# THE SINGLE FATHER CAREGIVER: AN AUTOETHNOGRAPHY OF MY FIFTEEN-MONTH JOURNEY CARING FOR MY SON WHO WAS DIAGNOSED WITH CANCER

by

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### **ABSTRACT**

Cancer Research is growing and helping people every day. The mortality rate for children with cancer is over 75%. The strides in research for a cure for cancer are making progress, but we have forgotten the unsung heroes behind the scenes parents. Research on the effects of parents with a child diagnosed with cancer is rushing to catch up. Parents were rarely considered before 2011. There is research on two-parent families and even less on single-parent families, with no research that focuses on single mothers. The single male parent caregiver has been all but forgotten. This research focuses on the burdens presented to the single male parent caregiver during the first fifteen months of the child's treatment program. This research was completed by a parent who lived this tragedy. The data collected in this research is from the autoethnography of the researcher. Thematic analysis emerged to answer how I can share my experience as a single parent caring for my child diagnosed with cancer help others going through a similar hardship. This research aims to help future parents in a similar situation. Also, the study illuminates the lack of research on this subject in future research to help parents with a child diagnosed with cancer.

*Keywords:* autoethnography, childhood cancer, parent caregiver, narrative medicine, illness narrative, dramatic analysis

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# **CHAPTER I**

# INTRODUCTION

As inevitable as death and taxes, children get cancer. Cancer has devastated families for decades. Have you ever had a child close to you diagnosed with cancer? I have experienced this tragedy. My son was diagnosed with cancer and admitted to the pediatric intensive care unit on January 6th, 2009. Shocked and devastated, I had no idea what to do or where to find help. There was no pamphlet, no literature, and no person with this kind of experience guiding me through; Ian, my son, my daughter Madison, and I were at the mercy of cancer. Yet, expectations for single parents in this situation could prepare those parents for the future. This study hopes to enlighten parents about those expectations, focusing on single parents but helping not all parents would be glorious.

This story published in an Amarillo College journal reveals a small dose of the surprise a parent feels at the beginning of this tragedy.

Cancer only affects fourteen out of every one hundred thousand children in the United States, but what if you are one of those fourteen children? My son, Ian, is the toughest kid in the world and led an everyday life for a five-year-old until one fateful day in January.

Ian's story starts with a typical day at daycare. Ian and his sister, Madison, were at daycare while I was working. Near the end of my day, I received a phone call informing me that Ian was hurt and I needed to get to the daycare quickly.

Later, Ian had hit his sister, and when she hit him back, he fell to the floor unconscious. There were two ambulances and one fire truck at daycare, so I rushed in to see Madison crying and Ian unconscious on the floor. Ian was starting to fade from white to a pale shade of blue while being worked on by the paramedics. In the background, Madison screamed, "Daddy, I killed my brother." Feeling helpless, I turned my attention to my daughter for the moment. Then, with Madison consoled to a point, our attention turned back to Ian as the paramedics were prepared to rush him to the hospital. We followed close behind the ambulance in my vehicle with horrible and frightening thoughts running through my mind. When we got to the hospital, they immediately put Ian on a ventilator and sent him to the pediatric intensive care unit. Five hours later, I was told my son had a mass in his chest; it was t-cell lymphoma, a type of cancer.

After being on a ventilator for twenty-one days, Ian was taken off and woke up from the chemical-induced coma he was put in during his first days of treatment. The doctors told me that if Ian started eating and held down food, he could go home and begin the long treatment program that would take three-and-one-half years. Ian weighed fifty pounds before he got sick; coming off the ventilator, Ian weighed nineteen pounds. He also had severe withdrawal symptoms from the narcotics that kept him in a coma, along with the weight loss. Finally, I broke down and laid my head on his bed. Ian patted me on the head as if to tell me it would all be okay.

The treatment program Ian began was an intense program of chemotherapy and ten straight days of radiation therapy. One night at four in the morning, I heard Ian vomiting in the bathroom. I asked him why he did not wake me up, and he said, "Dad, you need your rest. I'm okay." With all the therapy and doctors, Ian's spirit faded. Doctors

and nurses tried to reassure us that the first year was the worst and would get better. We were not convinced.

The Make a Wish Foundation let me know Ian had been granted his wish to meet the Dallas Cowboys during a weekly treatment. Three days later, an ESPN representative called, and they wanted to include Ian in a new yearly series called One Wish, to be aired the first week of July. I agreed, and our extraordinary adventure was about to begin. Ian was presented his wish in a video from Dallas Cowboy tight end Jason Whitten. One week later, after interviews with ESPN, we were off to Dallas to meet the cowboys. AC English Department 2014 Freelancer Page 11 Ian was to go to Valley Ranch, the Dallas Cowboys practice facility, and meet such Cowboys as Jason Whitten, Tony Romo, DeMarcus Ware, and Marion Barber. Terrance Newman, a cornerback for the Cowboys, put his head on Ian's shoulder and pretended to take a nap.

Ian was able to see the locker room, attend and participate in practice, and even ride on the team bus. The day's highlight was when Marion Barber signed and gave Ian an authentic Dallas Cowboy football helmet. I even received a signed football from DeMarcus Ware. ESPN documented all this fun and adventure on the My Wish series in July 2009. Then, with Ian's spirits raised and a new lease on life, it was back to Amarillo to work on beating cancer.

It's now five years later, and Ian stays connected, by e-mail, with his newfound friends on the Dallas Cowboys. He watches Cowboy games every week and loves football. School is hard from all the time missed in the hospital, but Ian never thinks of giving up. Ian's never-give-up attitude has inspired me to go back to school and get my business degree. So, to answer who is the toughest kid in the world, it must be Ian

because he is cancer-free and on the road to a long, happy life (Freelancer, 2014, Vol. 11, pp.10-11).

Telling my story so that other parents can benefit from my experience has been my goal since Ian has been cancer-free. The ability to spare one parent the confusion and hopelessness shortly after their child's diagnosis would be worth any effort. Doctors and nurses addressed my child with all resolve but lacked time to worry about me. My narrative can help future parent caregivers.

### Rationale

Researchers have researched two-parent families (Cerqueira 2016, Creswell 2014, Repka 2019, Flury 2007). The small amount of research on single parents is the concern of this study (Granek 2014, Klassen 2012). My narrative, using qualitative studies, could be the beginning of helpful information.

Ian's story is essential. The Make-A-Wish website (wish.org) allows kids and parents to read and understand that cancer can be defeated. My story is relative to the parent caring for their child because it gives the parent an idea of what to expect. The narrative can set guidelines for a parent to follow, allowing them to prepare for the upcoming, overwhelming journey. A luxury I was denied.

Research on single parents and how they are affected by a child's cancer diagnosis are slim to none. Most analysis is executed on two-parent families. Researchers must use previous studies of two-parent families to determine what elements in an oral history of a parent caregiver are considered to help a single parent in a similar situation. My narrative's main items of concern are financial, mental, and physical well-being and their

effect on healthy siblings. These elements are reviewed in two-parent studies before mapping the narrative of a single parent. Previous studies and my story reveal similar new features to help single parent caregivers. Analysis of themes in my story reveals the needs of a parent living this nightmare. Those themes translate into solutions for the parent, a small list of expectations during the first fifteen months of a child's treatment program,

Previous research shows childhood cancer influences the entire family. Healthy siblings are the most affected, and these siblings must be considered in a time when there is little to no time for anything other than the sick child's journey. Cancer in children is prevalent in our society and consumes victims; 1 in every 256 children is diagnosed with cancer (Cancer.net). Mortality rates are at an all-time low, but we must give attention to parents caring for a terminally ill child. Methods must be attained to care for the parents and siblings as much as the child, these parents are the unsung heroes of childhood cancer care, and siblings can be lost in the shuffle. This qualitative study examines how single parent caregivers for children with cancer acquire resources to survive during the first fifteen months of the child's treatment. How can sharing my experience as a single parent caring for my child diagnosed with cancer help others going through a similar hardship?

# **Chapter Summary**

This chapter introduces my story to the reader and gives a rationale for the research. Chapter II reveals previous research used to study and correlate the research in This thesis.

# **CHAPTER II**

# LITERATURE REVIEW

This chapter discusses four main topics. The four main topics are childhood cancer, two-parent and single-parent families dealing with childhood cancer, the parent/caregiver role and difficulties, and the impact on healthy siblings. First, literature on childhood cancer is reviewed to prepare the reader for how childhood cancer affects families. Next, two-parent families are evaluated due to the lack of research on single-parent families. Two-parent families are used to locating expectations of action when reviewing a single-parent narrative. Previous research revealed the expectations are burdens on two-parent families, hoping that responsibilities and needs benefit single parents in future research. Finally, single-parent families are reviewed for the differences presented in the limited text. The little attention given in this research to healthy siblings can and should be extended in further study.

The time constraints of work, appointments, and parents of their other children weigh heavily on parents with a child who has cancer. Parents must take care of themselves and care for their children, leading to self-neglect (Flury, 2011). However, omitting time to care for themselves, both physically and emotionally, allows such parents to devote more to the care of their children (Granek, 2014; Repka, 2019). The aspects of financial, emotional, physical wellbeing, and stress applied to healthy siblings are attributes that are important for a parent to consider when caring for a child with a

terminal disease (Gage-Bouchard, 2017). This information is well documented for twoparent families and healthy siblings, but where do single parents find the knowledge they need to be prepared to survive this process? This research began with a short review of childhood cancer and the overwhelming numbers involved.

# **Childhood Cancer**

This section reviews information on childhood cancer patients to give the reader an understanding of this devastating disease. Childhood cancer is a growing problem in the United States. The numbers are astonishing. One in every 285 children is diagnosed with cancer before turning six years old (American Childhood Cancer Organization, 2019). Forty-three children, with an average of six years old, are diagnosed with cancer every day (Childhood Cancer Diagnosis, 2018). Yearly, fifteen,780 children between birth and 19 are diagnosed with cancer (US childhood cancer statistics, 2020). Unfortunately, families are affected by a childhood cancer diagnosis.

Nonetheless, as treatment gets better, more children are surviving cancer (Mertens, 2014). The population of pediatric cancer survivors increases every day, with 10-year survival rates higher than any other year since childhood cancer statistics began in 1970 (Naughten, 2014). In addition, mortality rates decreased from 2000 to 2010 (Bhakta, 2017). This decrease leaves more children living at home with parents for a more extended amount of time.

Since discovering childhood cancer, treatment protocols have improved, which leads to better care for patients. "Improvements in treatment since 1975 resulted in> 45,000 cancer deaths averted from 2010" (Smith, 2014, p. 2). Children are surviving cancer declined from 2000 to 2010 overall cancer in children, but 1900 deaths still occur

in children every year (Smith, 2014). In recent decades treatments have been developed that have led to more children surviving cancer (Mertens, 2014). As a result, 380,000 children under the age of 20 survived cancer, which gives a ratio of one in 640 children who have survived their battle with cancer (Cancer.net).

The sheer number of childhood cancers today makes it likely that many families are impacted. Doctors and treatment protocols save more children's lives every day, but it is still essential to help improve the experience for parents who care for these children. A parent's responsibilities and needs are complex while taking care of a child diagnosed with cancer. The next chapter discusses some of the obligations experienced by a two-parent family.

# **Two-Parent Families/ Single-Parent Families**

This section reviews the difficulties that two-parent families encounter while caring for a child with cancer. In addition, elements from previous research are discussed that could help single-parent families.

Two-parent families face obstacles during their child's treatment for cancer.

These families must work together to overcome financial, emotional, and physical challenges. The restructuring of a family's lifestyle is complex, but such families must adjust their entire lives to meet these challenges.

Besides their child's illness, the primary concern facing such parents was financially related (Creswell, 2014; Gage-Bouchard, 2017). Work and finances can become strained for parents with a cancer child, so things like rent, food, and other

essential needs can become hard to acquire. Support from financial agencies, government programs, and close relatives and family members help with these needs (Gage-Bouchard, 2017). Still, two-parent family incomes are often more than allowed by the government agencies for assistance (Anonymous 2009, Sample 2010). Two-parent families can also split work and caregiving responsibilities, but finances can still become easily strained.

The most common conflict with parents bringing their children to appointments with doctors is time constraints related to their job. A parent's job can cause multiple complications with the child's treatment process (Eilertson, 2011). In addition, financial burdens lead to parents' unavailability at doctor's appointments. In other cases, parents who lack support from their networks can also make it difficult to meet caretaking demands (Cerqueira, 2013). It is also true that parents are drawn away from work to their child's bedside (Dolgin, 2007). Thus, maintaining a household and providing food and clothing become difficult even for two-parent families.

Treatment has progressed so that minimal therapy can be done at home, which opens more time to help with financial responsibilities. Doctors always follow a protocol best for the child and encourage parents to be involved with treatment as much as possible (Pizzo, 2016). Treatment programs allow parents to give some medications at home. Medication bubbles, a process that offers treatment over a 30-minute timetable, are delivered at home by a parent instead of forcing a trip to the hospital (Gribch, 2001). Care at home is one example of technology that allows parents to give treatment at home. The hospital stays always cost the parent time and money. Treatment at home can ease financial burdens on both two-parent and single-parent families.

In addition to financial challenges, working, rent, and bills, the responsibility for caring for a child with cancer can burden a family in other ways (Flury, 2011). For example, parents may experience symptoms of depression (Creswell, 2014). Such symptoms, which can include mental strain, loss of weight, and neglect of other siblings, can make a parent sick and unable to care for their child (Freida, 2019). Parents need to remember to care for themselves as much as for their children. These parents split time caring for healthy siblings, while single parents are concerned with the welfare of the sick child leaving healthy siblings on the outside looking in.

Overall, caring for a child with cancer is more accessible when two parents are available to help; however, imagine the plight of single parents. While two-parent families have the support of a spouse to help, a single parent endures all the responsibilities alone.

Single-parent families must rely on outside help to navigate childhood cancer but are perhaps more reliant on external support. Whereas a single parent with outside help is still overwhelmed, a single parent without consent can be left with complete devastation. Unfortunately, it is mainly unknown how caring for a child with cancer affects the lives of single parents (Klassen, 2012). The research referenced above on two-parent families established that families deal with financial, emotional, and physical challenges while caring for a child with cancer. Still, research on single-parent families in this realm is limited. This section reviews that little research.

Most single-parent families in this situation endure many financial disadvantages (American Cancer Society, 2018). Housing, food, and utilities struggle for two-parent and single-parent families; however, single parents carry this financial burden alone

(Cerqueira, 2016). In addition, single parents generally have lower incomes than two-parent families, allowing these single parents access to some government assistance (Gage-Bouchard, 2017).

Studies have revealed that single parents experience distress during care for a child with cancer is understudied, unmasking that single parents' stress lasted six months after being informed of the diagnosis (Dolgin, 2007). Single parents tend to have more frequent symptoms (Klassen, 2012). A parent's symptoms are sleep disorders, unhealthy diet and exercise, and depression (Granek, 2012).

The anxiety of a single parent can only be described by a single parent living this tragedy. One mother was quoted as "as a single mother, I've had to rely on others, including my parents and brother, as a support system during this challenging time" (Single parenting a child with cancer, Nd). The same mother tells readers that caring for a child with cancer cannot be done alone, even with exceptional services.

# Parent/caregiver

I see parents deal with a large amount of stress when caring for a child with cancer. Parents are present during all procedures during the child's treatment, and many procedures are invasive (Best, Streisand, Catania, & Kazak, 2001). Best and associates (2001) also inform us those parents struggle with anxiety, feelings of helplessness, and a disruption to their families' support system. The parent/caregiver needs to have a support structure to allow parents to cope with the child's diagnosis (Wortman, 1984). Not all parents/caregivers have a support system, but with or without support, they have many mental and physical challenges during their child's treatment. Steinberg, Ruland, and

Miaskowski (2010) identified over 200 issues with the parent caregiver in literature. Problems such as physical, social, and mental problems burden the parent.

Physical problems include sleep deprivation, fatigue, pain, loss of appetite, weight loss, and loss of physical strength (Carter, 2003; Makowski, 2007; & Teal, 1999). In addition, physical stress is promoted by mental burdens imposed on the parent/caregiver.

Social problems include the role of the caretaker, finances, employment, education, and isolation from an environment. Parenting goals change responsibilities, and relationship expectations change (Boyle, Blodgett & Gnesdiloff, 2003) Boyle. Blodgett and Gnesdiloff (2003) clarify that the burden increases with parent caregivers that also care for healthy siblings and elderly parents. Parents are stretched in many directions and worry when with their sick child and when their sick child is with family (Stenberg et al., 2010). The parent overextends themselves by trying to do it all while failing at the high standards imposed on themselves, often losing their jobs (Swanberg, 2006). Parent caregivers also report isolation and loneliness after losing their job because that time was when they could communicate with adults other than doctors and nurses (Grbich, Parker, Maddocks, 2001). Schubart, Kinzie, and Farace (2008) revealed that parents felt they neglected their own needs while caring for a child diagnosed with cancer. Caring for a child with cancer envelops all the parents' time and promotes guilt in an impossible situation. Emotional problems are often depression, anxiety, and loneliness. They also develop emotional reactions to caring, fear, uncertainty, hopelessness, powerlessness, and mood swings (Dumont 2006, Mystakidou 2007, Oldham 2006). Dealing with personal feelings was overwhelming (Grbich et al. 2001). Parent/caregivers relayed that too many responsibilities caring for a child with cancer

were a burden that often brought on a barrage of emotional illnesses and anxieties (Rose, 2013). Being a parent is challenging but adding a child's caregiver with cancer becomes almost impossible.

# **Healthy Siblings**

On the day my son, Ian was diagnosed with cancer, his sister Madison was with him at daycare. Ian hit Madison, Madison hit Ian back, and he collapsed on the floor. My decision to tell Madison was made for me at that moment. Apparently, from individual interviews in other research, there is a time between the parents learning to have a child's cancer diagnosis and informing the siblings (Long, Marsland, Wright, Hinds, Fann, 2015). The decision made for me led Madison to know the end was okay. The lack of communication leads a sibling to wonder if their brothers or sisters are alive (Long et al., 2015). In our case, Madison was desperate to know "she had not killed her brother." At seven years old, fearing she had killed her brother could not be mentally sound, she would need periodic counseling sessions to cope with the sudden tragedy.

Over 14,000 kids in the US develop cancer every year, disrupting family life for every member, including healthy siblings (Long et al., 2015). Not all kids diagnosed with cancer have siblings, but enough research has been started explaining the effects on healthy siblings. Aldefer (2010) and Wilking & Woodgate (2005) inform us that qualitative research has revealed that siblings of a child with cancer experience various emotions, loss of parental attention, and increasing responsibility and expectations. This injection of maturity can take its toll on healthy siblings. For example, my daughter Madison had anger issues in the 8th grade, initiated by the lack of my presence in her life.

I was her only visible parent, and I was with Ian most of the time. Counselors helped her through these issues. The child's treatment affects the family's day-to-day routine (Long et al., 2015).

Research on two-parent families outlines the needs for parents caring for a child with cancer, while the lack of research leaves single parents begging for information and resources. The single parent enters this tragedy alone. Single parent deserves some guidance to ease the stress of trying to help their child beat cancer. Through such an invasive process and the child receiving the best care, a single parent looks to the outside world to discover answers to survive with their child; solutions only the experienced can give, and research has denied. Through my experience and my daughter's actions over time, I know that a cancer diagnosis affected his healthy sibling.

Even with my experience in ongoing research for this thesis, there is limited research on the effect cancer has on the mental aspect of healthy siblings. Research informs us that the teachings and little analysis of these siblings lead to few answers to the long-term effects of siblings after a brother or sister has been diagnosed with cancer (Long et al., 2015). qualitative research may be the future to answer this problem (Aldefer, 2010).

# **Theoretical Background**

The doctor comes in and says you are sick and then leaves. He has given your diagnosis, but now what do you do, take the medicine prescribed and then get better or not. But has he helped you understand what is wrong? Did he understand how you described what was wrong, or did he read the science and act? Are you more confused, or

do you feel uncomfortable asking questions and doing as you are told? Science cannot alone help a patient deal with their illness and understand why they're sick or dying. Doctors must understand the patient's narrative to provide the best care for the patient (Charon & Rudnytsky, 2008).

### **Narrative Medicine**

Medicine has grown, and treatments have gotten better by leaps and bounds. Unfortunately, compassion and empathy have left most doctors and hinder their care for individual patients (Charon & Rudnytsky, 2008). Physicians are not to stay emotionless and not get too close to a patient, or it may affect their diagnosis. Doctors can learn from scholars and storytellers that narrative carries the knowledge that builds confidence for the doctor and the patient. A person's story and frame of mind can help a doctor diagnose and treat the patient with respect and thoroughness, which would help the patient deal with a tragic diagnosis. Narrative knowledge allows individuals to participate in their prognosis and better understand by using imagination, interpretation, and recognition of what information the doctor relays. (Charon & Rudnytsky, 2008). Understanding a terminal illness's nature and treatment protocols helped me deal with my son's cancer. I needed the communication the staff awarded me during a difficult time.

Illness is presented in stories from patients, the events of our lives, memories, physical ups and downs, and healthcare events develop how patients reflect on themselves during illness (Charon, 2006). We use our narratives to heal and teach life lessons to family and others, but we first must heal ourselves, and telling stories helps with that process. Something that was denied to patients and caregivers until Rita Charon

realized that people need to be heard in medicine.

Narrative medicine, developed by Rita Charon, uses narratives to help the health care systems be more productive in caring for sick individuals (Charon, 2006). Rita Charon (2006) explains that during her tenure as a doctor, she realized patients could reveal symptoms and aid in the diagnosis by sharing their narrative and completing a doctor's knowledge of the patient. As a result, she developed a new process to help patients care by listening to the patient's narrative. Listening and learning through narratives allows doctors to completely care for their patients, not just cure their physical needs.

Narrative medicine describes excellent skills to help deal with the patient personally. These skills are missing from medical teachings and how doctors handle patients. Narrative medicine provides the skills to recognize and interpret text and help patients more than just the physical aspects (Charon & Rudnytsky, 2008). Narrative medicine can help physicians understand how a patient explains symptoms and better communicate during a diagnosis. This leads both doctor and patient to be fully committed to the patient's full recovery, mental and physical. Narrative medicine understands patients and caregivers enter an illness together in body, mind, and spirit. The goal is to defeat sickness with complete and combined effort to heal the individual.

Narrative acts allow the patient to convey what is wrong with the mind and body. But without these narrative acts, patients cannot understand what is happening to them; doctors must learn the whole story to give complete help, not a patient (Charon & Rudnytsky, 2008). Also, narrative acts help an individual convey what to expect while being sick to another individual. Personal experience of an illness is invaluable

information to give to other individuals with similar illnesses. Narrative skills work between doctor and patient and in teaching, research, diagnosis, and personal responsibilities in medicine and research (Charon & Rudnytsky, 2008). Using narrative in medicine allows everyone to do the best job possible for the patient.

Narrative medicine deals with a doctor and patient relationship. Rita Charon explains how important a narrative is in medicine, research, and personal experience. When narrative medicine is used as the basis for parent/caretaker research, an illness narrative is also necessary to analyze. This research uses an illness narrative to present my parental narrative of my child's cancer treatment journey. The next portion of this thesis presents a description of the illness narrative. Narrative medicine and illness narrative work together throughout the analysis of this thesis.

# **Illness Narrative**

Charles Taylor (1989) states, "We understand ourselves inescapably in the narrative. Storytelling began in childhood and continued through adulthood, allowing a person to share and reflect on life events (O'Brien & Clark, 2010). Narratives of sickness have been used for years to inform and educate, then finally have been validated as a source for research (Robinson, 2001). Over time as I was able to help others as they heard the news their child had cancer, I realized that my personal experience mattered.

Shared personal experience can ease a patient or caretaker's mind (Ritchie, 2001). Writing about one's experience with illness allows the author to share a perspective of experience that helps both author and audience (Blury, 2001). I never knew a person who had a child with cancer but sharing my experience did help others. Shared experiences

allow the patient or caretaker to release helplessness and allow helping others (O'Brien & Clark, 2010). Individuals share their narratives which allows them to reflect on the events happening to them and comfort how they manage said events (Ritchie, 2001). Many researchers explain that narratives are therapeutic to both author and audience.

Frank (1995) explains sharing a story is important to recognize the illness, while Pennebaker and Traue (1993) add writing is therapeutic for the patient and caregiver. Carlick and Biley (2004) tell readers that writing an illness narrative is different than talking about it because writing frees the patient or caregiver from possible guilt applied by a live audience. The release of such stories on the Internet can produce support groups, but most authors begin to help themselves through a tragedy (O'Brien & Clark, 2010). Nevertheless, illness narratives give way to needed research that helps future victims and caregivers. My story was developed to heal me, nothing else, just me. As it ends up, my story becomes research that hopefully helps other parents with a child diagnosed with cancer.

Sharing personal illness narratives document the illness and how it affected the patient and caretakers' lives (O'Brien & Clark, 2010). O'Brien and Clark continue by claiming. Illness narratives are an exploratory method to relay suffering, autobiographical outlet, and express illness in a way medicine lacks from an individual standpoint. My story intends to do just that through research development and educating future parent caregivers on what to expect with a child diagnosed with cancer. Studying illness narrative has two objectives, one, to discover the experience of the illness, and two, to expose how the illness affects the identity, experience, and culture of the person involved

during the illness (Bury, 2001). These three aspects developed themes throughout the narrative to help these future parents. Chronicling illness and sharing those stories are important to the narrator's mental and physical health (Bregman & Theirmann, 1995). I drafted a short story during my son's treatment that was published later and was how I chronicled our journey

Researchers' access to unpublished and published accounts is untainted by researchers' needs due to the nature of the narrative being unsolicited. Because the narrative was unsolicited, the author has zero concerns about satisfying the researcher (O'Brien & Clark, 2010). Content from these authors is valid data in research because they were written for self, not for research. These narratives are honest thoughts from a writer that only cares about the truth and healing, nothing more, nothing less. The reason these narratives are sought for research is simply because of their clear reality.

# **Chapter Summary**

This chapter reviews childhood cancer, two-parent/single-parent families, parent/caregivers, and healthy siblings. The review outlines the relative past research to develop new research in this thesis. Along with that review, this chapter discusses the theoretical background narrative medicine and illness narrative used as a framework for this research. The next chapter discusses the method, autoethnography, and the steps of thematic analysis used to analyze my narrative in Chapter IV.

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# **CHAPTER III**

# **METHODS**

This thesis analyzes the autoethnography of a parent who has cared for a child diagnosed with cancer. Autoethnography is research designed to analyze a personal experience and understand the cultural effects of that experience. Three elements break down autoethnography, *graphy* to analyze, *auto* relates to personal experience, and *ethno* is the cultural experience (Ellis, 2004). By examining an autoethnography of a parent caring for a child with cancer, this research hopes to illuminate future parents' experiences and expectations in a similar situation.

# **Autoethnography**

Autoethnography allows the researchers' beliefs to influence the research rather than relying on facts and truth (Ellis, Adams, & Bochner, 2011). Previously researchers' influence was withheld from their projects (Kuhn, 1996), but soon it was realized that narratives and beliefs affected how people felt about themselves and others. Stories were more complex, taught morals and ethics, and compared feelings that affect social research (Ellis et al., 2011). This type of research heightened the personal experience and deepened the understanding of similar experiences between people of different backgrounds and social realities (Ellis & Bochner, 2000). Autoethnography is a sensible way to research a story such as mine. The story I tell has helped me deal with the

experience living with a child with cancer and can help others cope with a similar tragedy.

Autoethnography combines autobiography and ethnography, sharing an author's experience (Ellis, Adams, & Bochner, 2011). In most cases, these experiences expressed through stories are meant to be published, but always to share how the experience affects the storyteller's life and leads them in different directions. (Bochner & Ellis, 1992). My story was published in the Freelancer at Amarillo College in 2014, the 11th edition; I tried to heal and cope with my experience as I was still dealing with my son's cancer. In most stories, the narrative is used to cope and forces the person to analyze life and change during the crisis (Zahner, 2004). Revealing my narrative allowed me to share an event hard to discuss with even close family members. Writing and sharing my situation saved my mental and physical life.

Autoethnography is a personal narrative that evaluates cultural experience (Reismann, 2007). Autoethnography is written in thick and rich descriptions to interject a personal story or occurrence into the reader's thoughts. The author tries to make the experience meaningful and available to pertinent audiences and readers looking to relate their life to one another. The interactions described by the reader and their expertise with others living a similar tragedy can help both parties cope (Bochner, 1997; Ellis, 1995).

Generally, autoethnography depends on creativity and various forms of communication to develop a rapport with the reader (Spry, 2011). There are various ethnographer forms, such as native, narrative, reflective, and interactive narratives. This research analyzes a personal narrative form of ethnography. Personal narratives are stories of oneself that focus on their professional, social, and emotional life (Ellis,

Adams, & Bochner, 2011). Personal narratives can present an understanding of self or a tragedy that changes the author as an individual. The context of the author's life or specific event is used to enact change in the social culture of individuals dealing with a similar event. This research does precisely this; it looks to help others in similar situations.

Writing is a way of understanding and learning (Richardson, 2000). Writing self-reflection stories is therapeutic. It allows us to relate to our situation and understand how an event has changed our lives. Understanding oneself helps the author cope with intense, tragic situations and presents solutions to similar situations. In this thesis, a narrative helps the storyteller and the audience deal with the tragedy (Ellis, Adams, & Bochner, 2011). In addition, the narrative can help with social change, personal responsibility, cultural change, and reduce prejudice (Ellis & Bochner, 2000). These applications lead to future research, such as the parents' needs after the first fifteen months of a child's treatment process. My healing began with writing about my journey and continued through this research process.

The ability of authors and readers to relate to a problem and relay that problem to others is called witnessing (Ellis, Adams, & Bochner, 2011). Ellis, Adams, and Bochner (2011), also described witnessing as allowing a researcher to clarify other problems, such as the hopelessness of being diagnosed with a terminal disease. In addition, witnessing works to validate their sense of despair and help others relate to the author living through a similar situation (Ellis, Adams, & Bochner, 2011). Witnessing is a process that I used without knowing until much later during the beginning of this research. Nevertheless, the

witnessing process is invaluable for healing to begin. The writing process has many steps and starts with understanding epiphanies and how it affects the narrative.

It is pertinent that the text is appropriately presented to understand the story through epiphanies (Creswell, 2014). Epiphanies are special events in an individual's life that represent turning points. The impact variance is either positive or negative traits (Deucin, 1989). Autobiographers present epiphanies that, in retrospect, allow the teller to understand how the crisis affected their life path (Bochner & Ellis, 1992). While contained to an individual, epiphanies provide a story for others to relate to a similar experience. These people can attain ways to dissect an intense situation and discover ways to cope with this critical situation's feelings, financial, and other burdens (Bochner, 1984). Researchers write autoethnography to help themselves, families, and outsiders cope with an experience (Carey,2021). In retrospect, these steps helped me during this strenuous journey. Epiphanies are lost if the story does not have structure. This is where restorying is vital to the narrative.

I use restorying in this research as a tool to construct my narrative. *Restorying* analyzes a narrative and rewriting the story to make sense and present it in chronological order (Creswell, 2014). My story has a beginning, middle, and end, starting with when my son collapsed at daycare. The story continues through the first fifteen months of Ian's cancer treatment up until the period called maintenance. Maintenance is described as fifteen months until the end of the cancer treatment protocol. *Mapping* is used to configure dates and events into a chronological timeline (Doshi, 2013). Mapping is defined by Doshi (2013) as the activity or process that creates a picture or information that represents a narrative. I use mapping to confirm dates that mark necessary periods in

his first fifteen months of treatment. Using mapping as a tool allows my story to start from the beginning and finish at the end. My story must be researched in chronological order because medical stories begin with diagnosis and end with healing or death. The qualitative data produce themes that appear from a description of the story (Creswell & Poth, 2018). The researcher analyzes these themes for meanings of repeated words, phrases, and recurring entities that have meaning for the researcher provided by the narrative. Polkinghorne (1995) describes reviewing a narrative and extracting themes. This process, thematic analysis, is the most viable way to analyze a narrative of this type. (Creswell & Poth, 2018).

Narratives are gathered through many forms, such as observations, documents, pictures, and other data sources. These stories analyze various means such as thematic, structural, and performance strategies (Riessman, 2005). Rashman (2008) explains how themes are identified by the researcher in a narrative produced to affect change or knowledge of a social situation. This research uses thematic analysis to research the narrative presented in chapter four. The analysis helps answer the research question, where single parent caregivers for children with cancer acquire resources to survive during the first fifteen months of the child's treatment.

Analyzing a narrative for qualitative researchers is complicated. The challenge of representing the data analyzed in text with validity comes in many steps. These steps organize the data, code, organize themes, and interpret the data (Creswell & Poth, 2018). These steps are vital to deciphering the narrative.

Organizing the story is an important first step in researching qualitative data.

After gathering information from participants in the study, the data is organized in a

framework. This process is called restoring. Next, the story is organized by key elements or chronological order (Creswell & Poth, 2018). This research is based on one participant's story and is presented chronologically. The narrative must be well organized for the researcher to begin thematic analysis.

The thematic analysis outlines a process to develop codes and themes from qualitative data (Clarke & Braun, 2017). Codes are the basis for themes. Themes are building blocks to interpret analytic observations. The thematic analysis does not summarize a narrative. But instead, it identifies and interprets the narrative to present a certain view based on a research question (Clarke & Braun, 2017). Thematic analysis reveals themes that answer the research question of this research. For example, how can sharing my experience as a single parent caring for my child diagnosed with cancer help others going through a similar hardship?

Coding and themes are the second steps to analyzing qualitative data. This step allows the researcher to understand the narrative and determine an overall concept to analyze for decryption. Creswell & Poth (2018) explains that the researcher must read the narrative several times to understand the data entirely before breaking it into sections to research. Writing notes in the margins and highlighting recurring terms allows the researcher to review the data after multiple readings (Creswell & Poth, 2018). This process is called memoing. Memos are notes or highlight phrases, recurring words, or social support that make the story complete and give meaning to the reader (Lotto 1986). Memoing enlightens the data to an analytic meaning (Grbich, 2013). The next steps are to transfer memoing into codes. Coding is exact words, phrases, or social support that give a specific description or explanation of the data in the narrative (Creswell & Poth, 2018).

Qualitative research uses coding to make sense of a narrative. Coding involves breaking down the narrative into labeled and studied data (Creswell & Poth, 2018). Creswell & Poth (2018) explains that researchers develop a shortlist of codes that coincide with text in the narrative. Then, these codes are reviewed and reduced into smaller concise categories. These categories are reviewed, studied, and developed into five to six themes depending on the length of the narrative (Creswell & Poth, 2018). Identifying five or six themes can be difficult in a lengthy narrative. The researcher can separate the themes to develop a more valid line of research, which the researcher can review and interpret (Creswell & Poth, 2018).

Interpreting the data is the third step in researching qualitative data. This research uses a chronological approach to interpret the narrative. Denzin (1989) suggests using a biographical analysis to enhance and explain experiences related to the participants' narratives. The researcher looks for elements during a life-changing event. Epiphanies emerge from the narrative analysis (Creswell & Poth, 2018). The individual narrative describes factors that shaped how the event affected their lives and changed their attitude. Using coding to determine themes and sub-themes, the researcher can develop an analytic narrative outlook. Themes lead the researcher to interpret the analytic narrative presented (Creswell & Poth, 2018). In this research, the analysis has led to experiences for parents living this tragedy and coping mechanisms for future parents with a child diagnosed with cancer.

# **Steps of Thematic Analysis**

Thematic analysis is a method for analyzing qualitative data, reviews, narratives, or other data and identifying and analyzing repeated themes. A theme is a recurring word, phrase, or event that informs the research question (Braun & Clarke, 2006). The research has leniency in identifying themes, but themes must reflect the research question. The six-step development by Braun and Clark is used in the research to analyze the narrative in chapter four. The six steps are described in this section.

The first step of semantic analysis by Braun and Clark (2006) is familiarizing yourself with the data. Being the author and subject of the narrative in this research, I am familiar with the story, but following Braun and Clarke, I reread the narrative several times and made notes.

The second step is generating initial codes. Codes are the most basic form of data that can be analyzed meaningfully (Boyatis, 1998). Coding helps organize data at the most basic level (Kieger & Varpio, 2020). A code should be well defined to fit into a larger framework or template, allowing the researcher to label and make notes that patterns are occurring in developmental themes (Braun & Clarke, 2006). Braun and Clark (2006) describe that once the entire data is coded, it is time to apply step three, seeking themes

Step three in Braun and Clarke's process is searching for themes. The researcher analyzes data for wider significance (Braun & Clarke, 2006). Themes do not simply appear; the researcher creates them by combining and comparing codes and then analyzing how they relate to them to develop themes (Varpio, 2017). Themes work together independently to coherently answer a research question (Braun & Clarke, 2006).

Themes provide links between data and the research question, but the key themes cannot be revealed (Kieger & Varpio, 2020).

Step four of thematic analysis is reviewing themes. Again, Braun and Clark (2006) use step two in a two-step analysis process. The first step is to ensure each theme has a proper fit. The second step makes sure each theme has supporting data (Braun & Clarke, 2006). This process is complete when both steps are finished, themes are relevant to the research question, and with continued analysis, the themes yield little to no change (Kieger & Varpio, 2020).

Step five by Braun and Clark is defining and naming themes. The researcher listed the definition and description of each team as related to the research question. Themes must be brief and adequately described (Braun & Clarke, 2006). Braun and Clarke (2006) describe step five as finding the most important theme and providing a descriptive analysis of each theme related to the research question. This process provides key features of themes in context, explaining the importance of each theme (Braun & Clarke, 2006).

Step six is producing the report/manuscript. The report should present a narrative that supports the analysis clearly and precisely to support the research question (Braun & Clarke, 2006, 2012). In addition, the data should contain information to adequately understand how each theme answers the questions studied in the research (Kieger & Varpio, 2020). Using these six steps by Braun and Clark for thematic analysis, themes emerged to answer the research question in this study.

While analyzing the narrative through a qualitative lens using thematic analysis, themes help understand the personal narrative of living with a child diagnosed with

cancer. Those themes allow the researcher to analyze and discuss the social aspect of this narrative. The social aspect presents the tool that allows themes to lead to certain expectations for a parent consumed with this tragedy; a child diagnosed with cancer.

Themes promote future expectations for parents at the beginning of this journey and lead to this research's analysis, discussion, and implications.

The following chapter describes autoethnography and discusses ethnographical forms, such as personal narrative, which analyzes the story of a parent caring for a child with cancer. Thematic analysis and analyzing a narrative are described and used to interpret data in research. Also, this chapter explains how my story was published to help me heal and other expectations while living the tragedy of a child diagnosed with cancer.

This autoethnography study aims to help future parents care for themselves while caring for a child with cancer. In addition, this study answers the following research question:

**RQ 1**: How can sharing my experience as a single parent caring for my child diagnosed with cancer help others going through a similar hardship?

# **Chapter Summary**

This chapter discussed autoethnography and provided the steps for thematic analysis, and it also provided the research question for this research. The next chapter provides my narrative and discusses emerging themes discovered through thematic analysis.

# **CHAPTER IV**

# NARRATIVE AND THEMES

This chapter reveals the narrative being researched and emerging themes from that narrative. Therefore, the participant section is not added. The participant is a single parent with one child diagnosed with cancer and one healthy sibling. I am that participant during this experience. I was a single father with two young children doing the best I could with the resources available. We lived in a two-bedroom duplex, and I worked for my father as a painter making 8.50 an hour. The kids were in daycare because I worked 8-5, and I thought our world was hard but adequate for our situation. Then the sky fell, and we were in a disaster called cancer.

The narrative is researched through a qualitative lens and follows the journey of the single parent during the first fifteen months of a child's treatment for cancer. The following is my narrative. The narrative spans the first fifteen months of my son's treatment in four sections, the first 51 hours, the first 28 days, then six months, and finally up to fifteen months. After the narrative, the emerging themes are revealed.

# 51 Hours

On January 5<sup>th</sup>, 2009, I started what seemed to be just another normal day. I got up, got ready for work, and got my two kids, Madison, 7, and Ian, 5, ready for school. But little did I know that this day would change my life forever.

I began my normal day at work while the kids were at school, and at the end of school, the kids were picked up by their daycare to finish the day while I completed my day a

work. Near the end of my workday, I received a phone call from the daycare. The daycare director was frantic; I could barely understand what she was saying, but I did understand I needed to get to daycare right away because something had happened to one of my children. I assumed Ian was in trouble again. He was small, so he was picked on at daycare, but he learned to start defending himself from bullies. It made me think Ian was in trouble and needed my help from hurting a bully, but there were two police cars, a fire truck, and an ambulance when I got to daycare. All I could think was Ian might have hurt another kid that was bullying him. As I walked into daycare, I could see Ian lying on the floor and paramedics working on him to my left. He was a pale shade of blue. I saw Madison running from the director's office, screaming, "I've killed my brother." Later, I found out that Ian had punched Madison and Madison smacked him in the head. When she did, he fell to the floor unconscious. Astonished and dismayed, I felt helpless and could not do anything but stand listening to the paramedics. Finally, they put Ian in the ambulance, and Madison and I got into my truck and followed the ambulance to the hospital. On our way to the hospital, I called my mother and explained how Ian had collapsed and that she needed to meet me at the hospital as quickly as possible and help me deal with Madison.

When we arrived at the hospital, my mother was there; she beat us to the hospital and took Madison so I could address Ian. The nurse got me back to the room where Ian had been delivered. The doctors were working to resuscitate him, and I just stood there and watched in dismay as my son was clinging to life and doctors tried to bring him back from the brink of death. At this point, I was numb, helpless, and hopeless, not knowing what would happen, not even knowing why he was in this condition. I had a 1000-mile stare and a blank space where I usually conjured thoughts in comprehending what was going around me in life. Finally, the doctors' explained Ian was still alive, but they would need to put him on a ventilator and get him up to the pediatric intense care unit, PEDICU. They explained that it was on the third floor, and I needed to take the elevator and go there immediately.

As I sat in the hallway alone, waiting for a nurse to lead me into PEDICU, many things went through my mind. I could not fathom what was going on with my son, what went wrong, or whether I would lose him forever. While waiting in the hall, I only knew one thing to do: I called my best friend and asked him to come to sit with me until they let me into the PEDICU to see my son. My friend arrived and sat with me for what seemed like hours but was probably only minutes while I waited to learn the fate of Ian, my youngest child.

The nurse came and guided me to the room, and as I walked in, I was almost knocked backward on the floor by the sight I saw. My son was hooked up to a ventilator; tubes ran from him to machines to keep him breathing. The nurse explained that they had put him into a self-induced coma while determining what had happened. He was hooked

up to so many machines I didn't know how to react. Likewise, I didn't know how to act, and a numb feeling came over my whole body.

Currently, it was almost 9:00 PM. I've put in a full day's work, and a tragedy struck my family, but I still cannot sleep. I spent that first night just staring at him with my head on his bed and all the bad things that could happen running through my head. The next thing I knew, it was daytime, and nurses and doctors were coming in and out running tests on Ian, trying to determine what had happened. It was a diagnosis I needed to hear, but I was not ready to be told. I spent the whole second-day watching doctors and nurses come in and out of the room, draw blood, take tests, and do what they could to figure out what was wrong with my son. All I could do was stare at Ian or out the window. I was even afraid to go to the bathroom because I thought I might miss a doctor or a nurse giving me some information.

That day I felt more helpless and hopeless than any other day. There was no information, no relief, no answers to any questions, just constant traffic and me wondering and hoping my son would be OK. Then, on the third day at 10:00 AM, oncology doctors came into the room 51 hours after we began our journey and informed me that Ian had leukemia, non-Hodgkin's lymphoma cancer. The doctor, realizing that I had been awake for days straight, informed me that over the next few days, doctors would be telling me again and again that my son had cancer. From his experience, it takes multiple times telling parents their child has cancer before the parent realizes it's true. Fifty-one hours ago, my day began like every other day during the week going to work and getting my kids to school. I never knew then; 51 hours later, my family's life would

dramatically change. I was unaware that the next twenty-four days would be more of a surprise and life-changing.

## 28 Days

The next days in the PEDICU were incredibly stressful and complicated. The constant in and out from doctors and nurses made the days long and the nights even longer. In addition, constantly wanting to know what was going on was hard because the nurses could only answer my basic questions, and the doctors were doing their job, so information was few and far between. Finally, the hospital's billing assistant met me early one morning, asking me to sign Medicaid and food stamps papers. Medicaid was to pay for its hospital bills, and the food stamps were for our family. The staff there realized more than I ever would at the beginning how long this journey would be.

On day 4, Ian's primary oncologist came to see us, pulled me outside, and showed me an X-ray of Ian's chest; it was full of a tumor. The doctor assured me that he would have the tumor shrunk in four days, and Ian's chest would be clear. The doctor also explained that without Madison smacking Ian in the back of the head, I would have taken him home, fed him dinner, put him to bed, and never would've woken up, so his sister saved his life. That was the cure for Ian's cancer, with my head still foggy. You must understand that my mother had just gone through ovarian cancer, and in seven months, she had finished treatments and was cancer-free back to work. We were very blessed, so I assumed that would happen with Ian's cancer. I was wrong beyond belief. The doctor returned four days later and showed me a new X-ray, and the tumor in Ian's chest was gone. This event was the first real episode that led me to believe my son could survive his

diagnosis. I still believed if he woke up, we would be out of the hospital and on with our lives. I was extremely naive.

I had another situation that needed my utmost attention. Madison, his sister, insisted on having her grandmother bring her to the hospital to see Ian. I never thought this was a good idea, but when your seven-year-old daughter begs to see her brother realize she didn't kill him at daycare, it's hard for a parent to say no. So, I told my mother to bring her up to the hospital the next evening after school, and we would let her see her brother even though he was still on a ventilator and unconscious. I met Madison outside the room and tried to explain that her brother was on a ventilator, which was scary, but he was getting better. We entered the room, and I could tell this was a bad idea; Madison's face flushed; she almost lost her balance seeing her brother. Little brother on a ventilator was not what a seven-year-old should ever see. Finally, she asked if she could leave the room, and I walked outside with her and talked with her for about 30 minutes, explaining to her that Ian was getting better and that all the machines were helping him, and then as soon as he was awake, she could come back and see him again. Watching Madison that day almost broke my heart, but it brought me back to reality, and I knew I had to be strong and do whatever I could for my son and my daughter. So that evening, when my mother was there, I asked her if she'd start bringing me some clothes and a few things because I was not leaving. I was moving into the PEDICU to stay with Ian. She brought me clothes, and friends sent baskets, fruit and letters, and cards to keep my spirits up. The hospital had a chair that pulled out into a bed, and one morning I woke up with a handstitched blanket on me and another hand-stitched blanket on Ian. I later found out the

blankets were provided to us by the Ronald McDonald House. The Ronald McDonald House had a small office in the hospital.

In that office, I could sign in, get snacks, drinks, anything I needed, and across the hall, there was a shower where I could shave and brush my teeth. With Ian on a ventilator, I had plenty of time on my hands. One of the saving graces for my mental and physical health was that the hospital had an omelet cart every morning, and I could eat an omelet before the day began, a small thing but invaluable to me. The doctors wanted to keep Ian sedated until he was strong enough to begin treatments. During this time, I was alone except for the rare occasion a nurse or doctor came by to check on Ian. I found myself wandering the halls of the hospital late at night. I wondered what life was going to be like, where we were going to live, and how I would take care of my family and myself.

Wandering the halls late at night was when I felt the loneliest and probably felt the most helpless during this tragedy. One night when I was wandering the halls, I realized Ian would lose his hair from treatments or start losing it before he woke up from the ventilator, so I decided that I did not want him to experience the hair loss. My hair was long, almost down to my waist, so I went to the room where the shower was, used clippers and a razor, cut all my hair off, and shaved my head. I then went into the room, took the clippers, and shaved Ian's head so he would not have to go through the traumatic event of losing his hair. After I shaved my head, I came back in. The nurse stopped me at the door and said, "Sir, you cannot be in here,"; and I turned around and looked at the nurse. She realized it was me. She about fell off her chair laughing. I handed her my hair and asked her if we could get it donated to someone that made wigs for cancer patients;

she teared up and sent me into the room so that I could take care of Ian's haircut. At that moment, I finally woke up and started taking care of my son and caring about other things, including my daughter's life. The numb feeling had receded to a point. At the same time, I was at the hospital 24 hours a day with Ian and not seeing my daughter, only talking by phone.

Soon after the haircut, after 20 to 21 days in the PEDICU, the doctors came and told me we would try and take Ian off the ventilator. Ian had a mainline put in somewhere around day 5, and they had been giving him medicine to try to make him better. This mainline would allow them to take him off the ventilator but still medicate him. Finally, the doctors decided that he was strong enough to come off the ventilator at this time. The next day, they stopped their narcotics that kept him asleep, woke him up, and took the tube out of his throat for the first time in over 20 days. Finally, Ian was awake, and it was the first time I realized that he was still alive in my heart.

Later that evening, I noticed Ian was shaking, twitching, and having many issues like a drug addict coming off long-term drug use. I realized he was having withdrawals from the narcotics that kept him in a coma while on a ventilator. I argued with the nurse that this was no way for a five-year-old to wake up from a coma, and would she please call the doctor so we could put Ian back on narcotics and wean him off so he wasn't going through withdrawals. The nurse and I argued until she called the doctor. I had watched Ian drop from 50 to 19 pounds from being on the ventilator. I was not about to watch him go through withdrawals. The doctor agreed and put him back on our narcotics, and over the next few days, he was weaned off them, so the withdrawal symptoms were much less severe.

The next step was to get him to eat and use the restroom, which you would think would be an easy task for a young man that had been in a coma for over 20 days, but as you can imagine, nothing is easy during this time. Being on the ventilator, Ian had continued to use a diaper; he was beginning to eat, but he did not want to use the bedpan. Again, the nurse and I fought over him using the bathroom, and I explained that getting him to the potty would be much easier if he could go to the toilet. The hospital supplied us with a portable toilet, and sure enough, Ian started eating and using the potty. At this time, 28 days from when our journey began, Ian was ready to go home, and because I had not worked or been home in 28 days; the apartment we lived in had been considered vacated, and all our items were to be moved out as soon as possible. The only option we had was to move in with my parents, where she had already been for 28 days. As we left the hospital, I was very thankful Ian was alive, and I was very thankful we were headed home, but I was not excited about moving back in with my parents, and I had no idea what surprises this journey would throw at us next.

## 6 Months

The next six months would be a rollercoaster ride of epic proportions. Two days after we left the PEDICU and settled into my parents' house, we were due back at the hospital for Ian's first appointment with his oncologist. Luckily to find out Ian's oncology nurse was one of my good friends in high school, which helped somewhat with the nervousness and anticipation of getting treatment. Ian's oncology nurse said we had to take blood and run tests, making sure Ian was ready for treatment. She informed me that Ian would also have to do ten days of radiation treatment. The radiation treatment was at

another building located in the medical district. The treatments would mean more traveling between doctors.

Ian fought tooth and nail every time someone brought a needle near him, so drawing blood was a chore, along with everything else that involved sticking him with a needle. He fought with his oncology nurse and his doctors and even fought with the nurses at the hospital. Finally, he was bound and determined not to let them stick him with any needles. The nurses won the war of needles but just barely. So, after the blood test, it was determined Ian was ready for treatment; we went back across the street to the hospital to get ready for his first chemotherapy treatment.

Along with chemotherapy treatment, they would do a laparotomy, which is to stick a long needle in his back and pull fluid out of his spine, another way to evaluate for spreading cancer. After that, the doctor sedated him again, performed a spinal tap and laparotomy, and then hooked him up to chemo for the first treatment. Treatments usually lasted anywhere from 45 minutes to an hour, and then we stayed for another hour to make sure he had little or no reactions to the chemo. My job during this was to watch, so that's what I did and worried as the doctors poked a long needle in his back, then turned him over, poked a needle in his arm, and pumped poisons into his body to try and make him better.

The next day we headed to radiation, where he was fitted for a mask, and the doctor explained what would happen during the radiation treatment. During that treatment, he was put into a cylinder and asked to be extremely still while doctors and computers analyzed and radiated his head. The radiation treatments prevented any cancer from extending from the blood to his brain. Non-Hodgkin's lymphoma is blood-borne

cancer that can pass easily to other parts of the body if not aggressively treated with radiation and chemotherapy. This cancer is why Ian had to do both chemotherapy and radiation treatments. After treatments, Ian was always allowed to pick a toy, a blanket, or a pillowcase decorated with cartoons or animals to take home. This is the only time Ian was not trying to fight with the nurses and doctors in the first three months. During this time, I was dad, chauffeur, and witness, but most of all, I was helpless and unable to do anything but watch doctors and nurses poke and prod my son in the name of medicine. That took me back to that numb feeling that I felt in the PEDICU.

This process would go on for the next three weeks, two days in the hospital for treatment and radiation and then back home unless Ian spiked a fever of 101.5 or above, and then we were back to the hospital. When this happened, they would take samples that took 72 hours to incubate to determine if he had an infection or if something else needed to be done. During that time, Ian and I were in a room at the hospital and didn't leave. The assistant director of patient affairs would provide Ian with a video game and a small TV, so he had things to do. I was able to watch the larger TV up on the wall. Those days made me feel like we were back in the PEDICU—sitting on a chair staring at Ian again, staring at the TV, staring out the window brought back that hopeless feeling all over again.

At the end of three weeks, Ian was scheduled for surgery to put in a Porta-Cath, simply a tube running to a vein with a circular mesh coupling at the right underneath the skin to inject needles for all medicines. After that, it was easier for him to have treatments without being poked in the arm. Ian still fought this for the first two weeks until he finally realized that putting the needles in his port did not hurt. We were now down to only

fighting with nurses and doctors when they had to draw blood. His oncology doctor allowed Ian to push the propofol, a drug to knock him out, into the injection site when he was sedated for spinal taps. It cut down on his defensive measures of being poked with a needle. Ian fought with the doctors, nurses, and even me in most treatment measures until he received the port. He was an exceedingly difficult patient and did not react well to the doctors' medicine and other protocols. Ian's spirits were low, and he was giving in to cancer. And then a miracle happened, we met the assistant director of patient affairs; she dealt with the children. She was the one that had been giving Ian game consoles in the rooms during our hospital stays.

When we met the director for the first time, she came with wonderful news, Ian had been nominated to receive a wish from the Make-A-Wish foundation. Ian had fought doctors and nurses with all his heart and the difficult mental and physical rigors on my shelf and Madison; this was a welcome surprise. We met with people from the Make-A-Wish organization, and Ian told them he wanted to meet the Dallas Cowboys. Because this was a sporting wish, ESPN communicated with Make-A-Wish and asked if they could collaborate on his wish. This wish was to be presented in the My Wish series on ESPN. Finally, Ian determined he wanted to meet Marion Barber, a running back for the Dallas Cowboys, and granting his wish began.

Saturday afternoon, we went to the putt-putt golf course in Amarillo, TX. When Ian sunk his putt on the 18th hole, bells and whistles irrupted, and an announcement came over the loudspeaker. Ian had one prize, please come to the office. When we got to the office, a television was set up, and we were told to watch the television very carefully. Finally, the television came on, and Jason Witten, tight end for the Dallas Cowboys, told

Ian he would be invited to Dallas Cowboys' camp to meet Marion Barber and the rest of the Cowboys. Jason Witten also presented Ian with a Marion Barber team jersey. So, Ian, Madison, and I would soon be off to Dallas, TX, for Ian's wish to meet the Dallas Cowboys.

Before the trip to Dallas, ESPN came to Amarillo and set up shop in my parents' house. ESPN was there to do interviews, get background, and film the taping to air the My Wish series on ESPN in July. The series was invented to show how children with a terminal disease received their wishes and what went on during their adventure; the only stipulation was it had to be sports-related. Ian was one of the first recipients of this honor. Other recipients were given a 10-minute segment on ESPN; Ian's was 12 minutes. ESPN interviewed the family, me, and Madison; this was an adventure we would never forget. On the Make-A-Wish website, you can look up Ian Gregory and Marion Barber from the Dallas Cowboys and find Ian's segment aired on ESPN. This adventure was a welcome distraction from all that had been going on, the hard treatments for Ian, the numbness and dismay, helplessness, and hopelessness I felt during the last five months. This distraction of meeting the Dallas Cowboys was the first chance we could do something that made the family feel special, not the family of a child diagnosed with cancer.

The day we left for Dallas, they sent a limo to pick us up to take us to the airport. Madison and Ian loved the limo ride. It was the first time they had ever been in a limo. They were so excited I could barely keep them still. Then, the kids realized they would be going on an airplane, and the excitement tripled. We embarked on the airplane; the kids were scared at first, but then the excitement overcame them, and we lifted off and flew to Dallas, TX. I must admit the most scared the children were when we landed, which is a

different experience than taking off if you have ever flown. Once we got to Dallas, we were taken to a five-star hotel and put up in a wonderful room. Even better, our room was above a mall in Dallas, TX, the Galleria, where there was an ice rink, restaurants, stores, and all kinds of things to do, but we would be too busy to match at the mall.

On that first morning in Dallas, we were picked up in Jerry Jones, the Dallas Cowboys owner's private bus. A luxury tour bus took Mr. Jones around the United States for various activities. First, the bus took us to the Cowboys facility, where we were met by two cheerleaders that ushered us into the building where Jason Witten was standing waiting on Ian because he wanted to be the first one to meet Ian personally. Then a young gentleman comes and sits down next to Ian and asks him what he is eating. Ian said, "a banana and some juice." After that, the young gentleman asked if he could have a bit, laughed with Ian for a little bit, and got up and went into the Cowboys facility. Although I asked Ian who that was, I didn't recognize the guy; he said, " that was Terrence Newman," cornerback for the Dallas Cowboys; Ian knew all the Cowboys' names. Next, we took a tour of the facility and viewed the locker room. Finally, the apex of the first day for Ian was eating with the Dallas Cowboys players and coaches. The last thing we did that day was viewing the Super Bowl trophies of the Dallas Cowboys, and then we headed back to the hotel for some rest before going on to the final adventure of the day, which was my favorite part of the trip. After we rested and relaxed, the bus picked us back up, and we went to the facility to meet the Dallas cowboy cheerleaders, where we spent a couple of hours visiting with the girls and taking pictures. Madison and I are more interested in the Dallas Cowboys cheerleaders than Ian, but Ian may have just been very tired from a long day.

The bus picked us up the next day, and we went to the facility where Marion Barber invited Ian to ride on the team bus to practice. Ian accepted. We followed the team bus to the practice facility, where the coaches immediately scooped up and involved him in running back practice. Ian went through all the drills with Marion Barber carrying the football during tackling drills. Ian even got attached to the Bungie Drill used for running backs. He was over the moon excited. In the middle of practice, Ian heard one of the players come over and ask if he could take a picture with Ian and sign a ball. After that, the excitement just grew when the Dallas Cowboys' head coach asked Ian if he would help close practice for the day by meeting with all the players in the middle of the field in doing a 1,2,3 and Cowboys. This was how the Dallas Cowboys ended practice every day. At the end of practice. Marion Barber took time out of his busy schedule to play catch with Ian one-on-one and ask Ian to show off his touchdown dance. Ian obliged and proudly did his touchdown dance. That day ended, and Ian smiled from ear to ear for the first time in a long time. Madison was so happy to see her brother be normal, if only for a short time. I was personally able to forget about cancer, money, bills, and food, so many things. Instead, I focused on my son and daughter; it was the best day I could remember in such a long time.

The Dallas trip was not over. Make-A-Wish supplied us with a little bit of money and gift cards, so we could see the sights and do a lot of fun things. We went to the aquarium, the zoo, and Six Flags; the kids could be kids, and I could act like kids. This trip was the medicine we truly needed.

We returned home after the Make-A-Wish trip, and Ian returned to treatments. However, Ian was not the same kid. He had a whole new attitude about cancer and his treatments. What I witnessed was a miracle; he stopped fighting with the nurses and doctors and said, do whatever you want to me; I'm going to beat cancer.

#### 15 Months

Six months have passed since we began our journey, and Madison and Ian have come back from Dallas with new attitudes and a positive lease on life. But on the other hand, settling into a routine puts stress at the forefront of what I do every day. My short normality was done, and I was back to the stress of bills, appointments, and living off my family.

The Dallas trip was refreshing and allowed my kids to be kids, and I came back thinking we could do anything, including defeating cancer. Ian started treatments again, radiation is over, and we're only at the hospital every other week unless he has complications. I'm still unable to work, but I can spend a little more time with Madison, which eases my mind because I neglected her but needed to spend every minute with Ian. Just when I was hitting my wit's end again, Ian's oncology nurse informed me that there was a camp for terminally ill kids and their siblings; the camp is called Camp Alfie. Ian and Madison would go to a camp with other kids just like them, along with nurses and doctors from the oncology department to care for kids and transport them back and forth for treatments during camp if needed. Camp gave me a small break of eight days away from hospitals and treatments.

They did all sorts of fun things; the Corvette organization took the kids for rides, a Jeep organization took them on rides, and they could ride horses, fish in a small pond, and swim in a pool at camp. On the first day, all the kids, the counselors, and the doctors had a shaving cream fight, with almost 100 kids with shaving cream everywhere; the

pictures were amazing. At the end of camp, the children had a dance that always had a special theme, so the kids could dress up and have one last night of fun before parents came to pick them up the next day. When the parents arrived to pick the children up, there was a ceremony where each counselor talked about their kids and passed out awards, and the kids were able to say goodbye to all their new friends. Camp Alfie is a godsend and a special place for all terminally ill children and their siblings. It also allows parents to get a much-needed break from the everyday endeavors of dealing with a child diagnosed with cancer. I took the time to collaborate with my father and make some much-needed money because relying on my parents and straining their income is a lot for proud single parents to manage.

With Camp Alfie in the rearview mirror, we started back to bi-weekly treatments for Ian and me, trying to find time to spend with my daughter Madison. I was beginning to wear mentally and physically with the overwhelming demands of taking care of Ian and Madison. My family was trying to help as much as possible, which I understood was needed, and I had no idea how I would survive without them, but I was struggling. Finally, I asked Ian's oncology nurse if it ever got easier or if this was my life for the next three to four years. She responded and told me once Ian got to fifteen months and began the maintenance portion of his treatment, it would get easier; I just had to stand my ground and get Ian to the fifteen-month mark.

Time was flying by as it has during this process, and Ian was getting much better to where we wanted to do some things, so we planned a short trip on Labor Day weekend to our cabin in Eagles nest New Mexico. I thought it would be a good break for the kids, and Ian had been doing so well with treatment. I assumed we could go out of town for

three days without complications, but I was wrong. We got to the cabin, and we decided to go fishing the next day. While fishing, he poked himself with a hook, nothing deep, just enough to draw a little blood. We cleaned it up and thought nothing of it, but little did we know that Ian could not manage a simple poke from a hook because of his limited immune system. At first, it was just a little bitty black spot where he poked himself, so we cleaned it and kept antibiotic ointment on his finger, but the dark spot kept growing. Ian began to get a low-grade fever, and the two different spots where he touched himself were turning black too.

We had no idea what was going on with Ian. On Sunday afternoon, I decided we better get back home, take Ian to the doctor, and see what was happening to his finger. We got home, Ian's fever was extremely high, and his breathing was faint, so I took him directly to the hospital; they immediately admitted him. Ian had a staph infection. Ian's oxygen levels were down to 84, and his fever had spiked to 104; he was extremely sick. That hopeless feeling came over me, we were sitting in a room, and I felt that I could lose Ian. After all, he had been through and all the fight he had administered, I could lose him through something as simple as a fishing hook poking him in the finger. The hopeless feeling that I've done something wrong with my child ran over me as water ran over you in the shower. Over the next three days, Ian was given antibiotics and oxygen to help him recover from this staph infection. Ian was also given a blood transfusion to help with his cancer treatments because he could not do chemo. Of course, he had a bad reaction to the platelets, and the doctor administered epinephrine because Ian could not breathe. This moment was the most scared I've been for Ian in the last three months. Ian had been doing so well; something so simple brought him to the brink of death once again.

Luckily, antibiotics began working, his oxygen levels returned to 90 percentiles, and he was on the road to recovery. A plastic surgeon came in the next day and told us they would work on his finger and cut out the necrosis caused by the staph infection plus the two spots on his arm and chest that had also been infected. The surgery was done in the room under little sedation; it was quick and painless. He still has small scars today and doesn't even know why. As a dad, I see them, and it's a reminder every day during the treatment process that you can't take anything for granted with your terminally ill child.

Ian was back on his normal treatment program, and with school approaching, Ian's medical staff suggested that he go to school as many days as possible to feel like a normal kid. Madison is back in school full time, and as a very protective sister, she would eat lunch with him every day he was there and check on him as much as possible. Madison is a kid but took on responsibility like an adult. She was never asked to take a bigger role than just being a big sister, but I noticed she did more for Ian every day. This bond has lasted their whole life and never faded; it's amazing how a tragedy can bring the family together. Finally, the fall came, and both kids went to school. Madison full-time and Ian a day or two a week when he felt he was able. As I look back, going to school did help Ian, but I was constantly worried if he was sick, bullied, and something happened to him again. During the first fifteen months, I was unsure of the hopeless and helpless feelings ever left me completely. I want to think so, but I can't remember when I wasn't afraid for either of my children; it's something no parent should ever have to experience.

The next month was full of treatments, appointments, small wins, and losses for Ian in his fight against cancer. I remember waking up one morning at 3:00 AM Ian was in the bathroom throwing up after a day of treatment, and I asked him, "hey buddy, why

didn't you wake me up?" Ian replied, "Dad, you need to get your rest. I've got this; go back to bed, it is OK." I went back to bed and cried with a smile on my face simultaneously; that's a small example of how emotionally stretched I had become during this journey. I was a parent who was proud of his son, devastated by his son's diagnosis simultaneously. The weight on my shoulders was so heavy I felt like the world would come crashing down at any minute and all I could do was remind myself to get to fifteen months, and it will be better. Every time I reminded myself, I felt guilty because my son was the one with cancer, not me.

Finally, fifteen months arrived. Ian's treatments are going from every other week to once a month, Ian has made it to maintenance, and our hopelessness starts to turn to hope. No one could imagine that moving treatments from biweekly to monthly would be a big difference, but you can't imagine how the pressure on Ian and our family was eased. Getting to this stage in cancer treatment is a huge step for the patient, but it's even bigger for the family. A single-parent caregiver is still consumed with daily responsibilities, but the time between treatments is a welcome break. The patient's overall health improves, the parents' attitude changes, and siblings spend more time with the brother or sister, which was denied during these first fifteen months. The chance to do kid things and forget for moments about having cancer was the biggest step for Ian to beat cancer. It was a chance to be a dad and not just a caregiver.

Ian went from the worst patient to the best patient from a simple trip to see the Dallas Cowboys. I stumbled, fumbled, and did many things right and wrong during these fifteen months, but I had little to no experienced guidance to direct me on what a parent should do during this process. I was lucky to have immediate family and a good friend

that stepped up and happened to be Ian's oncology nurse; she helped me as much as she helped him. I could not imagine doing this alone or how a parent would survive the first fifteen months alone and without guidance. There were times when I went into a room and cried for hours because I had no idea how I was going to take care of my son, my daughter, and even myself. But, even with family, there was no time that I did not feel alone, helpless, devastated, and questioning how I would be strong for my son. Behind closed doors, I was a tragic mess, but in public, I buried my feelings deep and hid them from the outside world so I could be strong for my son. It was mentally and physically devastating. As I look back today, I still have no idea how I mentally, physically, and financially got through this time in my life. I hope that my story and the research can guide future parent caretakers who regretfully must fight through this terrible, tragic journey. I want to think of my family, daughter Madison, and Ian as the strongest kid I know.

## **Emerging Themes**

The narrative in this chapter was analyzed using the six steps of thematic analysis by Braun and Clark. Braun and Clark (2006) outlined six steps to performing thematic analysis. The six steps are: familiarizing yourself with the data, converting initial codes, searching for themes, reviewing themes, defining and naming teams, and producing the report/manuscript. Four major themes emerged from analyzing the narrative. The major themes are financial difficulties, caring for a healthy sibling, mental and physical health, and social support. These themes are explained in detail in this section and answer the research question in this paper. For example, how can sharing my experience as a single

parent caring for my child diagnosed with cancer help others going through a similar hardship?

While writing this autoethnography, various themes emerged that were clearly on my mind during the entire fifteen months of my story. Of course, the initial worry for a parent caregiver in this situation is the child diagnosed with cancer. Still, this research focused on specific themes that prepare and inform parents that find themselves in this predicament. My son's diagnosis was sudden and unexpected, which led to many surprises. As I reflected, I realized many of my obstacles could never be considered, even with sudden life changes. I was completely unprepared for even the smallest complication. Hopefully, the themes will enlighten parent/caregivers in the future.

#### **Financial Difficulties**

Financial difficulty is a common theme for most people in everyday life, but this theme intensifies when you add a diagnosis of a child's cancer. The parent/caregiver's first instinct is always what I can do to help my child fight cancer. But then, the shock of the diagnosis and the lost feeling fade, and reality adds a whole new set of problems to an already difficult situation. Financial difficulties reared their ugly head at the worst time in parents/caregivers' life. I was caught off guard before I could grasp my son's diagnosis.

My son's diagnosis came suddenly; it shocked my entire family. I was consumed with caring for my children. I moved into the PEDICU with my son and placed my daughter with my parents while at the hospital. My first episode of reality with financial difficulties was when the hospital sent a representative for me to fill out papers to put Ian on Medicaid and our family on food stamps. At the time, I understood Medicaid and how it would pay my son's doctor bills but could not understand why we needed food stamps

because I had a job that paid my bills and kept food on the table for my family. The hospital knew the journey my family was about to start and how difficult it would be for us.

The next bout with reality came when we were evicted from the apartment we had been in for two years. Being in the hospital with my son, I could not work and had not paid the rent or contacted the apartment complex, letting them know our situation. The management company deemed our apartment abandoned and locked the door but allowed my family to remove my belongings once our situation was clear. My situation was bleak, and at 30 plus years old, I was moving back into my parents' house. This inevitable fate of needing to be at the hospital with my son 24 hours a day led to this outcome.

I was extremely lucky that I had family that could help me take care of my daughter and had space for me and my children to live. I was able to work a day sporadically while my kids were at cancer camp because I worked for my father. Some single parents in this situation do not have a family to rely on, which leads to being homeless and leaving healthy siblings while caring for the child with cancer. In our situation Medicaid and food stamps allowed us to pay for my son's medical bills and put food in the refrigerator at my parents' house. There are so many other bills and financial responsibilities that the parent caregiver cannot care for while working. Through research, I have found that there is housing for parents where rent is relevant to income, so parents in this situation could pay little to no rent. TANF, Texas Assistance for Needy Families, gives parents up to \$1000 a month for bills and other family needs. Other institutions such as the Ronald McDonald House, St Jude's hospital, and Texas workforce

have resources to help parents/caregivers with a child diagnosed with cancer. My family is the only reason I did not rely heavily on these institutions and many others.

## **Care of Healthy Siblings**

Care of healthy siblings is necessary in this research because the brothers and sisters of cancer patients can never be left out of the story. My daughter, the healthy sibling, was always on my mind, but I found it hard to break away from the hospital and spend time with her. The constant state of guilt was always in my head, but I was required to be with my son. Not being with my daughter pulled me in many directions but always made me feel like I was failing as a father.

I made many bad decisions with my daughter during Ian's cancer treatments. However, Madison was a trooper and never held it against me, not even to this day. I always regret letting her come in and see her brother on the ventilator with tubes running from every part of his body, but she did need to know that she hadn't killed her brother. There is nothing a parent caregiver can do in that situation except to make the best time when they get to spend with the healthy sibling. A parent caregiver must make sure that you spend quality time with a sibling when the time allows, which in my case, the only option was quality over quantity.

Madison spent time with Ian at Camp Alphie, and the Make-A-Wish trip to see the Dallas Cowboys was particularly important for my daughter's mental status. It's extremely important, and I've learned from experience that a healthy sibling can spend time with her brother or sister with cancer. The parent caregiver must allow the siblings to fill as normal as possible, which allows us to grow bonds that last a lifetime. In the most terrible cases where the sibling passes, that small amount of time helps the healthy

sibling in the future. My knowledge comes from many discussions with my daughter after the fact, and once my son became cancer-free. Madison has been open and honest about how she felt during Ian's treatment.

As a parent, I was blessed to spend time with my daughter on unique adventures once my son was cancer-free. My daughter and I traveled many miles to and from softball tournaments where we could talk in the car. These trips allowed us to bond and have some sense of being a good father to my daughter. A parent caregiver must be there for the child diagnosed with cancer and find time with the healthy sibling. This time is hard to find but well worth it.

## **Social Support**

I never tell the story of my son's cancer without mentioning all the social support that allowed us to survive such a hard and tragic journey. Therefore, social support is a theme that must be presented in this autoethnography.

The first helpful entity in my story is always the hospitals, doctors, nurses, and staff at these facilities that cared for my family and me. The word hospital always strikes the fear of concern in people's minds, but in our case, it was the first crutch we used on the path to getting healthy. Without the doctors, nurses, and staff, we never would've survived the first steps, which we're getting my son well enough to go home. My son's oncology nurse, and my friend, is the only reason I retain my sanity through the first fifteen months of my son's treatments.

The second entity we encountered was the Ronald McDonald House. They greeted us during the hardest time with a blanket and the simple needs of a parent/caregiver living at the hospital. The Ronald McDonald House was my go-to for

snacks, a shower, or just a kind word. They never looked down on me in my time of need and were the first step towards feeling like I was not alone. When I was numb and confused, I still remember the volunteers and every kind gesture.

The third entity we dealt with may have been the most important to my family; it was the Make-A-Wish foundation. The Make-A-Wish foundation came to us when my son was most vulnerable and having the hardest time with treatments. Ian was fighting nurses and doctors at every turn and was slowly but surely succumbing to cancer. At this time, the Make-A-Wish foundation entered our life, and it completely changed my son's attitude towards treatment and my family's attitude towards his survival. Make-A-Wish gave Ian a trip to the Dallas Cowboys, and when we returned, he was ready to do whatever it took to beat cancer. In addition, Make-A-Wish involved another entity ESPN which allowed Ian to live the dream of meeting the Dallas Cowboys. Without Make-A-Wish and ESPN, I honestly believe my son would have given in to cancer and not be with us today. These two entities saved my son without a doubt. These two entities gave us hope for life after cancer and saved my son.

The final entity in this story is Camp Alphie. Camp Alphie is a cancer camp for cancer patients and their siblings. I have witnessed the effect this camp has on the children. This camp allows all the kids to feel normal and experience a week full of fun and laughter, something rare during cancer treatment. The bonding that goes on between these kids is something that lasts forever. My son saw a camper he had shared a bunk with just last week. As they caught up after all these years, you could still see the friendship and love for each other in their eyes. As a parent, Camp Alphie gave me the time to be a normal adult, work and play for a short period and not worry about my son's

cancer. I also met parents at Camp Alphie, whom I am still friends with today. This camp is an invaluable asset to the childhood cancer community and would be forever missed if it ever shut down. The tireless efforts of the doctors, nurses, and volunteers will always be in my heart.

## Mental and Physical Health

The theme of mental and physical health reflects how I felt and dealt with situations throughout the first fifteen months of my son's treatment. During analysis, many themes of mental and physical health were revealed. The themes are helplessness and hopelessness, loneliness, numbness, and experience, part of my mental and physical state.

Numbness mainly came at the beginning of my son's diagnosis. Numb is how you feel when called to your son's daycare and see paramedics work on him. Numbness comes from a cancer diagnosis and sitting in a chair staring at your son hooked up to a ventilator and multiple tubes keeping him in a coma. I was numb for the first twenty-eight days of our journey and every memory from that time seemed like a dream. As I was in the PEDICU with my son, I continuously expected to wake up from this horrible nightmare. Instead, hours turned into days, and days suddenly turned into weeks. There were many times that I lost track of what day it was, and one month it went as far as to ask the question what year it was, which is why the word numb(ness) is so appropriate for that time. I never knew when the numbness would end or if anything would be normal again.

The theme of helpless and hopeless was how my mind worked during my son's first fifteen months of cancer treatment. Helpless and hopeless was a constant feeling.

The moment I saw Ian lying passed out on the daycare floor, during the time they were working on him in the emergency room trying to save his life and even in the PEDICU as the doctors would come and go doing test changing IVS and administering medicine. I just sat there and stared as doctors and nurses came in and out of the room, trying to help my son as if I weren't even there. During those fifteen months, I was helpless for the first twenty-eight days. Then, when caregiving reverted to my responsibility, my hopelessness set in because I never thought my son could survive this disease. Every time we had to go back to the hospital, I felt the most helpless and hopeless, just him and me alone in the hospital room. You can never see the big picture or be positive when you watch your son go from 50 pounds to 19 pounds in just three weeks. Helplessness and hopelessness, put it mildly.

The theme of loneliness was continuous throughout my son's treatment, but it was the worst during the first fifteen months. There wasn't a time I didn't feel alone during those first fifteen months. In the PEDICU, I was always alone except for a few nurses and doctors. When loneliness was the worst, I was with family and still feeling alone because there was no way they could comprehend what was going on in my head. I am lucky that I had friends and family who tried to help me with my loneliness, but I know some parents/caregivers are going through this without family. Either way, the parent/caregiver is lonely during the entire treatment process, with or without family. There's no way to avoid loneliness in this situation. A parent caregiver must find that one person to confide in with their feelings to combat loneliness. In my experience, the best thing to do is to focus on what you can do and how you can do things better, be the best parent in a tough situation.

The next theme is experience. Experience comes with many avenues, but when you have a child diagnosed with cancer, you take any experience in a good light. I can look back is this experience as positive because this life-changing event worked out, and my son is cancer-free. Experience from a parent caregiver that loses a child possibly turns out different. I was in construction when my son was diagnosed with cancer, and now, I'm researching to help myself and others. Helping myself is finishing my master's, getting a degree, and not working construction. Helping others is making sure parents that live this tragedy in the future have somewhere to go to gain knowledge from someone that has lived this experience. I hope my experience can lead to two pieces of information delivered to parent caregivers at the beginning of the journey instead of learning firsthand. I hope my experience can help others.

Physical hardship came in many forms but was always an afterthought. The ability to work out or exercise seemed to be forgotten with my son's diagnosis. I was a stress eater that gained lots of weight that I never lost. It isn't easy to eat well, and overeating is better than not eating, which I know has happened to other parents. Some parents forget to eat or don't eat out of guilt for their child. The mental aspects of a parent/caregiver always lead to some form of physical regression.

My journey was riddled with indecision, surprise, and days of confusion. Yet, my son was saved from cancer and is a blessing to me every day. I was lucky to have friends, family, and medical staff that helped me survive this journey. Unfortunately, not all parents are as lucky, which drove me to complete this research. If this research can help one parent through the painful journey of having a child diagnosed with cancer, I believe I have repaid some of my debt for my son surviving cancer, a debt that can never be

repaid in full. The following chapter, chapter 5, addresses implications, related research, and future research.

# **Chapter Summary**

This chapter presented my narrative broken down into four sections, 51 hours, 28 days, six months, in 15 months. My narrative is split into those sections because the time frame during my son's treatment seems to provide breaks in the narrative at those moments. Furthermore, this chapter discussed the emerging themes and a description of each of those things. Finally, in the next chapter, I discuss practical applications related research future research and provide a conclusion.

#### **CHAPTER V**

# APPLICATIONS AND CONCLUSIONS

I began this research with the simple task of helping other parents like me. My introduction presents a story I wrote at Amarillo College in Dr. Naughton's English composition two class and later published in The Freelancer magazine. This story depicts the early difficulties in Ian's treatment process. My literature review follows this story by analyzing research on childhood cancer, parent caregivers, two-parent and single-parent families, and the care of healthy siblings. This past research lays the groundwork for my story and research to help parents living with a child diagnosed with cancer.

Why did I feel helpless at the beginning of my son's treatment? What made me feel the need to help other parents in my situation? I realized the lack of information led to my hopeless feelings as I thought back. Paramedics, nurses, and doctors held back pertinent information that would keep me informed and allow me to understand what was happening to my son.

When I arrived at daycare, paramedics worked on my son, and his skin color was blue. The paramedic said, "we need to load him and get him to Northwest Texas Hospital. You can follow us or drive to the emergency room." I arrived at the ER and stood in the corner of the room while doctors worked on my son. Finally, the doctor said, "go to the third-floor PEDICU, and a nurse will meet you there." The nurse on the third floor met me there and said, "when we get him settled in a room, we will come to get you; wait here in the hall." Finally, I was allowed in a room with Ian. He was multiple

machines controlling his medicine intake. I was in the room for the rest of the night and the next day. On the third day at 7:45 AM, an oncologist woke me up and said, "your son has cancer we will tell you multiple times, so it sinks in," then left the room.

Five days after my son collapsed at daycare, an oncologist pulled me from the room and adequately explained what had happened to my son. I was treated like the concerned parent I was, and the oncologist explained what happened and how they planned to help my son beat cancer. However, the doctor neglected to inform me of the treatment program's length. This was important because my mother had just defeated ovarian cancer in seven months. I believe Ian could do the same but once released from the hospital during one of his treatments, and his oncology nurse informed us the treatment program would be four to five years. The lack of information kept me in the dark about my son's diagnosis and treatment program, which is unacceptable.

I realized no parents should feel like I did during my son's illness and treatment. This research is aimed to help those parents and possibly open the eyes of the medical community to get these parents' help early in the process. Through narrative medicine, my illness narrative, and the themes from this research, I will spread my experience and help parents at the beginning of their long, hard journey.

Using narrative medicine and illness narrative as my theoretical background, I began the journey of remembering the hardest fifteen months in my life. This research uses narrative medicine and the work of Rita Charon as my theoretical background. Rita Charon's work on doctor/patient relationships fed this research. At the same time, I was

not the patient, my son was only five when diagnosed, so I was the arbitrator between doctor and patient. The doctor/patient parent relationship led me to write about how I felt and the situations during my son's treatment process. This process is called the illness narrative. Illness narrative is the writing of a narrative to help with the strain of dealing with an illness. This research could only be completed with my story, which would not have been completed without narrative medicine and illness narrative as a framework.

This research uses thematic analysis to analyze the story, and through this analysis, four themes were revealed. Those themes are financial burdens, care of a healthy sibling, mental and physical health, and social support. Finally, this chapter introduces implications for parents like myself and similar and future research to continue the work I've done to conclude my son's treatment program, which allows the help I provide parents like me throughout the full treatment process.

#### **Practical applications**

I spent my son's entire treatment process learning what to do and how to do it, but I lived my life in shock and awe during the first fifteen months of Ian's treatment. I never knew what to do and what would happen next. The first fifteen months were a blur, and I felt guilt and shame for not being able to take care of my son, my daughter, and even my family. Family and friends told me I was doing the best I could do and things would get better, but deep in my heart, I felt alone, guilty, and unfit as a parent. Any parent in any situation should never feel these feelings.

This research is set up to inform parents of the possibilities during their child's treatment. This research presents parents with problems and hopefully some solutions to help them through what surprised me. I never expected to lose my apartment, not work, or even take care of my family, but these things all happened, and I had no control. Each theme in this research was either a shock or life-saving entity that helped me survive Ian's first fifteen months of treatment. This research presents a road map to prepare parents for some of the difficulties of a situation no parent is prepared to cope with. This road is complicated. I did not understand the maintenance portion of a child's cancer treatment. I didn't know about making a wish or any other social support that allowed me to take back some control of an uncontrollable situation. I did not even know there was a Camp Alfie, a cancer camp that could make my children feel normal again, even if for a short time. Knowledge is the only tool parents have during this tragic time. I hope this research supplies some of that knowledge.

As I completed this research, the plan was to complete a book or pamphlet for parents at the beginning of the child's diagnosis. Pediatric cancer is battled every day, and

the quality-of-life directors in this region have created a binder to give parents beginning this journey. The binder has information for nonprofits, medical facilities, and other general Aid for parents with a child diagnosed with cancer. Unfortunately, what I did not find in this binder was help during that initial time of shock all parents experience.

Lack of any personal entries from a parent that has experienced this tragedy is missing. The deleted information to help single parents and no consideration for single fathers are also missing. The binders are a blessing but for later in the child treatment program. This research, my experience, revealed themes that appeared during my narrative, which would help to prepare a parent for the journey. My research with a cliff noted version for parents, a full version for an oncologist, oncology nurses, and PEDICU nurses would help parents in the early stage.

The plan to get this research to doctors, nurses and quality of life directors comes in a four-step process. First, I will use the physician's registry to email as many oncologists as possible in this region my research. In his first step, I will also use the hospitals' directories to email quality of life directors and other directors involved with caring for children diagnosed with cancer. The first email example will be in appendix 1 after the reference section of this research. Step one will get my research to the proper doctors, nurses, and directors of pediatric cancer departments. But will they read it?

Step 2 will try to assure that this research is read by following up the emails with a subsequent email that asks if doctors, nurses, and directors have had a chance to review my work. Again, the email will be short and to the point. It will contain a summary of my research and why it is important, finish with a thank you for their time, and include my email and phone for future questions. The example of this email will be in appendix 2.

The third step will be hand-delivered to the oncologist, nurses, and directors I know or were in contact with during my son's treatment program. Again, there are fewer people, but more work, and this step is willing to give my research a serious chance to be reviewed and discussed.

The fourth step will be to contact the quality-of-life directors in this region, the people who developed the notebook given to parents, and edit this book every year. I will request a meeting and hopefully present my research. I then will require and request to be a voice for the parents when the notebook is edited. This is a lofty goal, but I believe I can make my voice heard with my hard work and determination.

These steps will allow me to get my research to people who can help parents early in their experience. Doctors and nurses can help parents immediately with knowledge and information that can fight the lost, helpless feeling of a child diagnosed with cancer. The quality-of-life directors on the front lines of pediatric cancer are always helping the kids and parents survive. This research gives directors an idea of how to continuously help parents from the narrative of a parent that lived the experience. The only communication with parents gives those parents the chance to be cared for and their child during treatment.

The next section in this type of research is reserved for reviewing the literature cited in chapter two. Still, instead, I would like to expose some of the deficiencies in this topic. I would also like to show how the United States is falling behind countries like China in this type of research. The United States has done little research on parents and the effects of having a child diagnosed with cancer. The research done on the effects of healthy siblings during this trying time is just as lacking. The most astonishing aspect of

this type of research is that single male parents are exclusively left out of the process. The research done in this field has been strictly directed at single mothers or two-parent families. Fathers with the child diagnosed with cancer are not considered when this research is presented to the public. We must include all parents in future studies. We must consider the effects that research can have on fathers dealing with this tragic situation. I present a small section of related studies that shows the lack of research in the United States for single male parents and a section of future research that shows what we need to do next. My son's treatment lasted for five years, this research only covers the first fifteen months, and we must consider completing my research with future research that entails from fifteen months to the end of cancer treatment for the child.

#### **Related studies**

When I began this research, I found small quantities of similar research, but other research was revealed with time and effort. The research I discovered was associated with my analysis but none that was the same. For example, this research dealt with parents but rarely single parents, mothers of cancer patients but not fathers, and never an analyst who was the parent/caregiver of a child diagnosed with cancer. Some of this research I read is brought to light in this section.

The first paper I discovered was a systematic review of twenty-eight qualitative studies of parents' who experienced a child diagnosed with cancer. Gibbons, Steinhardt, and Beinart, 2012 analyze twenty-eight qualitative studies to investigate the parents of children with cancer. The authors revealed that the lack of this type of study had prevented a comprehensive investigation of parents' reactions and experiences dealing with the pediatric diagnosis. The systematic study was like my research as parents'

emotional and support structures were analyzed. This is where the research is divided as the authors investigated the basis of cancer treatment, the ability of parents to insert some control, and the ability of health care staff to provide clear and precise information. My research focuses strictly on the parent caregiver's difficulties and personal needs.

Gibbons, Steinhardt, and Beinart (2012) did consider some of the father's needs, but as a secondary caregiver or the primary breadwinner of the family dynamic. The needs of the father's single-parent caregiver were overlooked.

The second paper I analyzed was the parents' pediatric cancer experience by Moridi, Valice, Faithi, Nikbakht-Nasrabadi, and Khaledi (2018). This research had many similar themes, such as horror and hub, disturbance of normal life, and experience. These things were not worded exactly but covered similar ideas revealed by parents with a child diagnosed with cancer. Although different cultures, as this study was conducted in Iran, parents presented similar concerns. In both studies, parents were shocked and confused when first informed of the diagnosis. However, parents were also searching for ways to live a normal life and acknowledge the experience gained during their journey. Other than cultural differences, these parents were interviewed in a focus group, while my research comes solely from my personal experience.

The third study analyzed the qualitative experience of Chinese parents with children diagnosed with cancer by Wong and Chan. Wong and Chan (2006) focused on the psychological issues of parents when faced with a child diagnosed with cancer. The study states that over 50% of parents were mothers, and they dealt with emotional shock and sadness with informed of the diagnosis. However, the most relevant revelation was only 30% sought help for their emotional stress (Wong & Chan, 2006). The study by

Wong and Chan was the most like my study. However, several differences were glaring, with only one read-through. The cultural difference was apparent. Also, the study was with mothers and two-parent caregivers. My study again was from a single parent carrier story researched from an autoethnography. The difference in studies is Wong and Chan analyzed to reveal psychological needs why my research leads to revealing answers for the parents living this tragic journey.

The research section developed in this paper reveals that a single parent caregiver father is rarely considered available during this type of research. As the research by Reisi-Dehkord, Baratian, and Zargham-Boroujeni (2014) informs us in the title Challenges of Children with Cancer and their mothers, we have lots of work to do. A parent caregiver should not have to learn by example as I did during my son's cancer treatment, especially in the first fifteen months. Research is finally catching up to the parents and the experience of having a child diagnosed with cancer. The problem with rushing to catch up is someone is always left out. Research must consider all family units and work to reveal help for the families with pediatric cancer in the future. The entire family dynamic is involved when a child is diagnosed with cancer. Research in other countries began early, while research done in the United States has just begun. It is time for researchers in the United States to deal with this problem.

#### **Future Research**

The research developed in this paper specifically focused on my journey during the first fifteen months of my son's treatment, not the entire treatment cycle. My son's treatment lasted almost 5 1/2 years. Cancer treatment for pediatric cancer varies, but treatment for T-cell lymphoma is 3 1/2 years for girls and 4 years for boys (Cancer.net).

My son's treatment lasted 5 1/2 years due to delays of infection, illness, and other varied reasons. My study covered only the first fifteen months before the maintenance portion of treatment, leading to many other research avenues in parents experiencing a childhood cancer diagnosis.

The maintenance portion of my son's treatment should be studied. From month fifteen until the end of treatment, I faced many challenges, and as my needs changed, so did my story. As treatments became less frequent, I fought to find ways to get back to some normality. I struggled to know when my son was regular sick or to go to the hospital cancer sick and what we could do as a family that did not put Ian at risk while his immunity was still compromised. These items and many more are presented to me as a new challenge, and at this time, I was completely on my own to figure it out.

The second avenue of research would be focused on fathers and their needs during the child's treatment. Most research focuses on mothers or couples, and fathers' needs during this time are different. The single father caregivers are not represented in research and need to be considered. I dealt with many situations that would never have been presented to a single mother or a two-parent caregiver system.

A third element to be pursued in research is the effect of a cancer diagnosis on unhealthy siblings. The physical and mental aspects of unhealthy siblings have been mildly addressed but need more attention. Unfortunately, the healthy sibling is left out of research even more than the parents. When asked what medical and physical needs the healthy sibling needs and whether healthy siblings are affected long-term, research lacks these questions. The expectation that a healthy sibling is not affected by a diagnosis is irresponsible.

The research on parents with a child diagnosed with cancer is just beginning. Before 2011, we rarely, if ever, considered the impact on parents. Research on pediatric cancer has made enormous strides and has developed protocols to raise mortality rates among children above 75%. These strides are amazing, but we cannot forget the parents or healthy siblings in this tragic event. Everyone in a family is affected by the child's cancer diagnosis. Therefore, research must cover the entire family dynamic. The section shows plenty of work to be done to complete research to help parents live this tragedy. So let us get to work.

### Conclusion

I began this research with a short story I wrote at Amarillo college about my son Ian. The story began at the first of his cancer treatments; it was my first outlet to share how I felt and what I was dealing with in my life. That was the first time I realized writing about my situation could help me, but it might also help others. I watched my son fight in the battle against cancer and realized how strong he was and that I needed to work to better myself Out of respect for him. My son is not ten years cancer-free, and I am still in college trying to better myself and help others who must live this horrible, confusing, shocking journey. This research is a product of that first story and a long, confusing journey ending with my son cancer-free.

I began searching for stories like mine, and I found out that there were not very many and that it was a problem. Little research done in the United States was catered towards two-parent families can single-parent mothers, plus there was little research that involved my daughter. My daughter was the healthy sibling caught up in all this mess, and she was only seven years old; she was as confused as I was about the situation. The

literature review in this section covers a small portion of childhood cancer, parent caregivers and what they go through, two-parent families because the research on single-parent families was shockingly thin, and how to care for healthy siblings. So come to the research, I knew I had to do something to voice my journey and the complications of having a child diagnosed with cancer.

The theoretical background in the message in this section took more than one try to find a suitable accompaniment. However, the common thread was in sickness and my need to write and share Ian's happening to me. With that in mind, I chose narrative medicine by Rita Chacon and illness narrative covered by various authors. Narrative medicine, an illness narrative, informed me that the best way to cope with my situation is to write about it, which I did in this research. Themes from this research can lead to that information, implying that any new information can be added as discovered. We must collaborate with doctors, oncology nurses, and support services to develop this information.

My story began in the morning that I found out again was sick and continued through the first fifteen months until he reached the maintenance program in his treatment process. The maintenance portion of treatment begins after the first fifteen months and is considered less demanding than the first fifteen months. We were at the hospital four to five days a week during the first fifteen months, and it seemed like 24 hours a day, seven days a week, we dealt with cancer and nothing else. That first fifteenmonth was a struggle with many ups and downs, but we could not be today without that journey. After putting my story on paper, I used thematic analysis to analyze my story, and four themes were revealed. Those four themes were financial difficulties, care for a

healthy sibling, mental and physical health, and social support. These four themes were indicative do the struggle that haunted me during the first period of Ian's treatment. I knew these were the themes that I struggled with the most during my journey, and if I could answer any questions about these themes that would help another parent in my situation, the time and effort would be well worth it.

This research aims to help other parents in my situation and give them some love knowledge to help them through their journey. Traveling the journey of a child diagnosed with cancer is 90% shocking off in 10% learning that even the smallest positive outcome is a win. I have counseled parents in my situation, and the look in their eyes tells me the theater has lost as I was and confused, wondering whether their child would ever be healthy again. As a parent who lives that journey and comes out the other end, I can only assure the parents I talked to with perseverance that they may live to see the outcome that has blessed me today. But not feel that this research can help those parents two be prepared for what is to come and ease some of the on-the-job training I struggled through to cope with my son being diagnosed with cancer.

Research in the United States is so far behind other countries that it was my duty to point out the countries such as China that led in every category of pediatric research. Research on two-parent families dealing with a cancer diagnosis is the most researched. In contrast, single-parent families must follow research covering two-parent families and have little to do with their problems with a single parent. Single parent studies, all research is directed toward single females; the single male has been almost forgotten in research. We must develop research to help all parents in this situation. No parent should struggle and wonder what surprise I will be presented with my child's cancer treatment

today. We as parents are all different two-parent families single-parent mothers and single-parent fathers have different needs and complications with dealing with a cancer diagnosis. Helping parents is the goal, and we must succeed.

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**APPENDICES** 

Appendix 1

To: (Doctor, Nurse, or Director of pediatric oncology agencies)

From: (My email)

Subject: Research helping parents with a child diagnosed with cancer

Hello,

I am a single father with a child, eight years cancer-free, diagnosed with

leukemia. I'm also a graduate student at West Texas A&M University. My

research looks to help parents early in a child's diagnosis. Any feedback would

allow me to pursue avenues to help these parents. Questions, comments, and

discussions can be sent directly to me on the phone and email below. Your

feedback would be invaluable.

Thank you sincerely,

**Shane Gregory** 

Micheal Shane Gregory

Phone: (My phone)

Email: (My email)

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Appendix 2

To: (Doctor, Nurse, or Director of pediatric oncology agencies)

From: (My email)

Subject: Research helping parents with a child diagnosed with cancer

Hello,

I referred to research on helping parents in the early stage of their child diagnosed

with cancer to you on (Date) precisely 30 days ago. If you reviewed this research,

I'm anxiously looking forward to any evaluations, comments, or discussions on

the research that you feel appropriate. If you have not reviewed this research, I

implore you to look at this research and make contact with me. Your feedback

will be an invaluable tool in helping these parents.

Thank you sincerely,

Shane Gregory

Micheal Shane Gregory

Phone: (My phone)

Email: (My email)

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### Appendix 3

### A PARENT'S GUIDE: CHILDHOOD CANCER



## The First Seven

I am a parent who lived the experience of having a child diagnosed with cancer—receiving the diagnosis of cancer changed our whole lives. The news hits you hard, and then you are in a state of confusion. Having a support system is one of the most important resources you can have during this time. I am available to assist you with any non-medical questions you have or just need someone to talk to. shaneeregory3463@gmail.com.

have during this time. I am available to assist you with any non-medical questions you have or just need someone to talk to. shanegregory3463@gmail.com.	
Make sure that and have important numbers on "speed dial," including 911, yourself, other family, friends and support people, healthcare providers, and neighbors.	Write down questions and concerns as they arise. Make note of any changes you notice in your child's behavior both physical and emotional.
Prepare an emergency travel pack ready with his or her medication list, insurance cards, identification, medial allergies, and emergency contact information. Include healthy snacks and water for both the patient and you.	Find out what urgent medical problems you should watch for. Know what problems can be managed at home and which require urgent medical care in an emergency room.
Prepare and keep on hand an <u>up-to-date</u> medication record for the patient on hand in case you need to speak with his or her healthcare providers.	Make notes to help you remember important information you want to discuss with your child's doctor. Use a notebook or computer to keep information organized and in one place

# Important Phone Numbers

Set up a phone tree to keep important phone numbers in the patient's support network up to date.

Local Hospital	
Name and contact information	
Pediatric oncologist:	
Name and contact information	
Pediatric oncology nurse	
Name and contact information	
Palliative care specialists: child life specialists	
Name and contact information:	
Health and Human Resources: Food Stamps,	
Medicaid, Housing, Cash Assistance for Needy	
Families, Daycare, etc	
Name and contact information	
Responsible Family Member:	
Name and contact information	
Responsible Friend:	
Name and contact information:	

Important Notes

This is a picture of my son, Ian, during his Make-A-Wish trip and My wish series on ESPN

https://www.espn.com/video/clip/\_/id/4306948

This is a story I wrote shortly after my son Ian was diagnosed with Cancer

file:///C:/users/tlynn/Downloads/Freelancer2014Final-11%20(3)PDF

