began to grow back and she entered into fourth grade with a cute short hairstyle. She went to summer camp and after a year break went on to play lacrosse and travel soccer. Tina notes, “Anything she wants now she goes for with a confidence I have never seen. I think this whole experience may have changed her into that person. And she, since the treatment, is very strong, still very together, not a very emotional person.” Survivorship has this result on children. They have faced the greatest of all challenges and are now facing life with a different persona (Woodgate, 2006). However, this is also typical behavior of an only child as well, striving to achieve great things with ambition and will power (Leman, 1998).

One year after Payton’s treatment was complete she and Tina moved. Tina owned the house they lived in and they were comfortable there. However, before they moved into the house, the previous owner lost her daughter, who lived in the home, to cancer, and the year before Payton got sick the neighbor next door was diagnosed at 38 with non-Hodgkin’s lymphoma. Then, when Payton was recovering the summer after her treatment, two women who lived directly behind their house, who shared the backyard, were diagnosed with leukemia. Tina did not feel safe staying in that area. Also, Payton was one of six children in her school diagnosed with a form of cancer. They stayed within the same town but moved
across town. Tina chooses to rent now in fear that if people begin to be diagnosed in that area she will not stay there. She reiterates, “There is just so much cancer.”

*Before with the cancer-it was like being on a mouse wheel. You’re constantly just trying to keep a kid alive. I kept saying, ‘like oh my God my friends who have three and four kids and I have one and I’m trying to keep her alive.’ The one that I have is so much work to keep alive and then, to keep her emotionally well, to make sure she’s emotionally and mentally well through this.*

After treatment Tina went into a state of just existing. She didn’t really enjoy things. She had friends, socialized, but was going through motions. Her weight had dropped to 90 lbs and she was not sleeping or eating. She had overwhelming fear for her daughter. She was busy during treatment but after it ended the safety net was removed and she was forced to face reality. She developed irritable bowel syndrome and shortly thereafter sought help. Granek et al. (2012) found that parents and caregivers experienced mental and physical problems both prior to and during their child’s diagnosis. Many parents reported instances of anxiety, depression, and generally feeling down while their child was undergoing treatment and at its completion. Sleep disturbances and disruption of daily habits and routines to maintain one’s health were also common. Tina required a low dose antidepressant and it allowed her body to calm down and she was able to tolerate food and to sleep. She notes the antidepressant worked wonders but it wasn’t until her colleagues forced her to address her ailments that she recognized her own depression.

*She is my only child and I look at it like we were robbed of some of our youth together. Everyone has memories of their children in third grade and I have*
memories of her before cancer but it’s a blur and it’s not that innocent type of memory. I feel like we both, kinda, we didn’t complete her childhood. Everything I have I gave to her. Every piece of my soul, I gave for her to be okay. And it’s been- it’s just been a process, but I’m glad you know, I’m able to do it.

Betty

Betty begins her narrative discussing the time leading to the diagnosis. Samantha had a routine doctor’s appointment in June. The high school she attended was closing and she was going to be attending a new one in the fall. During the physical examination the pediatrician found a lump on her neck and referred her to see an ENT. The ENT found nothing and sent Samantha for a chest x-ray. The following day the pediatrician called and said they found Hodgkin lymphoma. Betty was at work and was devastated. She left work immediately, calling her husband. The pediatrician referred them to an oncologist.

They met with the oncologist and a treatment plan was established. The plan was to complete as much of the treatment as possible over the summer so that Samantha did not have to miss a significant amount of school. Betty describes the meeting: “I heard the word cancer and I heard nothing else after that. When the doctor said it I said, ‘What?’ I’m like, ‘you said what?’ And he replied, ‘It’s Hodgkin’s, it’s 99% curable.’ I replied, ‘What? Cancer?’” She goes on, “I’ve always donated to St. Jude because they send you those pictures and those commercials but I never thought it would happen to my family.”

The port for chemotherapy was scheduled to be placed shortly thereafter. Betty noted Samantha has difficulty with doctors and procedures and was terrified leading to the port placement. She cried the entire way to the hospital and did not sleep the night before. Betty
recalls, “I kept it together until they asked me to kiss her good bye. She was already out cold and I lost it. The doctor said to me, ‘Thank you for keeping it together.’”

After her first chemotherapy treatment Samantha began to have significant vomiting and diarrhea. She spiked a fever to 103.5 and was admitted to the PICU with the beginnings of septic shock. She was there for a few days and while there Betty noticed clumps of her hair in the bed. She recalls, “(sobbing) her hair was just everywhere.” It was all matted from lying in the bed and not being able to move much from the pillow. When they came home Betty placed her hair over the tub before she got in an effort to work the knots out before. As Betty tried to work the knots through with conditioner, clumps began to come out on the comb. Samantha saw the hair falling out and this as Betty recalls was a sobering moment of reality. “This was so hard for me. Like, it really just hit me. It really did. Hearing it was going to happen and seeing are way two different things.” Samantha saw her hair and she too was brought to tears. “Is that my hair?” She had beautiful long brown hair and she was watching it fill the tub and comb. Betty replied, “You know what? We are going to shave your head. They told us this would happen.” And so they went and had her head shaved; Betty could not watch. She had to leave. She couldn’t help but cry as she watched her daughter and she did not want Samantha to see her cry. She went outside to call her friend and just unloaded her grief and sobbed. Sloper (1996) writes of the parental need to have a source of support that is familiar to the situation but not intimately involved. Often, mothers prefer to speak to a good friend or sibling rather than a partner. Betty recalls the support for Samantha:
When she had her head shaved, my husband shaved his head, down to the itty bitty, so did my father, so did Uncle Jack, so did Uncle Billy, and my sister’s boyfriend. She got so mad and I said ‘if you want I’ll cut my hair short to support you too.’

Betty remembers her response, “If you cut your hair I’m going to be real mad at you, Mom because you want it long and beautiful for your wedding.”

Betty tried to return to work shortly after Samantha was home from the hospital. She did not feel comfortable leaving her and she requested a leave of absence. She stayed the key person in Samantha’s care and continued to care for her.

As time went on, Samantha was self-conscious, not wanting to leave the house. Betty recalls how her daughter loved Staples. She would try to get her out by offering her trips to buy art supplies. It took her over a week to leave the house. Once she was out she started to gain a little confidence and her friends were supportive of her. She started to go on outings again and went to the beach and wouldn’t wear a hat or wig. She went in the ocean and Betty went with her. She remembers the happiness and feeling of joy and freedom playing with her.

She had so much support from family and friends and we were with her, the whole time. I took off work, my husband he took off work or a half day. It was important that we were with her, the three of us together. I don’t think there was an appointment either of us missed.

The need for both parents to support the ill child is real and recognized by many going through cancer treatment (Sloper, 1996).
Samantha had completed her chemotherapy and was having her radiation treatment done when Hurricane Sandy hit. Betty’s sister lived in Long Beach and was displaced because of the storm. She was staying with Betty and her husband and Samantha. Betty struggled to get Samantha to the daily radiation treatment, mainly because of the lack of gas supply. She tells a story about going to the airport to get gas because she had heard the airports had a supply. Betty, her sister, and Samantha went to the gas station at the airport and were turned away because they were only supplying airport vehicles. Betty asked him for a suggestion of another station that may be open. Then, Samantha caught his eye from the back seat. He said, “God be with you.” Betty recalls, “I didn’t play the cancer card. That is bad. I would never do that.” However, the attendant saw Samantha himself and felt overwhelming sympathy for her. He would not allow them to give him any money for the fuel and replied to Betty, “This is for me.” Betty notes this experience as a time, along with many others when she saw goodness in people through the cancer experience. She recalls the physicians and nurses as well, treating Samantha with such overwhelming kindness that she would not have expected.

Following the treatment course, Betty learned her insurance had been exhausted. The bills were staggering. The costs were upwards of $50,000. A representative from the hospital worked with the insurance company and the bill was decreased to a few thousand dollars. Samantha was honored by the Michelle O’Neill Foundation. There is an annual volleyball tournament where people come from all over the region to participate. The proceeds were donated to Samantha and her family. The money raised from the foundation covered the medical bills.
Betty talks of happy times with Samantha, following the treatment. She recalls opportunities given to Samantha because of what she was going through by those trying to make things better for her. The family was treated to VIP service at a Yankees game, and while she admits they are not Yankee fans, they are Jeter fans and Samantha received a ball hit by Jeter and her choice of unlimited food, drinks, snacks, and treats. She said it was a day to remember. Also, they were treated to a day at Mets Stadium. They were allowed to go on the field and meet all the players as they warmed up. David Wright and several others signed shirts, balls, and other fan gear. David Wright talked to Samantha and gave her his batting gloves. Betty notes, “They were a little dirty because they were used, but we didn’t mind!” She stresses and remembers with a great smile how impressive the team was and notes, “They were real stand up kind of players.”

Samantha also received a Make a Wish. Betty describes the event,

*We went to Hawaii, which is the most beautiful place to go. She got to snorkel and we did all kinds of great things. We went in a submarine, all the way to the bottom of the ocean. We also went whale watching. It was absolutely, absolutely beautiful.*

Betty and Samantha’s dad have been together since before Samantha was born. They have always been a family and Samantha’s dad was very much involved in her care. Betty notes, “Samantha has always been daddy’s girl.” In fact, Betty thinks she grew closer to her father during the treatment. Clarke- Steffen (1997) found that fathers often have a change in responsibilities during the cancer journey and this may result in closer relationships with the affected child.
Betty and her now husband, Timmy, had a wedding planned for September 21. When Samantha became sick they were concerned about infection and her being at the wedding, and they decided to postpone the wedding until April. However, the date of September 21 held much significance. Timmy’s parents were married on that day and Samantha was very close with her grandmother who had passed away a few years prior. Betty and Timmy were married on that date in a civil ceremony and then the party followed in April. It was very important to Samantha that her parents be married that day. She remembers the happiness of Samantha being a bridesmaid and the celebration. She recalls the priest talking about Samantha in the ceremony and the sense of gratitude and appreciation for the day.

Betty ends with a summary of her feelings post cancer:

*My thing is every time we go to the doctor, until I have those results, my mind goes and it’s like what if it came back? ‘Cause you don’t know, right? So I don’t feel like we’re ever really safe from it anymore now. I kind of feel like that will always be over my head.*

*Dina*

Dina’s narrative focuses mainly on her daughter’s experience and difficulties she had throughout the time of treatment. She often refers to the family as a unit, with her and her husband participating in her daughter’s care and treatment.

She begins with life before cancer, describing a typical family dynamic. She and Mellissa had a strong relationship, sharing personal stories and details. She recalls Mellissa’s friends saying, “I can’t believe she tells you that stuff.” She talks of butting heads as most
15-year-old girls and their mothers do, but still remaining close. She points out that with Mellissa being an only child, all milestones were cause for celebration. Every birthday, communion, confirmation, and graduation was acknowledged and celebrated with extended family. She describes a happy life free from any significant worry. She notes:

*If anything is going to happen, you think it’s going to happen to you and not to your child. We just assumed we would go through her high school years and be happy and go to college and be successful – what every parent wants for their child.*

Mellissa noticed a large lump on her neck that developed overnight and showed her mother. Dina recalls,

*I will never forget. I was in this very room. She showed me the lump and it was visible and as soon as she said it, I knew immediately it was not going to be good. I don’t know why I felt that way. I just knew this was not good.*

They went to the doctor the following day. Mellissa was placed on an antibiotic to no avail and was sent to see a surgeon. A few days before the appointment with the surgeon, Mellissa told her mother it hurt in the middle of her chest when she breathed. Dina recalls, “*Then I knew, I knew it was not good.*” The pediatrician was good about informing them of what the differential diagnoses were, and they were not shocked to receive the diagnosis. In Sloper’s 1996 study, parents commented on the sensitivity and compassion shown when the diagnosis was given. While by nature of the information given, the experience is awful, parents did note that the experience was better and easier when supported by their pediatrician.
Mellissa had a CT scan done and they discovered a mass in her chest and neck. Dina recalls, “My husband came to my work and said ‘I need to speak to you outside.’ He told me they had found the masses and I lost it in the parking lot.” She attributes this mostly to the thought of telling Mellissa. “Telling her was excruciating.” It is common for parents to feel scared and unsure about sharing information including the diagnosis and changes in status and treatment plans. Clarke- Steffen (1997) found that many parents had difficulty telling their ill child and their siblings. Parents are often unsure how much information the child can handle, and Sloper (1996) found available resources for parents to assist them in the explanation to be an overall lacking service. Then they went to see the surgeon for a biopsy. It was then that the definitive diagnosis was made. They were sent immediately upstairs to the oncologist. They received the treatment plan and it all happened very quickly. She recalls getting the plan: “You are in shock. You really can’t comprehend or absorb anything.”

The treatment course began and Mellissa received her first chemotherapy dose. She got very sick with vomiting and lethargy. The next day when it was time to go for the treatment she refused. She would not go. Dina recalls,

*I will never forget her saying, ‘I was not sick before I started chemo and now I’m sick and I’m not going.’ I may not have answered her the right way but I said ‘you are going if we have to carry you because if you don’t go you may die and that’s not acceptable to me.’ She has to know how important it is. I can’t live with that. I will not allow you to die.*
Dina’s instinct to protect Mellissa was clearly engaged and she felt she had no other choice. As her child was threatened, she felt the need to protect and control.

Mellissa has a history for having vasovagal syncope. She has passed out on several occasions. The first time during this time period was after the mediport placement, followed by several episodes in the hospital. Dina recalls with a chuckle:

*She passed out in the doctor's office and he picked her up. He is a little man and she was 15 and dead weight. He was carrying her and clearly struggling, calling for a crash cart. I felt horrible, like I should help him. I knew she was okay since she does this.*

When the situation occurred, Dina recalls feeling awkward watching the doctor and being concerned, but now as she remembers it with a smile recalling his instinct to take care of her and, now, how funny the scene was.

Although Mellissa had a lot of support from her family, her friends were not as sympathetic. Dina recalls, “Not only did they not support her, but they were horribly mean to her. I mean horrifically, to the point I needed to call one of their mothers. I mean really, that’s disgraceful.” Social networks and support of cancer-free friends are an important part of the treatment and recovery process. It becomes especially difficult for adolescents who do not have the support of their “pre-cancer” friends (Mitchell et al., 2005). Dina explains how they minimally reconnected years later but she (Dina) had trouble accepting them. “It was very hard to be welcoming again when you know how they destroyed her.” She has multiple new friends and has gotten past the situations of years ago, but nonetheless it was a difficult time for Mellissa, and in turn, Dina.
Mellissa had a short break in treatment between chemotherapy and radiation. She ended chemotherapy in August and began radiation treatment in September. Radiation went as planned and Mellissa fortunately had no setbacks or complications at that time. Time went on and Mellissa entered the survivorship clinic. She had her routine follow-up care with annual CT scans and all was good. On her five-year checkup she again had her routine CT scan. They called for the results. Their routine was that Dina’s husband would call for the results and then share them with Dina. He called her at work and when she asked if he had heard, he sighed. She felt disbelief. “This was supposed to be over today,” she said. He was devastated. She was devastated. He said they had found a lump on the vertebrae in her neck and they believed it was secondary to the radiation.

Mellissa was once again admitted to the hospital and was taken to surgery to remove the mass. The surgeon met with Dina and her husband following the surgery and assured them he had removed it in one piece and was very confident that they had gotten it all.

When Mellissa woke up from surgery Dina distinctly remembers her asking if she can move her legs. Dina noted, “So she clearly has fears. She must have been afraid she was going to be paralyzed.” Two weeks after the initial surgery, when the pathology came back, the physician called and said they needed to do another surgery to increase the margins. Dina recalls, “Mellissa was on the phone with the doctor, he told her and she did not answer; she just handed me the phone and lost it.” She recalls that being a rough time. However, having a consistent and supportive physician that the ill child is able to have a connection with is beneficial to the coping experience (Sloper, 1996). Dina points out the connection with the physicians and nurses in the survivorship clinic as being instrumental in the care
received. Mellissa had no symptoms of the mass. Dina is grateful it was detected on that last CT scan. Now, Mellissa is cancer free but is back to going yearly for MRIs.

The time around tests is always stressful. Dina notes how Mellissa’s life is full of tests and results and waiting, and how it is not fair to her, or any of the children that go through it. She recalls talking to Mellissa about it and her reply was, “Mom you get so upset but it’s just part of my life. It’s just how it is.” It has become natural for her, which, Dina notes is sad, but feels it is a good way for her to cope with it.

Mellissa had severe anxiety attacks during and after treatment. Her parents brought her to see counselors and sought help for her. Still to this day her mother feels she keeps everything inside. She can cope with the anxiety but her mother notes that something changed in her when she got sick. She was never particularly vocal but her mother feels she holds much more emotion in. Her mom notes, perhaps she needed more of an intervention when she was seeing the counselor, perhaps a psychiatrist or medication. However, she did the best she could at the time. Counseling services are a necessary and oftentimes lacking support in the course of cancer treatment. Parents report initial support to be sufficient. However, follow-up support services especially for the ill child and siblings are not often used, nor were they noted to be an area of concern for them (Mitchell et al., 2005). This may indicate an unidentified need and underutilized service for the pediatric cancer population.

Dina and Mellissa grew closer during treatment and through the cancer experience. Mellissa hated the feeling of nausea more than the average person, and would always want Dina there when she felt sick. She got sick after the chemotherapy on a few occasions and Dina would often sleep in her bed with her. Dina notes, to this day she will still ask me to
sleep with her if she is not feeling well. “It makes me want to have a closer relationship with my daughter, because I could’ve had no relationship with my daughter.”

Dina confirms the cancer has changed Mellissa. “She has grown up before she should have. Of course, she has memories from before the cancer but it is such a part of her life now and she accepts it with a maturity beyond her years.” The process has indeed changed Dina as well. She notes she is much more of a worrier now than ever before. Not to the point of extremes but more than she was prior to this experience. She notes, “Once you have a child you always worry about them but about like them being snatched or falling or something but this is different worry.” Parental worry and concern is present in the majority of cancer survivor parents. Zebrack et al. (2002) discuss how the worries of mothers often directly relate to the actual or perceived worries of their children. As Dina described earlier, she knows Mellissa has worries as evidenced when she asked about being able to move her legs. It is difficult for Mellissa to express her worries.

Dina talks of two instances where things happened that strengthened her faith. She said she was in the waiting room waiting for Mellissa to come out of surgery and a woman approached her and said, “Trust in God everything will be okay.” Dina thought, “Why me? Why did she come over to me?” Then when they were in the recovery room after the vertebral mass had been removed, a woman gave Dina a small statue and the woman told her it had brought them a lot of good things and they wanted her to have it. She didn’t know anything about Dina, Mellissa, or their history. Dina and her husband wondered why again, she would give it to them. Then when the pathology came back and there was concern, they knew why.
Dina concludes, “*When the treatment was over I kinda felt like a safety net was taken away.*” During treatment they were there three or four days a week. Now they were not going to the hospital. “*We didn’t have the people around to feel secure with.*” Time passes and things subside. However, cancer forever changes you. Dina talks of how she is much less tolerant of people’s complaints. She says she always thinks, “*In the scheme of things does this really matter?*” Dina notes, “*It never leaves you. It’s always back there in your head somewhere, and I’m sure for her as well.*”

**Summary- Only Child**

An only child holds a position of dominance in a family. Whether the parents have one child by choice or because of other circumstances, the child is a “crown jewel” (Leman, 1998). The diagnosis of cancer falling on this one prize possession bestows even more angst and burden on the ill child. Parents do not have the ability to find joy in another child nor does the ill child benefit from the support of a sibling. However, it does allow a parent to devote all time and attention to this ill child. It is a unique experience and the described narratives indicated such.

**Metastory**

**Introduction**

When a cancer diagnosis falls on a child, it impacts a family in many ways, some severe and obvious and others more subtle. From the moment a mother hears cancer her world is shattered. Her once perfect or healthy child is no longer such. She may have visions of lost dreams and fears of worse losses. At the core of the mother’s experience is
her need to protect. She seeks to protect the ill child from the unavoidable suffering they will endure and may seek to protect her well children or spouse from the tentacles of the beast that is cancer. It is from this context that I describe a mother who has had a child survive Hodgkin lymphoma.

The Diagnosis

Hodgkin lymphoma may present abruptly with extreme neck, clavicular or axial swelling. However, typical presentation is more insidious. There is often gradual swelling either painless or accompanied by sensitivity. The swelling, either abrupt or gradual, results in a visit to the physician. A course of antibiotics results in no improvement and many tests ensue. It is often here that the mother’s instinct to protect is first activated. The mother serves as liaison between her child and physician, many times physician after physician. She struggles trying to explain that she just feels something is wrong. Test results are either inconclusive or reveal the need for a biopsy, perhaps the first significant blow to the mother’s image of a well-child.

The mother is called to a meeting with an oncologist, sometimes she is accompanied by her spouse, sometimes circumstances do not permit her to have support there. The diagnosis is revealed and in an instant the child sitting next to her is no longer the same child she has known and loved. As she looks around the room she is surrounded by social workers, physicians, nurses, a world she is not used to being a part of. It is a surreal or “out of body” experience. She hears what they are saying but cannot process it. She may leave the room to call her own parent, cry quietly or remain seemingly unaffected as she holds her shock, fear and disbelief in an effort to shield her child sitting beside her. She would only
want him or her to think there is nothing to worry about. If the mother is given this news without her child present she is given the task of telling her child that he or she has cancer. Some children may understand what cancer is, some may not. The mother approaches her child in an effort not to instill fear but to once again assure that everything is going to be fine. As she tells her child he or she has this deadly disease, she focuses on the great prognosis, something she may have learned about only 10 minutes ago. She shows no fear because she never would want her child to see that she is vulnerable. Her child looks at her to be his or her rock and support and she accepts that role. She fields questions such as “will I lose my hair?”; “why would God do this to me, have I been bad? “and “am I going to die?” As she struggles for the answers she assures that he or she will never be alone and she will always tell the truth. This date is forever written on her soul.

After receiving the diagnosis the mother is faced with the challenge of telling her other children and her extended family. Often times the siblings are old enough to comprehend what the diagnosis means but in some cases the siblings do not have a clear understanding and are fearful that they will lose their sibling. The mother shelters these children, while maintaining their trust in an effort to maintain a sense of normalcy for them. Some family members may already know that cancer is suspected and the news may not be a shock. Some families may have kept the testing and suspicions private until a diagnosis was confirmed. For these mothers, the task of telling others may prove overwhelming to the point where they can no longer answer questions.

The mother must make arrangements for her household, for her children and for her career. Siblings may be sent to stay with relatives or may be away at school. If the mother
has other children in school, they are often cared for by a relative or the primary caretaker becomes the father. She makes every effort to be sure her other children are provided for and feel as little disruption as possible. If the mother is currently not working outside the home or is fortunate enough to be able to take time off from work she will likely assume the role of primary caretaker of the ill child. Occasionally the mother will not be able to take time from work for various reasons including insurance coverage or stipulations by her employer. It is in these times that the primary caretaker of the ill child will often become the father. While at work the mother will think of nothing but her child and long to be with him or her.

Overall, the mother must first hear the diagnosis, process it and relay it to others. She must field every type of question possible from loved ones. She knows that what lies ahead is the daunting task of caring for this treasure that is in jeopardy while remaining a mother to her other children. In the event this is her only born, the diagnosis is perhaps that much more magnified as there is no refuge in another child.

**Treatment**

Treatment begins with preparation. Braces must be removed and cavities filled. The mother shifts into overdrive as she is met with queries or resistance from office staff regarding the urgency of her request. She finds it frustrating to tell her story over and over again to explain why an immediate appointment is necessary. When everything is in order, her child undergoes placement of a mediport, the routine procedure for administration of the chemotherapy. The port is placed under the skin just beneath the clavicle. The mother holds her child’s hand as she is dressed in a coverall, hat and booties, an outfit she has likely never worn prior and they are led to the cold, sterile operating room, again all the while trying to
maintain that there is no cause for worry. As she sees the fear in her child’s eyes, they slowly close, drifting off into sedation and the anesthesiologist thanks her for holding together. She kisses her child good bye, leaves her child in the hands of stranger and returns to the waiting room to wait for news that the procedure was successful. The mother may receive that news in less than an hour or she may be told, “There’s been a complication, a vessel was nicked. He will require just a few days in the ICU to heal.” When the child is discharged after the procedure the mother knows that in a few short days the chemotherapy will begin to flow through her child’s veins.

As the chemotherapy is initiated the mother will watch, screaming inside “stop, stop, this can’t be happening.” She looks down at her child, holds a hand and plays a video game with him or her; she wouldn’t want her child to sense her terror. Shortly after the chemotherapy is given, her child is thrown into fits of vomiting, becomes lethargic and has decreased blood counts. Her child is hospitalized for weeks at a time. She thinks to herself, “This was supposed to be out-patient treatment.” The mother spends every moment with her child. She does not leave his or her side. She finds herself wearing the same clothes for days on end. As her child suffers she feels helpless and prays for improvement. She watches as her child is draped in a cooling blanket to decrease the fever and shivers in discomfort. She holds a hand and tells her child that he or she will feel better soon. She looks to her husband as she holds back her tears. She is in a world she never thought she would be in. As her child improves, the hospital stay takes on a different focus. She begins to enjoy the time spent with her child, alone, talking and playing games, things they haven’t been able to do when he or she was well because of the stressors of everyday life. She cannot bear to leave for more
than a few hours even though her other children are home. She knows they are being cared for and her focus is her ill child. Her husband has assumed the care of those children. They come to the hospital to visit with her but cry as they leave without her. When she is home she is there physically but her mind is in the hospital. She cannot separate herself. How can she receive information from someone else? She needs to be the one the doctor speaks to as she is the one who understands. She is terrified that her child will ask for her and she will not be there.

The treatments continue and the vomiting is under control. Infection is under control as well. Her child has developed mouth sores and cannot eat or drink. Drooling and in agony from these ulcers, nothing helps. She demands pain relief. She is met with resistance as she yells, perhaps abnormally loud for pain relief for her child; her request is finally granted and her child is able to eat and sleep. She once again assures her child that she will take care of him or her. As visitors come by with well wishes and gifts, she is filled with anxiety. She is fearful of infection and thinks “please don’t touch him, please don’t touch her.” Her child smiles, knowing what she is thinking.

The chemotherapy comes to an end and the radiation begins. They arrive every day in the early morning hours. Her child is fitted with a mask and bolted to the table. Her child tells her that he or she is not afraid, but she sees her child squirm with anxiety as the mask is bolted to the table. She is told she must wait outside and it takes all her self-control to leave her child in the room alone. After less than five minutes the doctor opens the door and says with a kind smile “one down.” The radiation continues as planned for the next few weeks.
and comes to an end. As it ends, she feels a sense of relief but anxiety for the road ahead builds. This date is not as easily remembered in the years to come.

**Survivorship**

As the days, weeks and months pass the mother watches her child try to regain strength and return to school. She wonders where the paperwork is. Where is our certificate of completion? Where have all the people we have grown so close to over the past six months gone? She sees her child struggle to get back into socializing with friends. As school begins for the first time in almost a year, the classroom is a far cry from home school. The grades do not come easily. She is called to school on occasion when her child acts out in class. She wonders what has happened to the child that she knew. “He or she had never been a trouble maker.”

She longs for the days of a once “perfectly well” child. She cringes and loses her thought with each sneeze or ache. Her other children long for her attention and she slowly begins to give the affection they so desire. Her child sleeps for long periods still and she wonders if that is okay. Is this normal? She has returned to work but struggles to find meaning in her job. Nothing is anywhere near as important as what she just experienced.

As she sees her child struggle she notices a change. “It is in his eyes.” Her child is older now, not in years but in spirit. She longs for the carefree innocent days they once shared. “He was robbed of his childhood” and she is not able to retrieve it despite her undying efforts. “He is different now.”
As her child begins to gain strength he tries out for the softball team he was on before he was diagnosed and makes it. She is not as strong or fast as she was but she made it. His “hair is almost back” as thick and dark as it once was. Her weight is picking up. The mother starts to see the child she remembers coming back.

Time goes by and the child is invited to attend the survivorship clinic at the treatment hospital. As they sit down, the doctor goes over all the medication her child received and all the potential side effects and consequences of the treatments. She is overcome with grief as she hears it all really for the first time. She knew of these potentials but was “caught” in a whirlwind at the time of diagnosis and wanted her child to be cured. She chose the “lesser evil” at that time. The nurse comforts her and takes her outside. The mother wonders what she can do to keep her child safe from these consequences. She researches and fills the home with healthy foods and encourages exercise. She does whatever things she can to keep her survivor well.

Her child begins to date and confides in her that he or she wants to be a parent one day and is fearful this will not be possible. She doesn’t know how to answer other than, “you will be a wonderful parent.” She returns to her room and cries as she has no idea if this is true. She too wants him or her to feel the love only a child can bring.

Work begins to pick up for the mother and her child prepares to go off to school. She has begun volunteering at school for her other children and they are enjoying vacations as a family. She treasures the yearly visits to the survivorship clinic with her child. She still makes the appointments despite the fact that he or she is a young adult. She knows how important these visits are and wants to be sure to attend.
As the years pass, the tears have dried and scars have healed. However, in an instant the mother can tell you all the medication her child received and the exact day of diagnoses. She can tell you what was going on in the world at that time and every conversation she had. It is a time forever etched on her soul, as her child was threatened and it was she who nurtured him or her back to life.

**Emerging Themes**

Several core themes emerged from the narratives regardless of birth order. The first and most significant was the need to protect. The supporting themes are “things will never be the same,” “unique bond,” “shifting priorities,” and “lost innocence.”

**Need to Protect**

The core theme of protection was identified across the narratives. Below are several excerpts describing the mother’s intense need and reflex to protect her ill child.

*Terry*

“You have to wait out here.” All right. My daughter starts freaking out. ‘What do you mean she has to wait out there? I want her to come in.’ ‘No, we really can’t.’ ‘Are you sedating her?’ ‘No, she’s not gonna be asleep.’ I guess they just use local. I don’t know what they did, whatever, but she was awake for it, right? So I’m in the hallway, and my daughter’s screaming, screaming behind the door. There’s my daughter, a wooden door, and me. I’m hysterical outside, screaming through the door — so she can hear me, that I’m there. Anyone who walked by with a badge on, I begged to go in the room and check my daughter. I was a lunatic, and, and some
people did, and some people were like, ‘No, I’m sorry. I can’t.’ I was freaking out. I was freaking out. She was crying. She was hysterical, and it was just—and, and, ‘Ow, ow,’ and I didn’t even know what was going on in there, to the point where I actually almost laid down on the floor to look under the door. I was, I was beside myself. I didn’t know what to do. I needed to be in that room in the worst way, that I thought I was gonna jump out of my own skin. I needed to be in that room.

You know, I’ve been doing this every day, ‘cause I clean it, and I get the blood return, right? The poor woman—I, I probably—I was—I said, ‘Get out of the way, and give me gloves, and I’ll do it. There’s no way on the day of her last treatment that you’re putting in a new PICC. It’s not happening. It’s not happening. My daughter’s been through too much.’”

**Maria**

And he just, he listened to it and the whole time I felt like he was feeding off of me, just looking at me and, and saying, ‘Is it really going to be all right? Is it... you know.’ And I just reassured him the whole time and there was no reason for him to think otherwise.

**Diane**

I just like—just like gathered and, you know, took charge of her. Uh, so, um, you know, you do become very protective during times like that and, um, I think she really depended on all of us to make decisions for her and, you know, as you’re being offered options of different types of treatment it’s very—it’s very hard to make a choice for somebody else.
**Lyn**

[in reference to her husband] ‘Why do you have to be so involved?’ but he wants – like, you know, he was like just as much in as I was — you know? So it was every other night. And the one leaving felt gypped. Like we – Like if he asked us, I don’t know if I woulda let him stay there by himself overnight.

**Sheila**

I was always in that protective mode, but I think that that puts me on guard even more, um, but from a distance, ‘cause, you know, kids that age, they’re like, ‘What?’ I don’t want to be that parent, but I’m kinda forced to be that parent.

**Tina**

And this was at the end. And they started the morphine and they gave her a shot of morphine. And I remember going out to the peds ICU and she was still admitted. Payton was screaming – threw her wig across the room, screaming in pain. My daughter never did that. I’m, like, Oh, my God. She’s screaming. She’s in pain. So, I was at the desk and I said to the nurses, ‘She has to get more morphine. Like, she’s in too much pain. You – she can’t swallow.’ Payton – I said, ‘Payton, don’t worry. Mom will be right back.’ I’m in my pajamas. It’s, like, 3:00 in the afternoon and my sister went down to the coffee shop to get some coffee and I’m standing there in my pajamas screaming at them. I’m like, ‘Then give her more morphine.’ And she’s, like, ‘But, then, we’ll have to put her on oxygen.’ I go, ‘I don’t care if you have to knock her out. What is wrong with you people? This is a peds ICU.’ And I was screaming hysterically. I was – I was that lunatic mother because I could handle
anything, but not her in pain “Mom will always look out for her” and that’s when she knew.

*Patricia*

And yet you feel so bad for your child. [Crying] You try to understand why... this is happening to my child and not to me. And I remember my husband and I were sitting there... watching our son. And we didn’t know what to do how to help him. And you feel so helpless. [Crying]

The theme of protection was not limited to mothers. It was noted in other family members as well.

*Katherine*

My oldest flipped. He wanted it to be him. He wanted to be the protector. He – um, and they’re only – they’re two years apart but they’re only a year apart in school

**Things are Never the Same**

Throughout the narratives the idea that cancer has an impact on you in a way that leaves you forever changed emerged. It encompassed the principle that their child will never be fully whole to them despite a cure. This concept was evident across the birth orders and most especially affected the way the mother related to her survivor child. The following are excerpts pertaining to the life change.

*Betty*

Well, I don’t feel safe. I don’t feel safe anymore. So before, she didn’t have cancer, so it’s not something I ever had to worry about, right? Like, or that I even thought
about. I mean, maybe parents do, but I just didn’t. I was more worried about her tripping and breaking her elbow or, you know, cracking her tooth, or something like that, or getting bullied at school or something, right? But the last thing in my mind was cancer, and even though they tell me after two years, you know, she’ll be good I don’t feel safe.

Ellen

You really are mourning, even though it’s not a loss. It’s the loss of a healthy child. He’ll never be perfectly healthy to me. I’ll always be worried about him whereas the older had the same – prior – same and still healthy as can be. [Knocking] Yeah. That’s hard.

Katherine

Um, it’s like an out of body experience. I felt like I was floating. Ah, my whole – I didn’t realize it but my whole attitude had changed. My whole being had changed. My friends had noticed it, my family had noticed it. I was definitely a more confident person but I – but I was introvert – just everything was held inside myself. My own mother was telling me I’m depressed, I have to get over it. It’s not something you just get over. It’s something that you have to learn to live with but you don’t get over it. You never get over watching your child suffer.

Dina

As a person it definitely changed me. I have, I have very little tolerance for other people’s – and, and it, it sounds mean but I have very little tolerance for other
people’s like, um, you know complaining about little petty things, like little nonsense things like you’re expending all your energy complaining about something that means nothing ... makes me want to have a closer – a close relationship with my daughter because you know you – I could’ve not had any relationship with my daughter. She could’ve died. I can’t be changed more than that, I don’t think. It changed her father, too, and changes the whole you know dynamic to a certain degree, puts a lot of strain, though, I will say that, a lot of strain on, on the whole dynamic.

Liz

It affects that you, you know, you kinda get through that initial six months, and then your life – and I, and I – you know, I, I even just said it myself, like then we just jumped back into normal life. But you d-, it's just not possible. You know? Like it's n-, it, it's, it changes you forever. Um, and you can never change that

Shifting Priorities

As a child is diagnosed with cancer, the entire family’s world is turned upside down. Throughout the narratives, the concept of reprioritizing continuously surfaced. Whether the priorities were shifted at diagnosis, during treatment or after, the concept was evident across the birth orders. The shifting of priorities included household responsibilities, workload, and childcare. However, it also included values. The cancer experience has caused the participants to look at life from a different perspective.

Terry

She was supposed to be performing in her dance recital, and I didn’t let her go. I kept her home, and I said, “I can’t sit there and watch her dance in a dance recital.”
I couldn’t. I couldn’t, knowing that like in two days, she was gonna be – you know, just skip the darn thing, right, which was hard, but I didn’t – I, I kept her away from it. I just couldn’t bear going and selfishly talking to all these mothers. And I’ll be honest with you. It took a little bit longer than this, but at some point, I did become angry, and I did become bitter, and, and I couldn’t sit there and be all lah, lah, lah with these moms, who are like, ‘Oh, don’t the girls look pretty?’ and I’d be like, Who cares what they look like? In a week, my daughter’s gonna be in the hospital. Like, I was just like I couldn’t deal with anybody.

Katherine

The other kids were kind of ignored by me and not – not willfully ignored, just I had to put everything to Christine and my husband pretty much took care of everything with them. I’m not there and my husband did the best he could but didn’t know what I did. And a man’s version of raising kids is different than a woman’s.

Diane

And like who wants to – you know – we just did things that – you know – we changed what we normally did in the summer and it was like, “Okay, let’s entertain each other _”

Dina

I think there’s just so many people that complain about so many –unimportant things and I try not to – I get frustrated sometimes even like with my husband sometimes. He’ll be, he’ll be upset about something and I’m like I, I always say to him’ in the big
picture in the scheme of things is this really that upsetting? Is this really that(important) – and it’s, it’s normal for people to be upset and I get upset about things, too – but I, you know, I have l – a lot less patience for it. Um, I have a lot more, um, I, I guess I want to say faith or spirituality.

Lyn

"Eh, you know what? Life really isn't that difficult or isn't that bad, because you can always know what it was at the time, and what we were faced with, things can happen in life, so you appreciate life. You forget it, a lot, you know? For that like eight months, nine months, a year, whatever it was in all, all of that stuff, you know, it didn’t matter. My hair didn't matter. How much money we had didn't matter. None of it mattered. And I remember sitting there and thinking, 'I'll never think about those things again. I just wanna take my son and go home.' And then there are days where I'm like livid over the most ridiculous thing, and, you know, and I'll think about this, and I'll still be livid over that and say like, ‘Oh, it doesn't matter, you know, I'm still mad over this.’ But in reality, my husband and I say to each other, you know, maybe once a month, maybe every other month, like, ‘It really doesn't matter. Like – Really, in life, this is what's important?’ And I knew – like I knew what he meant.

Tina

It rocked my world to the point where I do, I wake up and I just am grateful for everything that we have
Unique Bond

Throughout the treatment process and into survivorship there is a unique bond that develops between the survivor child and his mother. Many participants touched on this bond and how it was fostered and matured through “good” times at the hospital or at home. These were typically things she would not have been able to appreciate or enjoy if her child was not sick. The bond developed lasts well beyond the treatment years.

Ellen

So I actually liked the fact – usually after the treatment he would sleep on the way home because he’d be feeling wasted already. But we did a lot of talking going – coming here, the half an hour drive here. So I really appreciated that. So – and that’s when I would catch up and find out he was doing. Was there something we should be talking to, you know, the people at the hospital about and so forth?

Katherine

It was only me and when we would come home, it was only me. I would have to lay in the bed with her. I think she slept with me for four months straight, like my husband slept in her bed. I miss the snuggling with her- and talking, rubbing her head...Like, um, I think it was just the time with her alone though, just having her to myself. It was – like laying with her in bed and just talking to her --and holding her hand and – and we have those moments, like she’ll still come home and snuggle with me. We’ll lie in the bed together, she’ll hold my hand, and we watch TV.
Diane

I mean it really – you know – that is another whole level of closeness that - you know – so but you know on the other hand I feel that you know once you had that much intensity then you have to like step back a little and, you know, allow the – you know the – because I didn’t have that same experience with the – with the – uh, with my other daughters.

Lyn

Okay, so we live in a house, and you think that you need this house, and, you know, you never have enough room. Meanwhile, the three of us basically — lived in this space — for like ten weeks. We were in the hospital for ten weeks, and we laughed so much all the time. I thought we were close before, but we were, you know, very close during that time. Me, my husband and Mark, we were just – all knew what we had to do, and we knew this was horrible, but we – you know, they used to tell us, ‘You're gonna get through this and you're gonna live your life.’ And I felt like it, like it made us closer, you know? I felt like we were close before, but it made us closer. Like, my husband and I, I feel like we – when things are bad, we're closer. Some couples I know, you know, it, it makes you, you know, um – what's the word I'm looking for? Drives you apart –But for us, it made us closer, definitely. Um, and it still does-makes us all closer. You know? It - I, I think it did bring us some good. Um, it's a bond, of course, that you can never change that, you know, I wish that we never had in, in a lotta ways, but, um, I guess that's maybe the positive that came out of it. Um,
yeah, I think, ah, you know, we’re, we’re definitely closer because of it, you know?

And I guess that’s a good thing.

Tina

It made us a bond that we have that nobody else has, I have to tell you, and especially she’s 14 now. A lot of the moms have conflicts with their girls. Payton and I don’t. I think that we have a special bond because of it. She trusts me completely. I never left her side. Never. You know? She’s always looking at me. But, it was, um, it’s – it’s – because of that, I – I cherish the bond we have, but I just wish we didn’t have to go through that to get it. But, I’m, kinda, grateful we do have it now.

Patricia

And actually I have to say that I was happy to be with him so much, because when you have teenagers, you don’t have – you don’t get to spend a lot of time with them anymore – they wanna feel independent, and they wanna do stuff without Mom and Dad anymore. It was nice to – to – I have to say I enjoyed my son. I enjoyed him. I enjoy him a lot. It wasn’t easy, but we were talking so much, and… not every day; it wasn’t every day he wanted to talk. But when he was, it was so beautiful. It was beautiful. And I was thinking, like, “If Paul wasn’t sick and Paul was in school, it wouldn’t be like this.” It was good. It was good.

Lost Innocence

It is evident, through listening to the narratives, that as well as cancer changing the mother, the survivor is also deeply changed. Many describe a strong, fearless child.

However, another common thread is the loss of innocence. Mothers describe their children as
having been robbed or able to understand things they shouldn’t. There is sadness in their voices as they describe innocence that was lost before its time.

**Katherine**

*Um, but it caused her to grow up way quicker. So there’s certain – certain things you understand and certain things you don’t. I just miss that innocence in her that was taken from her but I love the woman that she has become and how strong she is.*

**Diane**

*Actually she’s the one that just kept us all going - because she had such a great attitude, you know, like she was concerned about how everybody else was -You know it – so it takes some of your – you know – in a way it takes some of your freedom away to make decisions –*

**Dina**

*Sometimes she’s beyond her years, I feel like because of the experience she went through*

**Tina**

*St. Jude, you could see their faces and my daughter had that look. It’s a blank look that these kids have. It’s almost like they go into a zone of their own coping. And I used to see her watch the – play the way. We would play to distract her all day long. And I would see her in that zone. And I used to sit there and think, ‘God, here’s this eight year old girl, no hair. What is she thinking? Like, what?’ But, she was so strong. She used to pray every night that she wouldn’t die because she knew I would*
be devastated. So, she was more worried about me. And they go into this place that is so – and if you see that, I’m telling you, if you see those TV commercials with St. Jude, those kids have it in their eyes. You see this zone that they’re in and they go into it just to, kind of, deal. Like, you know, her friends, after the – after the treatment, she’s – she’s got different friends now because the friends that she had during, which surprised me, the friends that she had during the treatment, when she was done, she would say, ‘Mom, they’re silly. Like, I don’t think they’re funny’ because she was so – mature. She was at such a different level. Like, that’s stupid. Like, she became – and that was sad to me ’cause I felt like, Oh, you know, my daughter was, kind of, robbed of that innocent youth. She’s somebody you can talk to as an adult. Like, you can rationalize things with her because of that. As of eight years old – of age, you know, you look at it. She’s my only child and I look at it a little bit like we were robbed of some our youth together, you know? We went right into adulthood.

Patricia

Paul was always the – the boss. He was the leader- from character and from being the oldest. But his character changed in a way. He’s more quiet, more serious now. He was never a kid anymore - never a kid anymore. And I see that, uh, sometimes when the other... kids in the family are trying to be kids. He always has that – that look of... what you see in a more – in an older person. He’s not a kid anymore. I was sad for him. He stopped being a kid from 16. I – I feel that... he didn’t enjoy being a kid as a 17 and 18. He had to be... to think twice everything he did. And he
had to think, like, ‘Wow. They can do that, but... when I was this age... I wasn’t free like they are.’

Summary

In conclusion, the individual narratives all represented uniqueness. They illustrated how mothers, depending on their background, family structure, beliefs and support systems accept the diagnosis of cancer on their children, support them through treatment, and guide them into survivorship. The emerging themes identified, most especially the need to protect, are evident in the metastory illustrating the activation of the caregiving behavioral system, a reciprocal to Attachment Theory.
Chapter 5 Discussion

Introduction

The specific aims of this study were (1) to explore the life experience of a mother of a Hodgkin’s disease survivor prior to her child’s diagnosis, through treatment, and after treatment has ended as she has lived it and in her own words; (2) to relate her experiences to her attachment to this child who is now cancer free; and (3) to discuss the self-reported experiences in the context of the theoretical propositions of attachment theory and birth order as it applies to the mother-child dyad with this life experience. Narrative Inquiry was an appropriate method to achieve these aims as it allowed the mothers to express the experience as they saw it unfold, focusing on what they felt to be the important aspects.

The research shows evidence of the activation of the caregiving behavioral system as it relates as a reciprocal to Attachment Theory. The connection to birth order enabled the research to include different perspectives in relation to complicating factor of caring for well siblings. The results are of particular importance, as the prognosis for Hodgkin’s disease is good but the long term effects are great. Chapter 5 will discuss the results and future areas of research and practice as well as limitations of the performed study.

Connections to Attachment and Caregiving

The purpose of this research was to gain a deeper understanding of the experience of having a child survivor Hodgkin lymphoma while exploring it under the context of attachment and caregiving. It is evident through the narratives that the experience a mother has when her child is diagnosed with Hodgkin’s elicits a strong urge and desire to protect her child.
The satisfaction a child receives from being comforted by his or her mother is not easily replicated. This is described by Bowlby (1958, 1979). The mother serves as a figure that has proven reliable to the child. She has initiated that first attachment in the child’s infancy and subsequently developed the affectional bond as defined by Edwards (2002). As the participants describe their children looking at them for reassurance or in an effort to get a sense of security, so did these children in infancy look to their mothers for reassurance and reciprocation of their actions such as crying and smiling. The mothers’ reactions affected future behavior by the child. A positive response such as reciprocation of a smile or stroking and comfort during times of crying reassured the infant that the mother was responsive to his or her needs. As the child matures, so does the relationship between child and mother. However, the essence of the bond does not change. It would be only natural, given the existing bond, that the child would look to the mother to be their protector. Many participants describe the child’s demands and pleas for the truth. The mother reaffirmed the bonds made in infancy by fulfilling the need now requested or dictated by her child.

Another interesting component of the results of this study is how the child consistently seeks comfort in the mother. There are many fathers involved in the care and many participants described active involvement by their spouse or by the child’s father. However, when seeking comfort, the children continuously sought their mothers. In Harlow’s (1958) study with rhesus monkeys, he found that the monkeys relied on their “cloth” mother for reassurance and comfort when scared and threatened no matter its ability to provide the basic needs of nutrition. While the relationship between a human mother and her infant or child is far more sophisticated than the relationship a monkey has to a cloth surrogate, the
principle is in essence the same. The ill child clings to its mother for comfort when stressed. The results of this study further validate the findings of Harlow.

The reactions of the participants in this study toward the diagnosis and subsequent treatment show a clear activation of the Caregiving Behavioral System. As the child seeks to maintain and in fact utilize the bond they formed in infancy with the mother (attachment), the mother reciprocates with caregiving. She senses her child’s needs and responds by protecting and keeping the child close.

Throughout the narratives there are clear references to “closeness.” This is seen literally in that the mothers almost consistently stayed with their children for days on end but it was also seen in the relative sense. The mothers made reference to notebooks and a “need to be there” should something go wrong. They fed off of what their child was feeling and requesting from them and responded in a way that preserved the bond between them. However, what is also seen is that it is not something that is just “shut off” as the child enters survivorship and the elements of protecting the ill child as well as keeping them close are seen in years after the child has entered survivorship. This may be attributed to the mothers’ state of mind following the treatment for cancer. The point at which a mother returns to her “pre-cancer” self is not determined and arguably never occurs. As Bruce (2006) and Woodgate (2006) report, life is never the same. Life has simply become “before” cancer and “after” cancer. The residuals of the extreme duress are likely to follow the mother for the rest of her life, perhaps continuously engaging the Caregiving Behavioral System. This provides explanation for overindulgence or overprotective tendencies on the part of the mothers.
Similarities and Differences among Birth Orders

This research sought to explore the way a mother attached to an ill child as well as how the mother dealt with the diagnosis as it pertained to different birth orders. While there are differences across the individual birth orders, it is the similarities that are more striking. What the research points to is that it is not necessarily the actual birth order the ill child falls into but rather the presence or absence of other children that affects how a mother deals with the diagnosis and subsequent treatment.

Mothers who had a youngest child affected described the child to be spirited and “attached” prior to being diagnosed. As the child was treated their older siblings were less involved, mainly because they were away at school. The child, at the completion in treatment, remained with the tendencies to have a positive outlook and infectious happiness.

Middle children that were diagnosed with Hodgkin’s lymphoma had siblings both younger and older, presenting a unique challenge for mothers. They described their children in various ways prior to treatment but the mothers faced struggles of explaining the diagnosis and caring for the siblings at home during the treatment course. The mothers face the challenge of having other children that were old enough to understand the diagnosis of cancer and those that were not.

Mothers of oldest children generally had the worry of who would care for their other children in their absence. These siblings tended to be younger and it presented more
challenges in terms of actual child care. Mothers of ill children who were the oldest also found telling the younger children particularly difficult.

Mothers of only children were particularly unique. They made mention of this child being their only focus and having an ability to put all their energy into this one child. They also noted that they did not have to worry about child care or if they would be able to spend the time at the hospital with their sick child, as there were no other children to care for.

Across all birth orders with the exception of only children, the mothers reported similar struggles. Depending on the age of the siblings, the mothers struggled with how to tell their well children of the diagnosis. Some who had older children, noted the siblings to be helpful and able to participate in the ill child’s care. They reported a sense of understanding among these siblings. Those who had younger children did have difficulty with caring for the children at home. Most mothers admitted they cared for the ill child and the care of the well siblings was delegated to others. Also, across the birth orders, the mothers reported that their well children, in some form, and some more than others, served as a distraction to the cancer and provided them happiness.

In contrast, mothers of only children had only one focus: the ill child. They reported this as beneficial as far as logistics were concerned. They had no other children to be responsible for or to find care for. However, with one burden lightened it presented a unique challenge. As the ill child was their only they did not have another child to bring them joy or to share various life experiences. The majority of mothers, including those of only children reported a lost innocence. They saw their children grow up before their age as an effect of
the cancer experience. This presented a unique difficulty in that they only had one childhood and adolescence to experience and in a sense, it was lost.

Perhaps, the most intriguing aspect of birth order that was identified in the research is that of perceived birth order. Perceived birth order is essentially where a child feels they belong or self-perceived place in the family. As the mothers consistently describe their children post cancer as “fiercely strong” and how they “go after anything they want” or even how they are opinionated, they have all taken on characteristics of a leader or a first born. They have been changed as a result of the cancer experience and as it affects many aspects of one’s life it may in turn affect where they feel they belong in the family.

**Unique Perspectives Related to Hodgkin Lymphoma**

The results and implications from the research provide a unique perspective on cancer research, maternal attachment, and birth order. While examining mothers of Hodgkin survivors, the perspective is focused on those who have a child with a high likelihood for survival. This may imply that the mothers would experience less stress in relation to those who have a child with a poor prognosis. While this is true to some extent—mothers did report a feeling of hope based on the prognosis, the treatment for Hodgkin’s carries with it significant and costly side effects.

The development of secondary cancers is a major concern for those who have completed treatment for Hodgkin’s. The mother has an added stress going into survivorship of worry for what lies ahead. This fear is real with survivors having up to a 50% greater chance of developing certain cancers than those who were not treated (Horning, 2010).
Infertility was reported by many mothers as a concern for their child. The mothers expressed that they wanted their children to have the opportunity to become parents themselves. The uncertainty of the ability to reproduce causes angst in the mothers especially when asked about possible complications from their survivor child.

While all parents of childhood cancer survivors face a certain amount of uncertainty, mothers of children affected by Hodgkin’s disease particularly face uncertainty related to side effects and the formative age they are diagnosed (Horning, 2010). This research points to the concept that the uncertainty of what lies ahead is further complicated by family dynamics and support systems including the presence of other children.

**Limitations of the Study**

Limitations of the study include the relatively small sample size. The population chosen was specific and the small ($N=13$) purposive sample reflected such. Another limitation of the study is that only one interview per participant was conducted. While a second interview was not considered necessary by the researcher or participant, a second interview may have proved to uncover more details that the participant may have recalled after the initial interview. A third limitation was that the sample was taken from one region. While maximum variation sampling was used, the sample was relatively homogenous in regard to socioeconomic level.

**Implications for Practice**

In the practice realm, survivorship pathways are readily used and initiated shortly before treatment ends. With the knowledge gained from this study, evidence-based nursing
will develop, test, and implement regimes and protocols based on parents’ actual experiences. The mothers facing the time of uncertainty shortly after treatment ends will have the advantage of nurses and other healthcare support, which have a knowledge base provided to them by the mothers who have already been there. In using the narrative approach, the experiences will be depicted in rich, descriptive context, focusing on what the mother deems important and may educate the minds and abilities of current health care providers.

Education of current healthcare providers as well those that are currently enrolled in nursing and medical school as well as those in allied health are benefited by such research similarly to those in the practice realm. The shift is occurring where pediatric cancer is not viewed as a terminal diagnosis but as a somewhat chronic condition. With cure rates for childhood cancer at approximately 80% (American Cancer Society, 2013), the focus of education for the practitioners and parents is not on how to deal with a terminal diagnosis but to prepare for a lengthy but relatively predictable course. The information gained by this research will enhance the capabilities of educators to prepare the parents and practitioners in this manner, and to maximize the family’s quality of life through survivorship.

Pediatric cancer and survivorship is a growing topic with legislators. In May of 2013, Rep. Jackie Speier introduced H.R. 2058: Childhood Cancer Survivors Quality of Life Act into Congress. At present, the bill has been referred to committee. The fundamental purpose of the act is to improve and enhance research and programs on childhood cancer survivorship. Research gained from this study will augment legislation such as this, as well as future education, by establishing a need for government funded programs for parents after treatment has ended as well as enhance those for the survivors themselves. In addition,
current health insurance plans and government funded healthcare will potentially gain from improved quality of life for these families, early assessment and potential future and intervention from health care providers.

**Implications for Future Research**

The areas of future research in the area of pediatric cancer survivorship are endless. One of the most prominently discussed questions regarding parents of childhood cancer patients is the presence of post-traumatic stress disorder. One could apply this to parents of survivors as well. Bruce (2006) argued that the research indicates that parents of cancer survivors are prone to post-traumatic stress disorder. Learning of the disease itself qualifies as the stressful, life altering event. As cited in Bruce (2006), according to the DSM-IV, the stressful event must elicit a strong sense of fear, helplessness or horror. Certainly a diagnosis of cancer for one’s child is life threatening and potentially leaves the parents with a sense of helplessness and intense fear.

Perhaps one of the most interesting areas for research is in the area of mourning or guilt after a child is cured. This seems almost paradoxical as the popular opinion is that with cure comes happiness and relief. However, these parents have faced decisions that were thrust upon them in the blink of an eye and they chose clearly to have their child treated. But in doing so they committed the child to excruciating tests and procedures, treatments with unknown side effects, and isolated them from their peers. Of course, this was the lesser of two evils in that the other would almost certainly have resulted in death. In addition, some parents also feel a sense of loss for the healthcare environment consisting of familiar doctors, nurses, and families sharing their struggle. The treatment environment had become a home.
away from home. It is now, in the “peace” of survival, that the parents may examine their true feelings in this respect. Van Dongen-Melman and colleagues (1998) touched upon this. The research gained from this study may expand on the total experience of the mother and may open future opportunities to explore this area with more research.

Further research is indicated in exploring pain relief techniques. While much research has been done comparing various forms of analgesia for pediatric cancer patients including patches, creams, intravenous and oral medications as well as non-pharmacologic methods such as distraction techniques and positions of comfort, research is lacking in the parents’ understanding of the interventions used. As indicated by the research completed in this study, mothers have a need to protect their child and this includes alleviating or lessening the pain they are enduring. Various pain management strategies are often used yet it is possible that parents are not educated in the techniques and relief they provide. Research to gain a deeper understanding of parent and nurse interactions regarding pain relief is indicated.

More specifically, in the realm of this study, the attachment of individuals who have survived cancer and their parents may be used in treating other diagnoses. For example, the information obtained on the attachment styles of these parents can be equated to parents of other life-threatening conditions such as a traumatic event, cardiac arrest, or chronic conditions such as cystic fibrosis, epilepsy, and cerebral palsy. These areas are rich for future study.

**Conclusions**

Having a child diagnosed with Hodgkin lymphoma is a life-altering event. The life of the mother, as well as the entire family has changed to life before cancer and life after cancer.
Once the cancer diagnosis enters the family it never truly leaves it. From the moment of diagnosis, the caregiving behavioral system is activated, permanently changing the dyad. Birth order plays a role in how the mother and child react to the disease. The mother of an only child appears to have a unique experience, magnifying the effects of the dyad relationship. The mothers’ narratives served to enrich the understanding of the maternal perspective of caring for a child with Hodgkin lymphoma, with the qualitative approach giving “voice” to their individual experiences.
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Appendix A Exemplars of Narrative Inquiry

Analysis in Narrative Inquiry

The heart of narrative inquiry lies in the analysis. Contemporary narrative researchers perform analysis in a multitude of ways. The four predominant models are (a) thematic analysis, (b) structural analysis, (c) dialogue/performance analysis and (d) visual analysis. Each of the models has within them exemplars. The models, along with the exemplars are described below.

Thematic Analysis

Thematic analysis focuses solely on content. Its general focus and approach makes it an appealing method to many. It provides a way for researchers to thematically categorize experiences such as a recount of an illness. The exemplars in thematic analysis are Williams, Ewick and Silbey, Tamboukou and Cain. Details of their work are described below.

Williams

Gareth Williams (1984), a sociologist, utilized thematic analysis to analyze interviews of individuals describing their story of developing rheumatoid arthritis. He interviewed 30 individuals and used an opening basic question of how they felt they developed rheumatoid arthritis. Many people told long and complex stories. From the interviews, Williams created three case studies to discuss the evolution of developing the chronic illness. The case studies were not intended to represent the entire population but instead “to develop a theoretical argument: the arrival at chronic illness initiates a process of cognitive reorganization – meaning making” (Riessman, 2008, p. 55).
Although all the narratives were different, they were similar in that none of the narrators mentioned the medical etiology of the disease. Williams uses heavy direct quoting from the interview material. The three cases he used describe the etiology in three very different ways. The first focused on his work and described in vivid detail the way he knew something was wrong and that the cause was his work conditions. The second case study focused on stress and hardship of motherhood causing the disease and the third identified “God’s will” as the determining and causative factor. Williams attends to the accounts as reflections of ordinary discourse. He consistently goes back and forth between the narratives and the social underpinnings influencing them.

The distinguishing characteristic of William’s work is that he utilizes the long biographical account to conduct the thematic analysis. William’s study has become the exemplar for thematic analysis of the illness narrative.

*Ewick and Silbey*

Patina Ewick and Ellen Silbey published a study in 2003 examining the problem of citizen resistance to authority. The investigation was conducted on stories the authors were told when writing a book on citizens and the law. The authors describe a compelling relational theory of power. They worked with the narratives to carefully examine every day events to uncover the sociological concepts present.

Interview questions focused on problems or events that were clearly viewed as illegal such as vandalism as well as events not as clearly connected such as obtaining needed education for a child or medical care. The researchers asked the narrators to give examples
of these in their lives. The responses were a multitude of stories that described how everyday citizens felt they had “won” in these mentioned situations.

The authors in this study were not interested with the complex biographical story. They were interested in small sections that described a specific incident or event. The unit of analysis was the act of resistance. The study illustrates a way to work with narratives when told in the interview context. This exemplar is particularly of interest to sociologists as it provides a way to find meaning in everyday occurrences which may in turn lead to societal change (Riessman, 2008).

**Tamboukou**

Maria Tamboukou, a sociologist, was interested in how women teachers thought about and imagined space in a time when women did not have many opportunities. In her 2003 study, Tamboukou began by reading biographies written by the women and immersing herself in their lives and experience. She then examined letters and documents written by school teachers in the late nineteenth century England. From the letters, Tamboukou excerpted short narratives that described the visions and experiences of these women. Utilizing prior concepts, she “coded” the narratives. Emerging themes were further developed. “The researcher discovered how the freedom of imagined spaces and the material reality of other spaces were important for women teachers working within the confines of gender during the late nineteenth century” (Riessman, 2008, p. 63).

Tamboukou’s work is unique in that the narratives are utilized in brief segments. Existing themes are supported as well as emerging themes developed. She has become an exemplar in working with archived documents.
Cain

Carole Cain, an anthropologist, wrote about “identity acquisition” among members of Alcoholics Anonymous (AA). To explore this phenomenon Cain (1991) analyzed three kinds of data: (1) written documents published by Alcoholics Anonymous (2) field notes of observations at open meetings of AA (3) transcripts of taped interviews of individuals she met at AA. Stories were abundant in the interviews and at the meetings she observed.

Cain began her research with the written literature. The literature from AA contained many written accounts from individuals involved in the program. She outlined the common themes and story progression of drinking, coming to the realization that an individual is an alcoholic, seeking help, and recovery. Cain then examined her field notes and found very similar themes and story progressions. Finally, the interview transcripts were reviewed and analyzed. She applied thematic categories that had emerged from the previous items reviewed.

Similar to Williams, Cain was interested in the biography of the narrator. However, unlike Williams, Cain utilized the biography to develop patterns. Her focus was on the conformity of the personal narrative into the narrative modeled by AA. For example, the way AA views alcoholism as a disease over time became the focus of many of the narratives told in the meetings that Cain witnessed. Those that may have not initially told their story in that manner ultimately conformed to that theory. Cain has become an exemplar in working with ethnographic data by utilizing multiple sources and identifying the emerging commonalities and traditions.
**Structural Analysis**

Structural analysis refers to analyzing a narrative by the way a narrator puts the story together. The investigator looks at how the story is told. Here, the investigator examines how the narrator puts the story together, makes it understandable and “persuades” the listener. This approach tends to receive less attention in qualitative research and is a more complex analysis, with its roots in social linguistics and cognitive science (Riessman, 2008). Structural analysis, as Riessman points out, can be particularly useful when constructing case studies. William Labov, Catherine Robichaux, James Gee, and Catherine Riessman are illustrated as exemplars in this approach.

**Labov**

William Labov and Joshua Waletsky were discussed earlier and have been credited with the foundations of narrative research. Labov has gone on to further utilize the model and develop the narrative approach. In Labov’s later work, *Language in the Inner City: Studies in the Black English Vernacular* (1972), he utilized long term participant observation and individual interviews with young black teens in south central Harlem.

Labov breaks down the narrative into clauses and labels them accordingly for easy reference. He then determines the function of each clause in the particular narrative drawing from his previous work with Waletzky. Labov goes on to study incidents of violence and notes the speech cycle. He found a pattern in the narratives despite setting or narrator. Labov notes a questioning of social position that then results in a violent act. Labov saw this repeated throughout all the interviews. He utilized structural analysis to identify the elements in each narrative.
Robichaux

Catherine Robichaux, a nursing Ph.D. candidate at the time, studied critical care nurses and their practices when faced with ethical conflict. She was interested in how nurses behaved when faced with a patient for whom they felt extensive medical treatment was futile. She interviewed the nurses using broad open ended questions and conducted a thematic analysis. Common responses were identified. Robichaux noted a sequence where the nurse spoke for the patient, presented a realistic picture, and experienced resignation and frustration (Robichaux & Clark, 2006).

Robichaux then went on to study the nurses’ responses structurally and found that particular sequences of action were repeated in each of the narratives. She utilized Labov’s early model of structural analysis in her work. As is common in structural analysis, Robichaux constructed a chart with Labov’s elements on the left, a brief definition in the middle and verbatim examples from the interviews on the right. The work of Robichaux exemplifies how two types of analyses can complement and enhance each other.

Gee

There are times when a narrative is not as easy to understand or follow and the patterns are not clearly identified. All participants will not necessarily follow a direct path when telling their story. James Gee implemented a method of structural analysis for extended narratives of experience. Analysis begins with examining the spoken text. The narrative is spoken in units such as idea units, stanzas, strophes, and parts. Gee argues that stanzas are the universal unit in planning speech (Riessman, 2008). Gee focuses on how
something is said. He listens for changes in pitch and where the narrator brings the investigators attention.

Gee (1991) conducted research with schizophrenic women and asked them about their childhood. The responses often appeared to be unstructured and difficult to follow. Gee, utilizing the process of structural analysis of the narrator’s speech and where she puts emphasis, or rather, where the narrator consistently returns was able to clearly see the place that the narrator is coming from and what they are trying to express. Gee’s approach has been useful with individuals who are mentally ill, children, and long narratives of personal experience.

**Riessman**

While conducting research on women in South India with infertility Riessman (2000) utilized Gee’s approach. It provided a strong format for analyzing lengthy, complex, and emotional interviews. Riessman discussed her interview with a woman named Sunita. She described how she identified overriding themes and “codas.” This particular woman consistently mentioned overworking and infertility. She did not directly link the burdens from her mother in law, overworking, and miscarriage, but as Riessman points out, the connection is clear and can be inferred by the listener (Riessman, 2008). Riessman’s work has become an exemplar for utilization of Gee’s approach.

**Dialogue /Performance Analysis**

Dialogue or performance analysis describes how a dialogue is formed between the narrator and the investigator. More than structural or thematic analysis, this type of analysis requires close reading of contexts, including the influence of the investigator, setting, and
social circumstances on the production and interpretation of narrative. Dialogic/performance analysis asks the “who” a statement is directed at or “when” or “why.” It seeks to find the purpose of the story.

Riessman

Riessman (2008) discussed an interview with a man she called Burt. She described the vivid interaction they had while she was interviewing him. She tells that she had read the interview many times and was drawn to various aspects. Burt was a 43 year old man with advanced multiple sclerosis. He appeared far aged beyond his years. He discussed his marriage and divorce but drew the focus of the conversation consistently back to two items. The first was work. He discussed in detail the way the factory helped him when he got sick and how he didn’t want to leave. He set the scene and as Riessman described, drew her into the story. The other item in the interview that was discussed in great detail was Burt’s illness. He was very detailed in his descriptions of his illness progression and described how during the course of his illness his wife of 21 years left him for another man. At the end of the conversation Burt returned to discussing work. Riessman asked a question regarding income and loss thereof and he began to discuss in great detail the work he had done for many years in the factory. He took the opportunity and opened a door for himself to tell a narrative he wanted to tell.

Riessman’s analysis (2003) describes Burt’s job as a factory worker as his identity and his loss of job as a damaging blow to his identity. She pulled her assumptions and conclusions from where Burt took the story. His focus was not necessarily Riessman’s but
rather the emotion and degree in which the story was told around certain items that made his focus and intention clear to the investigator.

**Brown**

Liz Mikel Brown (1998), a psychologist, researched young preteen girls in rural Maine. She had two groups that she researched. The first, “Arcadia” had parents who were highly educated and had professional careers. The second “Mansfield” was less educated and was devastated by mill closings and industrial downsizing. Brown’s research consisted of group meetings with the girls where they discussed their feelings toward school and teachers. The sessions were videotaped and transcribed. A voice centered method of data analysis was utilized. The guide is utilized by Gilligan and Brown (1992). It requires four distinct listenings of the recorded interview or in this case, viewings of the video.

Initially, Brown identifies themes, then through listening and watching the emotion and interactions between the girls and the facilitator she identified areas of focus. In this case there was an overriding sense of class identities and anger identified in the initial thematic analysis. Brown described a particular instance of a lively session with the Mansfield group where the girls were discussing and interacting between Donna (one of the girls) and their teacher Miss Davis. Miss Davis states, “I don’t want your kind here” to one of the girls after a confrontation over a coat. In her performance analysis, Brown noted the gestures, tone, language, and overall excitement. Brown continued her analysis, linking the themes and dialogue with performance and interaction between the members of the group, teachers and facilitators. She identified perceived feelings of discrimination from the teacher toward the
girls and social inadequacy. The work went on to be an exemplar in dialogic/performance analysis.

**Gallas**

Karen Gallas (1994), an educator/researcher, researched children’s story telling in her racially diverse first grade classroom. The premise for the research was to explore the show and tell process and the language patterns of the children. Gallas frequently videotaped her classroom as a way to improve her teaching style.

In this research, Gallas also recorded her classroom. She turned her attention mostly to a girl named Jiana, a thin African American girl who lived in a shelter. Jiana initially struggled greatly with her speech and had extreme difficulty presenting for show and tell. Gallas continued to support her and allowed for interaction between Jiana and her classmates. Often times, her classmates “helped” her along and asked questions. It was this interaction and subsequent development of Jiana’s speech and ability to tell a story well and capture her audience that became the fruit of the research. Gallas’ work with children and speech development has become an exemplar in dialogue/performance analysis.

**Visual Analysis**

Traditionally narrative research has focused on the spoken word, with analysis done through interviews and dialogue or through written archives. There are, however, other ways to tell a story. Research through visual analysis integrates words with different visual genres. Types of images are video diaries, photographs, paintings, and collages. Exemplars in this area of research are Creef, Bell, Tamboukou, and Luttrell.
Creef

Elena Tajima Creef (2004) studied the experience of Japanese Americans evacuated from their homes after World War II and imprisoned in internment camps. Creef used historical documents and archived images to construct a story. She utilized the work of three photographers in her research.

The first photographer is Ansel Adams, a civilian photographer who spent 18 months in Manzanar prison camp and captured many images. He depicted, “Americanized” photographs of many young school aged girls. Dorothy Lange depicted the pre-evacuation process. One of the most poignant Lange images is of two young Japanese girls saluting the American flag at their school in California the day before the evacuations took place. The picture shows an elated girl beaming with childhood innocence. Creef interviewed that girl, now 50 years later. The child was separated from her mother that next day, sent to a different camp and never saw her mother again- an experience very painful to discuss and quite contrary to what is promoted in the picture. Creef carefully worked back and forth between what were common cultural beliefs as to the experience of the Japanese Americans, what was depicted in the images and what was remembered by the Japanese individuals when they told their stories. Creef’s narrators were very often the ones depicted in the images. Creef completed the story of confinement in the prison camps through Toyo Miyatake, a professional photographer when he was imprisoned. Miyatake too, had many images of “Americanized” girls but also showed the realities of guard towers and barbed wire. Creef became an exemplar through complimenting the visual images that existed with interviews and documents to complete the story (Creef, 2004).
**Bell**

Ellen Bell (2002), a sociologist, chronicled one woman’s story of illness. She linked Jo Spence’s images of herself through breast cancer diagnosis, treatment, and after with her essays. Jo Spence is a feminist British photographer known for making the unknown public. She was recognized for capturing the daily work of women inside the home. When diagnosed with breast cancer, Spence resisted Western medicine and sought alternative Chinese therapies. She decided to publicize a traditionally private time. Three of Spence’s images focused on by Creef in her research are “Mammogram,” “I Framed my Breast for Posterity,” and “Untitled.” In each, Bell was able to identify various subtle objects noted within the images. Bell’s work differed from Creef’s in that her focus was on one individual’s experience. She used images of a single person with the writings of that single person. She reconstructed the illness narrative similar to Williams yet from a different perspective. Bell becomes an exemplar through intertwining one woman’s experience through diagnosis and her death 10 years later through images and personal written stories.

**Tamboukou**

Maria Tamboukou (2007), a sociologist, has served as an exemplar in thematic analysis and is again an exemplar for visual analysis. Here, she tells the story of a Welsh painter, Gwen John who migrated to Paris at the turn of the 20th century to study. Tamboukou studied letters written by John and paintings done at corresponding times. Here Tamboukou described or reconstructed John’s identity.

John had come to be known as a recluse and Tamboukou shattered this image. She compared thematic elements across multiple paintings, drawing in the artist’s own thoughts.
expressed in her paintings and writings. Tamboukou wrote of John’s struggles with modeling, painting, and love. She interpreted her nude paintings created at the same time as letters to the artist’s “master” or mentor who was also her lover.

Tamboukou’s work reveals a different interpretation of the “self” for John. She reveals a complexity not otherwise appreciated. She has become an exemplar for her close analysis of historical accounts, self portraits, artwork, and autobiographical stories written by John.

**Luttrell**

Wendy Luttrell (2003), studied pregnant teenagers. Specifically, she looked at the questions “who am I?” and “who do others think I am?” She studied the teenagers at a high school in the Southern US with a specific program designed to keep them in school.

Luttrell designed an approach with three components: (1) journal writing by the teens (2) improvisational role play of pregnancy scenarios by the teens (3) self portraits accompanied by texts. The self portraits were often difficult for the girls to create and the process was captured in the researcher’s field notes and memos. Luttrell maintained a clear focus on the unit of analysis: the individual teenager; yet she utilizes multiple data sources: visual, written, spoken and observational.

Luttrell pays close attention to word choice but corrects and omits some of the wording chosen by the girls in an effort to prevent bias of the reader and promote understanding. The researcher utilizes classroom conversations to interpret items in the self portrait. Luttrell’s work is unique and exemplary because she was able to integrate multiple
facets of the research process described above to create a biographical story represented by a self portrait. She was able to pinpoint specific items in the image and create a clear understanding for the researcher on the narrative the participant was telling.
Appendix B Sample of Email Invitation

Dear XXXX

I am Jennifer Darcy, a Doctoral Student at Molloy College. I have been a nurse at Cohen Children’s Medical Center for 13 years. I am doing research on mothers of Hodgkin Disease survivors. I would like to invite you to be part of this research. You do not have to decide today whether or not you will participate in the research. Before you decide, you can talk to anyone you feel comfortable with about the research. I am available as is Dr Fish, to answer any questions you may have. If you are interested in being part of this research please contact me by replying to this email or contacting me at (718) 470-3145 or (516) 459-0176 so that I may give you more information.

Sincerely,

Jennifer Darcy Ph.D (c), RN, PNP- BC
Appendix C Informed Consent

North Shore-Long Island Jewish Health System

Cohen Children’s Medical Center

Consent for Participation in a Research Study

Title: A Narrative Analysis of the Stories of Mothers who have Parented an Adolescent Diagnosed with Hodgkin Lymphoma who are Currently in Early Survivorship

Principal Investigator: Jennifer Darcy, RN PhD(c)

Sponsor: Survivors Facing Forward

Introduction
You are being asked to join a research study. The purpose of a research study is to answer specific questions.

This consent form will explain:

- the purpose of the study
- what you will be asked to do
- the potential risks and benefits

It will also explain that you do not have to be in this study to receive care. You should ask questions before you decide if you want to participate. You can also ask questions at any time during the study.

Why is this research study being done?
The purpose of this research study is to gain an understanding of a mother’s experience of having a child who has survived Hodgkin’s Disease. Parenting a child with Hodgkin’s Disease is a major life stressor. We would like to find out more about the relationship between mothers and their children who have survived this disease. You are being asked to participate in this study because you are a mother of a child who has survived Hodgkin’s Disease. For the purpose of this study the researcher is specifically looking at the mothers’ experience and her relationship with her child. Mothers are specifically being interviewed because they are more likely to be the primary caregiver of a sick child.

How many people will take part in this study? This research study hopes to enroll 4-12 mothers.

How long will you be in this study?
The research takes place over 1 month. During that time, I will visit you for an interview. The interview will last for about 1-1½ hour. If you feel you would like to divide the interview into more than one visit that is acceptable.

**What will happen in this research study?**
If you decide to participate in the study you will be asked to complete a basic health and demographic questionnaire and participate in a minimum of one 60-90 minute interview with myself. You may have access to the questionnaire prior to the interview if you wish. During the interview, I will sit down with you at the Survivors Facing Forward Clinic or any place that you feel comfortable such as your home or a friend's home. The interview will consist of questions about your relationship with your survivor child before diagnosis, during treatment, and into survivorship. You can see the questions before deciding to participate.

It is necessary that there be an audio recording of the interview. This will allow for a more detailed and thorough analysis. We are also asking your permission to audio record the interview. This is required for participation.

**What are the risks of the research study? What could go wrong?**
You will be asked to share some personal information, and you may feel strong emotions when talking about some of the topics. You do not have to answer any question or take part in any part of the study that you do not want to. You do not have to give us any reason for not responding to any question, or for refusing to take part in the interview. No one else but the interviewer will be present unless you would like someone else to be there.

As in any research study, there is a risk of breach of confidentiality (unintentional sharing of your private information). However, there are procedures in place to minimize this risk.

**What are the benefits of this research study?**
This research will not benefit you directly. However, information we learn about this disease or condition may help patients in the future.

**Are there any costs for being in this research study?**
You will not have any added costs from being in this study.

**Will you receive any payments for participating in this research study?**
You will be paid $10 for your time and travel expenses for being in this study. Payment will be made at the end of the interview.

**What are your rights as a research participant?**
Your participation in this project is voluntary. The quality of your/ your child’s medical care will be the same, whether you join, refuse to join, or decide to leave the study.

If you do not join the study you will not be penalized or lose benefits to which you are
entitled. If you join the study you may withdraw at any time without prejudice to your future care at the North Shore-LIJ Health System.

**Could you be taken off the study before it is over?**
It is also possible that your participation in this study may end without your consent. This decision may be made by a researcher, study sponsor, or the Institutional Review Board (IRB - the committee that oversees research at this institution).

Reasons for withdrawal may include:
- failure to follow instructions,
- failure to show up for your interview,
- it is not in your best interest to continue on this study, or
- the study is stopped.

If you withdraw from this study or if you are withdrawn from the study, any data already collected will continue to be used. However, no new data will be collected.

**What happens if new information is learned?**
You will be told of any new findings that may change your decision to continue to participate. Your consent to continue to take part in this study may be obtained again.

**What information will be collected and used for this study?**
If you agree to be in this study, we will collect health information that identifies you. We may collect the results of interviews. We will only collect information that is needed for the research. This information has been described in this consent form. If you sign this consent form, you are giving us permission to collect, use and share your health information. This permission is called authorization.

**Who else will see your information?**
Study records that identify you will be kept private. You will not be identified in study records or publications disclosed outside the North Shore-Long Island Jewish Health System, except as detailed below.

The following reviewers may access your study to make sure that this study is being done properly:
- Representatives from federal and state government agencies such as the Office of Human Subjects Research Protection (OHRP)
- Representatives from the North Shore-LIJ Health System Institutional Review Board (IRB - the committee that reviews research at this institution)
- Representatives from Survivors Facing Forward
- Representatives from Molloy College
We will do our best to protect the privacy of your records but it is possible that once information is shared with people listed on this form, it will be released to others.

In the future, we may publish results of this study in scientific journals and may present it at scientific meetings. If we do we will not identify you.

If the researchers learn about potential serious harm to you or someone else or other public health concerns, it will be shared with the appropriate authorities.

**Will you be able to access your records?**
You have the right to know who has and who will see your records. To request this information, or for any questions related to your health information, you may contact the Research Privacy Officer at 516-562-2018.

**How long will your health information be kept?**
There is no limit on the length of time we will keep your information for this research because it may be analyzed for many years. We will keep it as long as it is useful, unless you decide you no longer want to take part or we close the study. You are allowing access to this information indefinitely.

**Can you change your mind?**
If you change your mind about being in the study, you may withdraw at any time. If you want us to stop collecting your health information, you need to send a letter to the researcher at the following address:

**Jenifer Darcy PhD (c), RN, PNP-BC**
269-01 76th Avenue
New Hyde Park, NY 11040

Your letter needs to say that you have changed your mind and do not want the researcher to collect and share your health information. You may also need to leave the research study if we cannot collect any more health information. We may still use the information we have already collected. We need to know what happens to everyone who starts a research study, not just those people who stay in it.

**Who can answer your questions about this study?**
If you have any questions about the study, you may call Jennifer Darcy at (718) 470-3145. You may also contact Dr Jonathan Fish at (718) 470-3460. If you have questions about your rights as a research participant, concerns about being in the study, or would like to offer input, you may contact the Office of the Institutional Review Board (the committee that oversees research at this institution) at (516) 562-3101.
A signed copy of this consent form will be given to you.

[Signature Page Follows]

**Summation/Signature**
You have read the above description of the research study. You have been told of the risks and benefits involved and all your questions have been answered to your satisfaction. A member of the research team will answer any future questions you may have. You voluntarily agree to join this study and know that you can withdraw from the study at any time without penalty. By signing this form, you have not given up any of your legal rights.

____________________________________________________________
Printed Name of Participant

___________________________________________________             ______________
Signature of Participant         Date

_______________________________
Witness’s Printed Name            Witness’s Signature            Date
(Note: A witness can be a member of the research team, but cannot be the same person signing consent as the investigator)

**Investigator’s Statement**
I have offered an opportunity for further explanation of the risks and discomforts which are, or may be associated with this study and to answer any further questions relating to it.

_________________________________               ____________
Investigator’s signature         Date

_____________________________________________
Investigator’s printed name
Appendix D Interview Guide

Interview Guide

1. Tell me about life with your child before they were diagnosed.

Probes:

What types of things did you enjoy doing together?

What were your plans for the future?

What was your relationship like with your other children? (if applicable)

What types of celebrations did you have?

2. What was the diagnosis like?

Probes:

What led to the diagnosis?

How did you react?

How did your other children react? (If applicable)

How did you tell your child they had cancer?
3. What was treatment like for you and your child?

**Probes:**

Who spent the time in the hospital with your child?

What things were your biggest fears?

What were your child’s biggest fears? Did you discuss the fears?

What stands out the most in your mind from that time period?

How were your other children during that time? (if applicable)

Who cared for them if you were away? (if applicable)

4. What is life like now with your child?

**Probes:**

What are your fears? Your child’s? Do you share your fears with each other?

Who do you talk to about your concerns?

Do you miss anything from the treatment time?

Do you regret anything?
Appendix E Demographic Form

Health and Demographic Questionnaire

Directions: Please place a check in the box or circle your response. To protect the confidentiality of your information, please do not put your name or any other identifiable information on this questionnaire.

1. How old were you when your child was diagnosed?
   - □ 25-30
   - □ 31-35
   - □ 36-40
   - □ 41-45
   - □ 46-50
   - □ 50+

2. How old was your child when he or she was diagnosed?
   - 9 10 11 12 13 14 15 16 17 18 19 20

3. What was your marital status when your child was diagnosed?
   - Single
   - Married
   - Divorced

4. What is your marital status now?
   - □ Single
   - □ Married
   - □ Divorced

5. How many children did you have when your child was diagnosed?
   - 1 2 3 4 5+

6. How many children do you have now?
   - 1 2 3 4 5+

7. Where does your survivor child fall in birth order?
   - Only child
   - first born
   - middle child
   - youngest child

8. Did your child ever experience a relapse of Hodgkin’s Disease?
   - □ Yes
   - □ No

9. Did your child have any other cancers?
   - □ Yes
   - □ No

10. Did any of your other children have cancer?
Yes  No  If yes what type________________

11. What is your Race?

☐ White Non-Hispanic
☐ Black Non Hispanic
☐ Hispanic
☐ Asian Pacific Islander
☐ Native American
☐ Other or more than one ______________________

12. What is your Religion?

☐ Protestant Christian
☐ Evangelical Christian
☐ Roman Catholic
☐ Jewish
☐ Muslim
☐ Hindu
☐ Buddhist
☐ Other______________________________

13. What is your highest level of education?

☐ Less than High School
☐ High School /GED
☐ Some college
☐ Associate’s Degree
☐ Bachelor’s Degree
☐ Masters
☐ Doctorate
☐ Professional Degree (MD JD)

14. What was your employment status prior to your child’s diagnosis?

☐ Unemployed
☐ Part time
☐ Full Time
15. What was your employment status during your child’s treatment?

☐ Leave of absence
☐ Unemployed
☐ Part time
☐ Full Time

16. What is your employment status now?

☐ Unemployed
☐ Part time
☐ Full time

17. What was your approximate annual household income during your child’s treatment? (optional)

☐ < 40,000
☐ 41,000-65,000
☐ 66,000-90,000
☐ 91,000-150,000
☐ 150,000+