

## ABSTRACT

### Parents' Adaptation and Coping Strategies in the Diagnosis and Treatment of a Child with Cancer

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This study examines the ability of parents to adapt to their child's diagnosis, along with factors that assist them in adaptation. The experience of diagnosis and treatment of pediatric cancer affects the patient's family along with the patient. Throughout treatment, parental roles are shifted towards caregiving in a medical context. To understand the effects of pediatric cancer more thoroughly on the parents of children with a cancer diagnosis, interviews were conducted with three mothers of pediatric cancer patients. The researcher filed information with the IRB to conduct not human subject research. A list of questions was used to direct the case interviews, allowing the subjects to share their medical experiences. Three interviews were recorded, providing an overview of the parental experience through childhood cancer. Forms of support were reviewed to determine helpful and unhelpful support techniques for parents. Coping strategies were noted to account for how parents adapt to a child's cancer diagnosis and treatment.

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PARENTS' ADAPTATION AND COPING STRATEGIES IN THE DIAGNOSIS AND  
TREATMENT OF A CHILD WITH CANCER

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## CHAPTER ONE

### Introduction

The relationship between parent and child is unlike any other relationship. A parent is given the responsibility to raise their child and care for him or her during childhood. When a child becomes ill, the parent is responsible for taking the appropriate steps for the child to be treated. Parents must adapt when a child receives a serious diagnosis.

Adaptation refers to adjusting one's behavior, routine, and expectations in order to be better suited for a new environment or situation. Families of children with chronic illnesses are forced to adapt once their child receives a diagnosis. Many aspects of the family's life change in response to the diagnosis and treatment of a child with a chronic illness. Maintaining a good quality of life necessitates that the family adapts well to the new diagnosis and treatment.

The care of a child with a chronic medical condition often follows the framework of "family-centered care," which refers to care that recognizes the critical role families play in the child's care (Rollins 179). For the family to adjust well to the new lifestyle of caring for a child with a chronic illness, normalization has been considered as an important aspect of adaptation. When a family does not experience normalization, parents can view their child as very different from other children, the illness becomes a major focus for the family, and the treatment can be viewed as a significant burden on the family (Rollins 182).

Of current available literature, common stressors stem from the uncertainty that comes with a cancer diagnosis. Parents often experience feelings of wondering why the situation has fallen upon them specifically. One such parent expresses the sentiment “Why me?” in an interview conducted by the Montefiore Health System (Chronic Illness in Kids). Parents tend to follow a line of thinking questioning if they are at fault for their child’s diagnosis. As with other traumatic experiences, it is natural to wonder how things may have changed if different actions were taken.

Parents often experience isolation because of their child’s medical care. Most of the population is unable to understand what it is like to walk through a child’s chronic illness as their parent. Parents play a critical role in their child’s treatment because parents are with children most often, especially for outpatient care. Much of the medication administration is done by the parents at home, while medicine administered intravenously is performed by medical personnel. Parents need to be able to stay organized to make treatment appointments, checkups, scans, etc. It is also initially up to the parents to bring the child in before diagnosis when they notice the child may be ill (Cipolletta).

Much of pediatric cancer treatment involves familial initiative in medical care from home. Management of chronic illness requires lifestyle changes, which fall on the responsibility of the parents to implement. Due to the responsibility family holds in a child’s treatment of chronic illness, the family must be able to maintain their own health and emotional well-being in order to adequately care for the child with the illness (Martire). An individual’s illness and treatment does not solely affect the individual but affects an individual’s family unit as well (Kanopy).

Due to the crucial role parents play in the medical care of a child with cancer, parents will often experience additional stress and feelings of isolation from their social circles. Daily routines change when a child receives a cancer diagnosis, and it is up to the parents to help the family adapt to the new shifts. Not only are parents responsible for managing their own stress in response to the situation, but they are responsible for helping their child manage his or her stress as well.

Parents caring for children with chronic illness must maintain responsibilities in reference to the child's medical care along with other parental responsibilities required of all parents. Parents of children with chronic illness are challenged with dividing their attention even more so than working parents of healthy children. Having more responsibilities in addition to caring for a child with a chronic illness leads to stress and can negatively impact a parent's quality of life (Kish).

Numerous chronic illnesses exist for which children receive treatment. Regardless of the illness or treatment unique to the child, a child's parents manage similar responsibilities and challenges they face. When caring for a child with a chronic illness, parents face potential challenges such as chronic grief, a lack of available information regarding their child's healthcare, and a lack of beneficial relationships with health professionals. However, though negative outcomes plague parents of children with chronic diseases, parents also note positive outcomes from their experiences of caring for their child through their child's illness and treatment (Kepreotes). A parent's capability for gaining positive outlooks amid challenging illness demonstrates the importance of healthy coping methods amidst the diagnosis and treatment processes.

When a parent loses a child to death caused by complications from chronic illness, a parent enters a stage of bereavement. Dutta's article, "Lived Experience of a Child's Chronic Illness and Death: A Qualitative Systematic Review of the Parental Bereavement Trajectory" discusses the parental experience through bereavement of a child's death from chronic illness. This explanation of parental bereavement includes holding space for grief to take its course. The review also emphasizes the importance of navigating losses and reconstructing lives following the loss (Dutta).

For a parent to maintain a healthy perspective during the diagnosis, treatment, and potential death of a child with cancer, the parent must have access to adequate support and maintain healthy coping skills. A parent needs to maintain emotional health and stability to care for a child with a cancer diagnosis through that child's progression of the illness and treatment. Maintaining good emotional health during challenging circumstances comes from using healthy coping methods and having access to adequate support.

The study serves to recognize the manners in which parents cope and adapt to the process of their child's diagnosis and treatment. The participants provided an overview of their story in reference to their child's treatment. In addition, the parents provided comments about the support they received. When a child receives a cancer diagnosis, that child's parent is forced to adapt to their new circumstances. The purpose of this study is to observe the ways in which parents adapt to a child's cancer diagnosis and the factors which help them to adapt, such as relationships, support, organizational skills, and faith.



## CHAPTER TWO

### Methodology

The researcher filed information with the IRB to conduct not human subject research, and the IRB categorized the research as exempt. The IRB responded with a document stating, “The above referenced research project has been determined to not meet the definition of human subject research under the purview of the IRB according to federal regulations at 45 CFR 46.102(e) & (l). Specifically, the sample size is insufficient to generate generalizable findings,” (IRB).

The method of one-on-one interviews was used to gather information regarding parents’ experiences with their child’s cancer diagnosis and treatment. Participants for the interviews were gathered using a flyer with information regarding the study inviting interested parties to contact the leading researcher. No incentives or compensation were provided for participating in the study.

The study had planned to have five participants in the study; however, three participants were available to participate. Having a small sample size limits the amount of data that is able to be collected and limits the scope for comparing results across interviews. The study was halted in the Spring of 2023 for the results to be reviewed prior to the end of April 2023.

Three interviews were conducted with mothers of children with a cancer diagnosis. A form of consent was provided to the participants indicating the purpose and methods of the study. The consent form indicated that by continuing with the interview,

the participants were providing their consent. The interviews took place at coffee shops in the local Waco, Texas area. This was to allow for a public setting with the ability to carry on a private interview. The participants were given the freedom to halt the interview at any point should they no longer desire to participate in the study.

During the interviews, a list of questions was used to cultivate conversations about the parent's experiences with caring for a child amidst the treatment of cancer. The questions focused on a theme of adaptation and methods in which aided the parent in adapting to the new circumstances of disease.

Each parent was given a form of consent that they agreed to prior to participating in the interview. The participants were informed that no question required an answer and that the interview could be stopped at any time if needed. The interviews were held for 60 to 90 minutes, with an average interview time of 80 minutes.

Interviews were chosen as the method for observation due to the opportunity for participants to provide complex answers to questions. It also ensured the participants were not limited by multiple choice questions or the task of writing answers. Using a conversational format is helpful for putting the participants at ease and cultivating an environment conducive for sharing personal information.

Only the primary researcher and participant was present for the interviews. No other individual was present for the interviews, though the interviews were audio recorded to allow for more specific review. Following the interviews, the primary researcher transcribed the audio recordings of the interviews to gather data. The interviews included emotional information, which necessitated deep engagement from the participants and the interviewer.

The questions asked in the interviews were open ended and guided the participant to discuss her experience with her child's pediatric cancer. The central questions focused on the experience of diagnosis and treatment of the participant's child, along with the participant's methods of coping through the experience. Methods of support provided to the participant was also questioned, along with the participant's judgment of the quality of the support provided.

#### *Case Summary Questions*

1. What type of cancer diagnosis did your child receive?
2. What did the average day look like for your family before diagnosis and after diagnosis?
3. What do you remember about the day you first received the diagnosis? Events, thoughts, feelings, etc. What was your initial reaction?
4. Who was with you at the point of diagnosis?
5. Who delivered the news to you?
6. How was your child made aware of the diagnosis?
7. What symptoms led up to the initial diagnosis? What were the first symptoms to appear?
8. How did the symptoms affect your child's daily life before diagnosis and after diagnosis?
9. How did your child respond to the diagnosis?
10. How did you view your role as a parent after the diagnosis?
11. What did treatments did your child receive?
12. How did the treatment affect your child? Physically, emotionally, mentally, etc.?

13. Did your family dynamics change with the diagnosis and treatment? If so, how did they change?
14. How would you describe your mindset during the process of diagnosis and treatment?
15. Describe your methods for handling your own emotional experience during the process.
16. Were there any times you felt incapable of handling the situation? Please explain.
17. Did you feel adequately supported during the process? What did that support look like? In what ways were you supported? Monetarily, relationally, practically, spiritually, etc.
18. Did the diagnosis cause any relational strain in your family?
19. What strengths have you seen in your family that have emerged through the process?
20. If you could offer any advice to another family that have emerged through this process?
21. Is there anything else that you haven't shared yet that you feel is important to your story?

After these questions were asked and answered, the interview was concluded, and the audio recordings were reviewed. The case summaries were reviewed through identifying common themes among the interview data and determining results from the common themes noted. The case summaries were not coded, as the scope nor length of the study allowed for such data analysis procedures.

The claims made from the analysis are warranted and have produced findings with methodological integrity. The data captured forms of diversity in response to forms of support provided to the participants. The researcher's perspective was managed in data collection by limiting the frequency of speech during interviews. The researcher did not provide information irrelevant during interviews and allowed the participants to answer questions without interruption. The researcher did not make comments or statements about the answers provided during the interviews. The direction of the interviews was guided by the interview questions and the answers of the participants.

The findings are grounded in evidence, and the contributions are insightful and meaningful. The findings detail the useful coping mechanisms parents demonstrate to maintain emotional stability while caring for their child amidst their child's treatment. The findings also reveal adequate methods of support that are useful in aiding parents to care for their children.

## CHAPTER THREE

### Results

#### *Case Summary One*

##### *Case Presentation*

Jack was diagnosed with Wilms tumor at age 4 in 2022. An interview with his mother took place on September 11, 2022. At the time of the interview, Jack was currently still receiving treatment for his disease.

##### *Summary of Disease*

Wilms tumor is the most common pediatric renal cancer. It is a tumor in the kidney, which is typically found in children under the age of 5. Treatment normally requires a nephrectomy, or removal of the kidney (nationalpcf.org).

##### *Case Summary*

During an interview, one mother shared her experience of her child being diagnosed with cancer and receiving treatment. The names of the individuals have been changed to respect their confidentiality; the mother will be called Amy and the son, Jack. The interview took place on September 11, 2022, for one hour and thirty minutes, where Amy was asked a series of questions regarding the diagnosis and treatment of her son, along with her own emotional experience during the process.

Jack was diagnosed with Wilms tumor, which is also known as a nephroblastoma ten days before his fifth birthday. He had a solid tumor and did not receive a diagnosis until pathology had been performed on it. The tumor was encapsulated in the kidney, requiring the entire kidney to be removed with a nephrectomy. In the procedure, the right

kidney, right ureter, and a portion of the renal vein traveling to the inferior vena cava were removed. Twenty-two lymph nodes were removed for sampling. Serous fluid was present, and the medical team wanted to ensure the tumor had not ruptured.

The initial diagnosis made of stage three Wilms tumor with favorable histology proved to be incorrect. It was later changed to a stage two diagnosis without favorable histology but positive for diffused anaplasia. The kidney had not developed correctly at birth and was missing the TP53 gene, which would cause cells to shut down. Due to the anaplasia diagnosis being more aggressive, a more aggressive treatment needed to be used.

Jack had been placed on an initial regimen of DD4A, a chemotherapy treatment made up of vincristine, doxorubicin, and dactinomycin to treat the first diagnosis. After the first cycle, which lasted for three weeks, the treatment was altered to treat the new diagnosis with revised UH1 chemo. A revised treatment was used because the original had a much higher dosage which results in unnecessarily higher toxicity. Jack would complete a ten-cycle regimen with radiation concurrent with the diagnosis. Following the nephrectomy, Jack had clear margins and received six sessions of right flank radiation. At the time of the interview, Jack had completed eight cycles of treatment with cycles nine, ten, and one to go. Treatment began with cycle two and will finish with cycle one.

Amy describes the process of treatment as “taking it step by step.” She explained that going through a cancer diagnosis causes grief, even if the diagnosis is not fatal. There is a loss of normalcy in life, which brings about grief. Amy immediately accepted the diagnosis and began contemplating the next plan of action. In her process of grieving, she kept herself busy with plans and figuring out ways to solve the problems coming up.

At the time of diagnosis, Amy recounts not being offered helpful assistance by the medical professionals. She was not made aware of the cancer diagnosis until after the surgeon informed Amy they needed to report to oncology. No one shared the news in person on the day of the diagnosis, which Amy believed could be improved.

Prior to Jack's diagnosis, he presented as smaller than the average child his age, though his mom recounts he did not appear concerningly small. He was fully potty trained but could not hold his urine at night or during naptime, which Amy now recognizes was his kidney failing to keep up. Jack's family did not notice any concerning symptoms until a small bump presented itself below his ribcage. The doctor immediately sent for scans and sent Jack and Amy to sit in the hallway to wait for the results. After an hour of waiting, Amy received separate phone calls with conflicting instructions. One phone call instructed them that they will have to go to a pediatric medical center. During another phone call, a surgeon from the hospital informed Amy that Jack needed surgery and believed the scans showed a Wilms tumor, but that they would not know for certain until it was removed.

Amy and Jack traveled to the pediatric medical center the following day. Amy recalls wishing to go to the hospital immediately after receiving the news and that it was difficult to wait until the next day. At the hospital, they were informed that Jack's right kidney would need to be removed. Amy's first response to the news was "that's okay, you can live with one." This comment surprised the surgeon but demonstrated Amy's logical thinking patterns. She looked at the situation as a problem to be solved and felt committed to doing everything in her power to solve the problem. She recalls feeling like "the world is happening, but my experience has been abnormal."



Amy appreciates the help they received from child life specialists. The first person she and Jack met in the clinic was a child life specialist. To prepare Jack for his procedures, child life specialists would explain procedures in age-appropriate ways and use a doll as an example for medical procedures. Prior to his nephrectomy, Jack was told about ports and how they function and was made aware that he would go to sleep for the surgery.

As a parent, Amy feels strongly about being transparent with her children, in ways that are age-appropriate and easy to understand. She and the medical team have taken the time to explain the details of Jack's medical condition and treatment, and they re-explain aspects as he gets older with terminology that he is able to understand. An example of the words used with Jack at the time is "We got the bump out of your tummy, but now you have to take medicine." This is how the adults in Jack's life speak with him about chemotherapy.

At this point, Jack is five years old and still does not use technical words to describe his medical condition or treatment. He prefers nicknames and likes getting to use "baby talk" to explain. He uses the term "medicine" to refer to chemo.

After beginning chemotherapy, Amy informed Jack that the "medicine" would make his hair fall out. She gave him the option to wait for the hair to fall out on its own or go ahead and cut it off. Prior to getting a diagnosis, Jack had been asking to shave his head bald, which caused much excitement for him when he was told he could cut off his hair. He chose to cut his hair, and Amy allowed him to help cut it as well. The family took pictures together before cutting his hair, and then a family friend cut his hair into a

buzz-cut. It had to be re-cut a few times before it stopped growing back in, and Amy would help brush it away as it fell out over time.

Early in the treatment process, when the treatment had been switched to revised UH1, Jack and his family were given the option to join a clinical trial for what will be known as UH3. They had three weeks to decide whether they would proceed with the clinical trial treatment plan as the plan began at cycle three. Amy recounts the deciding process as being miserable and exhausting.

To take part in the clinical trial, Jack would have to be treated at a different hospital in a different city because it was not offered at the hospital from which he was currently receiving treatment. They made the decision not to enter the clinical trial and later discovered that Jack no longer qualified when his diagnosis changed and was no longer presumed favorable histology.

Jack and his family were given the option to receive treatment “off-trial”, which would allow Jack to receive the treatment plan offered with the clinical trial without participating. According to Amy, she believes this is the best way to receive the treatment from a clinical trial because it allows for more flexibility for each patient’s case, whereas clinical trials are dependent on factors remaining the same, which may not be in the patient’s best interest.

Jack’s family ultimately decided against going off-trial because it would have added unnecessary additional toxicity. Amy identifies that clinical trials are excellent for children with higher stages of diagnosis, however, because Jack’s diagnosis was stage two, there was no need to add additional chemotherapy rounds. Jack’s oncologist talked with others across the nation and found that other oncologists are not treating stage one

and two patients with off-trial treatment and that there is no data to suggest UH3 is better for stage two. This solidified the family's decision to refrain from using UH3, which would have added an additional four cycles of chemotherapy.

Jack's treatment plan consists of two different types of cycles, which alternate in an inconsistent pattern. Amy has nicknamed the cycles "blue and yellow cycle" because when she initially received the info regarding the treatment cycles, she grabbed highlighters and began organizing the information with color coding. UH1 alternates between "blue" and "yellow" cycles, which can be pushed back if Jack does not meet his counts before receiving treatment for that week.

When asked how Amy views her role as a parent through the treatment process, she responded that there have been drastic changes in how she views her role. Before Jack had received a diagnosis, Amy had been well informed of the effect of ACEs, which are Adverse Childhood Experiences. The presence of ACEs in a child's life negatively impacts that child's life and future well-being. Amy has a strong belief in trauma-informed care and has sought to use the knowledge she has in the area to inform her parenting.

With Jack's illness, Amy has noticed that he has demonstrated behavior patterns that are consistent with those she has witnessed in her work with foster care. Due to the added strain of the diagnosis and treatment, Amy quit her job immediately after receiving the diagnosis so she could be fully focused on her son's medical journey.

Amy notes that the dynamics within her household have shifted. She also has an older daughter who grew up in foster care and has attachment issues and trauma associated with moving around. Due to Amy's awareness of her now-adopted daughter's

trauma, she ensured that her daughter would never have to stay at another person's house. To make this happen, Amy's sister and her sister's fiancé moved in with them to provide more assistance and have lived with them since the diagnosis.

Amy mentions that with treatment, there are many changes, some that are expected, and some that are unexpected and cannot be understood unless one experiences having an illness in the family. One of the most difficult aspects for Amy and her son's treatment was the count-dependent nature of the chemotherapy. This means that before each chemo cycle the medical team will check levels of hemoglobin, platelets, absolute neutrophil count (ANC), and white blood cells. If any of those levels are too low, Jack is unable to receive his scheduled chemotherapy treatment that day, and the entire treatment plan is pushed forward one week.

Amy recounts only one instance in which Jack did not make counts, which caused the treatment schedule to be extended. The requirement for meeting counts means that the family does not know with certainty when treatment will end. This proves to be challenging for Amy, as she describes herself as a planner who does not prefer having things up in the air. When others ask her about future availability, she is unable to provide concrete answers due to the variability that cancer treatment causes.

Amy's expectations for her son's routine medical care also changed. Prior to the diagnosis, Amy recalls only taking her son to see a medical professional if she felt the case was severe enough to warrant that action. When Jack first presented with a bump, Amy's husband wanted to go to the emergency department (ED) that night, but Amy chose to wait to bring Jack in for a clinic visit.

Now that Jack has a cancer diagnosis and receives chemotherapy, Amy takes Jack to the emergency room whenever he has a low-grade fever. Whenever they go to the ED, they must make arrangements to have another adult in the house take their daughter to school. Before going to the ED, Amy or her husband will text their phone number to the on-call pager, and a physician will return the call so Amy can let the ED know they are coming in.

Having a child with a serious illness means the role of the parent transforms to be the child's primary advocate. Amy remarks that some physicians do not understand the importance of parents being their child's primary advocate. Since the diagnosis, Amy has become more in tune with her child's needs as she has played a large role in her child's medical care. Amy became aware of the term "momcology," which refers to moms who have a child with a cancer diagnosis. This term recognizes that moms are the frontlines for their children.

As Jack's mom, Amy administers home injections after rounds of chemo to help increase his counts following treatment by stimulating bone growth. Earlier in treatment, Amy would have to administer daily injections, but they have switched to a time-release medication that allows for only using one injection per week.

With an involved medical regimen, Jack works with a large team of medical specialties. Since Jack's cancer involves his kidney, he sees a nephrologist, which he will continue to see following the end of his treatment because he now has one kidney. Additionally, he sees an oncologist, a nutritionist, and an audiologist.

Many children who go through cancer treatment require a nasogastric tube (NG) placed to combat malnutrition. This has not been a concern for Jack since early on they

learned to maintain a healthy weight. Three weeks after starting treatment, Jack's weight was lower, and his appetite was weaker. Amy asked the oncologist to refer them to see a nutritionist, which she claims was a game changer. Amy notes that often patients are not referred to nutritionists until it is emergent, so she appreciated addressing Jack's nutrition proactively rather than reactively.

Through experiences and conversations with other parents, Amy has noticed that oncology lacks preventative medicine, since preventative measures are dependent on the family's willingness to follow medical advice. It is up to the family to oversee the child's care and advocate for them in a collaborative manner with the medical health professionals.

During treatment, Amy noticed Jack's behavior had changed drastically, and he was irritable most of the time. Amy spoke with other parents she knew from the hospital and interacted with Facebook groups she had joined. One mom asked if Jack was taking steroids. This question reminded Amy about the steroid given prior to each chemo round to increase the efficacy of the Zofran (an anti-nausea medication). Amy brought up this concern with Jack's physician, who noted was a good call on her part. They were able to stop using the steroid because Jack was not experiencing high levels of nausea. This improved his behavior without causing any additional harm.

During treatment, Jack and his family experienced lifestyle changes. Though Jack was immunocompromised due to his treatments, his doctor gave him permission to go places and do more things than Amy expected. She had anticipated a greater shift in lifestyle than the reality they experienced, which shocked her. During the COVID-19 pandemic, Jack and his family did have to remain isolated, which was challenging. Amy

wanted to keep Jack clear of other children so he would not catch any secondary illnesses. The social isolation made the process of going through diagnosis and treatment even more challenging since they were not able to receive as much social support as they may have received pre-pandemic.

In terms of support throughout treatment, Amy felt as though she did not know what they needed as a family to be supported for a long time. Amy recalled one of the most difficult aspects of receiving help from others was the lack of initiative well-meaning people would take. She often heard the phrase “let me know if you need anything.” She recognized that those who said this often meant well, but she did not know who to ask for help because she was unaware of which areas certain people were more equipped to handle.

When desiring to help others, Amy believes it is best to be assertive. An example of this she gave is, “I really want to help in whatever capacity I can. If you think of any way you need help, let me know. In the meantime, here are some things I thought of that I could do for you. Can I do any of these things for you?” This example outlines how a person can help and demonstrates the person’s desire to help.

Jack’s family received some financial support, which Amy notes is a practical way of helping. One of Amy’s friends put together a meal train for the family, where others were able to contribute Grubhub delivery gift cards. Amy appreciated the gifts they received through the meal train because they often did not know what meals would look like on days spent at the hospital. Every Tuesday, Jack and Amy would be in the clinic for count checks and often would not know if they would be there for an hour or all

day. On the days Amy was not prepared to pack a lunch, she used the Grubhub gift cards for meals.

Another example of support for Amy came from her friend, who also had a child with cancer. This friend had walked through life as a medical mom for many years and therefore was knowledgeable regarding the best ways to help others in similar situations. Prior to Jack's surgery, this friend came to the hospital and let Amy and her husband know she would like to sit with them during surgery if it was not an intrusion. After the surgery, the friend left so she would not intrude in recovery. Amy appreciates the respect with which her friend handled the situation.

Another friend of Amy's asked her what she needed most at the moment. Amy responded by saying she wanted company for a specific night that was challenging. This friend immediately met Amy at the hospital to sit and be present with her. While simple, Amy recalled feeling well supported by that situation.

Amy also received support that caused more harm than good. One such example occurred with a friend who showed up at the hospital from out of town without any prior communication and made herself a little too welcome. This friend showed up in the recovery room after surgery, which Amy did not appreciate. She appreciated the friend's intention, but she set clear boundaries to avoid the occurrence of a similar situation in the future. The friend took pictures of Jack while in recovery. Amy notes a fine line between sharing a medical journey with others and exploitation, especially for children who cannot advocate for themselves. Amy did not want the pictures taken to be shared, and she wanted to be cautious of anything that felt exploitative or too personal. She also felt strongly about no one else exploiting her son's struggles for their own personal gain.



Amy does share aspects of their journey online with the purpose to help others but does not share Jack's personal difficulties.

In American culture, it is not uncommon for people to demonstrate inauthentic support. Amy believes a lot of things people will say in encounters with her are for the sake of making her feel that they are impacted. She has had encounters with others who have emotionally dumped on her, which left her feeling like she is unable to process her own feelings. Amy's parents did not handle the diagnosis well, and it led to Amy not feeling free to grieve because she had to allow her parents to grieve. She stated, "If you are not the parent of this child, you are grieving but in a different way."

Amy dislikes when people attempt to commiserate. She finds it uncomfortable and disingenuous. She also felt as though she was often having to break the bad news to people. People would come to Amy and ask about Jack's prognosis, which Amy felt was rude. By asking about the prognosis, Amy would have to relive things over again.

## *Case Summary Two*

### *Case Presentation*

Andrew was 17 years old when he was diagnosed with acute myeloid leukemia in August of 2012. He died from complications with the disease in December of 2012. An interview with his mother took place on September 29, 2022. Patient is currently deceased.

### *Disease Summary*

Acute myeloid leukemia is a blood cancer in which bone marrow produces many abnormal blood cells. Signs of the disease include fever, fatigue, and easy bruising and bleeding. The disease is diagnosed with blood and bone marrow tests (cancer.gov).

### *Case Summary*

The second interview took place on September 29, 2022. The names of the interviewer and her child have been changed for the sake of anonymity to Mary and Andrew. Andrew was diagnosed with acute myeloid leukemia at age sixteen and passed away four and a half months later. Mary shared her experience of walking through her son's cancer diagnosis, treatment, and grief.

Mary has three children, and Andrew was the youngest. She and her husband divorced a few years before Andrew was diagnosed and Mary recounts the time before the diagnosis being the happiest time in their lives. She had started dating a man, whom she later married. She was on good terms with her ex-husband, and her children saw their dad every day.

Mary first noticed her son was sick the summer before he was diagnosed. He started working with his dad in the summer, and at night he would come home to spend

time with her. Mary noticed a pattern developed where Andrew would come home and lay his head in her lap for thirty to forty-five minutes. They would watch television, or he would be on his phone. Mary noted this clingy behavior was unusual; he was a “mama’s boy” but he did not often show it in his behavior.

During that summer, Andrew was tired all the time, and he stopped asking to go out on Friday nights. When Mary asked him about this change, he said that he was tired from working and that his friends were doing things he didn’t want to do. Later that summer, their family took a vacation to the beach, where Andrew spent much of his time laying around instead of surfing as he usually would.

On one of the following days of the vacation, Andrew had a 103-degree fever, and at the end of the vacation, he started vomiting. Over the course of the week, he barely ate and ended up losing ten pounds. Mary took him to see the doctor when they returned, and the doctor ordered some lab work. Later, the doctor called Mary with the results and informed her that they were strange. He commented hoping the machines were broken because the labs stated Andrew’s white count was 400/mm<sup>3</sup>. The typical range for a pediatric patient is 4,800/mm<sup>3</sup>-10,800/mm<sup>3</sup> (nationalpcf.org). The doctor told them to go to the hospital right away and get the tests done again. They were told not to leave until the results had been read.

The new results showed 2100 for his white count. This was better but still significantly lower than it should have been. Andrew did not have to be admitted to the hospital, but the doctor told Mary not to let him go anywhere in public. This was difficult for Andrew as he was about to start his senior year of high school and did not want to miss out on important experiences.

On the day of receiving Andrew's diagnosis, Mary recalls having two of her children in the hospital. Her daughter had a critically ill condition with an aneurysm that was inoperable. Andrew was downstairs getting a bone marrow biopsy. Mary remembers within an hour going from having one child who was critically ill to having two children who were critically ill, one of whom turned out to be terminally ill.

The child life specialist (CLS) who worked with Andrew and his family was one of the most important pieces of his treatment. She introduced herself to Andrew and his family prior to the bone marrow biopsy. The CLS stayed with Andrew during the procedure since the family was not permitted to be present for it. She helped him decide what he wanted to do during the procedure, which was to listen to music. Once they made it back to the room with the family, the CLS wished Andrew well and said, "hope to not see you again." This parting phrase served to imply that so long as his tests turned out well, there would be no need for him to continue meeting with a CLS.

Mary made her way upstairs to meet with her daughter's doctor regarding the aneurysm while Andrew's test results were still processing. After returning to Andrew's room, Mary was informed that the doctor would stop by soon. Initially, the pathologist planned on letting Andrew see the samples from his biopsy in the lab. Mary noted this was one of the perks of being in a children's hospital. However, the pathologist later said he would be unable to do that because the lab was backed up. This was one of the first indications to Mary that something was wrong.

The second indication of poor results was the CLS returning. She engaged in conversations with Andrew and his sister, getting to know them better. Mary remarked being an early education person, meaning she understood the CLS' interest in getting to

know her children on a personal level meant they were not leaving. She recalls this as the moment she knew her life was about to come crashing down.

Five minutes later, the doctor and his assistant waved Mary out of the room. She shook her head and he nodded, demonstrating a level of nonverbal communication. Mary took her mother with her as they were led into a room with a round table. Mary said she now hates round tables. The group sat down, and the doctor said, “There’s no easy way to say this, Andrew has leukemia.”

Mary recalled having an out-of-body experience where she screamed, but to her, it felt as if the scream had come from somewhere else. The next thing she thought was “Get it together, your kid is sick.” She was the kind of mom that would put aside her feelings to take care of her children, so she attempted to compose herself. She thought, “One of the people that literally owns a third of your heart is sick beyond what you can help.” She found it difficult to accept that this was her second child to be critically ill, although her daughter never appeared sick. Andrew was different because he looked sick, acted sick, and felt sick. She recalled this bringing a new dynamic to the understanding of her child having cancer.

Mary’s mother gasped for air after hearing the diagnosis. The doctor gave space for them to begin processing, but they were on a time crunch Mary did not understand at the time. The doctor informed them that Andrew would not be returning home for the next six to eight months. Andrew’s tests showed more progression than they first thought. They scheduled Andrew to have surgery the next morning to have a port placed, through which Andrew would receive chemo. He would also have another bone marrow biopsy to confirm the type of leukemia. Mary described the protocol as being “fast and furious.”

Andrew's parents had four hours following receiving news of the diagnosis to determine which hospital protocol they would use for treatment.

Early in the process, Mary felt they were headed toward a bad outcome. Before receiving a diagnosis, Andrew had told his mother that he "was going out with a bang." Essentially, he predicted early on that he would be dying from cancer. His prediction caused Mary to carry on with stronger determination through treatment. The doctor informed Mary that Andrew had a thirty percent chance of survival to which she immediately responded with "that's not enough for me." The doctor agreed with her and looked at ways they could increase the survival rate. Even if Andrew went into remission, only eighteen percent of children with this diagnosis did not relapse. The odds for Andrew were bleak even from the beginning.

Later, Andrew's dad brought things from home to make Andrew more comfortable during his stay. Mary knew they were not leaving the hospital any time soon, so there were plenty of opportunities to ask more questions down the road. The doctor asked how they wanted to share the news with Andrew and Mary said she wanted to tell him.

They walked around the corner toward his room and heard the children laughing to a movie called "Cat Dog," which Mary to this day cannot watch. When they entered the room, Mary's mother walked over to Mary's daughter and Mary went to the foot of Andrew's bed. She wiggled his toes and asked him to turn off the movie so she could talk to him. He asked, "What's up?" Mary's response was, "Well, Andrew, you have leukemia." Andrew's sister fell, and the CLS and grandmother had to catch her. Mary recalled knowing she had to keep her focus on her son regardless of what was going on

around her. He did not appear upset or uneasy and simply asked, “Cancer, right?” Mary affirmed his question and he said, “We knew that.” Mary responded with, “No, you knew that.” Andrew said, “Okay, so now we all know that.”

Even with a life-changing event such as a cancer diagnosis, Andrew remained unphased. He had already prepared himself for the possibility of receiving a cancer diagnosis and accepted it easily. Mary let him know he would be starting chemotherapy soon, and he asked her how long he would have to stay in the hospital, reminding her of a previous agreement they made that she would not keep him cooped up. She informed him that he would stay for the day and in the morning would have his port placed and get another biopsy. He was unhappy about having another biopsy because of the pain it caused his hip. He already had a hip injury that would need surgery, which could no longer take place with the new development of diagnosis.

Andrew had assumed he would stay in the hospital for a few weeks, but his mother let him know he would have to stay for six to eight weeks. He responded with “What the hell?” Mary handled his small outburst with empathy and understanding. She explained to him that his cancer was bad, which is when the doctor stepped in to let him know that it appeared quite aggressive and that they did not want him to leave the hospital.

In reflecting on the events of the day, Mary realized that her family had just entered a new life. Within thirty minutes, they had gone from being the happiest they had ever been to living from one minute to the next in uncertainty. They continued to carry on and found stability where they could. There was a Chick-fil-A in the hospital, which became their staple. Mary’s mother chose to help by getting food for Andrew, but by the

next few days, the family was tired of Chick-fil-A and let Andrew know they could not eat it anymore.

On the first day in the hospital Andrew started out in a small room but the next day he moved to a large room on the floor since he would be staying a long time. Andrew's dad brought the decorations from Andrew's room at home to help him adjust to life in the hospital.

Mary remembers the treatment process being challenging. She at times felt overwhelmed because there was nothing in her power that she could do to take away any of her child's suffering. Andrew's treatment lasted for four and a half months before he died. Mary's sentiment to this fact is "thank goodness," which she remarks not everyone is able to understand. She is grateful that her son did not have to suffer for a long period of time. Many children with the same type of cancer will go into remission and relapse several times, which causes additional suffering. Andrew went into remission and then contracted a secondary infection which led to his death. Mary considers this as God rescuing him by calling him home to heaven.

When Andrew received his first round of chemotherapy treatment, two days after being diagnosed, she had difficulty watching "poison" being pumped into her child. She knew that it had to happen, otherwise she had no idea how much more time she would have with him. As his mom, she wanted to fight as hard as possible and did not want to miss a minute of his life.

They shaved Andrew's head at the beginning of treatment, and his sister shaved her head as well in support. She donated her hair because that was a tangible way she could support her brother. Following the first treatment, Andrew went into remission



according to the hospital's standards. He went through a total of four rounds of chemotherapy, one in August, one in September, one in October, and one in December. Throughout the course of treatment, he developed mouth sores and had significant weight loss. The loss of his hair was especially challenging for the whole family.

During the month of October (which is breast cancer awareness month), Mary along with other "cancer moms" struggled with all the attention placed on breast cancer. This felt especially difficult because Mary and the other moms believed very little funding is put toward cancers affecting children, specifically Andrew's form of cancer. Additionally, the treatment protocol for cancers affecting children have not changed significantly, and there is still not a harmless method of treating cancer without introducing patients to high toxicity. When it comes to cancers affecting children, there is also the hope that a child can find the intrinsic motivation to continue fighting, even though the brain is not yet fully developed. Andrew never gave up and loved life, even if it was in the hospital.

In October, Andrew developed fungal pneumonia, which rapidly increased in severity and caused a delay in his last chemo treatment. He had a temperature of 107 and narrowly escaped the ICU (Intensive Care Unit). He began hallucinating, which Mary describes as one of the best and worst parts of their story. His most consistent hallucination consisted of a black cat playing with a flower. The only time Andrew ever snapped at a nurse was because she giggled when he talked about that hallucination. He said, "That's not funny." Mary helped him calm down, validating his frustrations with the situation but reminded him that he cannot snap at people. She added, "Think about it, you're a big old burly football player sitting in this bed and the one thing you're seeing is

a kitten playing with a flower. It's funny!" This lightened the mood and Andrew began laughing as well. Ironically, Andrew did not even like cats. From then on, Mary told Andrew to let her know if he started seeing anything else.

Andrew's doctor spent time investigating the medications Andrew was taking and discovered he was having a major reaction between one of the antifungal medications and the chemotherapy. The fungal pneumonia caused his eyesight to deteriorate so he was unable to see as well. At one point he said, "I kicked cancer's butt, but with fungal pneumonia, I'm waving my little white flag."

Mary recalls feeling that at the time she thought she was being the best mom but now has second guesses. She never left Andrew alone because the thought of him being alone through all of it was too much. She was there as often as she could be, and if she was not there then his dad was present. Andrew never mentioned his mom's constant presence, so she hopes that he did not dislike it. She said that she can talk to him about it when she gets to heaven to find out how he really felt.

Andrew received his final chemotherapy treatment in early December. The next step in his treatment plan would include a stem cell transplant from his dad. He would have to stay in the hospital an additional six weeks after the transplant and would be completely done with treatment around early May. In December, he went for a clinic visit, where he nearly fainted. He was later admitted to the hospital.

Early Christmas Eve, Andrew presented with an infection that had settled in his groin. There was a discussion of possibly needing to move him to the PICU (Pediatric Intensive Care Unit). Mary remembers feeling amazed at how quickly cancer affects the body. Andrew's kidney function began to decline. By three in the morning on Christmas

Day he was transported to the PICU. It snowed for the first time in Andrew's life on Christmas Day, so he was able to see the snow. Andrew wanted to see his siblings and have Christmas festivities that day. Mary tried to convince him to rest and that they could celebrate Christmas the next day, however, he insisted on doing it that day. His family pushed through and had a five-hour-long Christmas celebration.

At nine in the evening, visiting hours were over in the PICU so all family but Mary had to leave. Andrew looked worse than he had all day, and the nurse said the doctor would be stopping by, but that Andrew was not looking good. They were going to have to intubate him soon but decided to give him twenty minutes to see if his vital signs improved. The nurse asked Mary to wake Andrew up if he started to doze off. Mary was upfront with Andrew and let him know he was not doing well, to which he replied that he knew. She told him he had twenty minutes to get it together before they place a breathing tube. She told him that even if they had to do this, at least he could rest.

The doctor called Mary out of the room and told her it was time for her "baby to rest." Mary called the family back up to say "goodnight" to Andrew before he was intubated. Mary spoke with Andrew for a moment alone and told him if he stayed there five days, she would stay five days; if he stayed there one hundred days, she would stay one hundred days, but if he felt like he needed to go he could go. He remained intubated until December 28th.

Andrew was extubated to see if he could breathe on his own. By this time, he was on continuous dialysis, and Mary knew that once his kidneys stopped working it wouldn't be good. By December 27th, he had a leaky valve in his heart, by December 28th fluid was being pulled off his lungs, and by December 31st he was jaundiced from his liver

failing. At this point, only his brain functioned. After being extubated, Andrew only opened his eyes once until the time he died. On January 1st, Mary sat down with him and told him he had done all the hard things. She said he had done everything he could do and that she would do the rest just like she promised. The nurse came in and said, “Andrew’s ready to go home.” Mary signed a “Do Not Resuscitate” order, and she climbed into bed to hold her child until he breathed his last breath at 12:46 on the morning of January 2nd. Mary had no doubt that her son had entered heaven. She got to be with her son when he was born and when he went to heaven. She said, “both days were equally as wonderful.”

During Andrew’s treatment and through dealing with his loss, Mary coped by staying busy and taking care of others. She and Andrew had a routine of making Build-a-Bears for every new patient on Andrew’s floor. Andrew would find out what the patient liked and give her ideas for how to make the bear unique, and Mary would go make the bear. During Andrew’s last chemo treatment, he made a comment that he was the only one without a bear. Mary got him a stuffed dog so he would feel just as special.

Mary spent her time knowing every detail about Andrew’s condition and treatment, all while caring for others as much as possible. She made friends with other parents on the floor, and she learned how to make pillowcases for the children in the hospital. Mary said, “You lose yourself if you don’t stay connected to others.”

After Andrew’s death, it took a long time for Mary to grieve. She claims to have gone through every possible phase of grief and that she will not feel okay again until she’s with her son in heaven. Mary has noticed that there are some things she can make sense of, but others that she cannot. She struggles with not knowing who her son would have become or what amazing difference he would have made in the world.

Mary is comforted in knowing that the God she serves has not asked one thing of her that He did not go through Himself. She views this as the epitome of a true leader and good parent. God the Father lost His Son just as Mary did, and He watched it happen just as she did as well. She knows she can be okay with what happened because she knows she will see him again. Until that happens, she chooses to continue talking about her son. She uses her voice because that is what she can do.

### *Case Summary Three*

#### *Case Presentation*

Will was diagnosed at age 3 with pre-B cell acute lymphoblastic leukemia (ALL) in 2016. An interview with the patient's mother took place on October 6, 2022. At the time of the interview, the patient was in remission.

#### *Disease Summary*

Acute lymphoblastic leukemia is a form of cancer in which the bone marrow produces too many lymphocytes (white blood cells). ALL is the most common form of leukemia affecting children (cancer.org). Signs of ALL include fever and bruising. It is diagnosed with tests that examine blood and bone marrow (cancer.gov).

#### *Case Summary*

The third interview took place on October 6, 2022. The names of the individuals have been changed to maintain anonymity and will be referred to as Carol, the mother, and Will, her son. Carol and her husband have three children, with Will being the middle child. At the time of the interview, Will was nine years old and Carol's other children were twelve years old and seven years old. Carol and her husband have been married for fourteen years, and he works as a chef. He worked as a history teacher in the past, and Carol has an arts background, now working for a local arts agency. Art has played a significant role in her son's processing and healing, even after treatment.

Will was diagnosed with pre B-cell acute lymphoblastic leukemia at the age of three. Leading up to this diagnosis, his family noticed changes in his health. Two months preceding the diagnosis, Will appeared restless, uncomfortable, and fitful. He experienced mood swings and excessive sleepiness. Will also acquired frequent colds and

respiratory infections. Carol has a history of asthma in her family, which she initially assumed was causing Will's issues.

Approximately six weeks before the diagnosis, Will had been sick, and he broke out in hives along his face and chest. His family assumed that the cause may be a food allergy, and so he was taken to urgent care. His condition would typically worsen on the weekends, so he had not yet seen his regular doctor about the issue. With the urgent care appointments, there were no long-term solutions suggested besides making an appointment with his primary care physician.

It was during this time that Carol began to feel that there was something else going on. A week before the diagnosis, she started noticing bruises that were showing up on Will's body and not going away. In her mind, she knew that was a sign of "something not good." She had a gut feeling that it could be cancer but tried to press it down for the time being. Will got sick again over the weekend, and he was taken to the clinic the following Monday.

At the clinic, Will saw a different physician than his normal primary care provider. Carol informed the physician of the changes in Will's health. The physician ordered a CBC (complete blood count) panel and a chest X-ray to investigate the cause of his chest congestion. The X-ray machine at the clinic was not functioning at the time, which meant Will was sent to another campus to get the image. However, once they made it to the other clinic, Carol received a phone call instructing her to take Will to the Emergency Department (ED) immediately. His blood work revealed his hemoglobin level of 5, which is much lower than standard healthy levels.

Carol called her parents to ask for help with her other children so she could take Will to the ED. She called her husband and told him to meet them there. Carol recounted how it felt as if all the events occurred at once, and how so much happened in such a short amount of time. Will and his parents were sent to the children's hospital after being seen in the Emergency Department. At the hospital, Will received a biopsy and other tests, which determined the cause of his illness to be leukemia, specifically Acute Lymphoblastic Leukemia (ALL). Carol and her husband found out on July 4, 2017 that their son had cancer.

The day Will received the diagnosis, beforehand, Carol and her husband were made aware that his illness could be caused by a blood disease or blood cancer. They had started to mentally prepare for what was coming. Carol recalled the night after receiving the diagnosis to be one of the hardest of her life. She spent it mentally and emotionally adjusting to the diagnosis and spent most of the night praying on the hospital floor. She recalled not wanting the diagnosis to be true. However, she desired to reconcile her emotions as much as possible so she would be ready to support her son.

Carol initiated her prayers by asking the disease to be taken away or for her to take on the disease for her child, which she believes would have been easier in many ways. Later on, this prayer changed to asking God to "keep Will here." She knew that Will would likely make it through treatment, but that death was still a possibility. Mortality was the most challenging aspect for Carol to cope with, and she recalled the weight of the situation being difficult to handle.

Though Will was three at the time of diagnosis, Carol and her husband made him aware of his condition in an age-appropriate manner. Carol informed him that the



physicians and nurses who were performing invasive and often painful procedures were there to help him heal. Carol also promised Will that the medical team would not do anything that she did not say is 'okay' for them to do.

Carol appreciated the oncology team and their thoughtfulness. At the time of diagnosis, they took Carol and her husband to a separate room to explain Will's condition and discuss the details. The oncologist answered all of Carol's questions, and Carol appreciated his word choice in relaying information. He said, "We know this is hard, and it will be hard, but we want to give you hope." He also informed Carol that Will would adjust more quickly to the treatment and clinic visits than his parents, which Carol mentioned was accurate.

From the beginning, Carol was impressed with Will's child life specialist. The specialist walked Will through many medical experiences and formed a good relationship with him from the beginning, which was crucial. The specialist focused on making sure Will felt safe and understood as much as possible about the events taking place.

Carol noted that the diagnosis Will received was difficult, however, they were blessed because it was an easier diagnosis to treat than other cancers. Though it would frustrate Carol whenever someone would say to them "that's an easy cancer." Regardless of how Will's diagnosis compared to other cancers, the illness and treatment were still challenging for Will and his family.

Will received three years of treatment, starting with an induction phase in the first month, where he then reached remission. Even though he achieved remission early on, he still had to receive the entirety of the treatment to ensure the disease would not return. Will's treatment was standard, according to Carol, and she remarked that he did not

endure too many complications. Will did not have to endure a second induction phase, which many children with ALL must do. Many patients will come close to remission, which causes them to repeat the induction phase. The second induction phase tends to be intense, and if remission is not achieved, a stem cell transplant is then considered.

The first year of Will's treatment went relatively well. Will was considered to have "taken the chemo well," which meant his dosage had to continue being increased to ensure the treatment was clearing the disease entirely. There came a point where Will experienced intense side effects of the chemotherapy. Carol noted that often others will not realize that the side effects of the treatment can be more difficult than cancer itself. This is especially true for children since children are younger and smaller than adults.

Will had rounds of steroids and support medications that were hard on his body. There were a few drugs he was given that caused him to hallucinate. The medical team was able to remove the drugs causing the hallucinations, which made a large difference in Will's quality of life. However, Will is still dealing with the medical trauma that ensued even though he is now two years post-treatment. Will experienced a total of four hospitalizations throughout the treatment process.

Carol commented that ALL is one of the most researched of all pediatric cancers and was one of the first pediatric cancers to be treated effectively by St. Jude's treatment protocol. At the same time, many pediatric cancer treatments have not advanced as quickly, and the treatments often do not consider the comfort of the children receiving them. The treatment for pre B-cell ALL has not changed much within the past twenty years. The treatment did change recently to last a total of two years instead of three years, right as Will was finishing his third year of treatment.

Throughout the course of diagnosis and treatment, Carol noted that her role as a parent shifted. She and her husband, prior to the diagnosis, always shared equal responsibilities in raising their children. During treatment, however, Carol became Will's primary caregiver. She noted there was no way around this arrangement, and it is typical for one parent to become the primary caregiver when a child has intense medical needs.

Carol appreciated her husband's support throughout the process, especially during days or weeks of intense treatments that would occupy Carol's focus. There would be whole days spent at the clinic, and on those nights the family would order pizza and enjoy one another's company to relax from the difficult day. Carol's husband would take care of the pharmacological tasks. He maintained the charts and tracked medications, while Carol was the one to give injections since Will sat in her lap every time his port was accessed, or he got an IV.

After Will received his diagnosis, the family's patterns shifted, and they relied more on support from family members who were close by. Carol's parents lived nearby and offered a lot of support throughout the treatment process. Carol would drop off her two other children with their grandparents early in the morning so she could take Will to his appointments. The first six months of treatment were intensive. Will had appointments at the clinic nearly every other day. There would occasionally be weeks when his body was given a break to cope with the intensity of the treatment. Will received monthly lumbar punctures where chemo would be delivered into his spine. He was sedated for each of those procedures, and Carol sat with him through all of them. At the time, she simply accepted the form of treatment, but later thinking back on it, she remarked that "it stopped her heart."

Will's family tried to protect weekends to maintain a sense of normalcy because weekdays were so often filled with medical visits and procedures. Carol's in-laws provided their family with a gift of a home so the family could live in a larger place with a backyard and more bedrooms. This provided the family with a sense of peace, and Carol remarked that it was a beautiful gift. Carol and her husband are slowly buying the house back from his parents now.

Carol noticed one of the biggest changes to daily life was the constant vigilance in noticing how her child was feeling. She would check Will's temperature all the time to make sure he did not have a fever. Even if he had a slight fever, that would mean they would have to take him to the Emergency Department. Carol and her family were also unable to go to church as regularly as they had in the past, as they tried to avoid being around illness since Will was immunocompromised.

During the first month of Will's treatment, he received daily steroids to help build his body to accept and digest all the medications. Carol remarked that "steroids are hell for adults and triple hell for kids." She noted that children do not understand what is going on, and the steroids increase their mood swings and pain perception.

Will received a blood transfusion in the hospital immediately after being diagnosed. Following the transfusion, he had a port placed for chemotherapy, so he would not have to get an IV every time he received chemo. After the first month, when he achieved remission, his treatment followed a rotating pattern of two weeks of oral chemo and five days of steroids. During 'steroid week,' Will would eat constantly, and he gained a fair amount of weight because of the amount he ate.

The following six months of treatment were an intensive phase where the most difficult chemo is given. The next six months are a broader cycle. This pattern continued, and in the second year of treatment, the treatments were spread out slowly. The monthly lumbar punctures were spread out to every twelve weeks. Treatment days at the clinic would consist of getting up early and numbing the port site on his chest. Having his port accessed was one of the hardest aspects of treatment for Will and is where a lot of his medical trauma stems.

Carol was grateful that from the beginning of treatment, Will had a nutritionist from the hospital who worked with them. The nutritionist told Carol to not worry as much about what Will ate but to make sure he was eating enough. They were given tips for making things that he would be able to eat and emphasized the importance of getting enough protein. When Will was not on steroids, he would hardly eat at all. He also endured mucositis and mouth sores that come from treatment, which contributed to Will not wanting to eat.

Many children who take oral chemo use liquid, which has a horrible taste. It was revealed quickly that Will did not like the taste, and he would refuse to take the medicine. After about ten days of struggling with the liquid medication, the child life specialist recommended that he could teach himself to take pills instead. Will was given the choice, and he chose to learn to take pills at three years old, which helped mitigate some of the stress.

Throughout Will's treatment, Carol found it important to have a good support circle surrounding their family. She initially had some expectations that all those in their life would immediately understand their situation and be supportive, which was not

always the case. There were intense displays of support at the beginning of treatment, but Carol noted that people's lives go on and support dwindled to some degree over time.

Carol and her husband had excellent communication throughout the process, which was critical to maintaining a healthy and supportive family dynamic. Both she and her husband are people of faith, and it was important for them to stay connected to their faith however they could. This included staying in practices that helped them, such as prayer and reading the Bible.

The internet was helpful for Carol in finding online support groups where they could compare experiences. Carol found it helpful to process grief with other parents who had experienced similar situations and had already walked the path she was on. She also would help other families who were earlier in the treatment process. She remarked, "It helps to help."

During the first six months of Will's treatment, Carol returned to counseling because she wanted to ensure that she was in the best place to support her son, especially since she was his primary caregiver. Carol's husband had more difficulty finding adequate support; therefore, Carol was often the support for her husband.

Carol often felt isolated during the progression of her son's disease and treatment. There were times when Will's counts would be low, and people couldn't visit him. Even though their family was part of a church, that is not where they found a lot of their support. They found the most support from others who saw them in their need and were able to be empathetic in the right ways at the right times.

The COVID-19 pandemic played a role in Will's treatment experience. He was near the end of his treatment when the lockdown began, which shifted to a dynamic

where Carol's husband could no longer go with Will to treatment. In the early parts of the pandemic, Will and Carol were completely alone. Carol noted that it was strange to see the rest of the world have concerns about issues that Carol and her family had already been dealing with for years.

As Will's treatment neared the end, he contracted more infections because his body was worn down. He was admitted to the hospital towards the end of his treatment, and Carol was the only one who could be there with him. Will had sores all along his throat, and his chemo treatments ended early because of how sick he got. There were a lot of emotions at the end of his treatment, a lot of joy but also grief. The family had a drive-by celebration for Will so others could show their support. His port was removed, and the oncology team brought Will a bell that he could ring to signify the end of his treatment.

Carol was proud of how she and her husband handled Will's treatment over its course. She believed it was important to teach children bodily autonomy and to help them understand what is going on with their bodies. For this reason, Carol would continually check in with Will and find places to give him back some control.

Even before Will became ill, he was an artist. He often used art in his treatment. He was a creator and was not content with coloring books. He desired to create drawings from scratch, and he continued to do that in order to process what was going on in his body.

Carol believes it is important for people to understand that pediatric cancer does not just affect a child's body; it affects all aspects of that child's life. She noted that society often does not treat children as whole persons, and that means adults have the

responsibility to advocate for children and to help them be aware as much as possible as to what is going on with their own bodies.



## CHAPTER FOUR

### Discussion

The experience of a parent walking alongside their child amid illness is one of unique suffering. Though many grieve when a child receives a cancer diagnosis, the parents grieve in an entirely separate manner. Parents are responsible for caring for their child as they normally would, with additional medical responsibilities to manage during treatment.

In most of the cases analyzed, the mother had intuition to know something was wrong before getting a diagnosis. Parents know their children best and know how normal presents for their child. This means a parent will be able to tell when their child is ill. Mary demonstrated this when she noted the changes in her son's behavior prior to diagnosis. Carol noted her son may be experiencing serious illness a week before his diagnosis because of the bruises appearing on his body. A parent's intuition is important in the diagnosing process of pediatric cancer.

Many parents of pediatric cancer patients have concerns about the lack of funding for pediatric cancer research in comparison to the funding given to cancer research for adults. About 4% of cancer research funding is allocated towards pediatric cancer research ([nationalpcf.org](http://nationalpcf.org)). In each of the interviews, the parent made comments about the lack of change in treatment for their child's specific diagnosis. The treatments that are still being used, are harsh for children to handle. Unfortunately, these treatments are not being advanced as quickly.

When asked about which methods of support were most helpful, the interview participants felt adequately supported in many ways, though recognized that people were not always sure how to be supportive. Amy would have liked others to take more initiative in their efforts to demonstrate support, but she was grateful for many of her friends and family who helped manage chores and other responsibilities. Helpful support often requires taking steps to reduce the load placed on the parents during their child's treatment.

In terms of financial support, Amy was grateful for the contributions towards her family's meals. Financial support is important when those supporting have the means, however, it is often not the most important area of support. Tangible acts of service are important ways to support families experiencing pediatric cancer treatment. Often, parents receive the most support from family. At this point in time, the internet is an excellent resource of support from individuals having similar experiences. Carol found much of her support through online groups, which she found through social media platforms. These platforms allowed her to connect with parents across the world who were also walking through pediatric cancer treatment with their children.

Though it is beneficial to provide support through physical means, emotional support is crucial for families experiencing cancer treatment. Emotional support can improve quality of life in stressful events and can strengthen families in their trials. Emotional support requires listening without judgement and demonstrating compassion.

Each of the participants discussed the importance of helping others even while experiencing their own difficulties. Mary made Build-a-Bears for other patients in the hospital, and Carol shared advice with others further behind in the treatment process.

Amy advocates for children receiving age-appropriate information about their care. Maintaining a service-oriented perspective helps provide a purpose behind the events taking place and can be an excellent coping technique.

Each parent has different methods for coping through their child's illness. Common methods of coping include gathering information about the diagnosis and treatment. Amy became an expert in her child's illness and treatment through her own personal research. Each of the parents demonstrated a high level of knowledge regarding their child's diagnosis and were able to maintain treatment and medication schedules.

Organization is another common method the parents used to cope through the treatment process. Amy described using highlighters to color-code the different chemotherapy treatment cycles for her son's treatment schedule. She and her family then used the designated colors when discussing her son's treatment. Carol and her husband used organizational skills to maintain their son's medications. Treatment for cancer requires good organizational methods, which can be beneficial for the parents in adapting life with cancer treatment.

Documentation of the treatment process is another useful coping technique used by parents. It can be helpful to keep records of the child's treatment process. Having the records can provide feelings of accomplishment at how far the child has come since the initial diagnosis. This can provide the family with encouragement to keep a positive outlook when difficulties arise from the disease and treatment.

Other families going through the treatment process tend to be a monumental source of support and resource, especially during hospital stays. Confusion and distress often accompany a cancer diagnosis and can be alleviated by social support from those

who have an intricate understanding of process of pediatric cancer treatment. Other families can provide advice from personal experiences along with solidarity from walking through similar circumstances. Having others around who know exactly what one is going through is critical for combating isolation. This is a reason group counseling programs exist to bring together individuals with common difficulties.

Another common method of coping is helping others. Serving others is an excellent way to shift one's perspective during challenging times. Serving can manifest in a variety of different ways. Amy used her social media skills to share information online to help others with similar circumstances. Mary chose to provide physical gifts for other children staying in the hospital. Carol shared advice with other families of child cancer patients. Helping others is a great outlet for handling painful circumstances.

Faith is a vital method for coping through difficult circumstances. It provides meaning to those circumstances regardless of the outcome. Mary is the clearest example of finding purpose through her son's treatment and death. Though her situation was not easy, she was able to adapt and cope well because of her reliance on a power outside of herself.

Regardless of the adaptive strategy used, each parent has dedicated every available moment and resource to caring for their child. Eventually, for the families who provided personal accounts, treatment becomes normal for the family, and the family can adapt to their new situation.

Each of the parents who provided their account of their child's diagnosis and treatment adapted to the new circumstance of a cancer diagnosis. There was not a family studied who was unable to adapt. Of the mothers observed, the specific factors enabled

them to adapt more easily to their changing lifestyles. Such factors include excellent organizational skills for Amy, as those skills aided her in adjusting to the new life initiated by the cancer diagnosis. Amy was able to use the skills she had already cultivated earlier in her life to help her family adjust to their new way of living during their child's cancer treatment.

The scope of the study had limitations due to the small sample size, however, timing and recruitment of participants did not allow for a larger sample size. Analyzing case studies from the smaller sample size indicates less variability of results to be determined from the study.

The use of interviews as the method for data collection allowed for in depth data collection of the participants' experiences through diagnosis and treatment of their child's cancer. Through providing personal experiences for the nature of the study, the study aims to provide a deeper insight into the process of diagnosis and treatment of pediatric cancer, especially in reference to the experience of the child's parents.

The interviews conducted for the study contained emotionally taxing information, which provided the researcher with experience in maintaining composure through emotionally difficult conversations. The personal accounts detail the challenges of families walking through pediatric cancer, and they are stories that deserve to be told. By sharing the stories of the participants, the aim is to provide a more holistic view into the intricacies of childhood cancer treatment and recognize the immense responsibilities parents maintain while caring for their child with cancer.

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