CHILDREN'S DISTRESS DURING HOSPITAL PROCEDURES:

THE ROLE OF CHILD LIFE SPECIALISTS

by

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A thesis submitted to the faculty of
The University of Utah
in partial fulfillment of the requirements for the degree of

Master of Science

in

Human Development and Social Policy

Department of Family and Consumer Studies

The University of Utah

August 2015

The University of Utah Graduate School

STATEMENT OF THESIS APPROVAL

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ABSTRACT

The goal of child life specialists is to make the hospital experience easier for pediatric patients and their families. They play numerous roles, from preparing for and supporting children during medical procedures to providing support to healthy siblings of sick children, educating other healthcare professionals, and advocating for the patient and his/her family. Child life specialists implement these strategies in order to alleviate the anxiety and distress that can occur with hospitalization. However, there is little research examining specific roles of child life specialists. Although some previous research has examined child life programs and child behavior during hospitalization (e.g., in the playroom, in an inpatient room), this research examines child life specialist intervention, along with specific child life strategies, while children are being administered procedures.

For this study, "procedures" referred specifically to IV insertions. Results indicated that child life intervention was related to lower distress in children ages 2-7 years, but was not related to lower overt distress in patients 8-20 years, perhaps because of a floor effect. The most common strategy used by child life specialists was distraction, whereas the least common strategy was providing an opportunity for a position of comfort. The child life strategy of providing support during a procedure was significantly related to lower distress in patients aged 8-20 years.

For my parents, sister, & Nils.

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ACKNOWLEDGEMENTS

I would like to acknowledge some individuals who have helped with the research for this study and helped me reach the culmination of my graduate degree. I would like to acknowledge Marissa Diener PhD, whose time and energy was essential for this research. I am so grateful for her advice as a mentor, her motivation as my thesis chair, and her friendship. I also want to acknowledge Russ Isabella PhD and Rachelle Albrecht MS, CCLS for their insights and investments in this project. I want to thank my mom, dad, and sister for their endless and constant support throughout my graduate journey. And to my Nils, who is my rock and the light in my life.

CHAPTER 1

THE ROLE OF CHILD LIFE SPECIALISTS

The goal of child life specialists is to make the hospital experience easier for pediatric patients and their families. Child life specialists strive to help pediatric patients by using techniques aimed at alleviating the anxiety and distress that can occur with hospitalization. Child life specialists normalize the healthcare system for children and help children and their families throughout the hospital process (Brewer, 2006; Christian, Thomas, 1998; Thompson, 1989; Thompson, 2009). Child life specialists "meet developmental, emotional, recreational, and educational needs of hospitalized children and their families" (American Academy of Pediatrics, 2000, p. 467).

Most of the healthcare system focuses on physical and medical issues, but excludes the psychosocial and emotional well-being of the patient. These socioemotional dimensions of health are also important, in addition to the physical health of the child. Thus, child life specialists focus on the psychosocial and emotional well-being of the sick child, and other aspects of the "whole child" (Thompson, 1989). Their focus on psychosocial and emotional well-being allows other healthcare professionals to focus on the physical problems of the pediatric patient. When appropriate, child life specialists communicate and collaborate with doctors, nurses, physical therapists, occupational therapists, counselors, technicians, and other healthcare providers about the emotional

and developmental needs of a child. This ensures that all aspects of the child's health are being considered.

CHAPTER 2

HISTORY OF CHILD LIFE

In the early 1900s, pediatric patients often had negative hospital experiences. Pediatric hospitalizations provided situations in which children often experienced emotional distress (Thompson, 1989). Children had no play opportunities, parents were unable to visit the ill child regularly, and pediatric patients were often not told the truth about their health and/or diagnoses. This led to poor adaptive behaviors in children and separation issues from parents (Thompson, 1989).

Hospital practices and services began to change in the 1950s because people began to notice the deleterious effects from negative hospital experiences in children. Part of these reforms included creating a child life specialist position, a person "specifically designed to address the nonmedical, emotional needs of children in hospitals" (Thompson, 1989, p. 77).

Child life specialists understand that physical health and emotional health are connected, and that both need to be addressed when children are in the hospital. In 1992, the Association for the Care of Children's Health (ACCH, a board whose members consisted of child life specialists, nurses, physicians, psychologists, social workers, and parents of chronically ill children) published guidelines for hospitals, which included the idea that hospitals have a responsibility to provide psychosocial care for both children

and families. In 1997, the Child Life Council published the mission statement of child life. This outlined the profession's intent to create interventions for children and their families that would alleviate the trauma associated with difficult medical situations (Thompson, 2009).

Child life specialists need certification to practice child life. Certification for child life specialists has changed over the years. The current requirements to become a child life specialist are a Bachelor's Degree, 10 classes related to child development (approved by the Child Life Council), an internship with a minimum of 480 hours under an approved Child Life Specialist, and a passing score on the Child Life examination (Child Life Council, 2014).

CHAPTER 3

NEED FOR CHILD LIFE

Many children are hospitalized each year. In 2009, an estimated 6.4 million children 17 years or younger were hospitalized in the United States, with 9 million children treated in Emergency Departments each year in the United States (Healthcare Cost and Utilization Project [HCUP], 2011).

Hospitalization can have many negative effects on children. It can lead to behavioral problems, anxiety, aggression, attitude changes, and disturbances in sleep and eating habits. These internalizing and externalizing behaviors can occur during hospitalization or after the child has been discharged from the hospital (Thompson, 1989; Thompson, 2009; Vernon, 1965). Thus, emotional care for hospitalized children is critical to prevent behavior and emotional problems.

Child life specialists can help avoid children avoid negative behaviors and emotional problems. Hospitalized children can experience anxiety. Child life specialists can help alleviate some of that anxiety by making sure the child feels safe, cared for, and informed during hospitalization. A child life specialist strives to help children in the hospital by becoming a safe person who explains to the children what is happening in a developmentally appropriate way, provides emotional support, and gives coping strategies to the child (Christian & Thomas, 1998).

Rene Spitz coined the term "hospitalism", which describes a condition where ill children suffer severe physical and developmental decline because of being ill, in the hospital, and not enjoying the typical daily activities most healthy children experience (Spitz, 1945). His ideas highlight the importance of psychosocial well-being for children's physical well-being, rather than focusing solely on isolating the children from human contact in order to protect them from pathogens.

With an awareness of the challenges faced by children and families and the threat to children's development posed by these risks, child life specialists strive to make the hospital experience easier for patients and families. The process of hospitalization and diagnosis can be overwhelming to a child. Not only do children experience painful procedures and feel poorly, they experience unfamiliar sights, smells, and sounds. They often do not know what to expect (Gursky, Kestler, & Lewis, 2010). One way child life specialists seek to make the hospital experience easier for children is to explain events that will occur in a developmentally appropriate way (Thompson, 1989). Like adults, hospitalized children cope better with known stressors than with unknown stressors, and preparation for medical procedures leads to effective coping behavior and lower stress levels (Gursky et al., 2010). Thus, one goal of child life specialists is to explain to the patient in simple terms what medical treatment he/she will receive. It is expected such explanations "first raise and then lower anxiety levels" in children, and will eventually "lead to more accurate expectations about forthcoming events and thereby reduce anxiety, particularly the fear of the unknown" (Jaaniste, 2007, p. 126).

In addition to alleviating children's immediate hospital-related concerns, child life specialists seek to impact the long-term emotional well-being of hospitalized children.

The psychological and emotional effects of hospitalization may pose a greater threat to a child's developmental growth than the actual physical illness itself (Northam, 1997, p. 370; Thompson, 1989; Wolfer, Gaynard, Goldberger, Landley, & Thompson, 1988, p. 244). If children develop as normally as possible during a difficult medical situation, they will ideally have a smoother transition to home and school from the hospital and continue to have a healthy childhood.

Hospitalization affects children not only emotionally but also physically. A child who experiences a traumatic experience early in life can develop biological memories, or delayed physical responses due to previous stressful environments or situations (Shonkoff, Duncan, Yoshikawa, Fisher, Guyer, Magnuson, 2010). These physical responses can have damaging consequences for the child's future mental and physical health (Shonkoff et al., 2010). Traumatic healthcare experiences can affect children throughout their lives; child life specialists help alleviate trauma and anxiety associated with difficult medical situations to mitigate long-term effects (Thompson, 2009).

In addition to the negative outcomes associated with traumatic hospitalizations, pediatric pain has long-term consequences, including influences on pain threshold and sensitivity. Pediatric pain can lead to long-term detrimental effects, including "lasting negative effects on neuronal development, pain threshold and sensitivity, coping strategies, emotionality, and pain perceptions" (Cohen, 2008, p. 134). Thus, Child Life Specialists are needed to help children deal with the pain and trauma associated with hospitalization in a healthy way (Thompson, 1989).

CHAPTER 4

MODERATORS OF HOSPITALIZATION

Hospitalization does not affect all children in the same ways. Moderators of hospitalization are factors that influence how a child will respond to and be affected by a medical situation. Child life specialists are trained to recognize these factors and create interventions for specific patients based on these factors.

Research in this area is complex because there are many variables that can be associated with children's ability to cope with hospitalization. The current study accounted for two main moderators of hospitalization: child age and child gender (Northam, 1997).

4.1 Child Age

Child age was included in this study because a child's understanding of and reaction to a medical situation varies on the child's age (Northam, 1997). Very young children do not have the cognitive or language skills to fully understand their illness, which is one reason why child life services are a vital part of the patient's healthcare treatment (Northam, 1997). Child life specialists are trained to explain medical treatments and procedures in developmentally appropriate ways, which is one way child life specialists aim to lower children's distress during hospitalization.

Past research examining the association between child age and anxiety during hospitalization is inconsistent. Older children are assumed to cope better with hospitalization; however, some studies have not demonstrated a link between a child's age and his/her anxiety during hospitalization; other studies show that younger children are more likely to experience anxiety during hospitalization (Koller, 2008). Despite these discrepancies, older children are assumed to cope better with hospitalization. Children between 6 months and 4 years of age are expected to show the most adverse reactions (Mabe, Treiber, & Riley, 1991).

4.2 Child Gender

Another potential moderator of children's distress during hospitalization is children's gender, which also shows inconsistent results. Some studies show that girls are more upset by hospitalization than are boys (Rennick, Johnston, Dougherty, Platt, & Ritchie, 200; Small & Melnyk, 2006); other studies show that boys are more distressed and anxious (Tiedeman & Clatworthy, 1990); still other studies show no gender differences (Bossert, 1994; Hart & Bossert, 1994). Thus, the research regarding gender is inconclusive as to whether girls or boys are more affected by hospitalization (Bossert, 1994). The present study will examine gender as a possible correlate of children's distress during IV placement.

CHAPTER 5

PAST RESEARCH ON CHILD LIFE

There is not a great deal of research on the impact of child life specialists on children's well-being. Most research has focused on the role of play in medical situations, procedure preparation for patients, or the well-being of child life specialists themselves (as there is a high burn-out rate) (Holloway & Wallinga, 1990; Munn, Barber, & Fritz, 1996; Thompson, 1989).

There are four main studies that have examined the effectiveness of child life specialists in children's well-being during hospitalization. The first study evaluated a model child life program. The study by Carson, Jenkins, and Stout (1985) had a nonequivalent control group design, where subjects were not randomly selected or assigned to experimental and control groups due to the low number of eligible participants. Ten children ages 4 to 15 were in the study. Five children (3 males, 2 females) were in the experimental group, and 5 children (all males) made up the control group. All children had a traumatic event requiring them to be in the hospital for an extended stay.

The focus of the study was play in the playroom (to escape the hospital room), and play therapy. Children in the experimental group participated in play activities designed by Child Development Specialists. These activities encouraged family

participation in the patient's healthcare and allowed for social and cognitive stimulation. Baseline information about each child's anxiety and self-esteem levels was gathered. Participants in the study were tested three times using the State-Trait Anxiety Inventory for children and adults. Children who participated in the child life program had reduced anxiety and either maintained or enhanced self-esteem compared to baseline levels. Children who did not participate in the program had increased anxiety levels over the course of their hospitalization.

Another study evaluated a model child life program that focused on intensive child life interventions tailored to each child's psychosocial and developmental needs (Wolfer, Gaynard, Goldberger, Landley, & Thompson 1988). This quasi-experimental study took place at Phoenix Children's Hospital in Arizona. The focus of this study was on eight components: admission orientation and assessment, stress vulnerability assessment, ongoing assessment and activity planning, developmental enhancement, psychological preparation, postprocedural medical play, family involvement, and supporting relationships. The study aimed to test a "full child life program", with three child life specialists involved with ongoing interactions with patients (Wolfer et al., 1988).

The study evaluated inpatient pediatric patients ages 3-14 who received child life intensive intervention during their hospital stay, and a control group of children who did not receive child life intervention as a part of their hospital stay. Child gender effects were not examined. Children who received the intensive child life intervention had less emotional distress during their hospital procedures, better coping strategies during procedures, lower pulse before, during, and after the procedure, overall better coping

adjustment, better understanding of the hospital experience, better understanding of his/her procedures, faster surgical recovery, and better posthospital adjustment relative to the control group (Wolfer et al., 1988). Children who received child life care had an overall better hospital experience and better transition posthospitalization, both physically and emotionally (Wolfer et al., 1988). Although this study is important in documenting the benefits of a broad child life program, it is important to note that Wolfer et al. did not examine support provided to children during their experience of medical procedures, which is the focus of the current study. We believe that in addition to examining child life programs as a whole, it is important to better understand which components of child life programs are important. Furthermore, research is needed on specific strategies that child life specialists use.

Brewer et al. (2006) completed a double-blind intervention study of 142 children between 5 and 11 years old to examine child life procedure preparation for same-day, elective surgery. "The Child Drawing: Hospital" was used to measure children's emotional statuses, where pre- and postsurgery drawings were given a numerical score of child anxiety based on certain aspects that were included in the drawings. A child life specialist blind to which children received child life intervention and which children did not receive child life intervention evaluated the drawings. Eighty children received child life intervention, and 62 did not. There were no statistical differences in anxiety by child age or child gender. Anxiety was significantly lower for patients with child life preparation compared to those in the nonintervention group, and anxiety was significantly higher for children in the nonintervention group. This study focused on one component of child life, preparation, instead of a whole model child life program (like the previous

two studies). The research reported here builds on Brewer et al. (2006) by examining a different component of child life, support during procedures.

A final study of child life examined the effects of child life procedure preparation and distraction on children's distress during laceration repair in the Emergency Department. Gursky, Kestler, and Lewis (2010) conducted a quasi-experimental study with a convenience sample that examined distress ratings and parental ratings of satisfaction for a group of children who received preparation and support from a child life specialist, and a group of children who did not. Twenty-four children who had a laceration repair ages 3-13 were in the study. Seven children received the individualized child life preparation and distraction, while 17 children received the standard care without a child life specialist. Children's distress levels were measured by using the Observation Scale of Behavioral Distress. Child distress was coded using eight indicators of distress in 15-second intervals. Distraction was the only behavior coded for child life specialists.

The results of this study revealed that children who received the child life intervention showed significantly less distress than children who did not receive child life intervention. Parents of patients who received intervention perceived less distress in their own children, and rated their overall healthcare experience significantly better than parents whose children did not receive the child life intervention. Parents were asked to rate their own distress levels; parents whose children received child life interventions reported lower levels of distress compared with parents whose children did not receive the child life interventions (Gursky et al., 2010, p. 220).

CHAPTER 6

THE CURRENT STUDY

The research reported here examined whether child life intervention during procedures is related to lower child distress. The focus was on IV placements, which is a common procedure for hospitalized children. We also examined specific behaviors used by child life specialists in an effort to better understand observed connections between the specific administrations of child life specialists and the effects of these on children's experience of distress. More specifically, three main questions were addressed.

(1) What strategies do child life specialists use during procedures? We do not actually know what strategies child life specialists use during procedures to try to help children's anxiety, or which of these might be most effective in reducing children's distress. My research uses naturalistic observation to provide insight into what interventions child life specialists use during procedures in their efforts to alleviate children's anxiety during procedures. This study will provide needed descriptive data on the strategies that child life specialists use during IV placement.

(2) Is child life intervention related to less child distress during IV placement? Past research has shown that child life programs as a whole alleviate children's anxiety. The present study extends this research by examining one specific role of child life specialists, procedural support. This question examines whether child life intervention is

related to lower levels of overt distress during procedures. I hypothesized that children who received the child life intervention during procedures would have lower distress levels during these procedures than would children who did not receive the child life intervention.

(3) How do specific child life specialist strategies relate to children's distress levels? This question examined how specific techniques used by child life specialists (e.g., distraction, positions of comfort, providing support) are related to children's distress levels.

Past research has examined patients involved in broad, intensive child life programs with a range of interventions of child life specialists. My questions focus on child life support during procedures, which has not been examined in previous research, with the exception of the Gursky et al. study.

CHAPTER 7

METHODS

7.1 Participants

The participants in this study were all receiving treatment at Primary Children's Hospital (PCH). The age range of the participants was 2-20, with the mean being 77.4 months, *SD*=33 months. There were a total of 41 IV placements observed; however, some data were missing because some parents did not complete the demographic questionnaire. There were 16 females (39%) and 25 males (61%) in the study. Parents were present during the procedures in 96% of the cases observed (see *Table 1*).

PCH is a Level I Trauma Center located in Salt Lake City, Utah. It is the main pediatric hospital for Utah, Wyoming, Nevada, Idaho, and Montana. PCH is affiliated with the Department of Pediatrics at the University of Utah School of Medicine. The most complicated pediatric patients in the region are admitted to PCH for care, especially young patients who require acute hospitalization. PCH has 289 beds, treats about 130,000 ambulatory patients, and has over 12,000 patients admitted annually. PCH is owned and operated by Intermountain Healthcare, a nonprofit, local healthcare delivery system providing care to 60% of the Utah population.

The inclusion criteria for participants in our study included the following: 1) The participants were at least 2 years old. This age range was selected in the context of the

larger treatment room study, so that the children would have sufficient cognitive abilities to understand where the procedure was taking place. We did not exclude patients above 2 years old who were getting an IV placed at PCH.

2) The participants and their parents spoke English, to allow for understanding of consent and communication with the researchers.

3) The participants were not on droplet isolation. This is a precaution the hospital puts in place when patients have certain contagious diseases. This eligibility requirement was important in the context of a larger treatment room study.

This study was approved by the Institutional Review Boards at the University of Utah and Primary Children's Hospital.

7.2 Procedure

There are two IV teams at PCH. One team is accompanied by a child life specialist, and one team is not. Children who need IV placements will usually get them done by one of the IV teams. Which IV team administers procedures to which children is a random process; thus, which patients have a child life specialist present for their procedures is also random. Researchers in this study observed IV insertions performed by both IV teams.

When a patient needed an IV placed at PCH, his/her nurse called the IV team. The IV team administrator received all calls for the IV team, and then distributed them to the two IV teams. Researchers stayed with one team during a research shift. When the team researchers were with received a call from the IV team administrator, the researchers went ahead of the IV team to the patient's room. Researchers approached the

patient's parents to obtain parent consent to participate in the study. If the patient was 7 years old or older, written assent from the patient him/herself was also obtained. Of the parents whose children were getting IVs placed and were approached to participate in the study, 79% agreed to participate.

The IV team usually arrived shortly after to place the IV. Researchers then observed the IV insertion and coded the child's behavior. If a child life specialist was present, his/her behavior also was coded. The researchers had clipboards with all of the behaviors in columns, allowing clear space for behaviors to be coded every 15 seconds until the IV was placed. The researchers also had a recording on their phone alerting them of every 15 seconds that they listened to with headphones during the procedure. A child life specialist was present in 24 cases (56%) and not present in the remaining 17 cases (42%)

7.3 Measures

Behaviors of the children receiving an IV and child life specialists (when present) were coded during the procedures observed as part of our larger study.

7.4 Child Behaviors

There were six child behaviors coded in relation to the larger study; however, the only code that is relevant to the present research is the patient's distress level during the procedure. Behaviors were coded every 15 seconds.

7.4.1 Distress level. Researchers coded the child's distress level every 15 seconds on a scale of 0-3. Zero was coded when the child was not distressed at all. One was

coded when the child displayed mild distress. Examples of "mild distress" included tenseness of the body, mild body language showing anger, sadness, or fear. Two was coded when the child expressed moderate distress, such as sniffling, whining, scowling, frowning, or furrowed brows. The child may have shown moderate anger, such as pushing away any physical support. The highest score (3) was coded when the child displayed severe distress. This included high intensity screaming, crying, or flailing. The child may have shown forceful resistance towards physical support from anyone. Any strong negative emotion was coded in this category.

Interrater reliability was established for this study. Five coders were initially trained on the coding scheme using videotapes of adults and children. Videotaped data enabled the coders to pause and discuss the child's distress level and to observe repeatedly. Once trained, coders assessed videotaped data separately, and then resolved discrepancies through discussion. Coders met weekly to prevent drift in coding. The interrater reliability for this category was high, with an interclass correlation .99.

For each participant, ratings for distress level were summed across 15-second episodes coded, then divided by the number of 15-second episodes coded for that participant. This provided the average level of distress for the duration of the observation for each participant.

7.5 Child Life Specialist Behaviors

When a child life specialist was present, his/her strategies were coded every 15 seconds. When planning and preparing for this study, researchers met with child life specialists at PCH to get their input on which child life strategies to code. We ended up

coding five child life strategies.

7.5.1 Explain. Researchers coded "explain" whenever the child life specialist explicitly explained something to the child related to his/her hospitalization or medical care.

7.5.2 Distraction. Researchers coded "distraction" when the child life specialist did anything to try and direct the child's attention away from hospitalization experience. This included asking questions about the child's life, talking with the child about non-hospital/medical topics, playing a game with the child, or playing with a toy with the child.

7.5.3 Provide choices. Researchers coded "provide choices" when the child life specialist gave the child a choice, either about something related to hospitalization/medical care or something unrelated to hospitalization/medical care.

7.5.4 Position of comfort. Positions of comfort are positions that a child can engage in with a child life specialist or a parent where the position is intended to enhance the child's sense of safety and protection. Researchers coded "position of comfort" when the child life specialist initiated or helped a parent initiate a position of comfort with the patient.

7.5.5 Provide support. Researchers coded "provide support" whenever the child life specialist displayed any kind of physical or verbal support to the child. Examples included the child life specialist saying to the patient, "You're doing a good job," or perhaps holding the patient's hand during the procedure.

For each observation including a child life specialist, the total frequency of each child life behavior was divided by the number of 15-second episodes coded for that

observation. This provided a score that represented the percentage of episodes the particular behavior was employed.

Interrater reliability for these behaviors was established on the same videotapes used for the child behaviors. There was strong interrater reliability for these behaviors, with the interclass correlations being .98 (Explain), .99 (Distraction), .83 (Provide Choices), .97 (Provide Support), and .90 (Asynchronous).

Table 1: Sample characteristics of child life intervention and comparison groups

	Intervention (*n*=24)	No Intervention (*n*=17)
Characteristic	Mean (*SD*)	Mean (*SD*)
Child Age	80.77 months (40.53)	88.62 (63.29)
Males	15	10
Females	9	7
Number of Episodes	27.54 (14.62)	33.35 (28.23)
Previous IVs	40.12 (96.57)	37.5 (29.71)

CHAPTER 8

RESULTS

8.1 Data Analysis

The main goal of the data analysis was to address the three main questions of this study: 1) What strategies do child life specialists use during procedures? 2) Is child life intervention related to less child distress during IV placement? and 3) Are specific child life strategies related to children's distress levels during IV insertion?

8.1.1 Preliminary data. The data analysis occurred in stages. First, I examined the association between age and children's distress using a correlation to determine whether age was related to children's distress levels. Child age was significantly associated with children's distress ($r(41) = -.55$, $p=.001$), with younger children likely to show higher levels of distress than older children. Given this significant association, children were grouped by age or age was controlled in subsequent analyses.

In the second stage of analysis, I examined gender differences in children's distress. Specifically, an Analysis of Variance (ANOVA) with child gender as the between-subjects factor and distress as the dependent variable was conducted to examine gender effects. There were no significant gender differences on children's distress ($F(1,39) = 2.025$, $p=.16$, $M = 1.19$, SD 1.07 for girls; $M = .76$, $SD = .84$ for boys).

Since gender was not significantly related to children's distress levels, it was not included in further analyses.

8.1.2 Research Question 1: What strategies do child life specialists use during procedures? For this question, the descriptive statistics of child life strategies during the procedure were examined. These analyses provided descriptive information on what strategies child life specialists used during the procedure, what the most common strategy was, the least common strategy, etc. (see *Figure 1*).

Distraction was the most common child life strategy. Distraction was used in 100% of the IV placements, and most children received distraction in at least 65% of the episodes (or the majority of the time the IV was being placed).

Explanation was the second most common strategy used. Ninety-one percent of the children received explanation. Eighty-six percent of the children received support during their IV placement, 60% of the children received choices, and 9% of children received positions of comfort.

8.1.3 Research Question 2: Is child life intervention related to less child distress during procedures? My central analyses determined whether child life intervention was related to lower levels of child distress during procedures. First, following Gursky's research method, and to account for age differences in the effectiveness of child life intervention, I split the participants into two groups (Gursky, Kestler, & Lewis, 2010). The first group had participants ages 2-7, $n = 24$. The second group had the remaining participants, ages 8-20, $n = 17$. I examined children's distress as the dependent variable in an ANOVA separately for each age group, as per Gursky's approach.

In the younger group, children who received child life intervention (M = 1.18, SD = .86) showed lower levels of distress than children who did not receive child life intervention (M=1.87, SD = .94); $F(1,19) = 2.94$, p=.05. That is, children who were 7 or younger and received child life intervention showed less overt distress during IV placement than children of the same age group without child life intervention. In the older group, children who received child life intervention (M=.48, SD=.63) did not have differing distress levels from the children who did not receive child life intervention (M=.13, SD=.20); $F(1,11) = .894$, p=.18 (*see Figure 2*).

8.1.4 Research Question 3: Are specific child life specialist strategies related to children's distress levels? This question was evaluated using a correlation between child distress and child life behaviors. The analyses were conducted separately for the two age groups, following Gursky's research. Child life support was significantly related to more child distress in the group with the older children ($r(35) = .48$, p= .043). None of the remaining child life behaviors were significantly related to child distress (*see Table 2*).

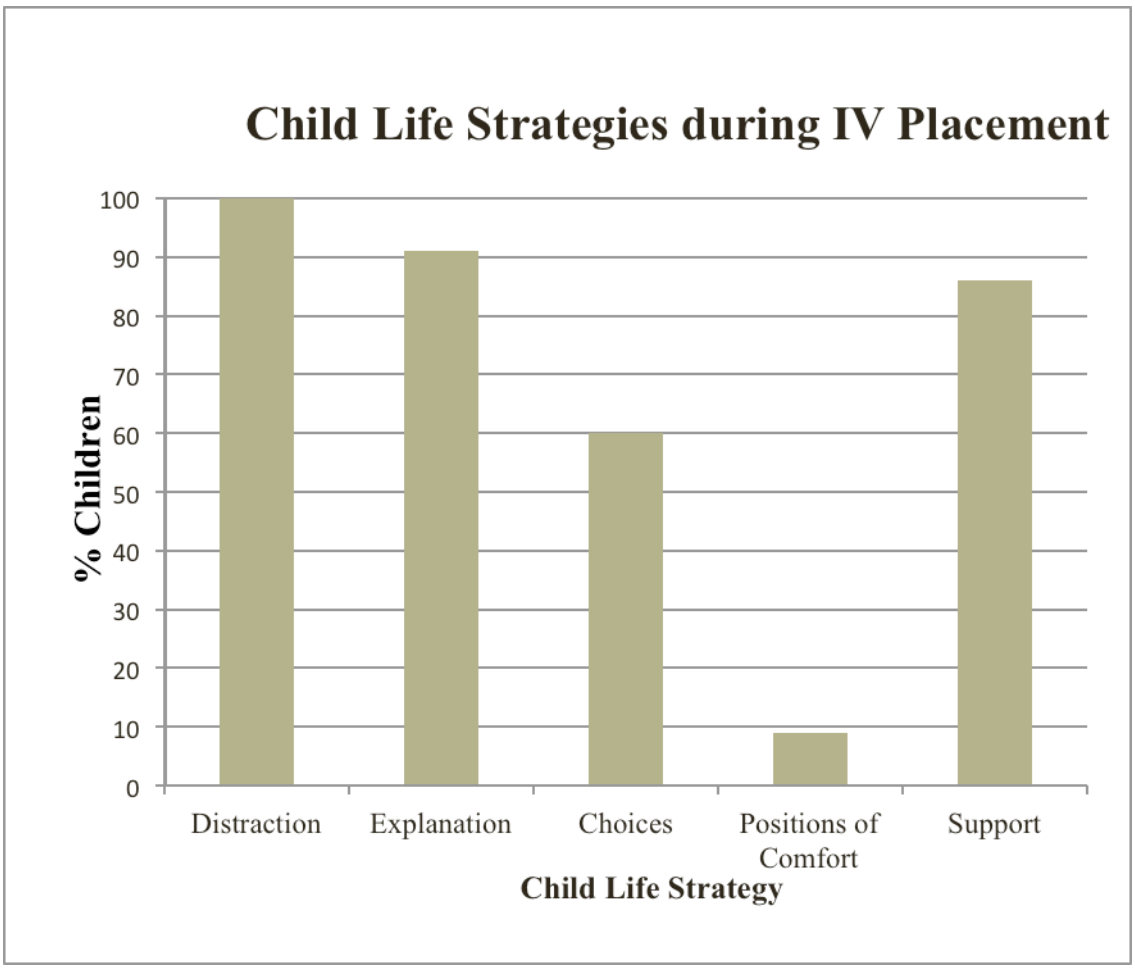

Figure 1: Child Life Strategies during IV Placement

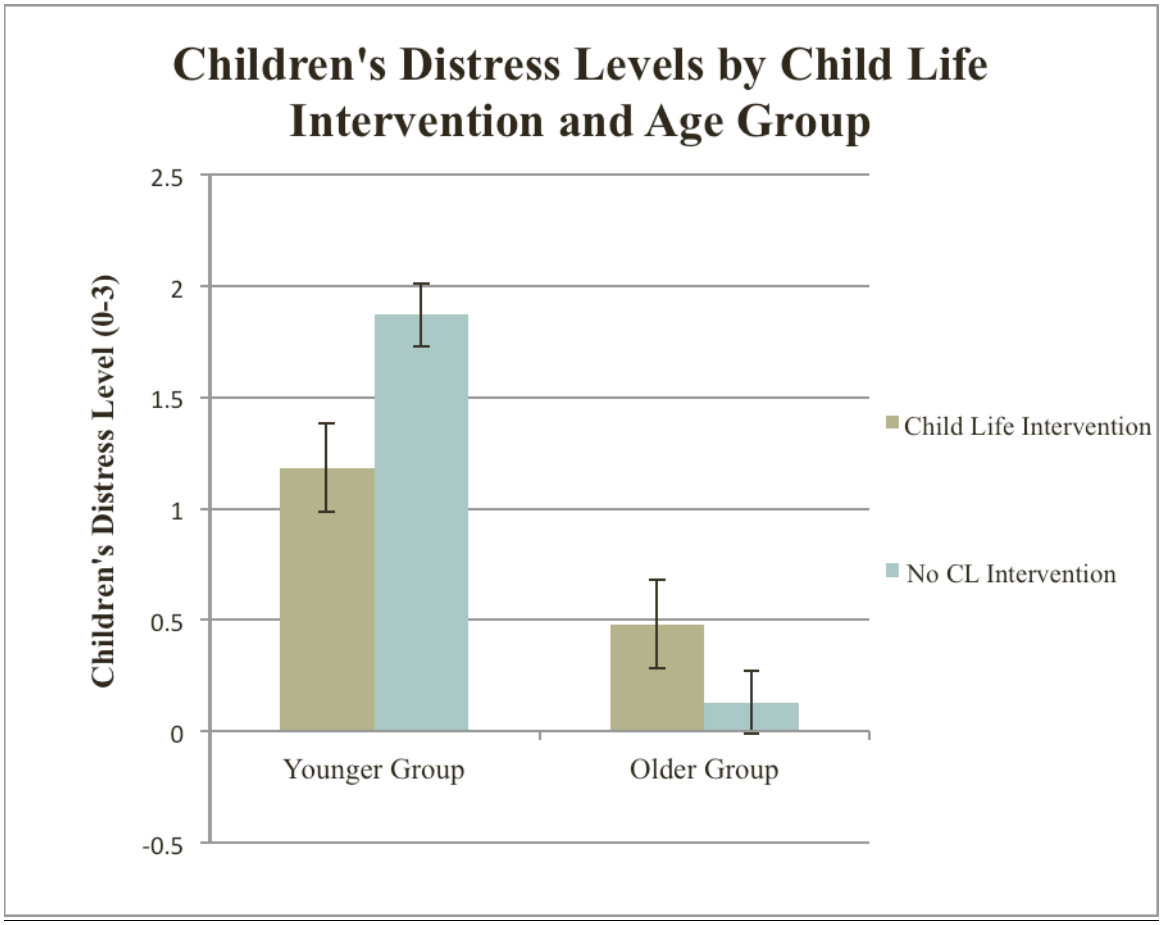

Figure 2: Children's Distress Levels by Child Life Intervention and Age Group

Table 2: Correlations between child distress and child life intervention strategies

	Younger Group	Older Group
Distraction:	-.34*	.27
Explain:	.05	.35
Choices:	-.06	.10
Position of Comfort:	-.25	-----
Support:	-.12	.46**

*$p<.10$ **$p<.05$

CHAPTER 9

DISCUSSION

Child life is a relatively new and growing field in healthcare. It is important to document the role of child life in the hospital setting to validate the profession and help it continue to grow within the healthcare field. Research on the influences of child life on children's distress levels is so important because it can show the ways in which child life specialists impact children's experiences during hospitalization.

Researchers observed child life specialists using many techniques to try to reduce children's distress. All patients who had an IV placed had a child life specialist who was very attentive to their needs and emotions during the IV placement. This study showed that distraction was the most common child life strategy used in both the younger and older groups. Every child in the study received some distraction during his/her IV placement, which is important because previous research has shown distraction to be an effective strategy to cope with distress (Gursky, Kestler, Lewis 2010; Thompson, 2009). Distraction is a good strategy for child life specialists to use because it can be used for patients of all ages to help alleviate distress.

Although distraction was not associated with distress levels in our sample, it could be that the present study may not have had the power to detect significant associations between distraction and distress. Explanation was also a common strategy

in this study. This is important to note because a main goal of child life specialists is to make sure patients and families feel informed about and prepared for medical procedures. Positions of comfort was used infrequently. This may be explained by positions of comfort being a strategy geared for younger children. Furthermore, this strategy may have been difficult to implement given the fast-paced situation of the IV team. Because there was often a list of patients who needed IVs placed and because the child life specialists arrived to the patient's room at the same time as the IV team, there was not sufficient time for the child life specialist to initiate a position of comfort before the IV placement started. In the Gursky study, child life specialists were given 15 minutes of preparation time with each patient before the procedure was done. This is a better model of effectively using child life specialists. Perhaps positions of comfort would have been used more if the child life specialists had more time to prepare the patients and their families for the IV placements.

The role of child life specialists should be prioritized in the healthcare setting so they can adequately attend to children's developmental and emotional needs during hospitalization. In this study, child life specialists faced some challenges in the hospital setting, such as not having adequate time to prepare patients before the IV placement was done. Instead, child life specialists entered patients' rooms at the same time as the IV team, and immediately started assessing, preparing, and explaining to the child what was going to happen. Ideally, this would be done before the IV team entered the room to protect the time of the IV team and to enable preparation of the child without the presence of the IV team. Past research indicates that child life specialists are important but have low power in the healthcare setting (Cole, Diener, Wright, & Gaynard, 2001).

In this study, observations demonstrated that the IV often did not wait for the child life specialist to prepare the patient. This could be due to lack of hospital protocols that would allow the child life specialist to have more time to prepare the child. It is important that healthcare professionals be educated on the importance of child life intervention, and that hospital protocols allow child life specialists to have enough time so that they can be utilized adequately in the hospital setting. This could lead to more pediatric patients being adequately treated physically, emotionally, and developmentally.

This study shows that during IV insertions for younger children, child life intervention was related to lower levels of distress. This is likely due to the fact that younger children tended to be more distressed overall than older children, and likely have fewer coping skills suited to deal with stressful medical procedures. This finding is consistent with what we know about younger children and hospitals, that they generally have much more distress and are more affected by hospitalization. One study shows that children ages 6 months to 4 years may be most vulnerable for hospitalization (Mabe, Treiber, & Riley 1991). Our results suggest that child life intervention during procedures may be especially important for younger children, as they typically have more overt distress. Given limited resources, child life specialists might choose to prioritize patients by child age if they cannot support all patients. That younger children showed less overt distress during IV placement when child life specialists were present indicates that child life specialists play an important role in alleviating children's distress during this common medical procedure. At the hospital under study, only one of the two IV teams had a child life specialist supporting the children receiving IVs. The research did not show that child life intervention was significantly related to lower distress levels in the

older group. There may have been a floor effect for distress in older children, in that they showed very low overall levels of overt distress. The older children in this study may have been feeling some distress during the IV placement, but not showing distress behavior in ways that we were coding (i.e., older children may be less likely to cry, but may experience distress in ways that are more difficult to observe). Future research should include less obvious distress cues, so that older children's distress can be recorded accurately, perhaps through self-report and/or physiologically based measures of distress. It may be that the low overall levels of overt distress in the older patients made it difficult to detect distress differences when child life specialists were present. However, other measures of distress that better detect distress in older children, such as self-report, may be more sensitive to differences.

The only child life specialist strategy significantly related to child distress was child life support. Child life support was associated with greater distress for older children. It could be that by showing support, child life specialists make it acceptable for the children to express the distress they may be feeling internally. Without that support, older patients may feel that they have to put on a brave face and dismiss the distress they are feeling. Older children have the ability to suppress the emotions they are experiencing, whereas younger children do not have these emotion regulation skills. Therefore, support may demonstrate to the older patients that it is appropriate and healthy to express some distress. Other child life strategies may have been significant for both the age groups if we had a bigger sample size, and therefore more power. Research in child life is difficult because child life specialists focus on the long-term mental and psychosocial health of children. Supporting a child during a painful procedure may allow

the child to show his/her anxiety or distress more at first. However, in the long run, children's anxiety may actually decrease because they have learned from the child life specialist how to feel their emotions and cope in healthy ways. The present study only examined immediate levels of distress; a longitudinal study would have been needed to detect long-term differences between those patients served by child life specialists and those who did not receive child life intervention.

A strength of this study is that this study addresses a major gap in the little research on child life intervention and child life specialists in general. This study is part of the small but growing body of research regarding child life. It is important that more research on child life specialists is conducted to document the role of child life specialists as members of the healthcare team. More research will also educate healthcare professionals so that they can be aware of the benefits of child life intervention, and perhaps greater policy can be influenced in the healthcare system so that hospital routines can accommodate the time it takes for proper child life intervention.

Another strength of this study is that it is meaningful for Primary Children's Hospital and other pediatric hospitals that have child life specialists. The results of this study highlight the benefits of child life intervention for younger children in terms of overt distress, and also highlight the need for hospitals and healthcare professionals to be accommodating to child life specialists so that child life specialists can adequately care for patients. Hospitals and healthcare professionals need to be more educated on the benefits of mental and emotional health for children; greater awareness and understanding will in turn lead to hospitals better utilizing child life specialists

A weakness of this study is that there is a relatively small sample size, which gives less power to detect significant results. Further research is needed with larger sample sizes to determine how specific child life strategies are related to child distress. Another weakness of the study is that all the data were collected at one hospital, meaning researchers may not have captured the full range of child life behaviors that child life specialists at other hospitals use to try and alleviate distress in children during procedures. Future research could sample more patients at different hospitals longitudinally to capture the influence of child life intervention over a child's development.

CHAPTER 10

CONCLUSION

Child life specialists used many strategies to try to help alleviate distress in children during procedures. Child life specialists were very active with the patients during procedures, explaining what was happening and distracting the patients. They also provided support during the IV placements. Notably, asynchronous behavior was not observed, indicating that child life specialists were attuned to the children's emotional needs. The child life specialists played an active role during the IV placements as they explained who they were, that they were there to help make things easier, and often introduced the IV team as well; these made the IV placements go smoothly.

This research also showed that child life intervention was related to lower distress levels in younger children during procedures. It is especially important for younger children to receive child life intervention during procedures. Child life specialists are important in the hospital setting, as they are trained to specifically assess patients emotionally and developmentally. Their unique and extensive training is a vital part of a pediatric patient's healthcare experience. Clear communication among healthcare members about the importance of child life intervention can help child life specialists be utilized better in the hospital setting. Another way that child life specialists can be better utilized is with more research. More research about child life intervention can help

validate child life specialists in the healthcare community. Child life specialists are important members of the healthcare team. With more research about child life and more education of healthcare professionals, child life specialists can be given more time to work with patients, which will lower distress in pediatric patients.

REFERENCES

American Academy of Pediatrics. (2000). Child Life Services and Committee on Hospital Care. *Pediatrics, 106*(5), 1757-1763

Bandstra, N. F., Skinner, L., LeBlanc, C., Chambers, C.T., Hollon, E. C., Brennan, D., & Beaver, C. (2008). The role of child life in pediatric pain management: A survey of child life specialists. *The Journal of Pain, 9*(4), 320-329

Bossert, E. (1994). Factors influencing the coping of hospitalized school-age children. *Journal of Pediatric Nursing, 9*(5), 299-306.

Brewer, S., Gleditsch, S. L., Syblik,D., Tietjens, M. E., & Vacik, H.W. (2006). Pediatric anxiety: Child life intervention in day surgery. *Journal of Pediatric Nursing*, *21*(1), 13-22

Carson, D. K., Jenkins, J., & Stout, C. B. (1985). Assessing child life programs: Study model with a small number of subjects. *Children's Health Care, 14*, 123-125.

Christian, B., & Thomas, D. O. (1998). A child life program in one pediatric emergency department. *Journal of Emergency Nursing, 24*, 359-361.

Cohen, L. L. (2008). Behavioral approaches to anxiety and pain management for pediatric venous access. *Pediatrics*, *122*(3), 134-139

Cole, W**.,** Diener, M**.,** Wright, C., & Gaynard, L. (2001). Health care professionals' perceptions of child life specialists. *Children's Health Care, 30*, 1-15.

Gursky, B., Kestler, L. P., & Lewis, M. (2010). Psychosocial intervention on procedure-related distress in children being treated for laceration repair. *Journal of Developmental and Behavioral Pediatrics, 31*(3), 217-222.

Hart, D., Bossert, E. (1994). Self-reported fears of hospitalized school-age children. *Journal of Pediatric Nursing, 9*(2), 83-90.

Hawthorn, P. J. (1974). Nurse - I want my mummy! *Royal College of Nursing and National Council of Nurses of the United Kingdom, 1*(3), 15-221

Healthcare Cost and Utilization Project [HCUP]. (2011). *Hospital Stays for Children, 2009*. Retrieved August 18, 2014 from http://www.hcup-us.ahrq.gov/reports/statbriefs/sb118.jsp

Holloway, D., & Wallinga, C. R. (1990). Burnout in child life specialists: The relation of role stress. *Journal of Child Health Care, 18*(1), 10-18.

Jaaniste T., Hayes B., & Von Bayer C. L. (2007). Providing children with information about forthcoming medical procedure: A review and synthesis. *Clinical Psychology Science Practice, 14*(2), 124-143

Koller, D. (2008). Child life assessment: Variables associated with a child's ability to cope with hospitalization. *Child Life Council Evidence-Based Practice Statement* 1-13.

Mabe, P. Alex, Treiber, Frank A., Riley, & William T. (1991). Examining emotional distress during pediatric hospitalization for school-aged children. *Children's Health Care, 20*(3), 162-169.

Munn, E., Barber, & C. E., Fritz, J. J. (1996). Factors affecting the professional well-being of child life specialists. *Children's Health Care, 25*(2), 71-91.

Northam, E. (1997). Psychosocial impact of chronic illness in children. *Paediatric Child Health*, *33*(5), 369-372.

Rennick, J.E., Johnston, C.C., Dougherty, G., Platt, R., & Ritchie, J.A. (2002). Children's psychological responses after critical illness and exposure to invasive technology. *Developmental and Behavioral Pediatrics, 23*(3),133-144.

Sheldon, L. (1997). Hospitalising children: A review of the effects. *Nursing Standard (Royal College of Nursing), 12*(1), 44-47

Shonkoff, J. P., Duncan, G. J., Yoshikawa, H., Fisher, P. A., Guyer, B., & Magnuson, K. (2010). The foundations of lifelong health are built in early childhood. *National Scientific Council on the Developing Child,* 2-29

Small, L., & Melnyk, B.M. (2006). Early predictors of post-hospital adjustment problems in critically ill young children. *Research in Nursing & Health, 29*, 622-635

Spitz, R. (1945). Hospitalism: An inquiry into the genesis of psychiatric conditions in early childhood. *Psychoanalytic Study of the Child*, *1*, 53-74.

Tiedeman, M.E., & Clatworthy, S. (1990). Anxiety responses of 5- to 11-year-old children during and after hospitalization. *Journal of Pediatric Nursing, 5*(5), 334-343.

Thompson, R. H. (1989). Child life programs in pediatric settings. *Infant Young Children, 2*(1),75-82.

Thompson, R. H. (2009). *The handbook of child life – A guide for pediatric psychosocial care.* Springfield, IL: Charles C. Thomas Publisher.

Wolfer, J., Gaynard, L., Goldberger, J., Landley, L. N., & Thompson, R. (1988). An experimental evaluation of a model child life program. *Child Healthcare Journal*, *16*(4), 244-254

Zurlinden, J. K. (1985). Minimizing the impact of hospitalization for children and their families. *The American Journal of Maternal/Child Nursing*, *10*(3), 178-182.