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### Keep Calm and Cope On: How Families Cope with Childhood Cancer

Christine Czapek

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Keep Calm and Cope on

(TITLE)

BY

Christine Czapek

**UNDERGRADUATE THESIS**

SUBMITTED IN PARTIAL FULFILLMENT OF THE REQUIREMENTS OF

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HONORS COORDINATOR

\_\_\_\_\_  
DEPARTMENT CHAIR

**Keep Calm and Cope on: How Families Cope with Childhood Cancer**

By

Christine Czapek

A research paper submitted to the undergraduate faculty in partial

fulfillment of the requirements for the degree of

Bachelor of Science with Honors

Major: Family and Consumer Sciences

Family Services Option

Faculty mentor:

Dr. Lisa Moyer

Eastern Illinois University

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**Abstract**

The purpose of the current study was to examine how childhood cancer affects the family system after a period of time (at least one year) has passed. A questionnaire was developed by the author and given to families that were recruited through a snowball sampling procedure. The final sample consisted of 17 families in various stages of coping after a child in the family was diagnosed with cancer. Findings showed that overall, the women in the study tended to cope in more positive ways than men, that siblings often reported to their parents that they felt excluded and can experience emotional and behavioral issues long after the cancer diagnosis, and that family roles are threatened when families are dealing with cancer.

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**Table of Contents**

Abstract .....	ii
Acknowledgments.....	iii
Table of Contents.....	iv
Chapter 1- Introduction.....	1
Statement of Problem.....	3
Research Questions .....	3
Limitations of the Study.....	3
Definition of Terms.....	4
Chapter 2- Review of Literature .....	8
Parental Coping Responses .....	10
Sibling Responses to Childhood Cancer .....	18
Family Role Changes After Diagnosis .....	22
Chapter 3- Methodology .....	25
Research design .....	25
Instrumentation .....	25
Reliability and Validity.....	26
Procedure for Data Collection .....	26
Proposed Data Analysis .....	26
Chapter 4- Results.....	28
Description of Sample.....	28
Results.....	29
Chapter 5-Discussion.....	39
Limitations .....	42
Recommendations.....	42

References.....45

Appendices.....48

    Appendix A: Instrument .....48

    Appendix B: Informed Consent Form .....54

# HOW FAMILIES COPE WITH CHILDHOOD CANCER

## Chapter 1

### Introduction

Over time, medical research and treatment improvements have made it possible for children to survive cancer. However, even though more children survive cancer, the long-term risks to children's health and well-being are compromised due to the potential side effects of treatment, the reoccurrence of cancer, and the effect a cancer experience can have on the entire family. Systems theory proposes that families are systems so intensely connected that every member is affected by one another's emotions, needs, distress, and expectations (Bowen, n.d.; McKenry & Price, 2000). A diagnosis of childhood cancer can be expected to have deleterious effects on the child as well as the other members of the family. The entire system experiences disturbances of daily life, changes in family roles, anxiety, depression, worries about cancer recurrence, and the fear of the loss and death of their loved one (Hagedoorn, Kreicbegs, & Appel, 2011).

Research has shown that parental relationships are impacted in a negative manner following a childhood cancer diagnosis (Silva, Jacob, and Nascimento, 2010). Communication, role changes, and increased levels of stress are effects that parents report in the immediate aftermath of their child's cancer diagnosis. Research has also noted that there are differences in the ways that mothers and fathers cope with a childhood cancer diagnosis. Mothers of children with cancer appear to experience more anxiety and depression than fathers do in the aftermath of the diagnosis of cancer. This could be due, in part, to traditional family roles. For example, mothers typically take on the caregiving role for the sick child, while fathers are usually the main breadwinners and handle the finances that the diagnosis may bring forth. Such traditional roles leave the mother with more pressure when caring for a sick child (Gerhardt, Gutzwiller, Huiet,



## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Fischer, Noll, & Vannatta, 2007). However, systems theory proposes that families have to adapt and change to new situations in order to function in a healthy manner. This means that mothers and fathers may have to take on different family roles and maybe even lose roles that they have occupied before the cancer. Unfortunately, the bulk of the existing research regarding coping, childhood cancer, and family roles has looked at the effects of cancer over short terms (e.g., up to one year following diagnosis) and not much, if any, has gone beyond. At this point it is unclear what effect a childhood cancer diagnosis has on family roles and coping over a longer period of time (at least one year following diagnosis). Another area of importance concerns the effect a childhood cancer diagnosis has on siblings.

Siblings of a child diagnosed with cancer can experience stress similar to that of the child with the diagnosis (Alderfer, Long, Lown, Marsland, Ostrowski, Hock, & Ewing, 2010). Siblings of children with cancer show a significant amount of post-traumatic stress symptoms, as well as negative emotional reactions such as shock, fear, worry, sadness, helplessness, anger and guilt. Unfortunately, families, friends, and sometimes even professionals focus all of their time and attention on the child with the illness and can overlook the healthy siblings. Because of this, “siblings have been identified as the most neglected of all family members during serious childhood illness” (Ross-Alaolmolki, Heinzer, Howard, & Marszal, p. 67). While research has documented the effects of a cancer diagnosis on siblings over the short-term (i.e., up to one year), it is not clear how siblings cope over the long term.

It may be more feasible and reasonable to expect to follow families up to a year after cancer is discovered due to accessibility, however, it is unclear how families adapt and change several years after diagnosis. The goal of Family and Consumer Sciences professionals is to improve the quality of life for individuals, families, and communities. As such, Family and

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Consumer Sciences professionals need to know how to best support families in the immediate aftermath of a childhood cancer diagnosis as well as long after the initial diagnosis.

### **Statement of the Problem**

The purpose of the current study is to examine how childhood cancer affects the family system after a period of time (at least one year) following diagnosis. Research shows that families cope in a number of different ways in the immediate aftermath of a diagnosis of childhood cancer (Patterson, Holm, & Gurney, 2004), but few look beyond one year after diagnosis. Since cancer affects the entire family, (caregivers, siblings, and the child who is sick) it is important to focus on how families cope and how family roles are affected more than a year after the initial cancer diagnosis.

### **Research Questions**

The following research questions will be addressed in this study:

1. How do parental roles and interactions change after a year (or longer) has passed after a child in the family has been diagnosed with cancer?
2. How are the siblings of the child diagnosed with cancer affected after at least one year post-diagnosis?
3. Do mothers' and fathers' coping strategies differ from one another after a period of at least one year after diagnosis?

### **Limitations**

Since the current study will rely on self-report surveys that are administered to participants online, and from one parents' viewpoint only, the data may not accurately reflect the second parents' and/or the siblings' point of view. The sample size will also be small, as the principle investigator will use a purposive snowball sampling procedure to find families that

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

have/had a child diagnosed with cancer and that are willing to participate in the research.

Finally, the surveys will rely on participants' memories, which can be distorted over time, as not every single detail is possible to retain for most individuals.

### **Definitions of Terms**

Most all of the definitions listed in this section were obtained from the National Cancer Institute, *Dictionary of Cancer Terms* (n.d) website. The definitions include words that are found in the current document.

**Anxiety:** Distress or uneasiness of mind caused by fear or danger or misfortune. A feeling of worry, or nervousness, typically about an imminent event or something with an uncertain outcome.

**Bone Cancers:** Occur most often in older children and teens. Primary bone cancer is cancer that starts in the bone. Metastatic bone cancer is cancer that started somewhere else in the body and has spread to the bone.

**Brain and Central nervous system tumors:** Second most common childhood cancer.

**Cancer:** A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems. There are several main types of cancer.

**Chemotherapy:** Treatment with drugs that kill cancer cells.

**Coping mechanisms:** Nurses aid support to the whole family by encouraging positive coping mechanisms.

- 1) Talking to someone
- 2) Receiving information and explanations
- 3) Open, honest family communication

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

### 4) Being actively involved in the patients care.

1) Talking to someone: Individual family members need to find someone that they can speak with that they can trust and will be honest with them. They need to know that they are loved and cared for.

### 2) and 3) Receiving Information and Explanations and Open Honest Family

Communication: This is discussed on an individual basis. Nurses can act as role models to parents by openly and honestly discussing information. Parents need to utilize the nurses because nurses can give them information so that they can explain and answer their children questions.

4) Actively Involved in The Patients Care: Each member of the family needs to feel involved. It is said to be true that it is better to include the sibling on family discussions and keep them aware of the patients progress because they are sensitive to changes in the parents behaviors and attitudes. Also, remember that the degree in which parents communicated to the siblings is influenced on how well they cope.

**Coping Skills:** The methods a person uses to deal with stressful situations. These may help a person face a situation, take action, and be flexible and persistent in solving problems.

**Depression:** State of despondency and dejection, typically felt over a period of time and accompanied by feeling of hopelessness and inadequacy. Dictionary.com (2014).

**Distress:** Emotional, social, spiritual, or physical pain or suffering that may cause a person to feel sad, afraid, depressed, anxious, or lonely. People in distress may also feel that they are not able to manage or cope with changes caused by normal life activities or by having a disease, such as cancer. Cancer patients may have trouble coping with their diagnosis, physical symptoms, or treatment.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

**Family Adaptability:** The tendency of a family system to change its power structure, role relation, and relationship rules in reaction to distress. (Olson, Sprenkle, & Russell, 1979).

**Family Cohesion:** The amount of closeness and mutual involvement experience in the family system. (Olson et al., 1979).

**Leukemia:** Cancer in bone marrow and blood the most common childhood cancer.

**Lymphoma:** Start in certain cells of the immune system called *lymphocytes*. Most often grow in lymph nodes and other lymph tissues like, tonsils or thymus.

**Neuroblastoma:** Start in early forms of nerve cells found in a developing embryo or fetus. Occurs in infants and young children.

**Posttraumatic stress disorder:** a mental disorder, as battle fatigue, occurring after a traumatic event outside the range of usual human experience, and characterized by symptoms such as reliving the event, reduced involvement with others, and manifestations of autonomic arousal such as hyperalertness and exaggerated startle response. Dictionary.com (2014).

**Radiation:** Energy released in the form of particle or electromagnetic waves.

**Relapse:** The return of a disease or the signs and symptoms of a disease after a period of improvement.

**Remission:** A decrease in or disappearance of signs and symptoms of cancer. In partial remission, some, but not all, signs and symptoms of cancer have disappeared. In complete remission, all signs and symptoms of cancer have disappeared, although cancer still may be in the body.

**Retinoblastoma:** Cancer of the eye. Occurs in children around age 2.

**Rhabdomyosarcoma:** Starts in cells that normally develop into skeletal muscles.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

**Sibling relationship:** “Relationships between siblings can be among the most rich and enduring that child and adults experience” (Professional Nurse, 1996). Siblings spend a lot, if not most of their time together building relationships and strong unique bonds. With the relationship that siblings make, they develop a sense of self-identity and personality. They learn to share and compromise through the experiences and time spent together. When one sibling is diagnosed with cancer, the other sibling begins to lose the sibling relationship. Drastic changes are likely to occur due to the demands from the critical disease of cancer.

**Stress:** In medicine, the body’s response to physical, mental, or emotional pressure. Stress causes chemical changes in the body that can raise blood pressure, heart rate, and blood sugar levels. It may also lead to feelings of frustration, anxiety, anger, or depression. Stress can be caused by normal life activities or by an event, such as trauma or illness. Long-term stress or high levels of stress may lead to mental and physical health problems.

**Support Group:** A group of people with similar disease or concerns who help each other cope by sharing experiences and information.

**Treatment cycle:** In medicine, a course of treatment that is repeated on a regular schedule with periods of rest in between. For example, treatment given for one week followed by three weeks of rest is one treatment cycle.

**Wilms tumor:** Starts in one or rarely both kidneys. I most often found in children about 3 to 4 years old and is uncommon in children older than 6. Swelling or lump in the belly.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

### Chapter 2

#### Review of Literature

Every day approximately 720 children in the world are diagnosed with cancer, making childhood cancer the leading cause of death by disease in children under the age of 15 in the United States. In addition, every year an estimated 263,000 new cases of cancer affect children under the age of 20 worldwide (Alex's Lemonade Stand Foundation for Childhood Cancer, 2014). Childhood cancer happens regularly, randomly, and spares no ethnic group, socioeconomic class or geographic region (Facts About Childhood Cancer, n.d). Any time a child is diagnosed with cancer, it affects the family as a whole, and nearly every aspect of the family's life has the ability to change. Changes can occur but are not limited to: relationships, family roles, coping strategies, and family routines. This can be a very difficult time for families as changes pose difficulties that are not necessarily anticipated by the family after a child's diagnosis of cancer, regardless of the type of cancer.

The most common types of childhood cancers include: Leukemia, brain and other central nervous system tumors, neuroblastoma, wilms tumor, lymphoma, rhabdomyosarcoma, retinoblastoma, and bone cancer (American Cancer Society, 2013). As a professional, it is important to distinguish among the different types of cancers because research indicates that the distress of a family correlates to which cancer diagnosis is presented. Coping strategies are affected by survival rates and the rates vary according to the type of cancer that is diagnosed. But, no matter what type of cancer, a diagnosis has a profound effect on family roles, dynamics, and distress.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Thirty years ago, the median survival period for a child diagnosed with acute lymphoblastic leukemia (aka: ALL), the most common form of childhood cancer, was only three to six months (Cancer Facts, 2011 and Cancer Facts and Figures, 2013). Today, over 60% of children diagnosed with (ALL) will survive five years or longer and sometimes survive for a typical lifetime (Papaikonomou, Nieuwoudt, 2004; Faulkner, Peace & O'Keefe, 1995). An estimated 48,610 new cases of leukemia were expected for 2013, making leukemia among children and adolescents the most common form of childhood cancer, accounting for 31% of all cancer diagnoses (American Cancer Society, 2013). Acute lymphocytic leukemia (ALL) and acute myelogenous leukemia (AML) are the most common types of leukemia cancer among children. Because of the major treatment advances in recent decades, more than 80% of children with cancer now survive five years or more. Overall, this is a huge increase since the mid-1970s, when the five-year survival rate was less than 60%. Again, regardless of the type of diagnosis, childhood cancer is challenging for families because of the effects on family functioning, lengthy and aggressive treatments, increased risk for mortality, and long-term morbidity (Gerhardt, et al. 2007).

Improvements have been made to cancer's long-term morbidity, which has drastically increased the survival rates for children. Being cured has been defined as 'extending beyond biological and physical outcomes, to include health within social, emotion, and psychological domains' (Van Dongen-Melman, 1997). Even though the survival rates for childhood cancer have improved and more cases are being defined as "cured," the long-term risks to the child's health and well-being have the ability to lower the families' overall quality of life. Long-term consequences can include; recurrence or second cancers, early death, stunted development, or negative cognitive functioning. These consequences negatively impact parental and sibling's



## HOW FAMILIES COPE WITH CHILDHOOD CANCER

quality of life in addition to the child that has been “cured.” In fact, research shows that many children that survive cancer question whether or not their life has improved. They respond by expressing that they still have to live with the side effects that come from the chemotherapy and/or radiation treatments and the constant worry that the cancer will come back (Van Dongen-Melman, 1997). In addition, sometimes there are unexpected late medical and psychosocial side effects. These concerns are not considered in the immediate aftermath of a cancer diagnosis, but the impact affects the entire family system and can alter family life and roles permanently.

The following section will review the existing literature on how families cope with childhood cancer. The first section will examine literature regarding how parents cope with a cancer diagnosis. The next section looks at how siblings are affected by another sibling’s cancer. The last section focuses on how family roles are affected by the cancer diagnosis. Each section will begin with older published studies, leading up to more recent studies. A summary of the findings for each section will be provided at the end.

### **Parental Coping Responses**

For the purposes of this paper, the term ‘coping’ refers to an individual’s psychological adjustment to pediatric cancer rather than general strategies used to cope with daily life (Grootenhuis, Last, 1997). The word ‘cancer’ is associated with the word death, and for most people, children should not be linked to death which can make coping with a child’s cancer diagnosis particularly painful for parents when they hear that their child has cancer. According to Hoekstra-Weebers, Wijnberg-Williams, Jaspers, Kamps, and van de Wiel (2012), “Cancer in children has a strong impact on parent functioning. Initially, parents of children with cancer are the ones to report high emotional distress levels and have more psychosomatic complaints than

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

norm populations” (p. 903). Dahlquist, Czyzewski and Jones (1996) noted that while parents are one of the most important emotional support sources for children with cancer, a parent’s ability to provide care and support depends upon their own response to the situation. If parents do not cope effectively (i.e., in a healthy manner), symptoms can cause acute and/or posttraumatic stress which can then inhibit parents’ ability to take care of their children. Clearly, the parental role is an important function to the family system when there is a child diagnosed with a life threatening illness.

Brown, Kaslow, Hazzard, Madan-Swain, Sexson, Lambert, and Baldwin (1992) studied the families of 55 children diagnosed with acute lymphocytic leukemia. Families completed self-report questionnaires at three specific points; first at diagnosis, then one year post-diagnosis, and finally one year after the completion of chemotherapy. The families in the study reported more family cohesiveness and marital satisfaction once the chemotherapy of their child was completed. However, Brown et al., (1992) noted that fathers generally did not come to counseling and were much more difficult to evaluate than the mothers because of it. Coping strategies that families used in the study included, problem-solving, maintaining a positive overall outlook, and using good communication skills with every member of the family.

Dahlquist et al., (1995) examined marital adjustments as it related to the coping process among 42 mother-father pairs of children with cancer. The study took place over a four-year period. Questionnaires were received from both the mother and the father in the same family. The children of the 42 couples that participated were given a diagnosis with cancer on an average of 20 months prior to evaluation. “Approximately 48% of the children had leukemia, 17% had lymphoma, 26% had solid tumors, and 9% had brain tumors” (Dahlquist et al, 1995, p. 544). The children in the study ranged in age from ages 22 months to 18 years with a mean age of 8 years

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

old. There were 19 girls and approximately 88% of the children were Caucasian. Based on how the parents described their child's medical status, each child was given a status of either improved or not improved since diagnosis using this specific criteria: "For tumor patients, if the tumor currently was smaller than it was at the time of diagnosis, health status was coded as improved. No reduction in size of the tumor, an increase in size, or metastases were considered not improved. For leukemia patients, if the child was in remission and had not relapses, health status was considered improved. If the child has relapsed or had not achieved remission, health status was considered not improved" (Dahlquist et al, 1995, p. 544). From this criteria, seven children were classified as not improved. Anxiety, depression, adjustment, and parents' response to stress were measured with questionnaires. Results showed that mothers scored considerably higher than fathers on anxiety at the time of diagnosis, but when compared to the mothers' scores at follow-up they were significantly lower for anxiety, whereas there was no change in the fathers' anxiety. This suggested that the mothers' mean state and trait anxiety scores decreased to close to normal levels over time. Parents of children whose health status did not improve were compared with parents whose children's health status did improve and the findings indicated that the fathers of children whose health had not improved reported less marital distress. Also findings showed that mothers appeared less anxious over time, but there was no evidence about the same type of change in fathers. From these findings, one can conclude that mothers' anxiety levels decrease over time after diagnosis but the fathers' anxiety levels do not change much.

Sloper (2000) investigated the levels of psychological distress in parents of children with cancer. Three hypotheses were addressed; the first hypothesis stated that parents would show higher levels of stress if their children experienced longer hospitalizations, relapses, or if the family experienced financial issues. The second hypothesis specified that higher levels of

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

distress at both 6 and 18 months post-diagnosis would be related to the resources and coping strategies that the parents used. The third hypothesis indicated that psychosocial resources would be significant indicators of distress. Sloper, used questionnaires to collect data. Results showed that parents whose children had completed treatment were not any less distressed than those whose children that were still receiving treatment. Also, family cohesion was an important resource for mothers and fathers and helped with adjustment to the cancer. The findings from this study suggest that mothers use the support from other parents and hospital staff to help reduce their distress. This was likely due to the fact that in the majority of the families, the mothers were the ones that spent more time in the hospital with their child. Sloper, noticed that further investigation on the issue of distress in parents would be helpful to understand parental reactions to the diagnosis and hospitalization. Sloper, pointed out that researchers need to study the families of childhood cancer survivors after an extended period of time after diagnosis and treatment in order to follow up on the effects on the parents and siblings over a longer period of time.

Additional research studies show that sometimes mothers and fathers cope differently from one another, like the findings from Sloper (2000). Gerhardt et al. (2007) used questionnaires to gather data from families that met the following criteria: The child with cancer was (a) eight to fifteen years of age, (b) receiving chemotherapy for cancer, and (c) in school full-time without special education. Overall, 49 families participated in the study. Families were surveyed 18 months post-diagnosis. The questionnaires asked participants about their marital status, education, occupation, income, number and age of children, and included a symptom check list, a measure of parental distress, a family environment scale, and a social support interview. Results indicated that mothers of children with cancer reported significantly more

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

anxiety than the control group, which consisted of mothers of children who did not have cancer. Fathers in this study did not differ between the two groups. The results also revealed that mothers of children with cancer responded better to the situation the larger their support network. Gerhardt et al. noted that mothers of children with cancer may be at a greater risk for distress relative to fathers due to characteristics of family roles. For instance, mothers typically play a larger role in caregiving while the father is traditionally the financial provider for the family. Overall, data found in this study showed that families of children with cancer are generally resilient during treatment, but that mothers typically show more distress and rely on social networks compared to fathers. However, it is important to note that research in this area is often conducted only with families of children that are in remission, rather than children that are considered “cured.”

Norberg and Boman (2008) assessed symptoms consistent with posttraumatic stress related to a child’s illness and generic distress in parents of childhood cancer patients. The study consisted of both a treatment and a control group. The treatment group was comprised of 474 parents of children who had been diagnosed with cancer. Among the 474 parents, 266 of them were mothers and 208 were fathers. The control group consisted of 176 parents; fifty-seven percent were mothers and 43% were fathers. Questionnaires were used to collect the data. Results indicated that parents showed increased distress symptoms, such as anxiety, depression, and traumatic stress, along with some marital conflict within the first year after their child was diagnosed. Also, parental distress varied depending on the time from diagnosis. Parents with more recently diagnosed children had higher levels of anxiety, depression, traumatic stress, and marital conflict compared to the parents of children that had been diagnosed for a longer time period. Mothers and fathers assessed within the first five years after diagnosis showed higher

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

levels of anxiety, depression, traumatic stress and marital conflict compared to parents of healthy children. Clearly, time has an effect on family coping after cancer.

Silva et al. (2010) conducted a meta-analysis that looked at the effects of cancer on marital relationships after children were diagnosed with cancer. The guiding question for the study was “How did childhood cancer affect parents’ marital relationships?” Silva et al. analyzed articles that were published between 1997 and 2009. Key words such as, neoplasm, child, marriages, spouses, family relationships, and nursing were used in finding the articles. Articles were selected for review if (a) the topic addressed parents’ relationships during childhood cancer; (b) participants included mothers, fathers, or both; and (c) the research design was either qualitative or quantitative. Fourteen specific articles met the search criteria. After careful review, Silva et al. identified four themes that emerged from the search (a) changes in the parent’s relationship during the trajectory of the child’s illness; (b) difficulty in communication between couples; (c) gender differences in parent stress and coping; and (d) role changes. There were positive and negative changes within relationships, communication, stress, and roles between parents when a child in the family was diagnosed with cancer. Fathers felt a stronger connection with their wives due to the longer time spent together caring for the sick child. On the other hand, fathers expressed that they felt interpersonal stress and a sense of isolation because the wives were more involved in the child’s illness. Negative changes such as high stress levels between couples, resulted in negative relationships. Some mothers in the Silva et al. study reported that, “despite a strong relationship with their partner, the adverse and stressful circumstances generated by the child’s illness weakened the connection with their partner” (p. 256). The meta-analysis confirmed that the experience of the child’s illness often is as stressful for fathers and mothers as it is for the child.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Litzelman, Catrine, Gangnon and Witt (2011) examined the relationship between child clinical characteristics and health related quality of life among parents of children with cancer or brain tumors and determined how parent psychosocial factors impacted the relationship. Parents, as well as the children living with cancer, were asked to participate in the study. The final sample consisted of 75 children with their parents. Parents participating in the study completed an in-person interviewer-assisted survey that included questions on socio-demographic characteristics and health behaviors. Litzelman et al. found that caregiver burden and stress interfered with the caring of a child in active cancer treatment. From these findings, it can ultimately help improve health outcome from children with cancer to reduce the health disparities among children with cancer, and address the health and parents and family of child with cancer. "Understanding the potential benefit of reducing burden, controlling stress levels, and seeking social support may help parents and their families cope with their caregiving role and improve their health and well-being" (p. 1267). It is likely that this improvement to parents' stress levels will improve the child's health and well-being.

Hagedoorn et al. (2011) examined the psychosocial consequences of a childhood cancer diagnosis for parents by conducting a meta-analysis. The researchers selected reviews and key papers that focused on the psychosocial consequences of relatives of child who are patients with cancer such as, parents and siblings of children with cancer, children of parents with cancer and partners of adults with cancer. The attention of this study was not to provide a systematic review, but to bring forth three areas of research on relatives and patients undergoing cancer together. Results revealed that parents of children with cancer were at an increased risk for anxiety, depression, and post-traumatic stress at the time of their child's diagnosis as well as several years after. Mothers were found to be at a higher risk for distress than fathers. The findings also

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

suggested that the distress tended to decrease with time for most parents, but different stressors such as worries of relapse and loss of the child lingered. Distress of a parent varied in the study depending on the diagnosis of the child. For example, parents of children with acute myeloid leukemia, brain and bone tumors reported more suffering and psychological distress compared to parents of children with acute lymphatic leukemia.

Hoekstra-Weebers, et al. (2012) examined coping and psychological distress in a longitudinal study with a sample comprised of 115 parents that had a child diagnosed with cancer. Parents' coping and psychological distress was measured with questionnaires at the time of diagnosis, 6 months after diagnosis, 12 months after diagnosis, and then 5 years after diagnosis. The study used a control group of 120 men and 110 women that were matched to the experiment group based upon demographics. The Goldberg General Health Questionnaire (GHQ) was used to measure psychological distress and the Utrecht Coping List (UCL) was incorporated to assess coping. The UCL includes seven subscales: Active problem focusing (e.g., viewing the situation calmly from multiple angles), palliative reaction pattern (e.g., drink, smoke, or otherwise divert attention away from the problem), avoidance (e.g., avoid the situation), social support seeking (e.g., asking for help from others), passive reaction pattern (e.g., withdraw into oneself), expression of emotions (e.g., using emotion to work off tension), and comforting cognition (e.g., consoling oneself with thoughts that things will get better).

Hoekstra-Weebers, et al.'s (2012) findings indicated that, overall, the experiment group used social support seeking more than the control group. When gender differences were examined the results showed that the mothers in the sample used social support seeking more often than the fathers but that they showed more distress when using passive reaction pattern and/or social support seeking, compared to the fathers. For fathers, the use of coping strategies



## HOW FAMILIES COPE WITH CHILDHOOD CANCER

at diagnosis reduced psychological distress at 6 months and 12 months but that their psychological distress increased when they decreased their use of avoidance, passive reaction pattern, expression of emotions, and active problem focusing. The findings from the Hoekstra-Weebers et al. study emphasize the importance of developing gender-based interventions when it comes to dealing with childhood cancer among families.

The diagnosis of childhood cancer is one of the most intense, troublesome, and lasting experiences that families can encounter. Overall, the literature shows that the life-threatening diagnosis and the initial medical treatments interfere with the daily life of the family as an entire unit and has the ability to hinder the normal routines and activities for a long period of time. Initially, the parental response to the diagnosis is more negative (e.g., anxiety, depression, marital stress) in the immediate aftermath of the cancer diagnosis, but over time, the negative reactions are not as prevalent. Parents become the primary focus of the family when it is time to respond and handle the critical news of a diagnosis, therefore; the finding emphasize that the more family cohesion and expressive support the family receives, the better their overall coping.

### **Sibling Responses to Childhood Cancer**

Childhood cancer may have long-lasting consequences, not only if the child stops treatment, but also after the child is said to have been 'cured'. The siblings of the child diagnosed with cancer are also affected by the cancer. For siblings, their brother or sister's illness and treatment is very hard. They notice that the illness causes changes in the family and may cognitively understand the situation, but that does not mean it is any easier for them to cope. Despite the expanding knowledge of the effects of childhood cancer on parents, the impact of childhood cancer on healthy siblings is less clear. Just because siblings understand the situation

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

does not mean that they are not having a hard time dealing and coping with it (Van Dongen-Melman, 1997). Siblings are particularly vulnerable to the adjustments and difficulties that are associated with the experience of a sibling diagnosed with cancer because of the intensive and lengthy treatments their sibling has to undergo. The attention of the family and friends has significantly shifted to mainly focus on the sick child leaving the healthy child out, which can make them feel less important in the family system. Research suggests that the siblings of a child diagnosed with cancer may experience similar stress to that of the child with cancer. However, families, friends, and even professionals tend to focus the bulk of their time and attention on the child with the illness and may overlook the siblings. Because of this, “siblings have been identified as the most neglected of all family members during serious childhood illness” (Ross-Alaolmolki, et al., p. 67, 1995). One way in which research has suggested to help is for parents to take the initiative to talk to their healthy children about his or her feelings and let them know that he or she is not left alone with their thoughts and emotions.

Houtzager, Oort, Hoekstra-Webbers, Caron, Grootenhuis, and Last (2004) found that family cohesion was an important resource for mothers and fathers which helped with parental adjustment in the family system. Houtzager et al. found that increased closeness in families of a child with cancer resulted in fewer adjustment problems for siblings by conducting a meta-analysis. The meta-analysis consisted of 83 participants aged 7 to 19 years old to assess siblings' reactions to another sibling's pediatric cancer at 1, 6, 12, and 24 months after diagnosis. The main research question was, “To what extent are cognitive coping strategies, family cohesion and adaptation related to the psychological well-being of siblings of pediatric cancer patients during the first two years following the diagnosis of cancer?” (593). The study looked at anxiety, quality of life, behavioral-emotional problems, and emotional reactions to the illness. The results

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

showed that the siblings of pediatric cancer patients were the most distressed shortly after their brother or sister was diagnosed. Siblings' symptoms rapidly decreased after the first 6 months. "The general trend of stabilization indicates that siblings show a remarkable resilience in their adjustment to illness over time" (Houtzager, et al. p. 599, 2004) . Siblings within a family of high adaptability during the disease process seemed to be more functional. Houtzager, et al. also found that sibling lower anxiety, insecurity, loneliness, and illness involvement helped the ill child remain optimistic. The ill child was more accepting of the changes taking place and handling the situation while keeping an open mind.

Nolbris, Enskar, and Hellstrom (2007) studied how siblings of children with cancer experienced everyday life. Ten siblings, who were at least age ten or older, had a brother or sister that was 6 months post-cancer diagnosis, and (the siblings with cancer) were undergoing treatment for either leukemia or a brain tumor, were asked to answer a broad-based series of open ended interview questions. The interviews were designed to give the siblings the chance to describe how they were experiencing their sibling's cancer in their own words. The themes identified from the interviews included the following: the description of the sibling's different situation with relation to normal life; worries and fears whether or not their siblings with cancer would survive the disease; and thoughts on the treatments and examination that their siblings were receiving. From these themes, Nolbris et al. were able to develop an overall theme, which was, "the awareness of a sibling-ship as a special relationship when a brother or sister had got cancer" (Nolbris, et al. p. 108, 2007). All of the participants in the study experienced anxiety and became more adjusted to the situation as time progressed. The findings also showed that the siblings who are not sick do not necessarily feel that their needs are being met.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Alderfer et al (2010) examined the psychosocial impact of childhood cancer on siblings by conducting a meta-analysis. The meta-analysis reviewed 65 relevant qualitative and quantitative papers that were published between the years of 1997 and 2008. The results showed that siblings of children with cancer showed a significant amount of post-traumatic stress symptoms, as well as negative emotional reactions such as shock, fear, worry, sadness, helplessness, anger and guilt. Like the parents of children with cancer, siblings' negative experience seemed worse the closer it was to the time of the initial diagnosis. What was different for the siblings from the parents, however, was that within two years of the diagnosis siblings started to have difficulties at school and that siblings worried a great deal about their own health after their sibling was diagnosed with cancer. The overall conclusion of the study was that siblings of children with cancer are at a higher risk for negative psychosocial effects than parents and should be provided with appropriate coping strategies and supportive services. The services provided to siblings should continue even after the child with cancer has gone into remission.

Hagedoorn et al. (2011)'s meta-analysis (see previous section for specific methodology information) examined the psychosocial consequences of cancer for siblings in addition to parents. The findings from their meta-analysis showed that, when a sibling was diagnosed with cancer, the siblings suffered from psychological morbidity and psychosocial problems such as, negative emotional reactions, sadness, helplessness, and school difficulties. Siblings of children diagnosed with cancer have often been referred to as 'the invisible child/children'. Because of this, research suggests that siblings of children with cancer have the need to express strong negative feelings, such as anger, jealousy and anxiety.

Overall, the studies reviewed in this section show that cancer negatively affects the entire family, but that the siblings have needs that are very different from the parents. Siblings may

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

appear to be on the path to healing in the immediate aftermath of a cancer diagnosis, but the effects of having to be ‘put on the back burner’ have long-lasting effects. These findings emphasize the importance the need for resources over time, particularly for siblings.

### **Family Role Changes After Diagnosis**

The effects of a childhood cancer diagnosis vary from family to family, but most families experience changes among intimate relationships, roles, responsibilities, needs, and future plans (Gerhardt, et al. 2007). Because childhood cancer can be extremely disruptive to a family’s daily life and emotional well-being, it affects all family members and therefore, the family systems theory is a relevant and appropriate theory to use to investigate the impact of cancer on family roles. Once a diagnosis is made, parents/caregivers can experience feelings of sadness, anxiety, anger, and even hopelessness. In some cases, facing the challenges of cancer may strengthen the parental relationship and commitment, and for others, it may cause more stress and create additional problems. This is particularly true if there is trouble in the relationship prior to the cancer diagnosis. The American Society of Clinical Oncology (2014) noted that caregivers can become overprotective and controlling in the face of their child’s cancer diagnosis, which can affect the exchange of information between the family and the medical team as well as with one another. Adjusting to role changes may not come easily, but according to the ABC-X Stress Model (McKenry & Price, 2000) it is necessary for healing. For example, a person who is mainly in control or serves as the caregiver may have trouble adjusting to a more dependent role. On the other hand, a person who typically takes on the caregiving role may have trouble taking charge and providing care in the face of cancer. The ABC-X Stress Model indicates that the more flexible families can be, the greater the likelihood that they will cope in a healthy manner (McKenry & Price, 2000).

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Alderfer et. al's (2010) meta-analysis (see previous section for methodology review) looked at the effect of childhood cancer on family roles. Findings revealed that the need for at least one parent to attend to the ill child at the hospital or at home, plus increased levels of parental distress, may make parents physically and emotionally unavailable. "Changes in family routines and roles may disrupt the day-to-day functioning of siblings, with some siblings assuming more household chores and responsibilities," (p. 790). Common themes identified in the Alderfer et al. study relevant to family roles included siblings' loss of attention and status within the family, an increase in responsibility, independence and maturity, and increased empathy, sensitivity, and compassion among the siblings. The role changes can curtail after school and other social activities for the family. With the disturbance of the everyday functioning that cancer may bring, tasks such as household chores may be completed by other siblings and/or the caregiver who normally does not take on that specific task. Cancer is messy for everyone, and in order to survive and thrive, family members have to sometimes adopt new roles.

Silva et al's (2010) study regarding the effects of cancer on marital relationships after children were diagnosed with cancer also examined family role changes after a child's cancer diagnosis. The findings showed that fathers found it more difficult to express and acknowledge their weaknesses and vulnerabilities to their partners because they were afraid that they would seem weak, when they were supposed to be the strong rock of the family. Some fathers reported that they felt guilty in their role of the breadwinner, because that put more emphasis on the mother's role of caregiver. Mothers in the study reported that during their child's illness, their role as a wife decreased but that their role as caregiver increased. This change appeared to have had a negative effect on the marital relationship. Also, mothers in the study indicated that they

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

became exhausted and tired from taking care of their sick child, but then the fathers were also exhausted and tired from working all day. Both seemed to feel guilty about this. Finally, mothers focused more on their involvement in the child's life with their physical presence while fathers were more likely to advocate for their child and wife. Overall, balancing the roles and the difficulties of childhood cancer causes additional stress on family roles. Relationships between couples and among families can be fragile during a childhood illness.

Overall, literature has found that, having a child diagnosed with a life threatening disease such as cancer impacts the entire family system. While initially the diagnosis is shocking for the family and they react with stress, anxiety, and depressive symptoms, over time the symptoms seem to dissipate, except for siblings. With siblings, there is somewhat of a boomerang effect where they suffer anxiety, guilt, anger, etc. with the initial diagnosis, and then seem to improve, but then display different types of negative reactions later on. With regards to family roles, the literature suggests that family members may have to temporarily change and alter their roles within the family, or even take on new roles in order to cope. What is not clear at this point, is how those roles change over time (longer than one year) and whether siblings are able to bounce back after the second round of negative effects.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

### Chapter 3

#### Methodology

The purpose of this study was to examine how childhood cancer affects the family system after a period of time (at least one year) has passed after diagnosis. The following research questions were addressed in the current study:

1. How do parental roles and interactions change after a year (or longer) has passed after a child in the family has been diagnosed with cancer?
2. How are the siblings of the child diagnosed with cancer affected after at least one year post-diagnosis?
3. Do mothers' and fathers' coping strategies differ from one another after a period of at least one year after diagnosis?

#### Research Design

The current study used a mixed-method research design. Surveys were distributed to potential participants via the Internet and included both closed-ended and open-ended questions.

#### Instrumentation

The survey that was used in the current study was developed by the principle investigator in consultation with her thesis advisor. Two open-ended questions were used to evaluate changes in coping strategies for the parents (caregivers) over time. An assessment of possible family roles was developed by the principle investigator to determine if there were role changes before and after a childhood cancer diagnosis after consulting the literature regarding marital and family roles. Finally, open-ended questions were created to assess sibling coping over time.



## HOW FAMILIES COPE WITH CHILDHOOD CANCER

### **Reliability and Validity**

Reliability for the quantitative items in the survey was determined by computing the alpha coefficient for the Czapek Family Roles Questionnaire. The results of the analysis indicated that  $\alpha = .73$ , which was considered acceptable by the principle investigator's thesis advisor. The entire survey was also examined by a member of the School of Family and Consumer Sciences' graduate faculty for evidence of face validity.

### **Procedure for Data Collection**

Subjects were recruited using a purposive snowball sampling procedure. The principle investigator advertised the study on her Facebook page, through the EIU School of Family and Consumer Sciences' faculty list serve, and on her advisor's Facebook page. A script was developed by the principle investigator and her thesis advisor to accompany the recruitment so that potential respondents would understand the nature of the study prior to volunteering to participate. Potential volunteers needed to fit specific criteria to participate: a) primary caregiver status (biological, step-parent, foster, or legal guardian), b) a child (under the age of 18) in their care that is at least one year past a cancer diagnosis, and c) be at least 18 years of age. If they matched the criteria for the study, they were directed to a website that contained the survey (see Appendix A) and the Informed Consent Form (see Appendix B). The survey was developed using Qualtrix software.

### **Proposed Data Analysis**

To evaluate how parental coping has changed from diagnosis until a significant amount of time has passed (at least one year), responses to two open-ended questions about coping were transcribed and then analyzed for commonalities. Once commonalities were identified, themes were developed and reported, using a selection of direct quotes to exemplify each theme.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

To determine how siblings coped with their sibling's cancer diagnosis over time, responses to the question on sibling responses were transcribed and analyzed for commonalities. After commonalities were identified in the responses, themes were created to illustrate the commonalities and direct quotes were added to the text to give the reader an idea of what the theme encompassed.

To answer the third research question, responses to the Czapek Family Roles Questionnaire were entered into SPSS (statistical software) and comparisons were made for each family role from time 1 (at diagnosis) to time 2 (post diagnosis) using a paired samples *t* test. In addition, the responses to the open-ended question about family roles were transcribed, analyzed for commonalities, and sorted into themes. Direct quotes were selected to illustrate each theme that was identified in the analysis.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

### Chapter 4

#### Results

The purpose of this research was to examine how families cope with childhood cancer a year or longer after diagnosis. A mixed-methods research design was used to collect data from participants. The three research questions included:

1. How do parental roles and interactions change after a year or longer has passed after a child in the family has been diagnosed with cancer?
2. How are the siblings of the child diagnosed with cancer affected at least one year post-diagnosis?
3. Do mother's and fathers' coping strategies differ from one another after a period of at least one year after diagnosis?

**Description of the sample.** The final sample contained 17 parents of children with cancer. The average age of the participants was 37.06 ( $SD = 8.29$ ) and the majority were female (94.1%). Frequencies were computed for the ethnicity of the participants and the findings showed that most participants were Caucasian (88.2%) and (11.8%) were Hispanic/ Latino. When the respondents were asked to identify the age of their child at the time of diagnosis, the average age was 3.96 ( $SD = 2.92$ ). Most of the children (64.7%) were female. At the time the data was collected, the average age of the child with cancer was 7.34 ( $SD = 4.35$ ). Nine respondents said that their child was considered cured of their cancer and the average age at the time of cure was 5.75 ( $SD = 4.69$ ). Fifteen respondents indicated that their child had siblings (range = 1 – 4). The mean amount of siblings was 2.07 ( $SD = 0.96$ ). When the respondents were asked about their relationship to the child with cancer, 82.4% indicated that they were the

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

biological mother, one was the biological father (5.9%), one was the child's grandmother (5.9%) and one was the child's aunt (5.9%).

### **Findings Sorted by Research Questions**

#### **How parental roles and interactions change after their child's cancer diagnosis.**

The first research question examined how parental roles and interactions changed after the diagnosis of their child. Participants were asked to "please describe in your own words, how your coping strategies changed before and after your child's cancer diagnosis." In addition, a quantitative family roles section was included to evaluate whether participants indicated that the family roles they occupied changed after their child was diagnosed with cancer.

Responses for the coping strategies qualitative question were examined by the principle investigator along with an independent reviewer (an undergraduate FCS student) for commonalities among the responses. After careful review, six overall themes were identified for this question. The first theme was named Anxiety as it exemplified feelings associated with worry/stress. Anxious behaviors and attitudes were conveyed through the open-ended questions as participants expressed that simple worries and stressors that once before were not simple worries and stressors became so. For example, one participant said, "I coped well during treatment although had anxiety. After treatment, I have a lot more anxiety about relapse and more stressed and anxious whenever child seems ill." This may indicate that because of the cancer diagnosis, any time the child became ill, the respondent possibly thought the worst, due to past experiences. While another participant indicated:

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

I have always been a worrier by nature. I let little things bother me. I think the dx just ramped up my worry. I worry about the cancer child. Small issues become big issues especially if I'm worrying over him more than usual.

Still another participant articulated that,

The only thing that is different is that I am less happy, I think. I used to have a lighter personality, but now I can never really get rid of the fear. I only assume that is how most moms feel after they have a kid. My kid's cancer could come back, but some person's kids could just as easily choke on something or fall down and hit it's [sic] head. I think my feelings are mostly normal.

Fear stemmed from the worry and anxiety of relapse which seemed to be a common trend for coping with a cancer diagnosis. Becoming fearful of something that one has no control over left little to no room for understanding the situation. The feeling of helplessness from not being able to figure out the situation themselves most likely added to the anxiety that respondents experienced. One participant expressed that when her daughter was diagnosed with cancer, it was hard for her as a mother to understand what was happening and what was going to happen next. Frustration grew within participants because of the lack of ability to do anything to prevent and help their child.

The second major theme centered on the Support that the participants were receiving, whether it was from the hospital staff, family members, extended family members, or other parents of children with cancer. Participants noticed that the diagnosis of childhood cancer made the family support system stronger. They grew closer with their significant others because they were there for them when they needed to talk. For example, one participant expressed,

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Before he was diagnosed I had no problems with coping skills, after diagnosis I needed a lot of family support and support from others such as hospital staff and other moms of children with cancer to cope with everything.

Another participant pointed out that,

We had family around which took a bigger role [sic] I. Helping care four our oldest son the first 7 months the youngest son was doing chemo and radiation. Husband worked 70+ hours a week so he would work, come straight to hospital to visit then go home to bed during inpatient stay. Other so. Would stay with family and come up for visits every couple days (on good days). When we were home, our immediate family was together and we just made it day to day.

And another noted that,

There weren't a lot of people I could talk to besides my husband, who went to see a therapist (who only spoke German). With my husband, we've always been able to joke about everything, even cancer; so I guess that was mostly how I coped.

The third theme that emerged from the data analysis concerned the Hobbies that the participants engaged in to help with the coping process. When a child is diagnosed with cancer, there is a lot of down time while families wait for treatment, wait to speak to a doctor, or wait for results. After reviewing the data, it appeared that participants showed interest in keeping themselves busy to make the time go by faster and refocus their thoughts. Some of the respondents indicated that they developed healthy hobbies. However, others took part in

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

addictive dangerous behaviors like consuming alcohol. For instance, one respondent indicated, “I also wrote a novel-fiction- to burn the waiting time.” While another stated,

I am a natural introvert, so during her treatment I realized I was a lot better off by having a creative outlet and having an understanding husband that let me voice everything that I was feeling without judging me.

One participant wrote, “Before: talked to friends. Exercised [sic]. Ate when worried or anxious. After: felt isolated and withdrawn. Journalled [sic]. Drank alcohol.”

The fourth theme found among the responses for the first research question was Spirituality. “Trusting in God, praying, and following the plan that was mapped out for us” said a participant. Another reported that:

I know that coping strategies are mainly placed in the psychological and psychosocial realm. I believe that you can't separate “coping” from your spiritual person. Needless to say, I think that my coping strategies were well grounded in my faith, trusting God that this was all part of His plan. When my daughter was diagnosed though, it shook my faith a bit since you never imagine that it could happen to your child. I didn't leave my faith, but I definitely questioned God more and didn't just take every circumstance at face value.

Another conveyed, “We relied heavily on pure faith.” Faith encompasses the unexpected and since having a child diagnosed with cancer leaves parents and loved ones feelings powerless and helpless during this crucial time, they chose to reach out to something bigger than themselves for support.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

The fifth theme that emerged from the data was Survival. There seemed to be a consensus among the respondents that they felt like they went on an auto-pilot mode in order to cope. For example, one of the parents wrote:

My husband felt like something had been burned out of him. [sic] we could the approach with our daughter that since we did not how ma days she had left, we'd live each one as fully as we could. If she couldn't live long, she at least could live large.

Multiple participates indicated that they went into a kind of "survival mode." "Before DX we were you g [sic] parents trying to manage two children close in age, after DX we went I [sin] to survival mode." Another said "I think my coping strategy then and now was just do what needed to be done."

The last theme that was identified by the principle investigator concerned the feeling of Powerlessness over the situation. Respondents expressed that they felt confused and lost when their child was hurting and not having any control over the situation was something that most of participants wrote about struggling with. Having lots of questions and concerns and not being able to get or understand the answers took its toll on the participants. One respondent specified, "At first I was very frustrated with my lack of ability to do anything." Another said, "It upended us emotionally to be powerless over the situation."

A quantitative section was added to the questionnaire to evaluate whether family roles changed before and after the child's cancer diagnosis, which was also part of the first research question. Seventeen potential family roles were posed to the participants and they were asked to rank how often they took on the role under consideration on a Likert-type scale that was scored



## HOW FAMILIES COPE WITH CHILDHOOD CANCER

from 1 to 5 (1 = never; 5 = always) before the cancer diagnosis and then again after the cancer diagnosis. Paired sample *t* tests were then conducted to determine which roles changed over time using a 95% confidence interval. The findings indicated that two of the roles changed at  $p < .05$ . These included cooking meals and romance. An examination of the means for the roles before and after diagnosis indicated that the participants took on the role more often *before* the cancer diagnosis. Two others approached significance, one at  $p = .06$  and one at  $p = .09$ . Since the sample size was so small for the current study, it was deemed important by the principle investigator's thesis advisor to report these results as well. These roles included educator and pet maintenance. The pattern of change was aligned with the other roles that had changed significantly; the participants had taken on the role under consideration less after the cancer diagnosis.

In addition to the quantitative items in the survey, an open-ended question assessed whether the respondents thought their family roles had been affected by the cancer experience. Most of the participants indicated that they did not experience family role changes and that everything stayed the same. "Roles havne't [sic] really change much," said one participant. Another participant noted, "They haven't really changed. My husband lost his job, so more stress on the family. His is taking care of home issue more while I am at work." One participant wrote that, "They haven't changed completely but I find it difficult to be able to complete household work now such as cleaning cooking." Finally, another respondent wrote:

The family roles really hasn't changed much. Our schedules are just busier and now the house isn't as clean. It is also much harder to get to the store or run errands. Stayed pretty much the same. We planned it this way.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

A comparison of the quantitative results with the qualitative section revealed that participants may not have realized that some of their roles had changed after the cancer diagnosis as they did not write about them changing. However, the quantitative analysis revealed that four of the seventeen roles were affected.

### **How siblings of the children with cancer handled the diagnosis at the time of diagnosis.**

The second research question asked how the siblings of the child who had cancer handled the cancer diagnosis socially, emotionally, and behaviorally at the time of diagnosis. Participants were asked to indicate “In your own words, please describe how your other children (if you have any), handled the cancer diagnosis socially, emotionally, and behaviorally, at the time of diagnosis.” Two themes surfaced after a careful analysis of the responses. The themes were named: Expression of Emotion and Withdrawal. For example, one participant wrote that “My daughter was sad and had a hard time expressing how she felt. She didn’t really understand why he wouldn’t play with her. We had to explain to her that he was sick. She was extremely quite [sic].” Another said “They were sad, scared, and insecure.” A third respondent stated:

It was hard for our oldest son, because he was at the age where he understood what could happen to his sister. We also made a radical change in our living situation (moving from a European city where we were missionaries, to an American city) so that was a challenge for everyone - new home, new friends, new everything. We tried to keep everything as normal as possible having him go to kindergarten every day and only visiting his sister in the evenings and weekends. The Child Life specialists helped us tremendously in helping him process everything. Her younger sister was born 3 months after our daughter's

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

diagnosis so she didn't know what was going on. She was an amazingly, calm baby that was the best therapy for all of us, even our daughter fighting cancer. Sometimes, when everything was stressful we would just take turns holding the baby and everything would feel great (plus a pint of ice cream if it was super stressful).

Another participant expressed:

Our son was in kindergarten, and didn't fully understand. Child life went to their school and gave presentations to both of their grades, which really helped. Max knew she was sick, and he worried about her. Both kids were great and supportive of each other. Eventually though She [sic] got so much attention, he said he felt invisible a lot of the time. That was quite hard on him, especially when we went to San Francisco for six months, and he and dad were home. His first grade teacher let him wander the halls and sit under his desk when he needed to--and loved him more than taught [sic] him that year I think.

One respondent with two children reported that, "Collin did well initially. Then at relapsed grew angry and violent. Patrick withdrew and struggles the majority of the time." And another wrote:

Both kids never thought of their life as any different or weird. Both very young at time of DX so it was their "normal". Older son wouldn't spend the night with anyone after treatments done. He was affected by the constant shuffle from us to family during I patient stays. He slept with us for over a year, first I. Our bed then slowly Dow to a pallet next to our bed then on to his on [sic] bed bit with his

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

brother in the room with him. Boys share a room now. Cancer son is just now starting to realize how different his life has been from other kids.

When a child is diagnosed with a critical life threatening illness, siblings may begin to withdraw from regular activities as a way of coping in the immediate aftermath. However, it seems that while siblings appear to bounce back after the family has accepted the cancer situation, siblings may fall back into unhealthy patterns of behavior. It also appeared that the siblings that were involved in the situation and were given proper and open communication handled the situation more smoothly.

### **How siblings of the children with cancer handled the cancer diagnosis a year or more after diagnosis.**

A second question tapped into the siblings' responses after a year has passed since the initial diagnosis. All participants had to be at least one year past diagnosis, so all of the responses assessed siblings' coping long after the initial diagnosis. The common theme among the responses seemed to be centered around Emotional Responses. As one respondent reported, "For the most part, they are not sad or scared anymore. Our 15 year son seems to be holding onto some resentment, has anger issues that didn't seem to be there before." Another said,

Both accept cancer as part of their lives and talk openly about it. Talk about friends that have died from it and understand how harda [sic] little of the emotional toll it took on our whole family. Daughter has no clue!

Another shared that, "Collin worries a great deal that it will come back again ad [sic] that he is going to die soon. Patrick does not talk about it at all...even when prompted."

One of the respondents reported on their child's advocacy for their sibling:

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Now we advocate for others. Our son shaved his head for St. Baldricks to honor his sister, and she held his hand. They see that we do fun things to raise money so that other kids won't have to be sick the way our daughter was. We don't shelter them from it, it is just a part of who we are now.

However, advocacy was not expressed by the other participants so it was not considered a theme.

### **How coping strategies differ between mothers and fathers.**

The third research question examined how partners differed when it came to coping with their children's childhood cancer diagnosis after a year or more had passed. Overall, after looking closely at the data, the principle researcher found distinct differences and similarities across the responses. Women's coping strategies included expressing their emotions, talking, eating, having a positive attitude, and by focusing on the problem. Participants indicated that they would talk about the cancer with other mothers who were undergoing the same experiences, with hospital staff for recommendations and guidance, and to family members for emotional support. Women also reported that they were more optimistic about the diagnosis and expressed positive attitudes by living out each day, day by day. On the other hand, men engaged in avoidance, worrying about death, isolating themselves, and burying themselves in their work. These were different from the women's coping strategies and appeared to be more negative in nature. Men seemed more focused on the need to provide financial stability during the diagnosis and this took precedent over everything else. However, it's important to note that both sexes reported an emotional response as part of their coping. It just seemed that for women the emotion was more focused on anxiety in a general sense, where for men it was more specific; the men were more likely to express fear of their child dying.

## Chapter 5

### Discussion and Conclusion

The purpose of this study was to examine how childhood cancer affects the family a year or more after diagnosis. Very little, if any, research has been conducted focused on how families cope over time. There have been studies completed at the six, eight, and ten months mark after a childhood cancer diagnosis, but not a year or longer after diagnosis. Although the current study was designed to examine both males and females, the majority of the participants in the current study were females. Thus, the results of the current study can only be applied to the mothers' point of view, as opposed to the fathers'. The majority of existing research regarding how families cope in the face of childhood cancer also relied heavily on female participants' point of view. In fact, many researchers noted that it was difficult to examine fathers' coping because of their lack of participation in research studies. Clearly, this gap needs to be addressed in future studies for an accurate account of family coping.

The current study revealed that mothers expressed a great deal of anxiety and worry about their children, which was similar to what has been published in previous literature. It is likely that this response can be attributed to the caregiver role that mothers are more likely to hold, in comparison to men. The women in the current study also reported that, taking up a hobby or having a strong sense of faith was critical to coping with their child's cancer. For example, some participants wrote novels about their experience and journey, exercised to clear their minds, and others tried to find meaning in the experience and prayed. The participants in the current study reported on their partners' coping, but it is important to note that the majority of the participants were female (94.1%) so the findings concerning the participants' partners were

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

from the mothers' point of view in almost all of the cases. Findings showed that the fathers used opposite types of coping strategies, such as avoidance and burying themselves in work to help get them through the situation. These coping responses suggest that men feel strongly about their role as the breadwinner and that they have to continue to work to help with the financial burdens that cancer can bring.

Siblings of children with cancer appear to experience many emotions and tend to feel invisible when their brother or sister is diagnosed with cancer. For instance, the participants in the current study reported that their other (non-sick) children displayed emotions such as sadness, worry, and fear for their siblings in the immediate aftermath of the cancer diagnosis, but that over time, they were able to experience more positive growth and advocacy. One participant discussed their (non-sick) child's involvement in cancer awareness. However, some of the respondents in the study reported that their (non-sick) children exhibited other types of behavior problems when a year or more had passed since diagnosis (of their sick child). Previous literature on this topic has indicated that the siblings of children with cancer often feel invisible and ignored; it is highly likely that the behavior issues noted by the participants in the current study were linked to these types of feelings.

As for family roles, prior to their child's cancer diagnosis versus after the cancer diagnosis, participants indicated that they did not feel family roles had changed a great deal within the qualitative portion of the survey. After further investigation, the principle investigator noticed that within the quantitative data collection that there were statistically significant changes from time 1 to time 2 for some of the family roles. This suggests that when parents are asked to talk about how their family roles were altered by the cancer experience in their own words, they either do not realize that there have been changes or they do not view them as changes.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

However, when presented with a list of family roles and a Likert-type scale where they can indicate how much the role fit them before and after the cancer diagnosis, they do note subtle, but sometimes statistically significant changes. One of the roles that changed concerned the person that prepares the family meals. The data showed that the participants in the current study prepared meals for the family less after their child was diagnosed with cancer. Perhaps prior to the diagnosis they had more time to prepare meals and go to the grocery store to shop for ingredients.

The respondents in the current study also indicated that the role of “family educator” had changed over time. The role of educator which was defined as “a class parent, PTA member, helping children with homework and school projects.” After the cancer diagnosis the participants in the current study noted that they took on the role of educator less than they did before the diagnosis. This could be due to the lack of time spent at home and the increased amount of time spent in the hospital after a child is diagnosed with cancer. Romance was another family role that changed before and after diagnosis in the current study. Romance was defined as “setting date nights, initiating sexual intercourse with spouse/partner etc.” The participants indicated that their participation in this role decreased after the cancer diagnosis. As was consistent with previous literature, the respondents may have had less time for romance after their child was diagnosed with cancer. All three of the family roles that experienced change are critical to family functioning and cohesiveness, as defined by systems theory, which emphasizes the importance of flexibility in family functioning in times of crisis.

Previous literature and the findings from the current study imply that when a child is diagnosed with cancer it affects the entire family. The findings in the current study suggest that social support, positive coping strategies, faith, and hobbies to help pass the time help families



## HOW FAMILIES COPE WITH CHILDHOOD CANCER

have an easier time making it through the difficult journey that cancer brings. The results from the current study also show that even after a year has passed since the initial cancer diagnosis, the families are still profoundly affected. Providing support groups for the families of children with cancer, particularly for siblings, over time (even after the cancer has been “cured”) would benefit these families a great deal.

### **Limitations**

There were several limitations to the current study. The first limitation was that all of the participants were randomly recruited from social media websites, and word of mouth during the week the survey was made available online. Another limitation concerned the snowball sampling procedure. While the snowball sampling procedure was appropriate for the current study as it was exploratory in nature, it limited the participants in the study and was not random. The survey was designed to answer specific research questions in hopes of discovering personal stories about coping with cancer. While survey methodology allowed for a wider distribution, an interview methodology would have allowed the researcher to follow up and ask additional questions and ask for clarification and more detailed responses. The survey included open ended questions, allowing the participants to express themselves freely and write their own personal responses (rather than checking off preconceived ideas on an entirely quantitative survey), but the principle investigator for the current study noticed that the responses became shorter and not as detailed as participants completed more and more of them. The survey did not come with any prize or incentive to participate, therefore it was completely optional and voluntary, which could have limited the amount of participants. Finally, the question about siblings’ responses to the cancer diagnosis was limited because it was not answered by the siblings themselves. Therefore, the responses to this question were from the adults’ perspective, not the child’s’.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

### **Recommendations**

Future research should try to recruit participants in a random fashion in order to make the findings more generalizable. In addition, other recruitment strategies should be explored in order to increase the sample size. Future researchers could try to recruit families from hospital support groups and/or cancer survivor support groups in addition to using social media. The current study looked at more than one type of cancer, but the sample size was too small to compute statistical analyses on the differences between cancer diagnoses. A larger sample size would allow for these types of analyses to take place and could extend the existing empirical literature on that topic.

A longitudinal research design would allow researchers to study families that have children with cancer from the time of diagnosis, allowing a much deeper and broader understanding of how childhood cancer affects the family over a long period of time. This type of design would be important to the Family and Consumer Sciences discipline because of the effects of childhood cancer on importance family relations over the lifespan, as well as to specific topic areas such as family in crisis, and disadvantaged families.

### **Conclusion**

Research on how families cope with childhood cancer allows practitioners, educators, hospital administrators and staff, and policymakers a more thorough understanding of how families are able to face the challenges that accompany a cancer diagnosis. The results from this study indicated that overall, women tend to cope in more positive ways than men, that siblings often feel excluded and can experience emotional and behavioral issues long after the cancer diagnosis, and that family roles are threatened when there is a crisis like this as the focus goes

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

from family functioning to family survival. Families that have a child with cancer need support networks, resources, counseling, positive interactions with other families facing the same issues, and policies that provide support and resources to hospitals for this purpose.

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

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## HOW FAMILIES COPE WITH CHILDHOOD CANCER

**Appendix A: Instrument****Keep Calm and Cope on Survey**

The purpose of this study is to examine the effects of childhood cancer on families after a period of time (at least one year) since the cancer was diagnosed. Research shows that families cope in a number of different ways in the immediate aftermath of a diagnosis of childhood cancer (Patterson, Holm, & Gurney, 2004), but very few, if any, studies look beyond one year after diagnosis. This survey is completely voluntary and the responses and results collected in this survey are completely anonymous. No identifying information will be collected. Participants can choose to skip any question(s) that make them uncomfortable without any consequences. Participation is completely voluntary. This research is being conducted as part of the requirements for the Eastern Illinois University (EIU) Honor's College requirements with the School of Family and Consumer Sciences. I can be reached via email ([ckczapek@eiu.edu](mailto:ckczapek@eiu.edu)) and my Honor's Thesis Faculty Advisor can be reached at [lmoyer@eiu.edu](mailto:lmoyer@eiu.edu) or (217) 581-8584 if there are any questions. This research was approved by the EIU Institutional Review Board on April 11, 2014 IRB # 14-066. Thank you in advance for your participation.

1. What is your current age: \_\_\_\_\_

2. Gender (please circle one): Male      Female      Transgender      Androgynous

3. Parental relationship (to the child who has the cancer diagnosis; if there is more than one child with cancer, please answer the question relevant to the oldest child with cancer):

\_\_\_\_\_ Biological Mother

\_\_\_\_\_ Biological Father

\_\_\_\_\_ Step-Mother

\_\_\_\_\_ Step-Father

\_\_\_\_\_ Foster-Mother

\_\_\_\_\_ Foster-Father

\_\_\_\_\_ Adopted-Mother

\_\_\_\_\_ Adopted-Father

\_\_\_\_\_ Other: (Please specify):

4. Your race/ethnicity:

\_\_\_\_\_ Caucasian

\_\_\_\_\_ African-American

\_\_\_\_\_ Hispanic/Latino

\_\_\_\_\_ Asian

\_\_\_\_\_ American-Indian

\_\_\_\_\_ Native Hawaiian

\_\_\_\_\_ Pacific Islander

\_\_\_\_\_ Native Alaskan

\_\_\_\_\_ Mixed

\_\_\_\_\_ Other: (Please specify): \_\_\_\_\_

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

5. Your current relationship status (please indicate only ONE):

Married                       Civil Union                       Dating  
 Single                       Divorced                       Widowed  
 Other: (Please specify): \_\_\_\_\_

6. Current age of child with cancer? \_\_\_\_\_

7. Age of child with cancer (at the time of diagnosis?) \_\_\_\_\_

8. Is the child considered cured of cancer at this point in time? (Circle one)

Yes    No

9. If so, please indicate the age of the child with cancer when they were considered cured? \_\_\_\_\_

10. Gender of child with cancer? (Circle one)

Male    Female    Transgender    Androgynous

Cancer Diagnosis:

Leukemia                       Brain Tumors                       Wilms tumors  
 Hodgkin lymphomas     No-Hodgkin lymphomas  
 Rhabdomyosarcomas     Retinoblastomas                       Osteosarcomas  
 Other: (Please specify) \_\_\_\_\_

Does the child with cancer have any siblings (please circle) (if yes, list how many siblings and their ages)

Yes    No

If so, how many siblings: \_\_\_\_\_

Please indicate each sibling's gender, age, and relationship to the child with cancer (circle one):

Sibling 1 gender: \_\_\_\_\_      Sibling 1 age: \_\_\_\_\_      Biological sibling      Step-sibling      Half-sibling  
 Foster

Sibling 2 gender: \_\_\_\_\_      Sibling 2 age: \_\_\_\_\_      Biological sibling      Step-sibling      Half-sibling  
 Foster



## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Sibling 3 gender: _____ sibling Foster	Sibling 3 age: _____	Biological sibling	Step-sibling	Half-
Sibling 4 gender: _____ sibling Foster	Sibling 4 age: _____	Biological sibling	Step-sibling	Half-
Sibling 5 gender: _____ sibling Foster	Sibling 5 age: _____	Biological sibling	Step-sibling	Half-
Sibling 7 gender: _____ sibling Foster	Sibling 7 age: _____	Biological sibling	Step-sibling	Half-
Sibling 8 gender: _____ sibling Foster	Sibling 8 age: _____	Biological sibling	Step-sibling	Half-
Sibling 9 gender: _____ sibling Foster	Sibling 9 age: _____	Biological sibling	Step-sibling	Half-
Sibling 10 gender: _____ sibling Foster	Sibling 10 age: _____	Biological sibling	Step-sibling	Half-

How long since initial childhood cancer diagnosis (in years and months)

Years: \_\_\_\_\_

Months: \_\_\_\_\_

Directions: Please describe, in your own words, how your coping strategies changed before and after your child's cancer diagnosis:

Directions: Please describe, in your own words, how your coping strategies differ from your partner's (or former partner's if you are no longer in a relationship with them):

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Czapek Family Roles Questionnaire

Directions: Indicate the frequency with which *YOU* took on each of the family “roles” listed below *PRIOR TO THE CANCER DIAGNOSIS* using the following scale:

	1	2	3	4	5
	Never				Always
Breadwinner/chief earner for the family	1	2	3	4	5
Nurturing for the children	1	2	3	4	5
Disciplining the children	1	2	3	4	5
Cooking the meals	1	2	3	4	5
Cleaning the house	1	2	3	4	5
Driving the children to/from school and other activities	1	2	3	4	5
Event planner (e.g., birthdays, holidays, traditions)	1	2	3	4	5
Yard work/outdoor work (e.g. mowing the lawn, shoveling snow)	1	2	3	4	5
Emotional climate control (maintaining a positive emotional climate; functioning smoothly)	1	2	3	4	5
Grocery shopper	1	2	3	4	5
Treasurer (e.g., pays the bills, manages the bills)	1	2	3	4	5
Spiritual/religious obligations	1	2	3	4	5
Educator (e.g., class parent, PTA, helping with homework)	1	2	3	4	5
Primary decision maker	1	2	3	4	5
Romance (e.g., setting date nights, initiating sexual intercourse with spouse/partner)	1	2	3	4	5
Peacemaker	1	2	3	4	5
Playing with the children	1	2	3	4	5
Leaders or executive of the family (holding authority)	1	2	3	4	5



## HOW FAMILIES COPE WITH CHILDHOOD CANCER

Playing with the children	1	2	3	4	5
Leaders or executive of the family (holding authority)	1	2	3	4	5
Pet maintenance	1	2	3	4	5
Physical security (food, clothing, shelter)	1	2	3	4	5

Directions: Please describe, in your own words, how the family roles have changed in your family before and after the cancer diagnosis:

Sibling Responses

Directions: In your own words, please describe how your other children (if you have any), handled the cancer diagnosis socially, emotionally, and behaviorally, at the time of diagnosis:

In your own words, please describe how your other children (if you have any), handle the cancer diagnosis socially, emotionally, and behaviorally, at the THIS POINT IN TIME:

THANK YOU FOR YOUR PARTICIPATION!

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

### Appendix B: Informed Consent:

#### **CONSENT TO PARTICIPATE IN RESEARCH**

##### *Keep Calm and Cope on: How families cope with childhood cancer*

You are invited to participate in a research study conducted by Christine Czapek and Dr. Lisa Moyer from the Family and Consumer Sciences at Eastern Illinois University. Your participation in this study is entirely voluntary. Please ask questions about anything you do not understand, before deciding whether or not to participate.

You have been asked to participate in this study because you have/had a child that was diagnosed with cancer.

#### • **PURPOSE OF THE STUDY**

The purpose of this study is to examine how childhood cancer affects the family system after a period of time has passed (at least one year) since the cancer was diagnosed. Research shows that families cope in a number of different ways in the immediate aftermath of a diagnosis of childhood cancer (Patterson, Holm, & Gurney, 2004), but very few, if any, studies look beyond one year after diagnosis. When a child is diagnosed with cancer, there are consequences for the entire family. Family roles, interactions, emotional responses, and overall well-being are affected. The effects of the diagnosis continue long after the child has gone into remission, or has succumbed to the disease; however, the bulk of the research on family coping has only looked at how the child and family have coped up to a year after the cancer diagnosis. Systems theory indicates that families are profoundly connected and affected by one another. Thus, it is anticipated that the effects of childhood cancer last long after the diagnosis. This research has implications for families, Child Life Specialists, therapists, teachers, doctors, hospital staff, hospital administrators, and policymakers.

The following research questions will be addressed in this study:

1. How do parental roles and interactions change after a year (or longer) has passed after a child in the family has been diagnosed with cancer?

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

2. How are the siblings of the child diagnosed with cancer affected after a period of time has passed (at least year)?

3. Do mothers' and fathers' coping strategies differ from one another over time after a child's cancer diagnosis (at least one year)?

- **PROCEDURES**

If you volunteer to participate in this study, you will be asked to:

Complete an online survey that includes both closed-ended and open-ended questions. The survey was developed by the principle investigator in consultation with her thesis advisor. Two open-ended questions will be used to evaluate changes in coping strategies for the parents (caregivers) over time. An assessment of possible family roles was developed by the principle investigator to determine if there were role changes before and after a childhood cancer diagnosis after consulting the literature regarding marital roles. Finally, some open-ended questionnaires were created to assess sibling coping over time.

- **POTENTIAL RISKS AND DISCOMFORTS**

It is possible that answering questions about your child's cancer experiences may cause some minor emotional distress. A list of resources for families of children with cancer will be provided to all participants at the end of the survey. All of the surveys will be completely anonymous; no identifying information will be collected. In addition, participants can choose to not answer any questions that make them feel uncomfortable.

- **POTENTIAL BENEFITS TO SUBJECTS AND/OR TO SOCIETY**

Research shows that families cope in a number of different ways in the immediate aftermath of a diagnosis of childhood cancer (Patterson, Holm, & Gurney, 2004), but very few, if any, studies look beyond one year after diagnosis. This research will serve as a foundational framework for future research on this topic and provide information to families, practitioners, Child Life Specialists, hospital staff,

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

educators, and policymakers to help families cope more effectively following the aftermath of a child's cancer diagnosis.

- **CONFIDENTIALITY**

All of the information collected in the current research study will be completely anonymous. No identifying information will be collected from participants.

- **PARTICIPATION AND WITHDRAWAL**

Participation in this research study is voluntary and not a requirement or a condition for being the recipient of benefits or services from Eastern Illinois University or any other organization sponsoring the research project. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind or loss of benefits or services to which you are otherwise entitled.

There is no penalty if you withdraw from the study and you will not lose any benefits to which you are otherwise entitled. You may also refuse to answer any questions you do not want to answer.

- **IDENTIFICATION OF INVESTIGATORS**

If you have any questions or concerns about this research, please contact:  
Dr. Lisa Moyer 1- 217- 581-8584 [lmoyer@eiu.edu](mailto:lmoyer@eiu.edu) (faculty mentor)  
Christine Czapek, 1-312-301-1238 [ckczapek@eiu.edu](mailto:ckczapek@eiu.edu) (principle investigator)

- **RIGHTS OF RESEARCH SUBJECTS**

If you have any questions or concerns about the treatment of human participants in this study, you may call or write:

Institutional Review Board  
Eastern Illinois University  
600 Lincoln Ave.  
Charleston, IL 61920  
Telephone: (217) 581-8576  
E-mail: [eiuirb@www.eiu.edu](mailto:eiuirb@www.eiu.edu)

You will be given the opportunity to discuss any questions about your rights as a research subject with a member of the IRB. The IRB is an independent committee composed of members of the University

## HOW FAMILIES COPE WITH CHILDHOOD CANCER

community, as well as lay members of the community not connected with EIU. The IRB has reviewed and approved this study.

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If you voluntarily agree to participate in this study please check the “agree” box to move forward to the actual survey. By checking “agree,” you agree that you understand that you are free to withdraw your consent and discontinue participation at any time.

I agree to participate

I do not agree to participate



**HOW FAMILIES COPE WITH CHILDHOOD CANCER**