

ABSTRACT

A Case for Child Life Programming: Parent and Sibling Perceptions

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Child Life Programs in hospital settings work with patients and their families to lower stress and educate families about their healthcare experience; however, Child Life Programs are not available in many medical settings. This project examines the impact of Child Life Programming from a sibling and parent perspective through a case project method. In-depth, semi-structured interviews with sibling and parent dyads about their hospital experiences were conducted with two families. Family Resilience and Stress Theory and the concept of disenfranchised grief were the theoretical framework and lens through which this project was conducted. Although there was no way to manipulate the experiences of the participants, this project illustrates the importance of grief-informed and developmentally appropriate interventions in a hospital setting for holistic care for parents and siblings when a family system experiences stress and grief during diagnoses, treatment and death.

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A CASE FOR CHILD LIFE PROGRAMMING: PARENT'S AND SIBLING'S
PERCEPTIONS

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CHAPTER ONE

Introduction

Introduction

This purpose of the project was to explore two families and their experiences with the healthcare system from the point of diagnosis through the death of a child or children. Two mother-daughter dyads participated in the project and were asked to share their experiences. One mother-daughter dyad did not have Child Life services or have interactions with a Child Life Specialist. The other mother-daughter dyad that participated in the project received services from Child Life Programming. The goal of the project was to examine the benefits of Child Life Specialists' interventions during the family's experience and explore the impact of psychosocial intervention. The project also examined factors that fostered resilience in individuals and families following the death of the family member. Psychosocial, also known as socioemotional intervention, is described as the process that involves "social and psychological behavior" (The Free Dictionary, 2017). Because Child Life is a young profession, this research is crucial in adding to the body of knowledge. The project results also underscore the importance of including Child Life Programming in the care process of children and their families. Although this project is not designed to answer the "what if" questions for the family that did not receive Child Life Programming, it does report on the confidence and self-efficacy of the participants that received Child Life services. The contradictory

experiences of the two families supports the potential impact and necessity of trauma and grief informed interventions during high-stress times for families in hospital settings.

Statement of the Problem

In the United States, nearly six million children aged 0-17 years are hospitalized annually (Healthcare Cost & Utilization Project, 2014). Our current healthcare system has the primary goal of healing physical ailments. Often overlooked are the social, psychological, and emotional care for the patient. The very purpose of Child Life Programming and Child Life Specialists are to provide “evidence-based, developmentally appropriate interventions” to promote normalcy in a healthcare setting, while also supporting typical developmental patterns and healthy coping strategies through play and various types of therapy (Association of Child Life Professionals, 2017). However, Child Life services are not billable for hospitals, so these interventions are often overlooked or nonexistent in hospitals (Catholic Health Association of the United States, 2011). Children within the healthcare system for their own medical needs or because of a family member’s health condition are often overlooked and expected to cope with their surroundings, even though they may not have the mental or emotional tools to do so. The oversight of the child’s emotional needs sets the child up for problems with coping throughout the overall hospitalization process. The lack of psychosocial support could also potentially contribute to difficulties later in life due to a lack appropriate coping skills and lack the ability to effectively deal with stress responses. When given socioemotional support, such as the support offered by Child Life Specialists, children and families are more knowledgeable about resources inside the hospital.

In a 2017 study by the May Clinic, it was noted that in hospitals and other healthcare environments where Child Life Specialists are available, patients may not be aware of the services they offer to patients and their families. When patients and their families are unable to have Child Life support, the complications and stress stemming from the healthcare experience grow, and the problems resulting from the stress, normalized, disenfranchised, ambiguous and anticipatory grief, and confusions from medical terminology and equipment manifest in longer-lasting ways.

Purpose of the Project

The purpose of this project was to examine the impact of Child Life Specialists as perceived by siblings and parents during the diagnosis, treatment, and death of their family member. Prior research in this area has focus on the impact of Child Life Specialists on the patient from the patient's or parent's perspective. The sibling perspective has been overlooked in the research literature; however, the sibling perspective could yield highly valuable information that would directly apply to Child Life Programming. This project followed the methodological parameters of a qualitative case study approach. Creswell (1998) describes qualitative research as "an inquiry process of understanding based on distinct methodological traditions of inquiry that explore a social or human problem" (pg. 15). A qualitative approach was a guideline for this project due to the exploratory nature of the topic. Qualitative methods are also ideal to address the need for detailed descriptions of interactions occurring during the healthcare experience and the need for detailed perceptions of interactions during the healthcare experience. A case project approach influenced the purposeful sampling

technique used to “show different perspectives on the problem, process or event” (Creswell, 2008).

One of the goals of this project was to gain insight about Child Life interactions from the perspective of a patient’s sibling. This initial goal was expanded to explore the experiences of a family who had Child Life Programming and a family who did not have Child Life Programming. The hope of selecting two mother-daughter dyads with vastly different experiences with Child Life was to demonstrate the scope and impact Child Life Specialists may have on a family during hospitalization. The data were examined, read, reread, and compared to identify themes throughout the families’ stories. The insight gained through the process could provide insight into the contributions of Child Life Programming.

Research Questions

This project explored Child Life Programming from the perspective of a parent and a sibling of a pediatric patient. The following research questions were addressed:

1. According to the parent-sibling dyad, how does Child Life Programming help the patient?
2. How does Child Life Programming support the family as a unit, and individuals within the family throughout the hospitalization process?
3. What is the perceived impact on the parent or sibling of a hospitalized family member if Child Life services are not offered?
4. How does Child Life Programming impact perceived coping and family resilience?

Definitions of Terms

The following terms were operationally defined for the purpose of the project to provide the reader with a consistent understanding of parent and sibling language used throughout the project.

Acute Illness – a disease with an abrupt onset and, usually, a short course (MedicineNet.com, 2017)

Acute Myeloid Leukemia (AML) – type of cancer in which the bone marrow makes abnormal myeloblasts, red blood cells, or platelets (National Cancer Institute, 2017).

Ambiguous Loss – loss with no verification of death, or no certainty that the person will come back or return to how they used to be. This could be a physical or psychological absence, and may freeze the grief process and paralyze functioning (ambiguousloss.com, n.d.)

Aneurysm – a bulging, weak area in the wall of an artery that supplies blood to the brain (WebMD, 2017).

Antibiotics – powerful medicines that fight bacterial infections by killing bacteria or keeping bacteria from reproducing (MedlinePlus, 2017).

Artery – blood vessels that deliver oxygen-rich blood from the heart to the tissues of the body (WebMD, 2017)

Association of Child Life Professionals (Formerly the Child Life Council, or CLC) – an organization that advances the field of child life by establishing and maintaining professional standards, enhancing professional growth and development of members, and

advancing the credibility of the child life profession by fostering research and promoting the standards of child life practice on a national level (Association of Child Life Professionals, 2017).

Bacterial Infection – an infection caused by bacteria in the body (The Free Dictionary, 2017).

Bereavement – a period of mourning or intense grief after the loss of a loved one (Dictionary.com, 2017).

Biopsy – the removal of cells or tissue for examination by a pathologist (National Cancer Institute, 2017).

Bone Aspirate/Bone Marrow Aspiration – removal of a small amount of bone marrow in liquid form for testing (MedlinePlus, 2017).

Bone Marrow – soft tissue inside the hollow part of most bones that helps form blood cells (MedLine Plus, 2017).

Cancer – a disease in which abnormal cells divide without control and invade nearby tissues (National Cancer Institute, 2017).

Cannula – a hollow tube with a sharp, retractable inner core that can be inserted into a vein, an artery, or another body cavity to give medication, oxygen, or other substances needed by the patient (MedicineNet.com, 2016).

Cardiopulmonary Resuscitation (CPR) – an emergency, lifesaving procedure that is done when someone’s breathing or heartbeat has stopped (MedlinePlus, 2017).

Chemotherapy (Chemo) – drug treatment that uses powerful chemicals to kill fast growing cells in the body. It is most often used to treat cancer, since cancer cells grow and multiply much more quickly than most cells in the body (Mayo Clinic, 2017).

Child Life Assistant – supports Child Life Specialists by providing a developmentally supportive play room for patients and families. They are not certified to be Child Life Specialists (Glassdoor.com, 2017).

Child Life Playroom – safe, supportive space dedicated for patients and families to have fun and socialize. Child Life organizes activities and allows child-directed and guided play in a room where there are no medical procedures allowed. For adolescent patients, an extension, known as the Teen Lounge, may also be available. (Children’s Hospital Los Angeles, 2017)

(Certified) Child Life Specialist (CCLS/CLS) – someone who helps infants, children, youth and families cope with the stress and uncertainty of acute and chronic illness, injury, trauma, disability, loss and bereavement through evidence-based, developmentally and psychologically appropriate interventions (ACLP, 2017)

Chronic Illness – an illness lasting three months or more (MedicineNet.com, 2017).

Comfort Positioning or Comfort Holding – sitting position developed to promote comfort for the child as well as sufficient immobilization for success of the procedure. Parents or other trusted adults are able to hold the patient in different positions, depending on the procedure and child’s needs (Giese, n.d.)

Complicated Grief – when feelings of loss are debilitating, and do not improve after time passes, as they would during a normative grieving process. In complicated grief, emotions can be so long lasting and severe that it may disrupt the griever’s life and acceptance of the loss (Mayo Clinic, 2017).

Creative Therapy – group of techniques that are expressive and creative in nature to help clients form expression beyond words or traditional therapy (Encyclopedia of Mental Disorders, 2017).

Culture – test designed to detect if microorganisms such as bacteria and fungi are present in a sample, such as blood (MedicineNet.com, 2017).

Cyclic Neutropenia – a rare blood disorder characterized by recurrent episodes of abnormally low levels of neutrophils (a type of white blood cell) in the body, which are necessary to fight off infections in the body (National Center for Advancing Translational Sciences, 2016).

Dialysis – process of removing blood from an artery... purifying it by dialysis, adding vital substances, and returning it to a vein (Merriam-Webster, n.d.)

Distraction technique – way of helping a child cope with a painful or difficult procedure by aiming to take the child’s mind off the procedure by concentrating on something else that is happening (Great Ormond Street Hospital for Children NHS Foundation Trust, 2017).

Emergency room (ER) – a hospital area equipped and staffed for the prompt treatment of acute illness, trauma, or other medical emergencies (Dictionary.com, 2017).

Family and Medical Leave Act (FMLA) - entitles eligible employees of covered employers to take unpaid, job-protected leave for specified family and medical reasons with continuation of group health insurance coverage under the same terms and conditions as if the employee had not taken leave. (United States Department of Labor, n.d.)

Flatline – to register on an electric monitor as having no brain waves or heartbeat (Merriam-Webster, n.d.)

Grief – deep and poignant distress caused by or as if by bereavement (Merriam-Webster, n.d.)

Healthcare play or therapeutic medical play – the use of games, toys, books, art, and role playing, sometimes with real or pretend medical equipment, to help children understand and become more comfortable with medical tests, procedures, treatments, and their illness. Therapeutic medical play gives children a way to express their feelings, fears, and anxieties and helps them learn ways to cope with things that may be stressful or upsetting (National Cancer Institute, 2017).

Heart valves – Four, one-way valves in the heart where blood passes through to different parts of the heart (MedicineNet.com, 2017).

Health Maintenance Organization (HMO) – an organization that provides comprehensive health care to voluntarily enrolled individuals and families in a particular geographic area by member physicians with limited referral to outside specialists and that is financed by fixed periodic payments determined in advance (Merriam-Webster, n.d.).

Intubate – the introduction of a tube into a hollow organ (such as the trachea or intestine) to keep it open or restore its patency if obstructed (Merriam-Webster, n.d.).

Invasive procedure – a medical procedure that invades (enters) the body, usually by cutting or puncturing the skin or by inserting instruments into the body (National Cancer Institute, 2017).

Kidney transplant – surgical procedure to place a healthy kidney from a live or deceased donor to a person whose kidneys no longer function properly (Mayo Clinic, 2017).

Laboratory Tests, Lab Tests or Labs – medical procedure that involves testing a sample of blood, urine or other substance from the body. Laboratory tests can help determine a diagnosis, plan, treatment, check to see if treatment is working, or monitor the disease over time (National Cancer Institute, 2017).

Leukemia – cancer that starts in blood forming tissue, such as the bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the bloodstream (National Cancer Institute, 2017).

Lumbar Puncture or Spinal Tap – a procedure in which a thin needle called a spinal needle is put into the lower part of the spinal column to collect cerebrospinal fluid or to give drugs (National Cancer Institute, 2017).

Nasogastric Tube (NG Tube) or Feeding Tube – tube that is inserted into the stomach through the nose to assist with feeding and nutrition (health.ccm, n.d.).

Neonatal Intensive Care Unit (NICU) – special area of the hospital for newborn babies who need intensive medical attention (Stanford Children’s Health, 2017).

Palliative Care – specialized medical care for people with serious illnesses that is focused on providing relief from the symptoms and stress of a serious illness, and improve quality of life for both the patient and the family (Center to Advance Palliative Care, 2017).

Pediatric Intensive Care Unit (PICU) – section of the hospital that provides sick children with the highest level of medical care, and may offer continuous monitoring and intensive therapies that are not available in other parts of the hospital (The Nemours Foundation, 2017).

Pediatrician – doctor who specializes in the branch of medicine concerned with development, care, and diseases of babies and children (Dictionary.com, 2017).

Pneumonia – an infection that inflames the air sacs in one or both lungs (Mayo Clinic, 2017).

Posttraumatic Stress Disorder (PTSD) – disorder that develops in some people who have experienced a shocking, scary, or dangerous event (National Institute of Mental Health, 2016).

Psychosocial or Socioemotional – a state of mental, emotional, social, and spiritual well-being (Study.com, 2017).

Pus – a yellow-white, more or less viscid substance produced by suppuration and found in abscesses, sores, etc., which white blood cells are suspended (Dictionary.com, 2017).

Referral – a written order from your primary care doctor for you to see a specialist or get certain medical services (HealthCare.gov, n.d.).

Respite Care – short term or temporary care of a few hours or weeks designed for the sick or disabled to provide relieve, or respite, to the regular caregiver (Investopedia, 2017).

Ronald McDonald House (RMH) – charity program to provide vital resources and compassionate care to children and their families being served by leading hospitals worldwide, by keeping families close to the hospital that feels like home to rest and refresh (Ronald McDonald House Charities, n.d.)

Sepsis – a potentially life-threatening complication of an infection that occurs when chemicals released into the bloodstream to fight the infection trigger inflammatory responses throughout the body (Mayo Clinic, 2017).

St. Jude's Protocol – collaborative approach between hospitals who treat cancer patients and St. Jude Children's Research Hospital to offer the best available treatments and contribute to the search for a cure (Cook Children's Health Care System, 2017).

Stoma – a small opening on the surface of the abdomen being surgically created in order to divert the flow of feces and/or urine (CliniMed, 2014).

Stool – solid matter that is discharged in a bowel movement (MedicineNet, 2016).

Terminal Illness – when a patient has reached a point where they, or their medical team, caregivers or loved ones, understand their illness is likely to lead to their death (Marie Curie, 2016).

Therapy Dog – dogs who go with their owners to volunteer in settings such as schools, hospitals and nursing homes to improve the lives of other people. Therapy dogs are not service dogs (American Kennel Club, 2017).

Triage – the process of sorting people based on their need for immediate medical treatment as compared to their chance of benefitting from such care. Triage can be done in emergency rooms and other settings when limited medical resources must be allocated to maximize the number of survivors (MedicineNet.com, 2016).

Venipuncture – the puncture of a vein for surgical or therapeutic purposes or for collecting blood or other specimens for analysis (Dictionary.com, 2017).

White Blood Cell – one of the cells the body makes to help fight infections (MedicineNet.com, 2016).

X-Ray – a quick, painless test that produces images of the structures inside your body – particularly your bones (Mayo Clinic, 2017).

Limitations of the Project

This project was limited in that: the patients in each family had different diagnoses and were in different hospitals. The interventions and needs were different in the experience of the mother-daughter dyad with Child Life Programming and the mother-daughter dyad without Child Life Programming. One hospital experience was in a children's hospital in a southern Metroplex, while the other hospital experience took place in a general practice hospital on the west coast. Because the information is based on a case study approach, the experiences reported are not universal. However, naturalistic

generalizations are still possible because “people can learn from the case either for themselves or for applying it to a population of cases” (Creswell, 2008).

Summary

Child Life Specialists can be an asset to the healthcare team, and can facilitate therapeutic interventions to promote normalcy and healthy coping strategies.

Understanding how the presence or absence of Child Life Programming from the perspective of a healthy sibling and a parent during their medical experience is vital in supporting the Child Life profession. The need for the presence of Child Life Programming in the healthcare environment can also be demonstrated. By introducing the sibling’s perspective about the personal interactions and perceptions of Child Life Specialists, or the lack of interventions, it is more apparent about the role Child Life programming plays in family-centered care. The necessity to provide psychosocial support for patients and their families for holistic care and promote resilience are also illustrated.

CHAPTER TWO

Literature Review

Introduction

The impact of trauma on an individual or family at any point of the lifespan can manifest in different ways and intensities. Similarly, interventions used to combat the effects of trauma are as diverse as the human experience. According to Stephanie Baum (2014), Certified Child Life Specialists (CCLS) are a part of an intervention strategy that is gaining prominence in the medical field to offset the negative aspects of a child's medical story. A 2006 study by Brewer, Gleditsch, Syblik and Teitjens, reflects a trend in current literature that have focused on the patient's experience and the work of the Child Life Specialist. When looking into other disciplines, researchers have noted the need to include different aspects of the family, but those studies are lacking. To form an integrative approach for the best outcome, the perspectives of the whole family are important, as parent-child interactions and sibling interactions are molded by experience, strengthened by events, and can be used as part of the therapeutic process when intentionally included.

Because Child Life Specialists work with a multidisciplinary approach and stems from different perspectives coming together, it is helpful to explore Child Life Programs and their impact with this same method. Further, by examining the work of Child Life Specialists through Family Resilience and Stress Theory and the ideas of disenfranchised or complicated grief, the necessity for coping skills offered by CLSs are illustrated. By

combining perspectives from Child Life, play therapy, nursing, social work, sociology, psychology, and others, more holistic and beneficial therapeutic plans are created.

Therefore, by studying each perspective, it is not only apparent about the impact each field has on Child Life Programming, but also the impact Child Life Specialists have on outside perceptions and processes.

The Role of the Child Life Specialist

To understand what is atypical, it is necessary to know what is typical. Certified Child Life Specialists (CCLS) are tasked with knowing the typical developmental process of a child. They are also involved in explaining combat medical procedures and diagnoses while also working to combat delays created because of a disruptive amount of time outside of a typical developmental context. According to the Association for Child Life Professionals (ACLP), the governing body of Child Life Specialists, CCLSs are “trained professionals with an expertise in helping children and their families overcome life’s most challenging events” (childlife.org¹). In addition to ensuring the integrity of CCLSs, the ALCP is “a group of trained professionals with expertise in helping children and their families overcome life’s most challenging events” in addition to their administrative duties (childlife.org²). Therefore, on every level of modern Child Life Programs, the best interest of the patient and families is rooted in developmentally appropriate interventions has made Child Life Programming a vital part of the healthcare team.

According to Baum (2014), the beginning of Child Life started with Emma Plank in the Cleveland City Hospital in 1955. Before Plank created the first specific program,

some hospitals had “‘play ladies’ [who] were hired to mitigate” medical issues recognized in research, which inspired “Emma Plank [to establish] the first Child Life Program encompassing the developmental, educational, and psychosocial needs of hospitalized children” (Metzger, Mignogna, & Reilly, 2013). Plank was educated alongside “Maria Montessori, [who] used the principles of child development to promote appropriate care for hospitalized children (Mayo Foundation for Medical Education and Research). Plank’s dedication to incorporating children into their own care and experience laid the groundwork for Child Life Programming. In modern healthcare, “humanizing healthcare for children was passionately embraced by its practitioners, but the success of such a revolutionary undertaking depended on validation of its presuppositions by others” (Thompson, 2009).

It may also be helpful to thoroughly define a Child Life Specialist (CLS) and their role on the healthcare team; however, a CLS takes many roles that present themselves in different combinations during each unique patient experience. CLSs are typically found in pediatric hospital settings, but can be found in adult hospitals, dentist offices, on mission teams, in clinics, doctor’s offices, and other health related places. CLSs “promote effective coping through play, preparation, education, and self-expression activities” with patients, and when possible, family members (Sorenson, Card, Malley, & Strzelecki, 2009). For example, a patient who is going to have an IV placed in their arm may have education presented by a CLS who allows them to manipulate and work with a tourniquet, an IV tube, and other materials that will be used during the procedure to allow the patient to ask questions and gain familiarity with their environment. In addition to the patient, “child life specialists play a vital role in educating caregivers, administrators, and

the general public about the needs of children under stress” and ways to include therapeutic interventions into the treatment process (Sorenson, et al., 2009).

Because of their education and experience with different family structures and cultural subgroups, CLSs are also able to “recognize the central role of family members to the child’s well-being and provide family-centered care” by intentionally incorporating parents and other family members into care and interventions whenever possible (Sorenson, et al., 2009). For example, a parent might be invited to hold a book for their child as a distraction during a procedure, create a schedule with the CLS for their child while they are at work, or participate in comfort holding techniques during a painful procedure. In a 2013 study, Metzger et al. note “CLSs help children cope with stressful healthcare experiences by capitalizing on their strengths and their interests” before, during, and after procedures throughout the hospital experience.

Child Life Programming is another aspect of Child Life that has many moving parts. Because the primary objective of CLSs are to normalize the medical experience, it can be stated that a Child Life Program’s “goals are to help children become more comfortable by addressing fears, clearing up common misconceptions about medical procedures and hospitalization, and preparing the child for hospital procedures in an age-appropriate manner” (Kaddoura, Cormier, & Leduc, 2013). With these goals, the aim of “child life is a nonmedical therapeutic service designed to address the psychological, social, and intellectual needs of pediatric patients... [and] assist children and their families in navigating and adjusting the pediatric health-care experiences” (Bandstra, Skinner, LeBlanc, Chambers, Hollon, Brennan, & Beaver, 2008). By assisting children

and families on multiple levels, the Child Life team is better able to fulfill their plans of holistic treatment, with the best possible patient outcome in mind. To meet the patient and their family physically, psychologically, mentally, and socially, there are many strategies that a CLS can use; however, there are main categories that these efforts fall into. According to a study by Kaddoura and associates (2013), “child life programs facilitate the coping and adjustment of children and families in three primary service areas: 1) providing play experiences; 2) presenting developmentally-appropriate information about events and procedures; and 3) establishing therapeutic relationships with the patient, parent, siblings, and other family members to support informed family involvement in each child’s care.”

Meeting therapeutic goals in each category varies case by case, but the CLS has a myriad of strategies at their disposal to assist children and families. Evidence-based practices are beginning to gain attention as the profession becomes more established. Although some strategies have more evidence-based support, “child life specialists use a variety of techniques with varying degrees of perceived efficacy” (Bandstra, et al., 2008). For example, healthcare play has perceived efficacy by the CLS and other medical professionals. However, there is a lack of peer reviewed literature to support these anecdotal successes. In addition to healthcare play, Bandstra and his research team note other examples of “evidence based techniques” that are used by CLS. These techniques include cognitive, behavioral, physical strategies and complementary strategies that “have shown promise in relieving or managing pediatric pain” (Bandstra, et al., 2008).

CLSs have noted that patients “who received preparation, rehearsal, and supportive care were significantly less distressed and more cooperative during each event” because of these nonpharmacological interventions (Brewer, Gliditsch, Syblik, Tietjens, & Vacik, 2006). When patients are more compliant to treatment, nurses and other medical professionals are better able to do their jobs in a safe and effective manner with less additional interventions, such as anesthesia. According to Christian and Thomas (1998), it was noted that “the child life program has also been an adjunct to pharmacologic treatments... [and in] some procedures, patients [needed] less medication or no medication at all after they [had] been prepared for the procedure by a child life specialist.” When less medication and additional interventions are used, it is less expensive for the hospital, safer for the patient, easier on the patient and family, there is a decreased risk for complications due to additional medications, and medical professionals are less stressed and better able to do the task at hand with a positive outlook (Child Life Council, 2006).

A CLS’s strategies and intentional efforts to include the patient and their families, while answering questions, can account for the lower need for anesthesia and other sedation techniques. Metzger et al. (2013) noted that “preparation for the procedure can reduce anxiety, improve cooperation and coping, allow for a sense of mastery and control over what is happening, increase in the level of trust between family members and the medical team, and improve long-term adjustment to medical encounters.” Like any other typically developing child, a patient is looking to understand and regulate their environment. Child Life Programming gives children the perception of normalcy in the middle of chaos, which is beneficial. Not to underscore efforts by other perspectives on

the healthcare team, it is noted that Child Life Programming is “most effective when delivered in collaboration with nurses, physicians, and other members of the health care team. The importance of communication, collaboration, and a multidisciplinary approach have proven to be vital part of family-centered patient care” (Sorenson, et al., 2013).

Including nurses, social workers, doctors, and other healthcare team members makes the healthcare experience less traumatic, as well as complete and effective for patients and their families. Additionally, when incorporating other perspectives, it has been noted that “the presence of a child life specialist has been extremely helpful in the trauma setting” which may or may not be within a hospital setting (Christian & Thomas, 1998). As a CLS find their niche in each hospital, expectations and the defining of roles can be a trying time between a CLS and other medical professionals. For example, it has been noted that “nurses and child life specialists rely on several resources in the hospital, but do not always recognize one another as a resource” so they may interpret the same event, like a patient crying, differently (Kaddoura, et al., 2013). However, when working together, the best possible intervention for each patient can be reached because each perspective has been heard and given importance in the treatment plan. One major way nursing resources and Child Life resources have been combined in effective ways becomes apparent when examining research on anxiety and other psychological aspects of a patient’s treatment. Specifically, “child life specialists support the nursing role by addressing a child’s anxiety level, which may affect compliance with nursing staff during initial admission visits, anesthesia induction, and recovery time” (Brewer, et al., 2006). With that, Child Life Programming has seen its usefulness within hospital settings, but finding the right balance with medical staff comes with familiarity and varies by hospital.

The National Child Traumatic Stress Network (NCTSN) Perspective

Outside of the hospital setting, trauma interventions and the role of educated professionals with expertise in development and family systems is underscored. Child Life Programming is prevalent in the work of The National Child Traumatic Stress Network (NCTSN), especially as they work with traumatic stress due to diagnoses. Specifically looking at pediatric cancer diagnoses, NCTSN has noted many similarities to the grief and posttraumatic stress seen in other scenarios; however, these feelings of grief and stress are often disenfranchised. For cancer patients and their families, acute stress is plentiful, but some families have the markings of traumatic stress. Acute stress is marked by a neurotransmitter influx in the brain, while traumatic stress can cause permanent changes in brain structure. For example, running late to a normal doctor's appointment may cause acute stress, while continually going to doctor's appointments for chemotherapy with a fear of the cancer spreading, or a perpetual fear of relapse, can become traumatic stress. Further, traumatic stress in the PICU comes from multiple factors, from "acuity and urgency of child's health conditions" to "death, bereavement, and end of life care decisions" (NCTSN, n.d.). To set the framework for stress on the body, the cycle of stress starting with the alarm state, moving to the resistance phase, and ending in the exhaustion stage should be noted. In the alarm state, the "fight-or-flight response" becomes apparent as people try to escape short term stressors and find homeostasis. The resistance phase happens when acute stress will not go away, and fatigue, sleep disturbances, and other problems arise, causing more stress, and beginning a cycle that piles more stress into an already stressful event. Lastly, the exhaustion phase

comes when unending stress causes illness, due to suppressed immune system functioning (Kaminsky, 2016).

With these stages in mind, the NCTSN has created special worksheets, tip lists, and interactive activities for parents and patients to work through issues, like going back to school and telling their friends about their diagnosis, to help spark conversation and work through stressful issues (NCTSN, 2014). However, the effect of traumatic stress is still there, so healthcare providers need to be cognizant of the needs of their patients and the families even if they are outside of the scope of the physical problem being treated. As noted in a presentation by the NCTSN, “trauma care providers have become quite facile with care of the injured child, and physical injuries can be treated with good outcomes [but] psychological injuries, most notably posttraumatic stress, have largely been overlooked. Complete and optimal care of the injured child and family must include assessment and intervention of this component” (NCTSN n.d.). This demonstrates the need for the addition of trained professionals, like a CLS, to complete the holistic treatment of patients and their families to combat stress that can lead to more serious psychological injuries.

One specific area of addressed by NCTSN in respect to stress during care involves pediatric cancer patients and their families. The NCTSN notes that a cancer diagnosis is a traumatic event, and can be disrupt every aspect of a family’s life. When something as disruptive as a cancer diagnosis enters a family unit, the stress put on each individual changes them. Most families see an event of this magnitude as something that splits their life narrative into pre-diagnosis and post-diagnosis phases. However, “studies

show that most survivors of childhood cancer do quite well psychologically... However studies also show that some cancer survivors and their families will experience continued distress from traumatic stress symptoms, even after cancer treatment ends” (NCTSN n.d.). The fear of relapse may control all future health thoughts and medical visits the family encounters, as the worst possible thing that could happen after beating cancer is that it comes back in some form. This continual stress makes the path towards posttraumatic stress seem inevitable without the proper interventions from Child Life Specialists and other therapeutic services. There is some hope that incorporating the family into care and finding family-based care can be helpful, as Child Life Programming has already shown to decrease toxic stress in patients. Unfortunately, there is still work to do for the family unit because it has been noted in the literature that “families facing childhood cancer, rates of PTSD are often higher in parents than in the child with cancer” especially mothers (NCTSN, n.d.).

The Impact of Trauma

When looking at trauma as a whole, it is necessary to incorporate the work of Dr. Bruce D. Perry, a primary figure in trauma intervention research, and the founder of the Child Trauma Academy. The work a CLS encounter is not likely this severe, but seeing how wide the spectrum of trauma and its effects are, allows skills to be built and adapted to the severity of each individualized therapeutic plan CLS and the healthcare team encounter. Because healthcare experiences and severe diagnoses do not discriminate on chronologic age, it is necessary to appreciate the effects of trauma on all stages in development; however, “traumatic events on infants and young children is minimized”

even though “children are not resilient, children are malleable” (Barbara on livingubuntu.wordpress.com, 2013). Because people are malleable, and not as resilient as the cliché states, the world and events we encounter are perceived through “the distorted filter of [our] own beliefs”, which later affects perceptions of events that happen later in the lifespan, good or bad (Barbara on livingubuntu.wordpress.com, 2013).

As an individual goes through the lifespan, “the brain is developing from bottom to the top, the process is influenced by a host of neurotransmitter, neurohormone, and neuromodulator signals” (Perry, 2009). Stress, as noted by the NCTSN, can be adaptive in an acute amount during the alarm state; however, it can turn toxic without proper resources to alleviate or work through stress. Children who experience stress, especially in high amounts, are especially prone to brain changes because of trauma. A human brain is close to eighty percent of its total abilities by age three; however, “the majority of children do not receive adequate mental health services” (Perry, 2009). Because children experience stress due to diagnoses or other factors their brains have a “veiled cascade of events [that creates] a common pathway to a variety of important long-term behavioral, health, and social problems” (Anda, et al., 2006). When these experiences cause toxic stress, a child’s brain development is changed. Different structures and their responses to neurotransmitters and other substances are affected. Anda et al. (2006) noted changes to the prefrontal cortex, hypothalamic-pituitary-adrenal axis (HPA axis) and the amygdala in children who have experienced excessive stress. Even the smallest change in brain anatomy “and physiology of the brain [can] affect multiple human functions and behaviors” (Anda, et al., 2006).

The timing of stress is almost as influential as the stress itself on the developing brain. There are noted benefits to small amounts of stress when they encourage an individual towards working to remove the stressor, like studying for an exam. However, children and families who experience hospitalization and extensive diagnoses may not have any control in removing a stressor. This is followed by stress turning toxic to their system. As reported by the NCTSN, parents, especially mothers, are more likely to have posttraumatic stress after a child is diagnosed, but typically, “the organizing, sensitive brain of an infant or young child is more malleable to experience than a mature brain” (Perry, 2009). Even throughout childhood, the timing can be crucial to determine the impact of trauma. According to Perry (2009), “the very same traumatic experience will impact an 18-month-old child differently than a 5-year-old.” As reported in *The Boy Who Was Raised as a Dog and Other Stories from a Child Psychiatrist’s Notebook: What Traumatized Children Can Teach Us About Loss, Love and Healing*, Perry also reported that trauma in his patients manifested differently. It was debilitating and even lethal in some cases. The CLS are experts in child development. They are well versed in critical and sensitive periods of development. With this knowledge comes the ability to influence the impact of a stressor. The effect of stress can be increased or downplayed based on the exact timing of stress in the brain. According to Perry et al. (1995), “abnormal micro-environmental cues and atypical patterns of neural activity during critical and sensitive periods, then, can result in malorganization and compromised function in brain-mediated functions such as humor, empathy, attachment, and affect regulation.”

The exact brain changes due to a stressful experience underscores the concept of plasticity of the brain. Although the exact manifestations in each individual brain are as

diverse as the human experience, “the malleability of the brain shifts during development, and therefore the timing and specific ‘pattern’ of neglect influence the final functional outcome” (Perry, 2009). It is crucial for professionals who work with a trauma population to remember because each patient, family member, and family unit will need their own individualized therapeutic plan that is culturally aware. A specialized therapeutic plan will combat the unique expression of stress in each form it presents itself. Further, “developmental experiences determine the organizational and functional status of the mature brain” so early experiences of stress must be handled appropriately with healthy coping to ensure those patterns are the ones that are encoded and held on to as a patient matures (Perry, Pollard, Blakely, Baker, & Vigilante, 1995). When treating patients who are at risk for traumatic stress, intentional efforts need to be made to recognize the effect each event may have on the brains. Specifically, even patients in the neonatal intensive care unit (NICU) should be holistically treated with the effects of stress in mind, as “the developing brain organizes and internalizes new information in a use-dependent fashion”, leading to the fact that ‘traumatic experiences in childhood increase the risk of developing a variety of neuropsychiatric symptoms in adolescence and adulthood’ even when the exact event is not remembered due to infantile amnesia or other factors (Perry, et al., 1995). Even after stress is gone, and the event is forgotten or minimized as the patient gets older, the changes stress induced by never go away. When there are “extreme, repetitive, or abnormal patterns of stress during critical or circumscribed periods of childhood brain development” permanent neuroregulation and behavioral changes can occur (Anda, et al., 2006).

If stress is recognized as part of the patient experience, steps can be made to mitigate the effects of stress so that it does not develop into traumatic or toxic stress and cause permanent changes in an individual. Children's brains, especially in those in the earliest stages of development, are so malleable that it may seem impossible to work against negative impacts; however, those same brains are also receptive to all the positive interventions that are offered (Schute, 2012). There are various "early intervention[s], which can ameliorate the intensity and severity of the response to trauma, [and] will decrease the probability of developing, in a use-dependent fashion, sensitized neural systems resulting in either persisting hyperarousal or dissociative symptoms, or both" (Perry, et al., 1995). There are also interventions to offset stress that can be incorporated into a therapeutic plan. According to Perry (2009), "therapeutic massage, yoga, balancing exercises, and music and movement, as well as similar somatosensory interventions that provide patterned, repetitive neural input" to the brain would help regulate an individual while also reducing negative behaviors associated with trauma. One of the most beneficial buffers to stress are consistent and healthy relationships. Parents, family members, healthcare professionals, a CLS, and other individuals in the child's life can be instrumental in offsetting the negative impacts of stress. Dr. Perry (2009) notes "the power of healthy relationships to protect from and heal... stress, distress, and trauma [should not be downplayed]... and multigenerational, multifamily groups were the main source of safety from the dangers of the world." As with any adult, "the number, quality, and stability of relational interactions matter to the child" (Perry, 2009).

The Family Unit

Due to the importance of developing positive relationships inside and outside of the hospital setting, it is important for a CLS to incorporate parents, siblings and other family members in the health care plan when it is healthy and helpful. Illness “may bring parents and other family members closer...especially those who communicate openly” so it is important to encourage and facilitate open and honest communication when working with a family (American Association of Pediatrics, 2014). Families with a child who has a chronic diagnosis may gain a “sense of cohesiveness, mission, mastery, and pride which builds the resiliency of the family” as well (American Association of Pediatrics, 2014). Further, the American Psychological Association noted that “facing [the] diagnosis head on is the best way to cope” making honesty even more crucial when working with a family (2016).

Because an illness impacts every member of a family, care and resources for each family member as an individual and resources for the family as a whole need to be incorporated into a CLSs’ skillset. CLSs may work with other people on the healthcare team, like social workers, to get the best possible intervention for the family unit, as “being diagnosed with a life-threatening or terminal disease is likely to trigger feelings of fear and grief” even though this grief is not typically recognized and understood like other forms of grief (American Psychological Association, 2016). Further, after the diagnosis of one family member, “illness can be stressful on the entire family” because it disrupts the routine and normalcy of a family unit (American Psychological Association,

2016). Because of this, self-care and respite care for caregivers are very important so that there is no burnout as treatment and hospitalizations go on.

Relationships are important for care and support, and “social networks can be valuable sources of support for [family members] in [the] community such as condition specific support groups, faith based groups, extended family, friends, etc.” (American Association of Pediatrics, 2014). La Clare (2013) notes the hospital setting, health care professionals can be a source of support, or a connection to other resources. These professionals need to be aware of “psychosocial implications of illness and its impacts on families so that they can properly assess and provide interventions...and utilize a family systems perspective when working with chronically ill children and their families” (La Clare, 2013). As parents and other family members are also impacted by hospitalization, “it is important to consider family systems in the delivery of care in pediatrics” (La Clare, 2013).

Parenting through Trauma

Second to research about Child Life Specialists and the patient, the impact of a CLS on the patient from the parent perspective offers a unique perspective to the value of Child Life Programming. There are many ways that a CLS can assist parent coping as they go through the emotions of having a sick child. It has been noted that parent grief during their child’s hospitalization is not thoroughly recognized. On a specific measure of parental coping while their child was hospitalized, “three parental coping patterns emerged: (a) maintaining family integration, cooperation, and an optimistic definition of the situation; (b) maintaining social support, self-esteem, and psychological stability; and

(c) understanding the medical situation through communication with other parents and consultation with the medical staff” (McCubbin, McCubbin, Patterson, Cauble, Wilson & Warwick, 1983). Parents, like children, need to maintain a sense of control and normalcy throughout their time in the hospital to combat some of the negative aspects of stress, find support systems, and get educated and feel heard during medical proceedings. Parents who have “regular or frequent contacts with pediatric care were more satisfied with their own involvement than parents with sporadic or infrequent contacts” because they are more aware and comfortable in that setting (Ygge & Arnetz, 2004). With education and the ability to ask questions, all parents can feel informed and more comfortable throughout the hospitalization. Without taking the time to communicate to parents, “involvement in care can also be stressful for parents, particularly when children are required to undergo examinations and treatments that can be unpleasant”, but parental involvement is so critical that it is easier in the long run to take the time to educate parents and invest in their understanding of their child’s care (Ygge, et al., 2004) Further, “parents’ high state anxiety was associated with their children’s high state anxiety” (Li, Lopez, & Lee, 2007) This demonstrates that the parent has an effect on their children, even when they don’t realize it.

Having a sick child is stressful to any parent, but there are some similarities and some differences between mothers and fathers who have sick children. In a 2008 study, Lannen et al. demonstrates that “both mothers and fathers with unresolved grief are more likely to report higher levels of anxiety and depression as well as decreased quality of life.” However, Lannen (2008) also notes that “mothers with unresolved grief were more frequently on sick leave and were more likely to require physician visits” but “fathers

who had not worked through their grief were more likely to experience difficulties sleeping and instances of waking up with emotional distress.” To feel empowered, Ygge et al. (2004) illustrated mothers demonstrated a need to be feel supported and heard by the healthcare team. According to Kreicbergs et al. (2007), fathers needed to know about their child’s impending death earlier so they would have a better chance at working through their grief.

Although it is disenfranchised grief, grief over a child’s diagnosis is difficult for parent. If the child dies, it has been illustrated that “parental grief [is] more intense and longer lasting than other types of grief” (Kreicbergs, et al., 2007). It is likely that this deep and pervasive grief is likely to be unresolved as time goes on. This leads to other problems as “unresolved grief is quite persistent with time”, so parents who do not get the help and support they need are setting themselves up for more problems (Lannen, et al., 2008). For example, “bereaved parents are likely to suffer from long-term anxiety and depression” which can make getting help even harder for parents who need help for grief as well (Kreicbergs, et al., 2007). Therefore, it is crucial for a CLS and other members of the healthcare team to be aware of resources and processes that can help parents and caregivers cope and grieve effectively. It has been shown that “parents who reported having access to psychological support during the last month of their child’s life were more likely to have worked through their grief in the long-term” (Kreicbergs, et al., 2007). Parents believed the healthcare team took “the initiative to offer them counseling during their child’s illness, and when parents felt that they had the opportunity to discuss their child’s condition with the attending staff, they were more likely to have worked

through their grief” than parents who were not as comfortable having conversations with the healthcare team (Kreicbergs, et al., 2007).

To offset grief stemming from diagnosis and/or death, it is vital to include parents in the care of their child. Parents may question their parenting role as doctors and nurses become the primary caregivers; however, “parents are the gatekeepers for their children” and their roles and abilities should be showcased to promote confidence and normalcy in the family unit (La Clare, 2013). Additionally, parents should be educated on their child’s condition so that they can parent in the best way possible in regard to their child’s diagnosis. Teaching parents how to clean tracheostomy tubes builds confidence, while promoting family-centered patient care, and giving parents the opportunity to feel valued as the parent. Additionally, “the physical limitations of ill children may place a higher demand on parents and families, thus creating more stress” so this mutual education can help mediate this additional stress (La Clare, 2013). According to La Clare (2013), parental stress is partially due to the financial toll an illness can take, as well as the uncertainty of their child’s life. When parents are connected to support systems and involved in care, this offsets stress and allows them to cope with financial stress a diagnosis brings because they have more support in other areas and are better able to devote their strained resources effectively.

Involving parents in treatment helps the child while also facilitating parental coping. This bidirectional stress mediator between a parent and a child can be helpful, but it takes proper education by a CLS or other medical professional to make it effective. According to McMurty (2013), parents commonly use reassurance behaviors to try and

calm their child during procedures, but “reassurance generally seems to be an ineffective comforting strategy during acute pain and can actually increase” the pain the child experiences (McMurty, 2013). Instead, a CLS should encourage a parent to use different strategies during the parent education process, and even demonstrate effective strategies while in the education phase of the intervention. Without this education, “most parents had difficulty accepting the role of helping their child manage this stressful experience” (Li, et al., 2007).

Encouraging parents to be active in their child’s care can be a useful intervention tool to lower stress from beginning to end of hospitalization. Ygge et al. (2004) demonstrate that parents are expected to be at the hospital all day and “encouraged to participate in the care process, but the role played by parents is sometimes unclear”. The CLS need to be intentional about including parents in the conversation and care for the child, especially when the parents are not able to stay at the hospital with their child due to work and other commitments. Li et al. (2007), noted that “parents could play a more active role in helping their child to experience less stress and respond more positively to surgery” which, in turn could also decrease the parent anxiety level. This cycle allows the child to feel less anxiety, so the parent, in turn feels less stress, making the child feel more comfortable, and so on. When a CLS educated the parents and included them in different aspects of care, it was shown that “parents were readily available, willing to participate in providing support for their child, and easily instructed”, so it was worth the effort and time to include them in the long term (Cavender, Goff, Hollon, & Guzzetta, 2004)

One way parents are visibly helpful in the care of their child is during position-distraction interventions. While holding their child on their lap or another conducive position, parents are able to comfort their child while also distracting them with a book, tablet, or toy. When used during venipuncture procedures in an emergency department, “children whose parents used a positioning-distraction intervention demonstrated significantly less fear” (Cavender, et al., 2004). It has also been shown that parents who participated in position-distraction techniques are involved in a “holistic intervention package that integrates current best evidence to sustain the integrity of the whole child during a painful procedure” while also valuing the family structure (Cavender, et al., 2004). Other forms of “parent involvement is imperative in the pre-operative psychoeducational preparation of their child for surgery”, such as blowing bubbles and healthcare play (Li, et al., 2007). When parents are given a role in the care for their child in the hospital, parents gain confidence in their ability to parent in an atypical situation. They know their child best, and parents should be seen as a resource instead of a hindrance.

Sibling Involvement

Another important aspect of family structures and functioning are the siblings of the patient. Because an illness disrupts family functioning, routines, parent stress and other aspects, “considerable significance has been attributed to sibling relations by behavioral scientists, [however,] little empirical research has been conducted regarding the interaction of siblings with each other” (Irish, 1964). Most literature includes siblings into the family unit, without taking special notice of the effects on siblings. When

siblings are accounted for, it is from the parent perspective, not from the siblings themselves; however, “chronic illness is a multifaceted concept that significantly impacts millions of families and siblings each year” (La Clare, 2013).

When their sibling is diagnosed, healthy siblings are impacted, as are other family members. According to La Clare (2013), “illness severity and the level of stress were statistically significant in their impact on the family” unit, so the siblings are invariably affected by a sibling’s illness in the same domains as the parents. A CLS can reliably help healthy siblings, in addition to the patient, because of their knowledge of typical child development, as well as stressors associated with illness and the grief of having a sick family member. La Clare (2013) notes that “healthy siblings are more impacted by their brother or sisters’ illness if stress is a present variable and may lead to further problems with adjusting to the illness” as they get farther and farther from a predictable routine. According to La Clare (2013), “illness impacts more than the physical and biological processes of the body; it spans the psychological, emotional and mental domains as well, confirming the all-compassing influence of health and illness” It is clear that these effects are present in the siblings as well, so a CLS, social workers and other members of the medical team need to be attuned to the needs of siblings as they treat the patient with a family systems lens.

When asked about the impacts of their child’s illness on their siblings, parents described “emotional influences, the disparity of attention giving, how the disruption in normal routines invariably impacts siblings... increased compassion and empathy to others who are different, protectiveness, independence, maturity siblings exhibit, and how

the family itself has gotten closer” (La Clare, 2013); however, “social problems involving children have focused attention on the adult-child dimension” or adult perspective instead of sibling interactions or child perspectives (Irish, 1964). Siblings are important pieces in a family unit, but they are often overlooked. The perspective siblings can offer and the individual needs of the healthy sibling, should be valued by Child Life staff and the medical team.

Benefits of Emotional Expression

Grief is a part of the hospitalization process, whether it be disenfranchised over a diagnosis or recognized because of death. No matter how it manifests, emotional expression can have benefits for every member of a family, and can be encouraged by a CLS. By verbally expressing or journaling emotions, “expressing emotions produced a variety of perceived benefits” for individuals who have a need to express their feelings (Zech & Rimé, 2005). Releasing emotions and verbalizing experiences can be a cathartic experience as it “serves the function of organizing complex emotional experiences” (Pennebaker & Seagal, 1999). Further, Pennebaker and Seagal (1999) note “when people put their emotional upheavals into words, their physical and mental health improves markedly.”

Although there is some question as to the legitimacy of the benefits, the perception of expressing personal experiences to others seems to have many short-term and long-term benefits. In a 2008 study by Kállay et al., it was noted that “the major benefits of emotional disclosure manifest themselves on several levels of functioning.” Other studies have also noted that emotional expression, “whether in written or spoken

form, [is helpful because] putting personal experiences into a story is associated with both physical and mental benefits across diverse samples” (Pennebaker & Seagal, 1999).

According to Nils & Rimé (2012), “immediately after sharing, participants involved in cognitively focused sharing felt comparatively less upset...and reported a lower level of negative affect”; however, other studies note that “those who express their feelings and thoughts related to the stressful event, would experience improvements both in their psychological (e.g., emotional) and physical (e.g., immune system) functioning” in the long-term, rather than immediate or short-term benefits (Kállay, et al., 2008). Either way, “from an emotional regulation perspective, expressing emotions should be beneficial only if expression allows one to re-evaluate the event” (Zech & Rimé, 2005). Therefore, in safe and nonjudgmental places, whether it be with a CLS, social worker, friend, family member, fellow member of a support group, or in another setting, it can be shown that expressing life events, whether they be positive or negative, can be helpful for an individual.

Play Therapy Perspective

Because Child Life started with roots in play and the recognition that play is necessary for child development, there are connections between Child Life and play therapy. A CLS uses different types of therapeutic play when working with patients and their families, like healthcare play or different art projects. There are many benefits to therapeutic play for patients, and the family when they are involved. “Therapeutic play activities are designed to help children verbalize their hospital experiences so they can cope with the trauma of hospitalization” by engaging them in conversation and giving

them an outlet for their energy (Froehlich, 1984), Additionally, therapeutic play is a way “to enhance children’s personal control” over their time in the hospital as they can control what happens in their play scenario (Li, et al., 2007).

Although a CLS is not a psychologist or play therapist, their knowledge of child development encompasses typical cognitive development, and ways to encourage proper coping and other psychological milestones. By using therapeutic play techniques, CLSs are able use their interactions as “an effective intervention in child psychotherapy” (Ray, Bratton, Rhine and Jones, 2001). Play can be a way to normalize the hospital environment, especially if there is a play room where medical staff cannot do any procedures. Therapeutic play can be a way to include parents into care and help gain perspective on the family structure for each patient. According to Ray et al. (2001), when parents are engaged in the therapeutic play process, they “increased the effectiveness of therapeutic play.” When parents are not included, “therapeutic play techniques can still be effective, yet not to the degree demonstrated by studies that involved the parents in therapy” (Ray, et al., 2001). As with other interventions in the therapeutic plan, incorporating parents can only make the positive effects of therapeutic play greater.

Social Work Perspective

Because social work and Child Life Programs are closely knitted together, especially in the hospital setting, it is crucial for the Child Life team and social workers to work together and use each other as a resources. Social workers have a unique perspective about grief, with additional ties to the community that can be used as resources for patients and their families. They also know that “adequate social support

can protect people in crisis from a wide variety of pathological states” and are able to support patients and families (Cobb, 1976). In relation to grief, social workers are able to recognize and give adequate support and recognition to disenfranchised and recognized grief. In a 1974 study by MacGregor, it was demonstrated that parents have the same grief as others when their child is diagnosed with an illness, but that grief is not recognized, so the “healthy expression of parental grief over a child's...illness is seriously inhibited, and problems, both for parents and the patient, are exacerbated.” Because of this, social workers are able to recognize grief as it is instead of over-pathologizing it, and work to resolve it in healthy outlets.

Disenfranchised and Complicated Grief

Grief is a complicated process that is unique to every individual; however, there is a universal need for people to fully experience their grief, and have their grieving process understood. “Disenfranchisement of grief... violates the mourner’s right to grieve” and complicates the process and coping of people after loss (Attig, 2004). Disenfranchised grief can happen in multiple contexts, including recognized settings of grief when “disenfranchising messages actively discount, dismiss, disapprove, discourage, invalidate, and delegitimize the experiences and efforts of grieving” (Attig, 2004). For example, when a sibling’s grief is discounted because she needs to “be strong for her parents because they are very sad”, or an individual is told to “get over it” because they never got to really be a parent, their valid feelings of grief become disenfranchised.

According to Doka (2016), “disenfranchised grief tends to intensify grief reactions” because the feelings get pushed aside for so long, they build and build until

there is a trigger that sets off these feelings until they are properly acknowledged and appreciated. This process can take years if the griever is continually forced to set their feelings aside. Disenfranchisement can also happen when those who are grieving are “excluded from rituals that could support...grieving” possibly because there is “a failure to empathize with the bereaved [and] a failure to respect the bereaved” (Attig, 2004). To successfully facilitate healthy grieving and a complete grieving process, we must appreciate that “grieving is about both suffering *and* resilience, experiencing the devastation and hurt *and* reaching through them to affirm life” (Attig, 2004). In Worden’s grief process, the bereaved must fully live through their grief and the loss, then be able to reinvest the energy that used to be invested in the dead somewhere else. If the grieving are not able to go through this process because their feelings of loss are not validated, they can get stuck in a stage without coping or reinvesting their energy into more productive and healthy outlets.

Similar to disenfranchised grief, complicated grief is known as the complications that can arise when grief is not appreciated or validated. It can present itself psychosomatically, biologically, or confused as a different psychological disorder. For example, “a basic profile of complicated grief can be compounded with symptoms of post-traumatic stress disorder... [with issues relating to] attachment and loss” (Neimeyer, 2005-2006). This process of complicating grief can be exacerbated by the different roles the bereaved had in relation to the dead and the means of death. Neimeyer (2005-2006) notes “complicated grief, and particularly a fracturing sense or meaning, were hallmarks of bereavement for those who lost loved ones by traumatic means”, especially in roles where the living was a caregiver for the dead, like a parent. When working with families

who are experiencing grief, it is important to let them know that their feelings are okay, and know what is normal culturally and individually, so that we can facilitate the healthiest coping possible on route to resilience instead of more problems.

Family Stress and Resilience Theory

When people experience stress, especially young children, there is an assumption that they will be resilient and “bounce back” from their experiences; however, the definition of resilience is not always consistent across disciplines or understandings. Further, there is more empirical data on distress instead of eustress on the process of resilience, so normative stressors are not as understood. Therefore, to ensure consistency, resilience will be defined as “a process by which individuals, relationships, and families adapt to contexts of significant adversity” (Ganong and Coleman, 2002). Further, as noted by Patterson (2002), resilience is “usually based on competent functioning after exposure to significant risk”, such as the death of a child or sibling.

When looking at resilience in the context of a family, we must define who the family is in each unique case, if there was the potential for them to fail and not be resilient, and the tools they had to ensure they would be resilient. When incorporating Child Life Specialists, they are a tool themselves to aid coping and set a family up to be resilient. A CLS is also a teacher for other coping mechanisms individuals and families can use. When looking at stress in a family unit, considering cultural and community factors that can aid or hinder coping and resilience. The Family Adjustment and Adaptation Response (FAAR) Model, it is noted that “the process of adapting to major, nonnormative stressors, such as the diagnosis of a child’s chronic health condition, often

involves changing prior beliefs and values as a way to make sense of the unexplainable” (Patterson, 2002). With poor coping, these responses can lead to negative outcomes along the general adaptation response, and eventually exhaustion, instead of healthier behaviors and responses.

Overall, the process of resilience is about regaining homeostasis within an individual, their microsystems, and in their mesosystem. Child Life Specialists, with their knowledge about development and family systems, are able to assist families as they try to regain balance in their lives after ambiguous losses, like diagnoses, disenfranchised grief, or validated loss, after something like a death. By offsetting some of the negatives that can prevent grieving, the subjective judgement about the severity of loss, better coping can be achieved while also equipping an individual to handle stress at later life experiences. As noted by Patterson (2002), families who have a child with a chronic condition are at “twice the risk for psychological or behavioral problems”, which are exacerbated when they are unable to grieve the way they need to, or lack the tools to cope effectively. Child Life Specialists can give families and individuals the tools to offset this added risk of other problems, and increase their resilience.

Conclusion

Child Life Programming has come a long way since its beginnings with Emma Plank in 1955 (Transatlantic Perspectives, 2017). By combining therapeutic approaches from different disciplines, a CLS has become an integral part to the healthcare team for patients and their families. The impact a CLS can have on their patients is beneficial for patients, parents, hospitals, and many others; however, the work they have started can

only get stronger as more and more literature proves their efficacy in the hospital and other settings.

CHAPTER THREE

Methodology

This project was conducted to explore the impact of Child Life Programming from the perspective of a mother-daughter dyad and the impact of a healthcare experience of a mother-daughter dyad who did not have Child Life Programming. These perceptions were explored through a qualitative approach that was modeled off of a case study approach to better understand the human experience through individualized journeys. These narratives can also be used to demonstrate what the experience means to the individual, their family unit from their point of view, and how other families in the same situation may also feel when if the family has Child Life Programming.

Participants

A purposive convenience sampling technique was used. Two mother-daughter dyads were chosen. One dyad was selected because of their direct experience with Child Life Specialists, and the other dyad was chosen because they did not have any interactions with Child Life Programming. The researcher required that the healthy sibling be an adolescent or young adult at the time of the interview; however, they could be any age when the experience occurred. Both families were recruited through a gatekeeper, which is “an individual who is a member or has insider status with a... group” (Creswell, 1998). The composition of the sample was completed based on healthcare experience and whether or not the family had interactions with Child Life Specialist(s). The total number of participants totaled four individuals, broken down into two mother-daughter dyads.

Instrument

A qualitative methodology that was based off of a case study method was selected for this project to investigate each individual's perceptions of their healthcare experience. The purpose of a case study, according to Soy (1996) is to bring "an understanding of a complex issue or object" to "examine contemporary real-life situations and provide the basis for the application of ideas and extension of methods." This methodology was appropriate because the project and research questions required an in-depth, holistic and personal understanding of the interactions within the healthcare system, and their perceptions about the impacts those interactions had.

This project was approved by the Institutional Review Board (IRB) at Baylor University. Personal, one-on-one interviews were conducted by the researcher, recorded, and transcribed to assist with the analysis. The interviews were semi-structured with open-ended questions and room for more questions as they arose throughout the interviews. The parent and sibling were interviewed separately. The interviews contained questions about the individual, their family structure, their experience with the healthcare system, their experiences with or without Child Life Programming, and how they feel this journey impacted them. The questions were created to address the perceptions of Child Life interactions, their experience, and what interventions they had or wished were available. There were also questions built in to build rapport and gain insight to the family, such as questions about parenting style and family traditions.

Interviews took place in person at a coffee shop in Waco, Texas. Before beginning the interview, participants were asked to complete an introductory information

sheet which included an objective measure of their experiences (Appendix C). Further, there were questions that were consistent across the interviews, but because of the need for clarification, the differences between experiences and diagnoses, and follow-up questions, the interviews were flexible (Appendix D). The researcher began with general questions to build rapport before getting into the more sensitive and emotionally charged questions. The participants were able to tell their stories, and explain things as they saw fit, while also being guided with structured questions to help maintain continuity throughout each case study.

Data Collection

Data was collected during the in-person, one-on-one interviews. Notes were taken during the interview, and each interview was audio recorded. Further, after recording, each interview was transcribed by the researcher so the data would go through a “holistic analysis” through multiple sources of the information (Creswell, 1998). Recordings were taken with an iPhone, and transferred to a password protected folder. The interviews ranged in length from 43 minutes and 21 seconds to 1 hour, 25 minutes and 29 seconds. All names used in the transcriptions and analysis may or may not be the names of the participants, as they were able to choose their own pseudonyms.

Data Analysis

Data analysis for this research began by transcribing the audio-recorded interviews into written text. The researcher read through each interview for content on the first attempt. The second reading was focused on finding specific quotes to be presented during oral presentations of the project on a PowerPoint. The third reading was used to

organize the data into categories pertaining to socioemotional aspects, the family unit, support systems, Child Life Programming, hospitalization and implications of these experiences on the individual. The socioemotional aspects were incorporated to find similarities and differences between the relationships, behaviors, and emotional coping in the participants. The family unit was analyzed to find similarities between participants, and provide a base for who the individuals are and how they see their family unit during and after stress. Support systems were analyzed to uncover what interventions, if any, were available for the participants to help facilitate healthy coping. Child Life interactions were analyzed to inspect the impact Child Life Specialists have on patients and their families when they are a part of the multidisciplinary healthcare team. Hospitalization was analyzed so that the diagnosis-specific needs and interventions could be explained and demonstrate how different diagnoses may or may not require different interventions or support based on the needs that are unique to each diagnosis. Lastly, the implications of these experiences on physical and mental health, faith, outlook and other factors were analyzed. These categories were informed by the theoretical framework provided by the Family Stress and Resilience Theory, which emphasizes the differences between families who experience stress and are able to be resilient and what factors may prevent resilience. The analyzing process included setting aside prior knowledge of the participants, Child Life Programming, and medical terminology and interventions. All of the data that were analyzed were explicitly within the interviews and not mixed with inferred outside information or speculation, other than the speculation of what would have happened with or without Child Life Programming, as explicitly discussed in the interviews.

Protection of Human Subjects

The project was approved by the Institutional Review Board at Baylor University. Participants were informed of their rights, and were instructed that they were able to end the interview or exit the project at any time during their interview. Consent and confidentiality measures were discussed before the audio recording was started with each participant. Participant were not required to sign consent forms, in accordance with IRB protocol for this specific project; however, they were given a copy of the consent form (Appendix B). Further, names of the participants and their family members throughout the project may or may not have been changed to protect the participants' confidentiality.

Verification

Although this project is modeled after a case study approach, the implications of this project can be applied to those outside of the project. In qualitative research, there are traditional measures of validity, such as internal validity, external validity, reliability and objectivity, or alternative criteria, such as credibility, transferability, dependability, and confirmability (Trochim, 2008). However, according to Creswell (2003) "validation" may be a more thorough and robust method of qualitative data analysis. Within validation, Creswell (2003) asserts that there are eight strategies that may be used by qualitative researchers. These areas are 1) prolonged engagement or persistent observation in the field, 2) triangulation, or using multiple sources, theories, methods, or investigators, 3) peer review or debriefing, 4) negative case analysis, 5) clarifying, 6) member checking, 7) rich, thick description, and 8) external audits. Within these measures, two of the eight should be present in any study to give validation. This project

meets four of the eight validation requirements through rich, thick description, external audits, peer review or debriefing, and triangulation. Through these validation measures, we can ensure the project will contribute to the body of knowledge, and have implications in the Child Life profession and other healthcare measures outside of the four participants and their direct experiences.

Summary

This project has a methodological approach of a qualitative case study with a sample of four individuals, divided into two mother-daughter dyads. The participants completed a personal information sheet and an in-depth interview about their experience in the healthcare system while their family member was sick, and if they had interactions with Child Life Specialists during that time. All participants were made aware of their rights and gave consent for the project. Audio recordings of the interviews were transcribed and reviewed by the researcher for themes. Through this analysis, the researcher was able to draw conclusions from the collected data regarding the efficacy of Child Life Programming.

CHAPTER FOUR

The Journey

Note: from this point forward, names may or may not have been changed for confidentiality, as noted by an asterisk () by each name's initial use*

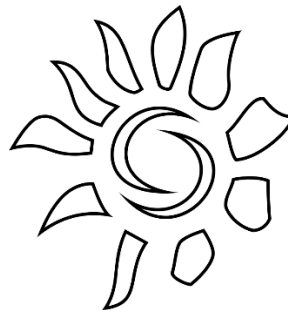
Phillip and Adam's Story

Phillip* and Adam* were born at 25 weeks gestation on June 16, 2003. They lived their lives in a general practice hospital on the west coast. Phillip's name was planned, even though his parents did not know he was going to be Phillip until he was born. Similarly, Adam's parents could not tell he was a boy until he was born, but his name was not chosen until he was born. Adam's water broke at 25 weeks; however, Phillip was born first, even though he "wanted no part of it". During their lives, Phillip's mom noticed that he maintained his asocial attitude, because he wanted to sleep and not be touched. He did not like loud noises, and had a strong dislike of loud voices near him. Adam, on the other hand, was "a nosy one, and always had his eyes open" to see what was going on around him in the neonatal intensive care unit (NICU).

Because they were born so early, Phillip and Adam had some other medical issues, and needed to put on weight before they had the chance to go home. In September of 2003, Phillip's doctors noticed he had a blockage in his intestines. Instead of inserting a stoma like they had planned, his doctors changed their minds and tried to stitch his intestines back up. This resulted in an infection, and Phillip died of an infection due to sepsis on September 9.

While his family grieved for Phillip, Adam continued to grow and gain strength in the NICU. In October, Adam was close to getting discharged from the hospital, but his doctor wanted to reinsert a nasogastric feeding tube (NG tube) so he could put on a little more weight before leaving the NICU. A nurse placed his NG tube into his lungs instead of his stomach. Because of this mistake, Adam contracted pneumonia, and died because his body was not able to soak up the formula. He died on October 10.

Both boys died in their parents' arms, and are survived by their parents, older sister, younger siblings, and other family members.



Cameron's Story

Cameron* was a “pretty great”, “very country” 17-year-old prankster. He loved all types of music, loved to laugh, play sports, spend time with his close group of friends and tell corny jokes. His mom remembers his “beautiful hazel eyes” and his love of Christmas trees. Cameron was diagnosed with acute myeloid leukemia (AML), and spent his last months on earth in a children's hospital in a southern Metroplex area. Even after Cameron moved into the hospital, he was still polite to everyone he met, shared his wide range of music tastes, and found talents he did not realize he had through his interactions

with staff in the hospital. Cameron had an amazing ability to keep his family grounded and smiling throughout their journey.

After Cameron's AML diagnosis, chemotherapy wiped out his immune system. With this, he contracted a bacteria that the hospital had never seen before. Cameron's organs started to fail, and he died at age 17 with his family by his side.

Cameron is survived by his parents, siblings, stepparents, stepsiblings, and other family and friends.



The Parent Perspective

Introduction

Parents are vital to the family unit, and can keep family systems grounded during stressful events. Tammie* and Julia* had different experiences in the healthcare system while their sons were patients; however, there are some similarities in their journeys. Through Cameron's fight, Tammie worked with Child Life Specialists to promote normalcy in the hospital. Phillip and Adam's mom, Julia, also spent most of her time in the Neonatal Intensive Care Unit (NICU), but did not have the support systems in place during or after their hospital experience. Through their stories, it is apparent that Child

Life Programming can support parents as well, and genuine connections and support within the healthcare setting are crucial to promote resilience and holistic family-centered care.

Family Dynamics and Traditions

Although their healthcare experiences are quite different, Tammie and Julia are similar in their personal lives and have similar family dynamics. Both moms have education and professional experience in child development, which informed their parenting styles and their interactions and expectations of the healthcare system. There are also some differences between Julia and Tammie. Tammie was remarried close to the time of Cameron's death, but she co-parents with her ex-husband so well that hospital staff could not tell that they were divorced. On the other hand, Julia and her husband were married about a year before Phillip and Adam were born, and are still together.

After losing their children, Tammie and Julia have become more intentional about not taking small moments and time with their families for granted. Additionally, there are some new traditions they have started, or enhanced, since their children died. For Tammie, her family spends time near water to connect with Cameron, and they have a large collection of Christmas trees to honor Cameron because he loved them. With that, Cameron has a special white tree that gets a new ornament every year and has a box that stays underneath it. Family members write letters to Cameron and place them in the box. In Julia's family, to connect with Phillip and Adam, the family used to visit their graves before moving out of state to connect Phillip and Adam to the younger siblings they never met. Julia emphasizes family dinners and celebrating birthdays and holidays. Julia

also sings *You Are My Sunshine* to her children, and sang to Phillip and Adam when they were in the NICU. These things still connect Phillip, Adam and Cameron to their moms, and promote constructive coping and resilience within their moms as individuals and within their families.

One additional similarity between Julia and Tammie is their memory of how they parented their other children while balancing their time in the hospital. Julia notes that she and her family “weren’t a complete family” while Phillip and Adam were in the hospital because she spent most of her time with them. Additionally, Arcadia* bounced around her relatives’ homes, and stayed with her grandparents most of the time, especially as they moved to be closer to the hospital. Similarly, Tammie noted that Kennedy* and her oldest brother were lost in the Cameron chapter of their lives, but it was harder on Kennedy because she still lived at home. Tammie tried to “juggle all these balls” as a mom, but Kennedy was home most of the time for school, living with her soon-to-be stepdad, and always in limbo about who would pick her up from school each day. Tammie also noted that this experience may have made her more of a “helicopter mom” in some ways because she now knows how quickly things can happen.

Both Julia and Tammie were impacted as parents during the time they spent in the hospital with their sons. The balancing act between their own needs, the needs of their sick children and the needs of their healthy children shifted their roles and expectations of who they should be as a mom; however, they both became more aware and gracious towards the times they have to spend with their families, and have found ways to connect

with their children after their deaths while continuing to be strong and promote resilience for their families.

Psychosocial Factors

Building and maintaining genuine relationships are crucial to working with another person on a holistic scale. On a family scale, both Tammie and Julia have ways of connecting within their family units, and noted how having relationships with hospital staff impacted their experiences. In accordance with the Family Stress and Resilience Theory, the potential for resilience in both families was there, and there were multiple stressors between diagnoses, treatments, and deaths; however, the relationships and support pushed the families, and Tammie and Julia as individuals, on their respective paths towards resilience.

Within her family, Tammie facilitates ways to connect with Cameron and remember him as he was before cancer, chemo and infections started to deteriorate his body. There were some moments that changed how Tammie interprets the world, especially after Cameron died and she had to live through the “very last thing you wanted to happen in... life”. In accordance with Erik Erikson’s psychosocial theory, Tammie was in a crisis between generativity and stagnation, as her role as a parent was different than anything she ever expected or wished it would be. Knowing that she had “this kid you just have to keep functional in school, and you’ve got this kid that you... have to be there for because he’s already told you he’s going to die” while also making sure to go to work and get your hours for FMLA and care for herself, shook her expectations and dreams for her own life and the life of her child. Tammie also noted that she had the ability to

combat those fears because she was able to make sure Cameron was never alone in the hospital, and that there were some days that she and Cameron's dad would stay the night together as a team.

One of the reasons the hospital environment is so stressful is because of the lack of control, and with more stress, there is a bigger reality that a family will not become resilient. Tammie noted that she had to "believe everything would work out" and know that people were working with her to "make [our] life the best it can be while we're together". Even with big life changes for herself and for her children, the ability for Tammie and her family to find refuge in each other as they try to live the lives that they know Cameron would want them to live.

Similarly, Julia and her family went through "rollercoasters of emotions" as they lived through the excitement of pregnancy, uncertainty of premature births, hope of discharge, and the devastating deaths of Phillip and Adam due to malpractice. Even after Phillip and Adam died, Julia and her family had to go back to the same hospital for the care of their child who was born a year after Adam died, and "it made [Julia] angry and... upset to have to deal with" hospital politics and judgements when she wanted to ensure her son would be cared for. Julia was in Erikson's stage of crisis between intimacy versus isolation. Because of those psychosocial needs and the traumatic loss of Phillip and Adam, comments from others about "making time with her husband to make sure they didn't get divorced" and her inability to find resources for herself and her family left Julia "overwhelmed" and "lost". The family tried to get themselves grounded by occupying themselves with education, marathons, and other hobbies, but those were just temporary

bandages over deep wounds. Julia remembered that “Arcadia felt like she had to take care” of her, and that conflicted with her efficacy as a mom. On one hand, this experience made her “more of a mama bear” when fighting for her kids, but those feelings of inner strength were mixed with feeling like “such a crappy mom” because her daughter was forced to grow up fast and care for her.

Hospital and Medical Involvement

There is a wide range in the standard of family-centered care in the hospital setting. Phillip and Adam were in the NICU at a general practice hospital on the west coast, while Cameron was in a children’s hospital in a southern Metroplex. Although the patient demographics are fundamentally different based on age, hospitals in any area with any patient base can still be intentional in the services they offer to their patients and their families. When holistic care is offered, patients are healed faster, so they get out of the hospital earlier, reducing costs. Further, patients and families who are approached from perspectives outside of just physical ailments, they have better pain management, and are less likely to return for the same medical needs. As described by Julia and Tammie, the hospital environment matters.

Julia delivered Phillip and Adam via cesarean section at an HMO hospital that “didn’t promote [or] really offer” services other than care for physical needs unless it was asked for. After Julia was discharged, she went back and forth from the hospital, and was not able to stay in the hospital with her boys. The nurses were Phillip and Adam’s overnight caregivers, and took over roles Julia and her husband would traditionally take as Phillip and Adam’s parents because they were attached to multiple monitors and other

machines. Even when Julia felt empowered enough to seek help for Arcadia or herself, the staff within those services “didn’t seem very prepared” to work with a young child, or informed about their story and what their needs were. There were some nurses that “make that place go around” who explained medical interventions and other things about Phillip and Adam to Julia and her family, but the hospital did not offer mental health services, so Julia had to “find groups [to support her mental health needs] at another hospital”. Further, Arcadia missed out on opportunities to be with her brothers because the hospital was “boring” for her, so Julia did not take her to the hospital. This could have been a crucial time for sibling intervention, but instead, Arcadia stayed at home with family members, because she was not valued as a sibling working through the uncertainty and grief of her siblings living and dying in the hospital.

Tammie was an integral partner in Cameron’s healthcare team. The doctors took her aside to discuss Cameron’s diagnosis and prognosis, and let her tell Cameron that he was sick. Cameron’s medical team worked with Tammie to help create a routine together, so Cameron would stop sleeping in so late, and enabled Tammie to care for Cameron in a way that would honor his privacy, and his own emotional needs as an adolescent. The hospital had a caseworker who would work with Tammie and her family, and ensured that Cameron’s information would be used for research by following St. Jude treatment protocol. Further, when the healthcare team was not aware of any information coming out of that research, Tammie was comfortable enough to advocate for herself and ensure the bacteria that killed Cameron “was getting worked on by somebody” so that other children have a chance to get better treatment. Because the healthcare team respected Tammie as a mom, they were able to incorporate her as a tool in Cameron’s treatment. It did not make

it easier when Cameron died because there is nothing that can prepare or fix that hurt; however, Tammie was better able to care for herself, through services like the Ronald McDonald House, and in turn, was better able to be the mom she wanted to be for Cameron.

Support Systems

Because Julia had so little support from the hospital, she sought help from family, friends and her priest. She still finds support from her family and friends, but has struggled finding the mental health support she wanted for herself and Arcadia. For Arcadia, she wanted some sort of play or creative therapy; however, the psychologists the hospital offered sat with Arcadia and “threw some pamphlets at her” about grief. She also attempted to find counseling for herself, but had trouble finding resources through her hospital or insurance.

Julia tried to find bibliotherapy resources for Arcadia through a friend who worked at a mortuary, and had some luck; however, she wishes “there would be more resources, and that people wouldn’t forget about the siblings so much”. As she tried to find resources to help grieve, Julia was continually shut down, and was unable to promote resilience in her family. This, in turn, manifests itself years later, as there are days when Julia cannot get out of bed. However, there are newer resources via technology that have assisted Julia find peace and connected her to other families who have experienced similar losses, which has started a new coping method for Julia and helped her find the peace she desperately searched for.

In stark contrast, Tammie had lots of support from the hospital environment, but had trouble finding genuine support from friends because the people in her circle did not really understand. However, Tammie had emotional support and interventions in the hospital for herself and her children, so she had access to resources and had knowledge about different mental health options outside of the hospital. Different interventions built Tammie's knowledge about available resources and her confidence and efficacy in reaching out and participating in services. Having the support she needed from the beginning did not prevent mental health needs in the future, but Tammie knew that she had access to supportive resources, and "a place that loved [her] enough that tried to put those things in place." Additionally, within the hospital, there were services available that Cameron did not need, like occupational therapy and speech therapy, but still allowed Tammie to see that any service they would need is "right there in-house". Tammie also noted that they had access to therapy dogs in the hospital, an art therapist for both Cameron and Kennedy, and a teacher so Cameron could still go to school while he was hospitalized.

Interactions with Child Life Programming

In addition to support from family, friends, and traditional hospital staff, an increasingly important, supportive piece of the healthcare team are Child Life Specialists (CLSs). Commonly seen in children's hospitals, like the one Cameron was in, a CLS can be found in outpatient settings or in general practice hospitals for pediatric patients who do not have access to a children's hospital or for children of adult patients. At Cameron's hospital, Child Life was there before any doctors met with him, stayed with him through

his procedure, and “hung out with him the entire time”. Later, after his doctors realized Cameron had AML, Child Life came back and became Cameron’s “people” throughout his hospital stay. Julia mentioned that she “had a friend that said they had a Child Life Specialist... [who] would come in and work with the... siblings and the baby, or take the siblings to work with them, [but Julia and Arcadia] did not have any of that stuff.” With these juxtaposing viewpoints, the value of Child Life Programming on the family, and for the parent specifically, are demonstrated.

Tammie initially realized that Cameron’s diagnosis was going to be drastic because of their interactions with Child Life Specialists. When the CLSs that were with him during his procedure that morning came back and started asking “get-to-know-you questions”. When the doctor came to talk to Tammie before telling Cameron his diagnosis, Child Life Specialists stayed with Kennedy and Cameron because Tammie “totally trusted them”. Later, when Tammie told Cam he had cancer, a Child Life Specialist caught Kennedy when she dropped to the floor with shock.

After that first day, Cameron and his family met more of the Child Life team, and had access to additional services. Cameron went to a support group with other patients once, but chose not to attend any more sessions because he felt like he needed separate himself from the negativity within that group; however, a Child Life Specialist offered him that resource every week. Child Life Programming kept Cameron moving with a stationary bike and by playing football in the hallway with him, even when he was close to his death, so that his muscles would stay strong. They translated medical terms and brought school to Cameron. The Child Life Specialists got to know Cameron, and were

able to bring movies to him because they knew what he liked. The Child Life team helped Cam prank his doctors with elaborate mechanisms to dump flour on them when they walked in the door. The Child Life team set up visitors like the local NFL team or other organizations for patients, and Cameron was able to interact with them inside the hospital.

All of this was important to Tammie, because she knew Cameron was loved by a team of women who are now seen as part of their family. As a parent, Child Life Programming was instrumental in Tammie's experience with Cameron in the hospital. They allowed Tammie to still be his mom. The Child Life team also gave Tammie resources that she would have never dreamt she would need, like hotel discounts for family members, or restaurants who provide meals and discounts for families who are in the hospital. The Child Life team also bridged the gap between Tammie and the medical staff, and provided explanations and access to a medical library so Tammie could understand and help her son. A CLS also made sure Kennedy had support, and made sure Tammie was taking care of her own "emotional and mental health... [because] they cover the whole person." Child Life Specialists made such an impact on Tammie, that she now has a dream of becoming a Child Life Specialist so she can bless another mom with a mold of their child's hands, cry with them years later, and keep another family "afloat... sane... [and] laughing" throughout their time with Cameron in the hospital. The Child Life team gave Tammie and her family "what [they] all needed when [they] needed it" and Tammie cannot imagine going through this journey without them. Even after Cameron's journey ended, Child Life Specialists attended his funeral, and still spends

time with Tammie and Kennedy whenever they visit the hospital. In the words, of Tammie, Child Life is “not just a job. [It is] a calling.”

Julia and her family, in addition to not having the mental and emotional support after the fact, did not have Child Life intervention during Phillip and Adam’s time in the NICU. When asked about Child Life services, Julia knew what it was, and wished she would have had “some kind of Child Life Specialists [to]... guide [Arcadia] through it, or... tell her that this is normal” so that she wouldn’t have felt so alone or had to grow up so fast. Because they did not have Child Life Programming, or any other service like Child Life, Julia is able to see the how negatively one can be impacted because Arcadia was “left to figure it out what was going on by herself”, and Julia did not have the support for herself to be there for Arcadia as well. Julia knows people who had babies in the NICU and had Child Life services, and wishes that she would have gotten the same care because she has struggled for years with nowhere to turn. Many of her emotional needs could have been met in the hospital with Child Life services, and Julia would have been better equipped to support Arcadia and find other resources for her family in their pursuit of resilience. Instead, Julia and her family have never been able to fully process what happened with Phillip and Adam, and still struggle with those emotions today.

Faith, Mental Health, and Long Term Implications

With or without Child Life Programming, losing a child has long term effects on a parent. There is not a norm for losing children in modern American society, so many people who have not experienced this loss do not know how to approach parents who do. Implications on Julia and Tammie’s faith, cognitive processes, health, and other factors

underscore that having support does not fix grief or make trauma okay, but it does make coping easier and helps validate the experience and grieving process.

Julia and Tammie both identify as Christians. Tammie notes that her faith is stronger, different, and that going through this experience without Christ scares her and “makes her stomach hurt just to think” about it. Because of her faith, she was able to tell Cameron it was okay to die because “there is no safer place than Heaven” and “someone so much more capable” is in control. Similarly, Julia mentioned that her faith “has always been really strong” and that the support from her priest was instrumental through this time.

Both Julia and Tammie have had mental health diagnoses that have led to both moms seeking out psychological support from counselors. Additionally, Tammie has been able to manage her PTSD symptoms with medication and monitoring from her psychiatrist, while Julia has battled with anxiety and depression. However, Julia and Tammie both have times where they “lose it”, even years after their experiences with losing their sons. For example, when Arcadia was applying to colleges, Julia “had a huge breakdown” because she felt like she was “losing another one” of her children. Knowing that these issues can occur, it is imperative that individuals within the healthcare system provide support and resources for these parents so they have access to care beyond their physical bodies when they need it most. Without that support, as seen in Alan Keith-Lucas’s grief model, grief that is not appreciated and lived through can lead to detachment, and causes more problems as time goes on (1994). Instead, parents need

resources to help assimilate their grief into their lives in healthy ways so families can gain mastery over their emotions, and strive towards resilience as a family unit.

Other long term implications for Tammie and Julia are reflected in the choices they make. Both moms noted that they are more conscientious of spending time with their families, and making sure they “take those moments and cherish them”.

Additionally, Julia has noted that she feels more compassionate towards children.

Tammie feels more capable of doing things she never thought she would be able to do, and that is reflected in her dream of becoming a Child Life Specialist and ability to do things for other grieving moms that she never thought she would be able to do.

Conclusion

There is no way to ever “get over” losing a child; however, Julia and Tammie exhibit the ways that adequate support can enhance the grieving process, while a lack of resources and psychosocial support can tear someone down in their most vulnerable time. Although the diagnoses and hospitals were different, the individualized support systems for Tammie’s family from Child Life Programming helped create stability and normalcy during their time in the hospital. Meanwhile, Julia was left to find resources on her own, and took time away from her grieving process until they manifested later in life. Through their stories, the needs for families in crisis to have resilience-promoting resources becomes apparent, and the services offered by Child Life create those resources that are vital to a holistic, family-centered process that benefit parents and children alike.

The Sibling Perspective

Introduction

The sibling perspective is often overlooked in research, especially in the context of Child Life interactions because the focus is primarily on the patient. When sibling interactions are included, they are generally from parent observations. Therefore, Arcadia*'s lack of Child Life Programming and Kennedy*'s love for her Child Life Specialists add value to the body of knowledge, demonstrate the full range of Child Life interactions, and illustrate the implications of Child Life Programming is not available for a young child.

Family Dynamics and Traditions

Like their moms, Kennedy and Arcadia are two individuals who have been impacted greatly by their experiences in the hospital with their brothers. Kennedy lives with her mom and stepdad, but still sees her dad regularly. She also has lots of siblings. Arcadia is currently a student in college, but she still communicates with her parents and younger siblings regularly.

Kennedy, although her parents are divorced, still notes how her parents are still partners. Kennedy also knows that she has the support of her siblings and large extended family. Because of this, Kennedy is very family oriented. She also noted that as she was growing up, she was closest with her oldest brother, but became closer to Cameron after his cancer diagnosis because they had common ground with their challenging medical diagnoses. The day Cameron was officially diagnosed with AML was Kennedy's one year checkup on her brain aneurysm, so they bonded in the hospital, and Kennedy noted

that she felt that she and Cameron had a unique understanding about each other and were able to grow very close in the last months of his life because of it.

As for traditions, Kennedy also noted that Christmas is important to her family. For the last Christmas Cameron had, while he was in the hospital, Kennedy said that “everybody [crowded] in that little hospital room” to celebrate, and they made Cameron’s favorite breakfast like they always did. In the hospital, Kennedy and her family were “still able to do the big parts” of holidays. Additionally, Kennedy said family dinners were very important while Cameron was hospitalized, and that she and her mom would even bring food from the Ronald McDonald House to Cameron’s room in the hospital so Cameron could eat with them.

Similarly, Arcadia and her family are very close. During this experience, Arcadia noted that her parents “did the best that they could, [but] they were just all over the place.” This influenced her family’s decision to move out of state and follow Arcadia to college so that they could remain close. Arcadia also mentioned that this experience drew her family closer together, especially as they were the only consistent support throughout Phillip and Adam’s journey. Because of this, they have a tradition to celebrate Phillip and Adam’s birthday every summer. Additionally, if the family cannot get together for Phillip and Adam’s death anniversaries, they make sure to call or text throughout the day to remain connected.

Psychosocial Factors

During their experiences in the hospital, Arcadia was left alone to figure things out or did not come to the hospital with her parents because there was not a lot for her to

do; conversely, Kennedy was at the hospital with Cameron whenever she was not home to go to school. The ability for Kennedy to also get support within the hospital while her brother was there made a world of difference in her experience and coping.

When her brothers were born, Arcadia was in Erikson's crisis stage between industry and inferiority. Because she didn't understand what was going on, Arcadia was unable to find mastery in her surroundings. She mentioned that she "was very scared just because of all the machines... so I walked in not knowing what I was seeing... and the whole [NICU] procedure was nerve wracking". Further, Arcadia did not have the support and validation of her own feelings. People have mentioned to her that at her brother's funeral that her dad was crying on her shoulder, and she was comforting him. Arcadia noted that she was "glad [she] could be there for my dad, but it was a lot of responsibility for [her]... and pushed down [her own feelings]." Arcadia also said that experience "made [her] feel like what [she] was going through wasn't as serious, or [that it did not] hurt as much as what [her] parents were going through." Although Arcadia was able to explore relationships, she was not able to gain confidence in her own feelings and the way she related to others through this process.

In addition to the emotional process within the hospital, Arcadia described the time Phillip and Adam were in the hospital as a time that went against all of her expectations and dreams of what an older sister should be like. She said that she "was kind of lost" through their time in the NICU because there was nothing to prepare her for what she was seeing, or what her brothers were going through. She was unable to reconstruct her schema for what an older sister should be.

On the other hand, Kennedy was in the middle of ending her journey through industry and inferiority, and transitioning to Erikson's next stage known as the crisis between identity and role confusion. Kennedy already had a relationship with Cameron, but was not used to his role as a patient; however, she noted that she had a "better grasp on reality when everyone else [had her] back" throughout Cameron's journey and her own. While Cameron was in the hospital, Kennedy noted that she was mad and confused because she also had a script for her life, and Cameron's diagnosis did not fit. Because they were in a small school district, Kennedy was going to be in the same school building as a sixth grader while Cameron was a senior. She looked forward to having her older brother show her the ropes and give her some insight while she was "on the bottom of the food chain." Kennedy struggled because none of those dreams and expectations happened. Kennedy did not get to watch Cameron's senior football season, go to his pep rallies, or pass him in the hallway. Kennedy also noted that she "didn't get to see him because his home was no longer my home, so it was just kind of hard."

However, Kennedy was able to interact with Child Life Specialists and other mental health professionals, and knows that her "journey is not even close to being over". She regularly reaches into her "emotional tool belt", underscoring her successful resolution through the industry versus inferiority phase. Further, she also knows "better [ways] to cope with things" and knows that "people still care for her", illustrating the beginning of her success in finding her identity in the next stage of psychosocial development.

Hospital and Medical Involvement

The hospitals Kennedy and Arcadia's brothers were in were very different, but those environments affected Arcadia and Kennedy. Medical staff's interactions with family members can enhance the medical relationship, or they can make everything harder. Arcadia noted, like her mom, that some of the nurses got close to their family because Phillip and Adam were in the hospital for so long. However, Arcadia and her family "had a lot of issues with that hospital, [because of] things that were not safe", so they moved and started going to a new hospital and seeing different doctors. With that move, Arcadia noted that "the new hospital and doctors were much better" for her and her family, especially when her younger sisters were born.

Kennedy had very different feelings towards the hospital that Cameron was in. Because Cameron did not leave the hospital after his AML diagnosis, "the hospital was his home, so [Kennedy and her family] had to transform it into his house." Like Arcadia, Kennedy sad that they saw the nurses so much that they were "like new family"; however, Kennedy also noted the impact doctors had on Cameron's care, especially after Cameron went to the ICU. Kennedy said the doctors did everything they could to fight the bacteria that ultimately caused Cameron's death, and "they just tried to keep him comfortable the best they could, [with things like] heated blankets." Additionally, because Cameron was in a children's hospital, they were more equipped for interactions with pediatric patients and their siblings outside of medical needs and psychosocial interventions. The hospital has a playroom that is run by Child Life assistants and Child Life Specialists as a safe place with no medical staff or procedures. Further, the hospital

has a build-a-bear, and Kennedy noted “the hospital is amazing... [the hospital is full of] kid things, so it’s just fun. It’s like a big playground.” Unlike Arcadia’s family, Kennedy and her family still seek treatment at the same hospital because their experience was so positive.

Support Systems

Support during stress can come from many sources, and are vital in coping effectively and gaining mastery over grief; however, support can come from unexpected places. During Cameron’s hospitalization, Kennedy said that Cameron was her biggest support, especially when they connected over their diagnoses. Cameron had a gift to keep everyone grounded and laughing throughout his fight with cancer. In addition to Cameron, Kennedy has found support from a Child Life Specialist’s therapy dog and Child Life staff themselves. Some of the Child Life Specialists that Kennedy connected with are also counselors at summer camps that she attends that are designed to connect families with others who have lost children. Although Kennedy had the support within the hospital, she still works with a therapist; however, Kennedy mentioned that she liked the Child Life team more because they were genuine. Some of the therapists Kennedy has worked with were “just digging into” her life instead of trying to really get to know her. Kennedy has worked really hard to find a therapist to work with, while also staying in contact with staff in the hospital who helped her throughout Cameron’s diagnosis and her own medical journey.

Arcadia’s main source of support came from her parents; however, Arcadia’s parents were working through their own grief and shock, so while her parents tried to

explain what was going on, it was hard for them because they didn't have all the answers. While Arcadia's parents spent almost all their time in the hospital with her brothers, Arcadia got really close to grandparents and other family members. Her "family did the best that they could but... everyone was in a state of shock", so she was still unable to get the consistent and informed help she needed. Outside of the family, Arcadia also noted that she had "support from all over the church."

Within the hospital, Arcadia realized that "no one really helped us" from the hospital, and the therapists that the hospital had for her weren't medically, trauma or grief informed, especially when working with young children. Therefore, "most support came from outside the hospital", and Arcadia remembers going on a vacation with her family to reconnect after Phillip and Adam died. She made a Phillip and Adam build-a-bear, and was able to dress her bear in some of Phillip and Adam's clothes. This helped her connect with her brothers, and was a coping strategy. Later, when Arcadia was in high school, some of her friends lost their brother, so they created a type of support group, which Arcadia described as very helpful, and restarted her healing process. However, this was years after Phillip and Adam died, and Arcadia is still struggling to find support and fully process all that happened. She noted that she thinks "it was a kind of domino effect... if [she] would have had the support [she] needed from the beginning, it wouldn't have been as bad as it was, and [she doesn't] think [she] would have to be dealing with this grief and working through it in college."

Interactions with Child Life Programming

In addition to outside support from family and friends, Child Life Programming can be integral in interventions within the hospital for siblings. Because the Arcadia's hospital only gave services when they were asked for, she mentioned that "they meant to get me a Child Life Specialist to... help me... [but] they never came." Child Life Specialists were not there to explain what was going on in the NICU, work through the extensive handwashing procedure with Arcadia, or support her needs as an older sister. Arcadia noted that it would have been really helpful "if [there] would have been someone to prepare" her for the NICU. Conversely, Kennedy mentioned that "Child Life was always there to break it down" for her when she did not understand what a certain monitor was for, or what the "scary words" meant.

Through her whole experience with Phillip and Adam, Arcadia recognizes that "it would have helped a lot... not necessarily [making it] easier, but I would have been able to prepare for what was happening" if she would have had Child Life Programming there to help her process what was going on in developmentally appropriate ways. Further, she noted that a Child Life Specialist "would have validated that... it was a difficult time [and] maybe [I wasn't experiencing the same type of pain as my parents] but it was a type" of pain. Either way, "Child Life would have shed some light on what was happening" with Phillip and Adam, and would have been able to support Arcadia after their deaths, and give her the support and help in finding support groups and other capable care when she needed it most, instead of this process getting put off until Arcadia reached college.

Kennedy, like her mom, loved Child Life Programming. From the beginning, when Child Life Specialists came and asked them lots of get-to-know-you questions, to current times, when the Child Life team still makes time for Kennedy at camp and in the hospital, Kennedy said that she “couldn’t imagine this journey without them.” The Child Life Specialists were “peppy and excited and just lots of fun” to be around, and “made everything a little bit easier to understand” for Kennedy and her family. In addition to making things fun, Kennedy said that Child Life Programming “made things a lot more normal” while she was in the hospital with Cameron, so she felt comfortable asking for help, or for some time with a Child Life Specialist to talk about whatever she wanted. Everything did not have to be about Cameron when she was with the Child Life Specialists. She could talk about school, or her own feelings, or anything else.

When talking about her experiences with Child Life services, Kennedy also noted that they allowed her to be herself and validated her feelings. According to Kennedy, there were specific times that the Child Life team would facilitate family meetings, times that were just for Cameron, and times that were just for her to “color and talk, or do arts and crafts... or paint, and they just kind of made things fun... [but] it was a big deal to them to make sure everybody was aware of what was going on.” When Kennedy would go with the Child Life Specialists, they would also let her mom know what was going on so everyone was on the same page, even though Kennedy was not the official patient. Child Life Specialists understood that her health and needs were just as important, and it was necessary to involve and genuinely care for every member of the family to provide the best support for Cameron. Even after Cameron died, the Child Life team still works with Kennedy because “the journey is not over.” Kennedy mentioned that “they were a

big part in our life, just as much as they were in” Cameron’s life. Kennedy also felt supported by their Child Life Specialists because “they knew that it’s okay, there’s always going to be better days.”

Faith, Mental Health and Long Term Implications

With any stressful event, there are long term implications that can affect many dimensions within a person. Although Kennedy and Arcadia were young and “just the siblings” they were still affected by their brothers’ deaths, and still have to cope with the loss they experienced. Kennedy noted that she will “be on this journey the rest of my life” but she has “lifelong tools” Child Life Specialists taught her that she can “still actually use” to manage her emotions, communicate with others, and handle stress. However, Kennedy also know that there will be days when she struggles “because sometimes we just can’t help it”, but it is normal, and she can handle it. Child Life Programming gave her the ability to identify when she would need help, to advocate for herself and her needs, and recognize the worth of her feelings. Additionally, these experiences have sparked a desire in Kennedy to become a doctor, although she did have a desire to be a Child Life Specialist for a while.

As far as her faith, Kennedy mentioned that Cameron’s ability to stay strong and keep everyone grounded made it seem “like God had prepared him for everything that was going to be thrown at him” and that is why he was the way he was. Arcadia noted that she struggled with her faith until she got to college, just like everything else, because she did not understand why God could hurt her through Adam and Phillip’s deaths;

however, when she got to college, she found a support system who started going to church with her, and her faith is stronger than ever.

Like Kennedy, Arcadia mentioned that “there are times when [she] can’t hold her emotions together”, especially when she has triggers in class over things she never fully processed in her childhood. For example, when taking a class over death and dying, Arcadia struggled to focus on what was going on in class because she didn’t process her emotions towards Phillip and Adam’s deaths. This also impacted Arcadia’s field of study. She was originally a psychology major so she could work with grieving kids; however, she shifted to child and family studies because she likes focusing on the family. Arcadia’s memory is spotty from this time, which makes it harder to fully process and cope with everything that happened. She does remember feeling like her parents were trying to replace Phillip and Adam when next brother was born a year after Adam died; however, once she recognized this, she was able to mend that relationship, and everything with her siblings is fine. One repercussion that has had serious implications in Arcadia’s life is her wariness of doctors and hospitals in general. Even though she has had some positive healthcare experiences, she still carries deep wounds as a result of Phillip and Adam’s death. Arcadia notes that she is “definitely scared... [even going in for] check-ups and stuff” at the doctor now, and questions if she really wants to have her own children later in life because she is nervous that she will get a nursing team or doctors that will not keep them safe. We will never know what it would be like if Arcadia had Child Life interventions; however, it is apparent that any type of positive and capable support would have beneficial in equipping her to handle the hurt later in life.

Conclusion

Although Arcadia and Kennedy have both managed to gain insight and inspiration from their experiences in the hospital with Cameron, Phillip and Adam, there was always the potential that their resilience would not develop. Luckily, Kennedy had adequate support from multiple resources. Arcadia had support, but definitely had holes in her care that still affect her almost fourteen years later. With this, the impact of Child Life Programming on children who aren't the patient are illustrated. Children are malleable to their early experiences, especially when those experiences are accompanied with high levels of stress. Support that has training in grief and trauma, and is sensitive to medical scenarios is vital to ensuring the siblings do not get lost in the shuffle. Their feelings are valid, and siblings need safe spaces to grieve and process; however, they also need competent adults, like Child Life Specialists, to facilitate these emotions and give them the words and the tools to ensure that coping is effective. Without these tools, children may go into a downward spiral. Luckily for Arcadia, she is capable and strong enough to make her experience into something positive; however, had she been given the same tools and validation that Kennedy had, her mental health and emotional coping could be stronger.

CHAPTER FIVE

Discussion and Conclusions

Discussion of Findings

Child Life is a relatively new profession, and within the small research base, the sibling perspective has been largely neglected. A qualitative project with the methodological parameters of a case study was designed to compare parent and sibling perceptions about Child Life Programming with parent and sibling perceptions of a healthcare experience without Child Life Programming. Using a case study methodology, semi-structured, in-depth interviews were conducted with two mother-daughter dyads, totaling four participants. The following research questions were addressed:

1. According to the parent-sibling dyad, how does Child Life Programming help the patient?
2. How does Child Life Programming support the family as a unit, and individuals within the family throughout the hospitalization process?
3. What is the perceived impact on the parent or sibling of a hospitalized family member if Child Life services are not offered?
4. How does Child Life Programming impact perceived coping and family resilience?

This project demonstrates that Child Life Programming can help the patient, and is noticeable by the parent and sibling. For Cameron, Kennedy and Tammie noted how Child Life Specialists made the hospital his home. Further, CLSs can support each

individual within a family unit, as well as the family as a whole through communication and intentional therapeutic strategies. For example, the Child Life team organized family meetings and one-on-one interactions with Cameron, Kennedy, and their parents. When Child Life Programming is offered, families are more comfortable and better able to make the most of their time in the hospital. Additionally, emotional coping skills and self-efficacy is built. Tammie and Kennedy were more resilient with the interventions from Child Life, and that resilience has helped them years after Cameron has died when other stressors occur.

All of this is underscored by the events Arcadia and Julia faced when Child Life Programming was not available. For example, Child Life services were not offered, so their healthcare experience was not helpful for family resilience. Additionally, they are still having trouble coping with Phillip and Adam's deaths over ten years later. Now that they have started the healing process, Julia and Arcadia are finally starting to gain the emotional tools they needed when the boys died; however, if Child Life interventions or other appropriate interventions would have been available, they could be much better off emotionally and mentally today. Further, if they would have been given coping strategies when Phillip and Adam died, they would be more resilient today when other stressors occur.

There were also six main themes that emerged through the data analysis process. These themes gave insight to the perceptions siblings and parents had during their healthcare experience, and how the presence or absence of Child Life Programming affected the participants. The participants were asked to describe their experience when

their son/child was in the hospital. When describing their journey, the first theme that emerged was the psychosocial impact of this experience. Some participants were still able to achieve the positive end of each crisis, as described in Erik Erikson's psychosocial theory; however, one participant was not able to achieve the positive end during this experience. Similarly, whether or not the psychosocial goals were met also influenced whether or not resilience was met. Both families had the potential to break, but both families were able to be resilient to a certain point. This does not mean that families were completely healed from this experience. All four participants still have hard days; however, positive interactions that facilitated psychosocial coping made it possible for the families to rise above and grow together through this experience. The family who experienced Child Life Programming and other specific interventions for their needs seems to be more resilient than the other family as a whole, but both families were able to avoid falling apart completely.

A second theme that emerged were observations about family life and traditions. After the deaths of their family members, both families noted that they have started new traditions to connect themselves to their son/brother. Further, each family has become more intentional about appreciating the moments they have together, and is more aware of their love and appreciation for each other. They grew together by assisting each other cope and become resilient as a family unit.

The third theme that became apparent during analysis was the support individuals received outside of Child Life services. For some, having Child Life Programming and other professional support made support from friends seem insincere; however, for the

mother-daughter dyad who did not receive adequate professional help, friends were the best support outside of the family. In both cases, family was very important in coping and working towards resilience.

The next theme that appeared was the differences in hospital environments and other medical aspects in each case. In one family, this experience challenged the schema that hospitals are safe places for healing. Medical staff was inconsistent, as some of the nurses were supportive and went above and beyond, while other doctors and nurses were reckless and caused deaths through their malpractice. In the other family, the hospital and medical team were diligent and made the best out of a tough situation. The nurses became a part of the family, and doctors and nurses tried to keep them as comfortable as possible.

The fifth theme that developed throughout the interviews was the impact of Child Life interactions. For the dyad that had Child Life interventions, those women were integral in the holistic care of each individual and the family as a whole. Through individualized interventions and genuine attention to the personalities and interests of the patient and his family, Child Life Specialists made the best and most normal life in the hospital that was possible. In the dyad who did not receive Child Life Programming, they struggled to get resources to help them process and cope. The resources that were offered were not equipped to handle their needs. This, in turn, negatively affected them years after the experience, and kept them from fully processing what happened.

Lastly, a theme of faith, mental health and long term implications from this experience emerged. Faith was an instrumental tool in helping these families make sense of the deaths, and assisted in coping as their faith grew stronger. For mental health, all of

the participants have struggled with mental health, some diagnosed and some not. For the dyad who had Child Life Programming, they were more equipped and more competent in finding mental health resources outside of the hospital. Further, they were better able to own their emotions and take intensive measures when necessary. Similarly, the dyad without Child Life Programming has issues with mental health, but they still struggle with finding resources to help them cope and regain balance. Therefore, having appropriate interventions does not end mental health struggles, but it does seem to give individuals more self-efficacy in searching for help when needed, while also feeling more control over their care and emotional well-being. Lastly, the long term implications of these experiences affected career dreams and family goals for the participants, some positively and others negatively.

Limitations

The current project provides insight to the benefits of Child Life Programming, and what can happen to families when Child Life interventions and other resources are not available. However, this project is limited because of the following factors:

1. The sample size is limited to two mother-daughter dyads, totaling four participants. One dyad had Child Life Programming, and one dyad did not.
2. Participants were highly-educated, and currently live in central Texas.
3. The participants had healthcare experiences that ended in death.
4. The mother-daughter dyad who experienced Child Life Programming had an extraordinary experience, and the mother-daughter dyad who did not had

extraordinary circumstances that led to the deaths. These extreme ends of the spectrum may skew perceptions.

5. One hospital was a pediatric hospital and one hospital was not.
6. Diagnoses were different between participants, so interventions and implications of those diagnoses could be different.

The limitations may impede generalizations to families who are outside the scope of the current research

Recommendations

Based on the findings in this research, the following recommendations for future research are offered:

1. Include families whose experiences do not end in the death of the patient.
2. Compare families within the same diagnostic categories instead of across different diagnoses.
3. Include fathers and other siblings, especially male siblings when possible. For more in-depth information, extended family who also interacted with Child Life Specialists could be included.
4. Keep the hospital demographics consistent, i.e. only participants from pediatric hospitals.
5. Use families who have a more typical experience, instead of families who fall on opposite sides of the spectrum with their experiences. The large difference made this project easier to illustrate the benefits, but including families who

do not have extraordinary experiences or circumstances may make the data more generalizable.

Implications

The purpose of this project was to examine the impact of Child Life Programming on siblings and parents from their own perspective. By studying this phenomenon, the impact of appropriate psychosocial therapeutic interventions became apparent. The conclusions of this project have implications for future research, Child Life Specialists, healthcare professionals, social workers, therapists, psychologists, counselors, psychiatrists, and other individuals in the helping professionals.

The findings from this project indicate that Child Life Programming is an integral tool in facilitating processing, coping and resilience in families and individuals. When those resources are not available, and other therapeutic interventions are ill-equipped to meet the psychosocial needs of the client, long term issues can surface and spiral out of control.

This project notes that having appropriate interventions do not prevent negative outcomes from surfacing. Instead, when mental health crises occur, those who had access to interventions from Child Life are more capable of finding mental health support that fits their needs. Individuals who are able to interact with Child Life Specialists are also better able to identify their emotions and needs to ensure they are able to regain balance in their lives and find their footing. Overall, Child Life Specialists' knowledge of development and family systems allows them to make individualized therapeutic plans that can assist patients, siblings, parents and other family members cope and become

resilient together. Without Child Life Programming and other grief and trauma informed professionals, families and individuals who experience extreme stress are less likely to regain their balance after their stressor. They are more likely to break and start a downward spiral because they are unable to find and/or are unaware of services that are available to help them. Child Life interventions can offset these negative starts, and equip individuals to identify their emotions and needs, while also setting them up to achieve mastery and healthy coping habits they can use throughout their life.

Conclusions

Although we will never know what would happen if both families received Child Life Programming, the narratives illustrate how not having Child Life Programming can be detrimental to individuals and families. The current project examined how interactions with Child Life Specialists, or the lack thereof, impacted families and individuals from a parent and sibling perspective. The methodological parameters of a qualitative case study approach was used with a theoretical framework of Family Stress and Resilience Theory. This project describes the impact of appropriate psychosocial intervention from diagnosis to death of a child/sibling. Further studies should look to include more families, and continue to incorporate the sibling, as they are vital to family structure, and can benefit from these interventions as well. This project has implications for Child Life Specialists and other healthcare professionals, as it demonstrates a need for Child Life Specialists to be a part of the healthcare team. Further, people in the medical field need to be aware and competent in working with children and families through grief and trauma from more than a physical perspective. Holistic, family-centered care can be improved as healthcare

professionals incorporate Child Life Specialists into their teams, even in hospitals that are not strictly for pediatric populations because family members of all ages benefit from appropriate psychosocial intervention.

APPENDICES

APPENDIX A

Letter of Introduction to Parents

Dear Parent,

I hope that this time sharing your story blesses you and brings you peace. Thank you for sharing your heart and story. We are in the process of collecting some information for a thesis project, and we are thankful that your story can be included.

There are some things we want to make clear about the study before we begin. The Institutional Review Board (IRB), is not requiring a signed consent form because this information would not require consent outside of a research setting. Additionally, the only thing that will connect your name to this study would be a signed consent form, so in the interest of confidentiality, it is not required. However, we want to make it clear that you do not have to participate, and we can stop or take a break at any time. To protect confidentiality, we will use pseudonyms, and the only people who will have access to the interviews, transcriptions, and key will be the research team.

In this study, we are going to ask about your experiences in the hospital when your sibling was hospitalized. We have some set questions we would like to ask you, but we know you have an important story, and we want to make sure you can express and speak about anything you want included. We are hoping this project can add some valuable research to support Child Life Specialists. That being said, we also know some of this information can be hard to speak about, and we want to make sure that you feel safe and supported. We have a list of resources for you, if you feel the need to reach out for a wider support system.

Thank you for your time in completing this questionnaire, and for participating in this study. We hope that this gives you a chance to find love and healing.

In Him,

A handwritten signature in black ink, appearing to read "Sarah Pitman". The signature is fluid and cursive, with the first name "Sarah" written in a larger, more prominent script than the last name "Pitman".

Sarah Pitman

Notes about the study:

I am very interested in studying the effects of Child Life Specialists on the family, but from a parent's and sibling's perspectives, instead of the patient's. I know it can be hard

to talk about, but my hope is that hearing your story will give insight to the ways having Child Life (or not having Child Life) can impact the family unit as a whole, and individuals, through this difficult time. I am going to ask you questions designed to help share your thoughts, feelings, and perceptions. There are no right or wrong answers. I will be recording the interview. You can take a break or stop at any time. I will give you a handout with questions, but we can go off of that sheet, and I may ask questions to clarify; however, if you are not comfortable, you do not have to answer anything you do not want to.

Thanks again for your time!

APPENDIX B

A Letter of Introduction to Siblings

Dear Sibling,

I hope that this time sharing your story blesses you and brings you peace. Thank you for sharing your heart and story. We are in the process of collecting some information for a thesis project, and we are thankful that your story can be included.

There are some things we want to make clear about the study before we begin. The Institutional Review Board (IRB), is not requiring a signed consent form because this information would not require consent outside of a research setting. Additionally, the only thing that will connect your name to this study would be a signed consent form, so in the interest of confidentiality, it is not required. However, we want to make it clear that you do not have to participate, and we can stop or take a break at any time. To protect confidentiality, we will use pseudonyms, and the only people who will have access to the interviews, transcriptions, and key will be the research team.

In this study, we are going to ask about your experiences in the hospital when your sibling was hospitalized. We have some set questions we would like to ask you, but we know you have an important story, and we want to make sure you can express and speak about anything you want included. We are hoping this project can add some valuable research to support Child Life Specialists. That being said, we also know some of this information can be hard to speak about, and we want to make sure that you feel safe and supported. We have a list of resources for you, if you feel the need to reach out for a wider support system.

Thank you for your time in completing this questionnaire, and for participating in this study. We hope that this gives you a chance to find love and healing.

In Him,

A handwritten signature in black ink that reads "Sarah Pitman". The signature is written in a cursive, flowing style.

Sarah Pitman

Notes about the study:

I am very interested in studying the effects of Child Life Specialists on the family, but from a parent's and sibling's perspectives, instead of the patient's. I know it can be hard

to talk about, but my hope is that hearing your story will give insight to the ways having Child Life (or not having Child Life) can impact the family unit as a whole, and individuals, through this difficult time. I am going to ask you questions designed to help share your thoughts, feelings, and perceptions. There are no right or wrong answers. I will be recording the interview. You can take a break or stop at any time. I will give you a handout with questions, but we can go off of that sheet, and I may ask questions to clarify; however, if you are not comfortable, you do not have to answer anything you do not want to.

Thanks again for your time!

APPENDIX C

Consent Form

Baylor University

Family and Consumer Sciences: Child and Family Studies

Consent Form for Research

PROTOCOL TITLE: The Efficacy of Child Life Programs: Parent's and Sibling's Perspectives

PRINCIPAL INVESTIGATOR: Sarah Pitman

SUPPORTED BY: None

Purpose of the research: The purpose of this study is to study the efficacy of Child Life interventions in chronic or chronic-traumatic children and their families. We are interested in understanding Child Life Specialists help patients and their families cope in an effort to prove the value of their work.

We are asking you to take part in this study because you have a child who has experienced Child Life and you and your family could provide valuable insight to the type of intervention, and the benefits of working with a Child Life Specialist.

Four families, at the most, including parents/guardian(s) and adolescent siblings, when applicable, will be interviewed to take part in this research study through Baylor University.

Study activities: If you participate in the study, you will meet with the Principal Investigator, and be interviewed about your experience with Child Life Programming. Your child will be interviewed about their experience with Child Life Programming. All interviews will be audio recorded to ensure reliability until the interviews are transcribed and stored on a password protected and encrypted Box folder. After your interview with the Principal Investigator, you will not be required to participate in any other part of the project.

Risks and Benefits:

No foreseeable risks: To the best of our knowledge, taking part in this study will not hurt you.

Risks of Completing Tasks

You may get tired during the tasks. You can rest at any time.

Interviews

You may feel emotional or upset when answering some of the questions. Tell the interviewer at any time if you want to take a break or stop the interview.

Questionnaire/Survey Risks

You may be uncomfortable with some of the questions and topics we will ask about. You do not have to answer any questions that make you feel uncomfortable.

Psychological Testing/Sensitive Topics

This research study involves psychological testing. The questions being asked may be sensitive and personal in nature. It is possible that answering some questions may cause some stress. If you should feel uncomfortable, we will have a list of resources for you to follow up with.

Loss of Confidentiality

A risk of taking part in this study is the possibility of a loss of confidentiality. Loss of confidentiality includes having your personal information shared with someone who is not on the study team and was not supposed to see or know about your information. The researcher plans to protect your confidentiality. Their plans for keeping your information private are described later in this consent form.

There may be other risks of taking part in this research study that we don't know about. If we learn about other risks, we will let you know what they are so that you can decide whether or not you want to continue to be in the study.

Benefits

Others may benefit in the future from the information that is learned in this study. Further, the information collected in this study will support the profession of Child Life by providing evidence for the efficacy and beneficial outcomes of Child Life intervention.

Confidentiality: In this project, the research team will do everything we can to ensure you and your child's privacy. Your name will be replaced with a pseudonym, and the key that ties you and your child's names to the information you provide will be stored on a password protected computer in an encrypted Box folder.

Authorized staff of Baylor University may review the study records for purposes such as quality control or safety.

Questions or concerns about this research study: You can call the researcher(s) with any concerns or questions about the research.

- Sarah Pitman – (940) 536-8313 or Sarah_Pitman@baylor.edu
- Dr. Joyce Nuner – Joyce_Nuner@baylor.edu

If you want to speak with someone not directly involved in this research study, you may contact the Baylor University IRB through the Office of the Vice Provost for Research at 254-710-1438. You can talk to them about:

- Your rights as a research subject
- Your concerns about the research
- A complaint about the research

Taking part in this study is your choice. You are free not to take part or to stop at any time for any reason. No matter what you decide, there will be no penalty or loss of benefit to which you are entitled. If you decide to withdraw from this study, the information that you have already provided will be kept confidential. Information already collected about you cannot be deleted.

By continuing with the research and completing the study activities, you are providing your consent.

APPENDIX D

Personal Information Sheet for Participants

Personal Information

Name:

Phone Number:

Email Address:

I am a parent participant

I am a sibling participant

Current age:

Age at sibling's diagnosis:

Name of the child(ren) who experienced hospitalization:

Age at the time of the diagnosis:

Child's diagnosis:

Date of the diagnosis:

Hospital(s):

If you would like to choose your own pseudonym, please state here:

If you would like your child to have a pseudonym, please state here:

On a scale of 1 to 5 (1 being not at all, 5 being very deeply)

_____ Do you feel that this experience affects your everyday life?

_____ How often do you find yourself sharing your story with people?

_____ Do you feel like you had a supportive group of friends and family during this time?

_____ Do you feel like your partner/other family members are “on the same page” as you in your perceptions surrounding this event?

_____ Do you feel like hospital staff helped you during this experience?

APPENDIX E

Interview Questions for Parents

Beginning Thesis Interview Questions for the Parent Participant

****allow follow up questions and conversation to happen****

1. Tell me about your family: who lives in your house, ages, dynamics, etc.
2. How would you describe your parenting style? Discipline?
3. Do you have traditions in your family?
4. Does your family have any type of faith background?
5. What kinds of support systems are in place for you and your family?
6. Describe your child: temperament, personality, etc.
7. What is your child's diagnosis, and what did that diagnosis mean for you and your family?
8. How has your child's diagnosis impacted their development?
9. Have you noticed any delays/regressions in their development their diagnosis?
10. Did you know what Child Life was before your child was diagnosed?
11. What types of things did Child Life do for your child?
12. What resources or supports did Child Life offer you as a parent?
13. How did Child Life help or hinder your experience throughout your child's illness?
14. Are there interventions for your child, like OT, speech therapy, etc.? Do you use these services? If so, how do these appointments effect the family as a whole, your child specifically? (Financially, with your child's progress, etc.)
15. How do you feel your child compares to children in the same situation/normalized developmental contexts? How does your child compare to siblings?
16. How has your child and their needs impacted your family? Positives? Negatives?
17. Are there specifically play therapies or interventions in place for your child (ex: healthcare play)? Any bibliotherapy?
18. How has Child Life impacted your child? The family as a whole?
19. How has new technology and information (neuroscience, research, etc.) impacted the interventions and other ways your child has been influenced based on their diagnosis?
20. Do you feel that the impact of Child Life and interventions your child gets would be more or less important, or have been different if your child was older or younger?
21. What does your child's diagnosis mean for them personally? For their quality of life and life expectancy?
22. What resources do you wish were available?

23. What does Child Life do with/for your child? Siblings? The family unit? People outside of the family?
24. How do you think this diagnosis/process would be different if you did not have Child Life? Would your child have the same level of coping, understanding, or normalcy without it?
25. Is there anything else you want me to know about your time with Child Life?

APPENDIX F

Interview Questions for Siblings

Interview Questions for the Sibling

****allow follow ups and conversation to happen****

1. Tell me a little about yourself, like how old you are and what you like.
2. What is your family like?
3. How old were you when your sibling was diagnosed?
4. How did you feel when you found out your sibling was sick?
5. What do you remember about your sibling's illness?
6. What was different when your sibling got sick?
7. What things were the same?
8. What did you think about Child Life?
9. Did you have specific interventions or interactions with Child Life that were for you instead of your sibling?
10. What kinds of things do you wish Child Life could have done?
11. What were some of the things you really liked about Child Life?
12. After you met with Child Life, how did you feel? Did you understand what was happening better?
13. How do you think having Child Life made it easier for you when your sibling was sick?
14. Did you see Child Life helping your sibling in any ways?
15. What did Child Life do to help your parents?
16. Is there anything you want me to know that we haven't talked about yet?

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