

THE EFFECTS OF IV PREPARATION ON CHILDREN'S PAIN  
PERCEPTION AND COPING OUTCOMES

by

Emily R. Bellino

A thesis submitted to the faculty of  
The University of North Carolina at Charlotte  
in partial fulfillment of the requirements  
for the degree of Master of Education in  
Child and Family Studies

Charlotte

2018

Approved by:

---

Dr. JaneDiane Smith

---

Dr. Cynthia Baughan

---

Dr. Kristie Opiola



## ABSTRACT

EMILY R. BELLINO. The Effects of IV Preparation on Children's Pain Perception and Coping Outcomes. (Under the direction of DR. JANEDIANE SMITH)

The purpose of this study was to examine the protocol for intravenous (IV) preparations in the pediatric population. Specifically, the study collected survey data on IV preparations performed in healthcare settings by certified child life specialists (CCLSs). Participants were asked to complete a survey about IV preparations they performed. The surveys were completed by the CCLS after IV preparations occurred. The survey sought to garner more information on the practice of IV preparation and how these preparations affected children's perception of pain and coping outcomes. The survey was conducted using the Qualtrics system (Qualtrics, 2018). The participants completed the survey regarding patients they conducted an IV preparation for, as part of their normal responsibilities. Eligible patients did include those with disabilities, so more information could be provided on the outcomes of working with this population and what adaptations to preparations need to occur to accommodate all children. The results of the study indicated that CCLSs use a variety of approaches to IV preparation and the majority of specialists provide preparatory services to children with disabilities. Implications for further research include obtaining the same type of information on other common pediatric procedures as well as obtaining information on CCLSs previous educational experiences with children with disabilities.

## TABLE OF CONTENTS

LIST OF TABLES	vi
CHAPTER 1: INTRODUCTION	1
1.1 Statement of the Problem	4
1.2 Research Questions	7
CHAPTER 2: REVIEW OF THE LITERATURE	9
2.1 Theoretical Background	10
2.2 Complexity of Pain Management	12
2.3 Efficacy of Procedural Preparations	13
2.4 Procedural Preparations for Children with Disabilities	15
2.5 Summary	18
CHAPTER 3: METHODOLOGY	19
3.1 Rationale	19
3.2 Participants and Setting	20
3.3 Piloting of the Instrument	21
3.4 Procedure	22
3.5 Data Collection	23
3.6 Instruments	24
3.7 Data Analysis	24
CHAPTER 4: RESULTS	25
4.1 Research Question 1	25
4.2 Research Question 2	27
4.3 Research Question 3	28

CHAPTER 5: DISCUSSION	30
5.1 Limitations to the Study	32
5.2 Implications for Further Research	33
REFERENCES	36
APPENDIX A: RECRUITMENT EMAIL	39
APPENDIX B: INFORMED CONSENT	40
APPENDIX C: SURVEY	41

## LIST OF TABLES

TABLE 1: Institutional Practices	25
TABLE 2: Approaches to Preparation	26

## CHAPTER 1: INTRODUCTION

According to current research, pain in children is poorly understood and the quality of pain management specifically for hospitalized children remains suboptimal (Voepel-Lewis, Piscotty, Annis, & Kalisch, 2012). In an article by Voepel-Lewis and colleagues (2012), pediatric pain is viewed as an entire social transaction between the patients and their caregivers, or nurses or other hospital staff, who are treating them such as a physician, child life specialist, or technician. According to the authors, there are tools to accurately assess pain but there is a mismatch between the commitment to improving pain, implementation of steps to improve pain, and actual patient outcomes (Voepel-Lewis et al., 2012). In other words, we can assess pain but we may not be acting proactively to help manage the pain such as implementing procedural preparations consistently. This research provides information for individuals involved in healthcare so they are aware of how to accurately treat patients' pain and what changes need to be made in order to deliver the best care to their patients.

Other issues with properly assessing and treating pediatric pain are cognitive theory and developmental components. According to Jaaniste, Hayes, and von Baeyer (2007), the main theories that underline information provision for medical procedures, which will be a main component of this study, are the script and schema theories. The script and schema theories are regarded as avenues for understanding the pain experience in children (Jaaniste et al., 2007). Schemata are the cognitive mechanisms by which human beings understand the world. They are mental representations of our expectations of a situation (Bartlett, 1932). Script Theory came about much later; Silvan Tomkins stated scripts are the rules by which we predict, interpret, respond, and control our

surroundings (Tomkins, 1978). These theories are very similar to, and play off of Piaget's theory of cognitive development in children (Piaget, 1936). The researchers who conducted this study believe schemata and scripts can be used in the provision of preparatory information to ensure patients are creating an accurate representation of the procedure in their minds, thereby reducing the negative perceptions they have about their procedure (Jaaniste et al., 2007). These theories provided the evidence for procedural preparations and their ability to influence an individual's perception of pain. According to Thompson (2009), procedural preparation includes providing support during all phases of a procedure starting at introduction of the procedure and supporting the child until the procedure is complete. For the purposes of this paper, the term procedural preparation encompasses the entire process of preparation and support throughout the entire procedure.

Another issue regarding pediatric pain is the difficulty of accurately measuring children's pain. Currently published pain scales claim validity and reliability in their ability to measure children's pain, whether it be from a parent's perspective or a self-evaluation directly from the child. For example, Miró, Huguet, and Jensen (2014) reviewed the pediatric version of the Survey of Pain Attitudes scale (Peds-SOPA) and found pain attitudes are important components of treating pain in the pediatric population. However, a limitation of their study was participants did not include children with any disability besides chronic pain. Their implications for future research suggested including children with an array of disabilities (Miró et al., 2014). This research supported the difficulty in assessing pain in the pediatric population and introduced the issue of children with disabilities being excluded from research.



Stemming from this discontinuity between accurately assessing and treating pediatric pain, are issues of implementing procedural preparation programs effectively and providing preparation to children with disabilities. There is a great deal of research on the efficacy of procedural preparation in the typically developing population, related to reducing the amount of pain experienced by children during various medical procedures (Brown, David, Cuttle, Kimble, Rodger, & Higashi, 2015; Cox, Ortega, Julio, and Martin, 2016; DeMore, Cataldo, Tierney, & Slifer, 2009). Procedural preparation has many benefits, including offsetting delayed medical effects of medical stressors (e.g., pain sensitivity, immune functioning), more complete understanding of a procedure and diagnosis, and reduced anxiety which contributes to improved coping (Cohen & MacLaren, 2007). However, there are numerous barriers to implementing these programs into everyday practice.

Cohen and MacLaren (2007) reviewed the current literature and listed several barriers that affect the way procedural preparations are implemented into daily practice. They discussed how individuals in healthcare incorrectly believe the cost is too great to utilize these preparations. However, the data are being misconstrued. The common belief is that there is only time and money for procedures that are considered “medically necessary” because of the harsh economic climate of healthcare settings in general. Thus, procedural preparations may not be included as part of routine care. However, researchers counter this argument that preparations could be deemed medically necessary for all because of the potential negative outcomes (e.g., incomplete procedures, patient fear, high pain levels) for patients who are in pain who are not being dealt with properly (Cohen & MacLaren, 2007). Grissom and colleagues (2015) included a secondary

objective that analyzed the cost effectiveness of specific procedural preparation against the cost of sedation. They found child life services are a vital component of cost-effective healthcare because of CCLSs unique position to provide procedural preparation. The researchers directly compared the overall cost of a procedure with the cost of a child life specialist providing preparation against a procedure that had to include sedation and no preparation. The procedure without preparation accrued a higher cost due to the need for sedation (Grissom, Boles, Bailey, Cantrell, Kennedy, Sykes, Mandrell and Mandrell, 2015).

Another major barrier mentioned regarding procedural preparation is time; whether it is the amount of time it takes to carry out an intervention (e.g., twenty extra minutes), or a sufficient amount of time prior to the procedure being implemented (e.g., pushing back procedure to include preparation). To overcome this barrier, some procedural preparations are now being done in patients' homes to cut down on the time used during the hospital stay which also directly affects costs (Cohen & MacLaren, 2007). Although these preparations have been found to result in positive outcomes (e.g., holding still, less crying) for children experiencing various medical procedures, time is still a major concern regarding the pediatric population who are receiving and benefiting from the preparations.

### ***Statement of the Problem 1.1***

The majority of research identified for this project related to preparing children for procedures in the healthcare setting explicitly focuses on typically developing children. The research described previously by Miró and colleagues (2014) excluded all children with any cognitive delay. Numerous other articles state the same limitation or

implication for further study (Boerner, Gillespie, McLaughlin, Kuttner, Chambers, 2014; Rothman, Gonen, Novack, & Shelef, 2016). However, there are a few examples of research where specific procedural preparations were conducted with children who had a specific disability or were within a predetermined group of diagnoses. For example, a study done by DeMore and colleagues (2009) used a training program that included a behavioral component. They slowly introduced the process of an overnight EEG to children with a very specific diagnosis, Smith-Lemli-Optiz syndrome (SLOS), to see whether they were able to successfully complete the EEG with children who had a diagnosis of SLOS. The program was deemed effective since the majority of the children involved were able to successfully complete the EEG procedure. Implications from the study suggest the results achieved are generalizable to pediatric populations with a broader range of disabilities (DeMore et al., 2009). Such studies provide evidence for the utilizing procedural preparations for children with disabilities for various medical procedures.

Another study by Crawford and Raven (2002) used Mickey and Minnie Mouse dolls that were adapted with gastrostomy buttons so patients could manipulate medical equipment. The researchers chose these dolls because they are not affiliated with any particular race or culture and are well-known by the pediatric population. The preparation involved a home visit with the doll to familiarize the family with how the gastrostomy tube (g-tube) functions. The dolls gave parents an opportunity to practice hooking up the feeding tube and other tasks they will perform after their child has a gastrostomy tube placed in the child's abdomen. All information was explained to the child (e.g., components of the g-tube, how it works, what the procedure would be like) at their

developmental and cognitive levels. The information was intended to prepare the child for the procedure and to give them a better understanding of what having a g-tube would look like. Once the instruction was complete, the families were given an informational booklet. For a particular patient, this process started 12 weeks before her surgery was performed, and a hospital staff member visited the family at home once a week. Crawford and Raven's study demonstrated the possibility of successfully preparing children with disabilities for a g-tube procedure and showed a child's disability should not be a barrier to effective procedure preparation. Additionally, procedural preparation was beneficial with respect to increasing effective coping, reducing fear, and allowed patients to express fear (Crawford & Raven, 2002). For the purposes of the current study, a specific procedure that is common in the pediatric population was studied.

The primary purpose of this study was to describe various ways CCLSs prepare children for IV placement. The study examined the protocol for IV preparations that are presently used by certified child life specialists (CCLSs) and how these preparations related to the patient's perception of pain and positive coping outcomes. The preparations were conducted in various units (e.g., inpatient, outpatient, acute or planned procedure settings) and included all children during the preparation process. Additionally, data were collected to describe modifications needed to ensure equal care was given to children with varying developmental and cognitive levels.

This study examined the variety of approaches for IV preparations typically used by certified child life specialists and how these various preparations effected children's perception of pain and coping outcomes. Specifically, the researcher sought to discover if the specialist saw a difference in anxiety and fear following the preparation and if

children were able to cope effectively to complete the procedure. Participants included child life specialists who performed IV preparations in accordance with their own (a) routine(s) (e.g., all children get IV preparations, only children of a certain age receive IV preparation), and (b) assessment (e.g., based on prior familiarity with the child, medical team request, family request, observed need). In addition, the researcher explored what, if any, modifications occurred for the preparations so they were effective for reducing pain in all children, including those with disabilities. Srouji, Ratnapalan, and Schneeweiss (2010), stated “there is a need for more research to illuminate optimal pain management and strategies that take these special needs into consideration to improve the treatment of pain in children.” This study included children with any type of delay or disability who have received child life services at some point in their lives.

### ***1.2 Research Questions***

The aim of this study was to examine the variety of approaches for IV preparations typically used by CCLSs and how these various preparations effected children’s perceptions of pain and coping outcomes. The survey gathered detailed information regarding the preparation process (e.g., materials used, reason for choosing preparations), typical protocol for IV preparation on the specialists’ unit, decisions to use certain materials and why, child’s developmental level, accommodations that were made for a child with a disability, and implementation of measures to assess pain and coping (e.g., pre- and posttest pain scales). Through survey research, this study answered the following questions: 1) What approaches to IV preparations are used by Certified Child Life Specialists? 2) What changes in pain perception and/or coping are observed by the

child life specialists as a result of IV preparation? 3) How are children with disabilities prepared for IV preparations?

## CHAPTER 2: REVIEW OF THE LITERATURE

To identify relevant literature on the efficacy of procedure preparations in the pediatric population including those with disabilities, the following research databases were utilized: Academic Search Complete, PsycINFO, PubMed, Medline, and ScienceDirect. The terms, *procedural preparation, procedure preparation, pediatrics, pain, pain perception, theories on pain, pain theory, script theory, schema theory, special needs children, children with disabilities, coping strategies, pain attitudes, children, and coping outcomes* were used in the electronic search.

The sheer volume of procedures that the pediatric population undergoes in the healthcare setting in one day is extensive. On top of the overwhelming experience of being in the hospital, children are poked and prodded numerous times, have constant disruptions to their daily routine and sleep, and are taken from their rooms for other routine medical procedures. During their first few hours in a medical setting, children may not have an understanding of what is going on around them or why these things are happening to them. They are still at a point in their lives where their brains are continuing to develop and new concepts and skill sets are being formed. This is especially true during the process of adapting and coping to the new sights, sounds, and experiences encountered in a hospital or emergency room. In order to understand how children comprehend pain, it is necessary to return to the theoretical framework of how children are able to form an understanding of their world.

## ***2.1 Theoretical Background***

### *Script Theory*

Script theory (Tomkins, 1978) provides a framework for understanding the way that human beings perceive pain. According to Tomkins, our response to the stimuli surrounding us, and how we form theories about the way the world works are the mechanisms responsible for forming scripts. These scripts are responsible for helping human beings move through life; toward events that are rewarding and away from events that result in a “punishing affect.” In general, scripts resemble a set of rules we live by, but they are always changing and evolving as we experience new things (Tomkins, 1978). Human beings create “scenes” or scripts of what we believe an experience will be like; that is how a judgement can be made about an experience that could be potentially painful and our natural inclination is to stray from or resist experiencing the event. For example, many people have a fear of needles. They know needles are associated with a painful event and even though they know that a needle procedure can provide a benefit, such as with getting a flu vaccination, they avoid the experience altogether because they recognize the pain that may be associated with the injection.

### *Schema Theory*

Another common theory the scientific world uses to understand pain is schema theory founded by F. C. Bartlett (1932). Bartlett believed schemata are developed by an active organization of former responses. Eventually, all the responses will assume the form of accepted conventional representations. Bartlett believed the representations dictate the way a person reacts to a recurring situation (Bartlett, 1932). In regard to pain, a human being’s mental representation dictates one’s reaction to the pain experience. To



continue with the flu vaccination example, people who do choose to receive the vaccination regardless of their fear, may have a preconceived idea of how this injection will feel. The idea they envision about the pain potential is an example of a schema and one's schema will direct the way a person reacts to the experience.

### *Piaget's Theory of Cognitive Development*

The authors of the theories previously mentioned were able to explain the method human beings use to organize stimuli surrounding them and how one forms judgements and opinions about the stimuli. A more widely-known theory, based specifically on children's cognitive development is Jean Piaget's cognitive theory (1936). Piaget focused on how children create a mental model of the world. Piaget identified stages in which children display their cognitive. Piaget used the term schemata as well to describe the mental representations children use to understand the world but he emphasized that children use schemata as a building block for intelligent behavior as well as a way of organizing knowledge (Piaget, 1936).

One could combine these theories to create a broad understanding of how children take in stimuli from their surroundings to create a personal representation of a specific concept. Utilizing the flu vaccination example, a script of a certain situation can determine whether or not an individual partakes in receiving a flu vaccination and their schema determines their reaction to the vaccination. These concepts combine to form an entire account of how a situation may occur. A person's schema is responsible for one's reaction, whether that be crying, looking away, or anxiously fidgeting during the procedure. These theories can be applied to this study to understand how a script or schema is formed by a child, and the child's idea about pain, in part, determines how one

will react to the painful stimulus. In other words, if children have a preconceived idea about how an IV injection will feel without having any knowledge besides the fact that there will be a needle, their script and schema may cause a problem for them by forcing one to think the procedure may feel a certain way. Knowing that experiences are mental representations, allows the possibility for schema or scripts to be altered or influenced.

Ideas about certain concepts are malleable and children are impressionable.

Implementing IV preparations and providing procedural support enables CCLSs to potentially make procedural representations more accurate for children. In this study, the information obtained from the surveys provided insight into how IV preparations are being implemented and the outcomes associated with the procedural preparations. The IV preparation may have acted as an influence on the child's idea of how painful the IV was. In addition to realizing that pain is a complex entity in and of itself, it is important to realize that managing pain is just as difficult.

## ***2.2 Complexity of Pain Management***

The scientific world has spent a great deal of time trying to understand and interpret pain. The challenges in understanding the process of pain proves to be an even more daunting task in the pediatric population. Voepel-Lewis and colleagues (2012) delved into this issue of accurately assessing pain in pediatrics in their review of the "Pain Assessment as a Social Transaction" (PAST) model. According to research, pain is seen as a very personal and individual experience. There are numerous factors that affect a child's expression of pain such as psychological, social, situational, and intrinsic. The PAST model described pain on a continuum that ranges from suppression to exaggeration of pain. The researchers believed that with some adaptations, the PAST model can

accurately be applied with the pediatric population if hospital staff look at the patient holistically (Voepel-Lewis et al., 2012). Clearly, the obstacles of recognizing and treating pain in the pediatric population are recognized and further investigation is needed to discover the best ways to deal with the challenge of understanding and treating pain. Srouji and colleagues (2010) outlined the most effective tools for correctly assessing pediatric pain for various age groups. The authors stated self-report measures are the most valid tools to accurately assess children's pain (Srouji et al., 2010). However, this statement comes with a limitation; children with developmental disabilities may have a diminished capacity to describe or communicate their pain to another person. Srouji and colleagues (2010) explained when communication is not possible, such as with younger children, behavioral and physiological measures are used to supplement the lack of communication. Behavioral measures (e.g., crying, facial expressions, body postures and/or movements) are frequently used with the youngest populations in order to measure pain.

Physiological measures are also used to measure pain. Heart rate and blood pressure, respiration, oxygen saturation and palmer sweating are physiological symptoms of pain. The authors stated there is a need to carefully consider children's developmental age when assessing pain, such as young children and children with developmental disabilities (Srouji et al., 2010). Realizing that pain is difficult to treat in all of the pediatric population, it is important to know that there is research available that discusses preparations for procedures. The goals of these preparations are to decrease pain and create positive outcomes in the pediatric population following these procedures.

### ***2.3 Efficacy of Procedural Preparations***

Studies show different procedural preparations are efficacious in reducing pain in the pediatric population. The preparations are as varied as the procedures. For example, Nguyen, Nilsson, Hellström, and Bengtson (2010) explored the efficacy of “music medicine” in reducing pain in school aged children diagnosed with leukemia and who were scheduled for a lumbar puncture. In their study, “music medicine” was described as children wearing headphones and playing music of their choice during the procedure. Their research involved a randomized clinical trial wherein the experimental group was instructed to wear headphones and listen to music of their choosing during their procedure. The control group was instructed to only wear the headphones but had no music playing. Results of the study suggested that music effectively distracted the patients from the procedure and helped the children endure the pain and anxiety associated with the lumbar puncture. The researchers believed that this outcome was possible because the children equated the music that they liked to previous pleasant situations. The feeling of familiarity and sense of control might have eased their minds and made for a positive outcome (Nguyen et al., 2010). The hope that these procedure preparations in general will provide positive outcomes across all procedures.

The current study focused specifically on children undergoing IV placement. IV-line placement is a common procedure in the pediatric population, therefore the researcher focused specifically on IV procedures. Results provided insight into a commonly used procedure with the pediatric population. Ortiz, O’Connor, Carey, Vella, Paul, Rode, and Weinberg (2017) studied 4 to 11 years old children receiving an IV placement. They found that procedural preparation (a) supported healthy and adaptive coping, (b) minimized the distress experienced by the patients during IV placement, and

(c) resulted in a reduction in children's pain as observed by their parents. These results are just one of many studies of procedural preparations utilizing non-pharmacological measures to successfully treat pain while improving positive outcomes in the pediatric population (Ortiz et al., 2017).

There is evidence for a vast number of positive outcomes resulting from procedural preparations. For the purposes of this study, the focus was on the practice of IV preparation and any changes in perception of pain and positive coping outcomes following these various preparations. Another common theme between the studies mentioned children with disabilities are not included in the research population. Pediatric patients with disabilities were excluded from the majority of the current literature on procedural preparations, however, there are few examples of procedural preparations designed specifically for children with disabilities and these will be discussed in the following section.

#### ***2.4 Procedural Preparations for Children with Disabilities***

Research on procedural preparations conducted with children who have disabilities is extremely limited. The majority of studies do not specify a reason as to why children with disabilities are excluded as participants. Research conducted on children with disabilities focuses on a specific diagnosis (e.g., SLOS, cerebral palsy). However, disability research implies the results may be generalizable to children with other disorders. For example, DeMore and colleagues (2009) studied children with SLOS (Smith-Lemli Optiz Syndrome), a condition that encompasses many different disorders and health conditions into one diagnosis. In this study, behavioral training was provided to 17 children aged 4- 17 years. The children received procedural preparation that

included task analysis, differential reinforcement of appropriate behaviors, and escape extinction in order to prepare for an overnight EEG procedure. Based on the task analysis, researchers came up with a step by step process for each child individually, so they could successfully cope during and complete the procedure. The researchers used reinforcers to congratulate a child on each successfully completed step of the process. The reinforcements were selected by listening to parents' accounts of what the child's preferences were and therefore unique for each child. The results of this study showed behavioral training was successful in children diagnosed with SLOS. The authors stated that children with this disability have a specific set of characteristics, however, their results may be generalizable to children with a range of developmental disabilities (DeMore et al., 2009).

Crawford and Raven (2002) explored a procedural preparation focused on a group of children with a wider variety of disabilities. The participants of their study were children aged 0-19 years with conditions including Cerebral Palsy, Hurlers Syndrome, Lissencephaly, Alternating Hemiplegia in Childhood, Autism and Lennox-Gastaut Syndrome. Ability and independence levels in these populations varied; ranging from total dependence on caretakers to a general amount of independence. Crawford and Raven (2002) utilized Minnie and Mickey Mouse dolls with gastrostomy buttons for procedural preparation. Although there were obvious downsides to using fictional characters, the authors stressed the intentionality of their decision. The preparation that began at home was a major learning tool for parents because the dolls enabled parents to see where the device would be placed on their child and presented parents the opportunity to practice g-tube maintenance (Crawford & Raven, 2002). This study showed the use of

an inanimate object can successfully prepare children with disabilities for a procedure, when the object was presented at a developmentally appropriate level of the child.

Additionally, parent involvement and preparation were important for this study.

Cox, Ortega, Julio, and Martin (2016) took participants through three different experiments aimed at helping children with autism successfully complete a MRI. The participants were gradually introduced to the steps of the MRI procedure. The step was considered successfully completed when the child made no attempt to leave within 5 seconds of the instruction. Depending on their success levels, participants were exposed to prompting and reinforcement procedures to persuade them to cooperate with the mock scan. During the second portion of the study, the researchers evaluated a progressive differential reinforcement procedure to try to establish incrementally longer periods of time where the child would remain still. The technique used in this study proved effective for establishing motion control during a procedure for children with autism. The utility and generalizability of this intervention is supported by the treatment gains demonstrated in all participants in spite of their various levels of disability associated with Autism. In the final experiment, the researchers completed a real MRI scan and focused on having the children stay completely still for a set period of time. Only three of the children from the second phase of this study participated in this phase. The research assistant had limited contact with the child during the scan and the child was prompted to stay still utilizing the same procedures that were used during the second phase of the study. All of the children successfully completed the scan with less than 5 mm of movement. The results showed support for the use of reinforcement-based approaches to ascertain motion control among patients with autism spectrum disorder who require an MRI. This study

suggests that adapting one's approach can produce successful outcomes. Procedural preparations using behavioral interventions were able to eliminate the medical risk and cost of procedural sedation (Cox et al., 2017).

## ***2.5 Summary***

After reviewing the literature, it is clear that procedure preparations are effective in reducing pain and improving coping. The procedure preparations can be completed through many different approaches, using a variety of materials across procedures. However, research on procedural preparations targets children who are typically developing; there is minimal research available that addresses preparations for children with disabilities. The importance of discovering how to effectively treat pain in both of these populations is vital and the current study provided information on IV preparations completed with both typically developing children and children with varying disabilities.



## CHAPTER 3: METHODOLOGY

In order to explore the common practice of IV preparations in children, the researcher conducted a descriptive study using survey research. It is the hope that the current study will garner further interest in studying procedural preparations. This study investigated the variety of approaches to IV preparations used by CCLSs, CCLSs' perceptions of the IV preparation, and the perceived effect of IV preparations on children's perceptions of pain and coping. Additionally, the study gathered information on modifications and/or adaptations CCLSs implemented to make an IV procedure successful for all patients, regardless of the presence of a disability.

### ***3.1 Rationale***

The rationale for this study was the researcher's discovery that children with disabilities are often excluded from empirical investigations pertaining to procedural preparation and support. The gap between evidence of efficacious procedural preparations for typically developing children and children with disabilities is obvious from the published literature; implications for further research with children with disabilities were noted (Rothman, Gonen, Novack, & Shelef, 2016; Miró et. al, 2014; Boerner, Gillespie, McLaughlin, Kuttner, Chambers, 2014). The need to provide the same caliber of care to all patients is of the utmost importance and a standard for the child life profession (Association of Child Life Professionals, 2018). Srouji et al. discussed how pain in the pediatric population in general is undertreated and that special consideration is needed for children with special needs (Srouji et al., 2010). Boerner and colleagues (2014) specifically stated evidence-based interventions for needle pain are

needed when implemented for children with disabilities. They argued there is strong empirical support for managing needle pain in typically developing children but the research for children with disabilities is lacking (Boerner et al., 2014). By conducting this study, the researcher aimed to provide insight on the current practice of IV preparation and how procedural preparation influences pain experience and coping outcomes of young children. The study also provided information on what components need adaptations to accommodate children with disabilities and/or ideas for more appropriate preparation techniques for this population.

### ***3.2 Participants and Setting***

The participants of the study included CCLSs working in children's hospitals throughout the United States with experience in a multitude of departments. The departments reported included: general pediatrics, radiology, emergency department, surgery, preoperative, hematology, oncology, adult, intensive care, intermediate care, neonatal intensive care, outpatient clinics, specialty clinics, hospice, imaging, inpatient rehabilitation, trauma center, infectious disease, and transplant units. A total of 79 participants accessed the survey. A total of 29 completed the entire survey and another 15 surveys were partially completed. Information from the completed and partially completed surveys ( $n=44$ ) were analyzed to gathering descriptive information. Information obtained on the CCLSs included: years in the field, educational background, and departments worked in. The CCLSs had varying educational backgrounds and ranged in level of professional experience from one to 36 years ( $n= 43$ ,  $M= 8.6$ ,  $SD= 8.8$ ). A commonality in the educational background of the participants was most participants reported that they obtained a graduate degree or were in the process of obtaining a

graduate degree in Child Life. Other degrees mentioned were Psychology, Social Work, Child and Family Development, and Child and Family Studies. This study surveyed CCLSs who are employed in various children's hospitals throughout the United States who have established child life departments. Over half of the patients (55%, n=40) that received IV preparations were between the ages of three and seven years old.

### ***3.3 Piloting of the Instrument***

Prior to beginning data collection, the survey was piloted with four CCLSs. These individuals have child life backgrounds but are currently working in alternative settings (e.g., outreach programming manager, outreach programming director, professor). The CCLSs were professional contacts of the research team and individuals with varying levels of professional experience. Piloting the survey addressed the issues of content and social validity by presenting the survey to those in the field and receiving feedback as to whether the survey was accurate and representative of all facets of the construct in study. The CCLSs provided feedback on the logistics of the survey and suggestions on various questions (e.g., adding answer options, clarifying questions). They were advised to complete the survey while reflecting on a previous experience preparing a child for a IV placement in order to provide information and evaluate the flow of the survey, content, applicability of questions, and to gain insight on other information that would be beneficial to obtain.

The CCLSs were contacted via email and provided pilot data. These individuals provided feedback on the structure of questions (e.g., making questions a "check all that apply" format), suggestions for additional questions, and additional responses to questions. Consideration was taken from the feedback provided and changes to the

survey (e.g., adding a question, changing the wording of questions, making questions a “check all that apply” format) were made. The CCLSs who piloted the study did not provide any data for the actual study.

### ***3.4 Procedure***

The researcher recruited participants by sending out an anonymous link to the survey generated through the Qualtrics system (Qualtrics, 2018). The email contained an overview of the study including information about the researcher, the purpose of the study, and contact information for researcher (Appendix A). The email provided a link to the electronic survey that participants could access if they were interested in participating in the study. The email included the request for participants to complete the survey multiple times but stressed that participants were not obligated to fill out the survey more than once. The survey also included the contact information of the researcher for any questions that participants may have had. The primary method of recruitment was through a national forum geared toward child life specialists, the Association of Child Life Professionals (ACLP). A notification email was sent to all individuals who subscribe to the forum. Approximately 4,000 individuals in the child life field received the invitation to participate. Only ACLP members have access to this forum. ACLP members were permitted to post information on various topics and post surveys to get opinions and feedback from others in the child life community regarding various topics within the field. The researchers also disseminated the recruitment email to professional contacts of the research team.

Informed consent was obtained electronically at the beginning of the survey (Appendix B). The informed consent page included contact information of the researcher,

potential risks of participating in the study, overview of the study, request for as many responses as a CCLS is able to provide, potential benefits of the information provided, and information on confidentiality. Once the CCLSs consented to participate by indicating “I agree”, they completed the survey as many times as possible over a one month period. Once a child was referred to the CCLS for an IV preparation, the CCLSs conducted the IV preparation that best fit the institution’s protocol, or they felt was the most beneficial for the child based on their observations, assessment, and/or prior knowledge of the patient. After the preparation and procedure were finished, the CCLS completed the survey once they had the time to reflect on the experience (Appendix C). The survey took approximately 10 to 15 minutes to complete. The CCLSs could skip CCLS demographic information after completing the first survey. CCLSs were able to skip questions they did not want to answer which accounted for the discrepancy in total number of participant responses for varying questions.

### ***3.5 Data Collection***

Data that were collected for this study included: (a) demographic information of the CCLS, (b) general demographics of the patient (e.g., age range, previous IV preparation experience(s), current or prior disclosure of disability from child and/or to the CCLS’s selected approach to IV preparation (e.g., modeling procedure, video/graphic, interactive medical play, diversion/ distraction techniques, or other, (please explain). Data collection took occurred over a one-month period. A reminder email was sent at the end of the second week of data collection.

### ***3.6 Instruments***

#### **The Effects of IV Preparation on Children's Perception of Pain and Coping**

##### **Outcomes**

(Appendix C) – is a researcher-developed survey. The questions in the survey were created using current literature and theory. The survey questions were intended to objectively gather information on how CCLSs approach IV preparation. To address a gap in the current literature, questions inquired as to what are the best ways to prepare pediatric populations for this procedure, including children with disabilities. In addition, survey questions were generated using the theoretical frameworks aligned with understanding pain and coping. The survey has 17 questions (e.g., open-ended, multiple choice, Likert scale) with four demographic questions about the specialists and four demographic questions about the patients. There are three questions about the CCLSs common practice for IV preparation and four questions about the IV preparation itself. The survey took 10 to 15 minutes to complete.

### ***3.7 Data Analysis***

Data from the current study were imported from Qualtrics (Qualtrics, 2018) to SPSS (IBM, 2016). The researcher used descriptive statistics (e.g., frequencies, percentages, means, standard deviations) to analyze the demographic and Likert questions data. The open-ended questions were analyzed by the researcher for similarity in responses and are reported in narrative format. The analysis of commonly used approaches for IV preparations provided insight into the child life specialists' perspectives regarding best practice for IV preparation with all children.

## CHAPTER 4: RESULTS

The researcher gained insight into the common practice of IV preparations performed by CCLSs throughout the country that were reached using a professional forum geared toward CCLSs. Professional contacts of the research team were also contacted to participate in the study. The questions in the survey were formed in order to answer the following research questions: 1) What approaches to IV preparations are used by Certified Child Life Specialists? 2) What changes in pain perception and/or coping are observed by the child life specialists as a result of IV preparation? 3) How are children with disabilities prepared for IV preparations? For the purposes of this study, the term procedural preparation encompassed the entire process of preparation and support throughout the entire procedure. The results section will be organized by research questions.

### ***4.1 Research Question 1***

From this study, there is evidence that there are myriad approaches to IV preparation. Almost half of participants in the study reported they used a variety of approaches for IV preparation and did not follow a specific protocol at their institution (See Table 1).

Table 1	
<i>Institutional Practices</i>	
<u>Factor</u>	<u>Frequency(n=43)</u>
Protocol	3 (6.98%)
Variety	40 (93.02%)

*Note.* The variation in sample size is due to varying response rates for each question.

Diversion and distraction materials were reported as the most commonly utilized items for IV preparation at 34.18% (n=79) for each approach. Interactive medical play

and the use of modeling techniques was the second most commonly utilized preparation technique. The CCLSs were informed that they could choose as many approaches to preparation as applicable. Meaning that these approaches could have been used in conjunction with each other and there was no limit to how many approaches a participant could select (See Table 2). The majority of participants indicated that they used more than one preparation technique for an individual preparation.

Table 2	
<i>Approaches to Preparation</i>	
<u>Factor</u>	<u>Frequency (n=79)</u>
Video/ Graphic	1 (1.27%)
Role Play	5 (6.33%)
Modeling procedure	21 (26.58%)
Interactive medical play	23 (29.11%)
Diversion/ Distraction techniques	27 (34.18%)
Other	2 (2.53%)

*Note.* The variation in sample size is due to varying response rates for each question. Participants were able to select more than one approach to preparation.

In order to understand how CCLSs in the field are making the decision on which preparation techniques to utilize, participants were asked their reasoning for choosing the preparation techniques. The majority of participants reported that their reason for choosing that specific preparation technique was based on their own observation and assessment of the patient. Only 6.98% (n=3) of participants indicated the reason for choosing the preparation was because of a protocol implemented at their institution. More than 75% (n=24) of participants reported the patient interacted with the CCLS *and* the materials during the preparation process which indicates that preparation practices are facilitating patient involvement in their own care. These results suggest there is a variety



in approaches to IV preparation practices and that an institutional protocol for IV preparation was not prevalent in this population.

#### ***4.2 Research Question 2***

The second research question addressed CCLSs perspectives on how their IV preparations influenced coping outcomes and pain perceptions of their patients. There were 43 participants that responded to the question asking for CCLSs to indicate whether or not they utilize pre- and post-op pain assessment for IV preparations. Nineteen participants (44.19%) indicated that they do not use a formalized system for pain assessment. There were 31 participants who indicated the level of anxiety they observed in their patient prior to the preparation and almost half (48.39%, n=15) indicated that they observed an obvious uneasiness and fear exhibited by the patient prior to the IV preparation. A substantial number of participants (29.03%, n=9) reported their patient appeared extremely anxious/fearful and was physically exhibiting their fear. Additionally, participants were asked a question regarding the amount of pain their patient was expecting to experience that the CCLSs rated. There were 31 participants reported the perceived pain level of their patients and nearly half (45.16%, n=14) of the participants reported their patients expected to experience intense pain during their IV procedure.

CCLSs indicated positive coping outcomes as a result of the preparation. A total of 96 outcomes were recorded. Participants were asked to identify specific outcomes that resulted from the preparation based on their observations and assessment. The participants were asked to select as many options as appropriate that applied to their patient. The results showed 28.13% of participants felt their patient managed their

anxiety/ fear well and that 27.08% of participants indicated the patient utilized coping strategies as a means of dealing with the procedure. About a quarter (23.96%) of participants stated their patient held still during the procedure; which was viewed as a positive outcome for the procedure. Only 12.5% of participants indicated they perceived a reduction in pain in their patient due to the preparation.

### ***4.3 Research Question 3***

Participants were asked to report on their level of comfort when working with children with various disabilities and if they provide preparatory services to children with disabilities. All participants except one explained that they provide preparatory services for children with disabilities (n=41). The data indicate that 60.47% (n=43) of participants work with children with various disabilities on a weekly basis and 53.49% (n=43) feel “somewhat comfortable” working with children with disabilities and 41.68% feel “extremely comfortable.” The participants were asked whether or not the patient they were performing the IV preparation for had any disability that they were aware of and indicated yes or no. The list of varying disabilities that CCLSs explained they provide preparatory services for includes: Autism spectrum disorders, genetic syndromes, muscular dystrophy, arthrogryposis, scoliosis, cerebral palsy, hip dysplasia, club foot, spina bifida, miscellaneous birth defects, developmental delays, visual impairments, physical impairments, cognitive/intellectual disabilities, Oppositional Defiance Disorder, seizures, Attention Deficit Disorder/Attention Deficit Hyperactivity Disorder, Down’s Syndrome, Obsessive Compulsive Disorder, and sensory integration disorders. The most common form of disability for this population was “developmental/ intellectual delay” with CCLSs reporting 12 patients (n=59) as having this type of disability. Participants

were instructed to indicate as many disabilities as applied to their patients so there is a chance that comorbidities for these patients were reported.

The participants answered questions regarding whether or not they needed to make adaptations to their preparations in order to meet the needs of their patients. The CCLSs were asked to indicate what adaptations they made, and they were instructed to indicate as many as applicable. A total of 51 alterations were reported. There were 12 participants (23.53%, n=51) that indicated that there was no adaption needed for the IV preparation. However, the most common form of adaption in this population was the utilization of a “combination of approaches” in order to effectively prepare the patient (n=12). In addition, 21.57% (n=11) of participants indicated they used language adaption to accommodate their patient.

When analyzing the data from the question regarding how their patient’s delay/disability influenced the preparation, a prevalent response was that adaption was not considered a factor. One CCLS stated *“Every child is prepared based on their developmental level, so they were prepared as any child at their level would be, meaning the delay didn’t ‘change’ the preparation because every patient is different.”* Those who did indicate an adaption to preparations specified they geared the preparation toward the patient’s interests and developmental level. One participant indicated redirection was needed in order for the preparation to be successful. This participant said the patient was *“Fixated on wanting to play games with the teaching doll (wanted to brush its hair and play with its bow), needed redirection to the prep.”* Another CCLS reported their patient had a language delay and stated *“Patient was not willing to communicate at first. Patient had mother communicate for her.”*

## CHAPTER 5: DISCUSSION

This study was designed to garner information on the common practice of IV preparations and CCLSs perspectives on the changes in pain perception and coping outcomes for all children being prepped for an IV procedure. Although the information provided is not from the perspective of the patients, the perceptions of CCLSs can still provide valuable information into the IV preparation process and associated outcomes. There is an underrepresentation of children with disabilities in published research, however, the results of this study show that the majority of CCLSs who participated in this study did include children with disabilities in their everyday practice (Boerner, Gillespie, McLaughlin, Kuttner, Chambers, 2014; Miró et. al, 2014; Rothman, Gonen, Novack, & Shelef, 2016). The findings from this study contradict the published literature in regards to children with disabilities. In this study, children with disabilities were included the majority of the time, unlike what is reported in the published literature (e.g., Rothman et al., 2016; Shelef, 2016). This may be due to changes in practices occurring over time. In addition, the current study focuses on CCLSs specifically. It is possible that other fields who utilize procedure preparation with children with disabilities do not utilize CCLSs. For example, DeMore and colleagues (2009) utilized behavioral therapists to provide preparation to children with developmental delays for an EEG procedure. Behavioral therapists were also utilized in the study done by Slifer and colleagues wherein distraction, exposure therapy, counterconditioning, and topical anesthetic were used to obtain cooperation with burn patients who were intellectually/ developmentally delayed (Slifer, Hankinson, Zettler, Frutchey, Hendricks, Ward, & Reesman, 2011).

Results of the current study suggest the majority of CCLSs are comfortable working with children with disabilities. In addition, some CCLSs stated that they do not consider a child's disability a factor in adaptations because every preparation is based on the needs of the individual child. There were participants who indicated that they did provide adaptations to preparations (e.g., increment training, language alteration, material alteration). However, the majority of participants indicated using a combination of approaches (e.g., preparation more than once, material alteration) was the adaptation for their preparation. Just as many participants indicated there was no adaptation to their preparation. The discrepancy between the results found in this study and the current published literature indicate procedural preparation may not be thought of the same way by different individuals in varying fields and even within the field of child life. The results from this study showed that some CCLSs did not see a child's delay as the factor for altering their preparation; they think of it as an expectation for their services. For professions outside of the child life field, and other CCLSs, adaptations may be thought of as an additive and not an expectation (DeMore et al., (2009).

Findings from this study are based on the perspectives of CCLSs and indicate positive coping outcomes such as holding still, managing fear/anxiety well, and using coping strategies, as a result of the IV preparation. In addition, there was a reduction in level of perceived pain for some patients according to the perceptions of the CCLSs. These findings are consistent with the literature on pain perception and coping outcomes. Previous studies such as research done by Nguyen and colleagues (2010) studied the effects of music medicine in reducing pain during a lumbar puncture. Their study demonstrated the efficacy of procedural preparation in reducing pain (Nguyen et al.,

2010). Ortiz and colleagues (2017) also demonstrated a reduction in pain levels due to IV preparation as well as an increase in positive coping outcomes and reduced amounts of distress (Ortiz et al., 2017). The consistencies between studies do suggest procedural preparation is effective and has the potential to induce positive coping outcomes and reduced pain levels for patients with and without disabilities as perceived by the CCLSs.

The current study also coincides with theories mentioned previously. Script and Schema theories provide a framework for how we form perceptions about certain concepts and how these concepts have the potential to be altered (Bartlett, 1932; Tomkins, 1978). The majority of participants indicated their patient expected to experience mild to intense pain due to their impending procedure. However, they still reported numerous positive outcomes as a result of the preparation such as holding still, reduced pain, and managing fear/ anxiety well. The positive coping outcomes and the changes in pain perception perceived by the CCLSs that completed this study, indicate that IV preparations have the potential to change patients' perceptions and preconceived ideas about how a specific procedure will affect them.

### ***5.1 Limitations to the Study***

One of the limitations of this study is that the survey is from the perspective of CCLSs and not from the perspective of the patients. Therefore, the information regarding perceived pain and coping ability is considered subjective because it is not from the perspective of the individual experiencing the IV preparation process. In addition, the data that were analyzed did include partial responses. However, data from completed and partial survey were still analyzed because it provided valuable information regarding IV preparation practices. A further limitation of the study was the use of a non-published

survey. In an effort to address this limitation, questions in the survey were developed using current literature and theory and as a result provided content validity. Additionally, the survey was piloted by four child life specialists in order to provide content and social validity. Another limitation to note is that the survey was posted on an online forum, so there is no guarantee that the individuals completing the survey were certified child life specialists and the limited participant pool. The survey was sent to over 4,000 individuals; however, 79 participants accessed the survey. Of those, 15 participants provided partial data and 29 participants completed the survey in its entirety. It is important to recognize that although the survey was sent out to a large group of individuals, the participant pool was still limited to only those who subscribe to the forum, and the answers provided are not representative of an entire population of CCLSs.

### ***5.2 Implications for Further Research***

There is a need for further research on procedure preparations in child life settings. The current study was one contribution to research in the child life field. More studies should be conducted on other procedures that are common in the pediatric population in order to garner information about best practices for this population. Procedural preparations should be routinely studied in order to gather more insight into how we can positively influence children's perceptions of intimidating medical procedures. Continued research will assist in the process of building a strong evidence base for procedure information and provide CCLSs with information on practices they could implement in their daily routines. In addition, there should be continued research that includes children with disabilities in the preparation process, so information can be

shared throughout the child life profession on how children with disabilities are included in everyday practice.

Further research would be beneficial on the educational backgrounds of CCLSs. This information could provide information on why CCLSs felt “somewhat comfortable” providing services to children with disabilities and what prepared them to effectively provide these services. The current study included a survey question that asked for the educational background/ degree of the participant. Since the majority of participants indicated that they are comfortable working with children with disabilities, it would be beneficial to know what these individuals have experienced in the past that made them feel comfortable working with this population. Information on what, if any, specific classes, additional trainings, and internship experiences have been provided to prepare CCLSs for working with children with disabilities would be valuable. Future research could provide insight into specific classes or what components of participants’ educational background have prepared them to feel comfortable providing developmentally appropriate interventions to children with varying disabilities.

In the future, it would be beneficial to structure the survey in a way that direct relationships can be explored between CCLSs responses regarding preparing a child with a disability and the adaptations that were made. Information should be gathered on whether or not it was the disability of the child that resulted in the need for adaption, or if the adaptations were needed due to another factor. In addition, reaching out to individual hospital programs and having a specific staff collect data may be more beneficial for obtaining completed surveys. Structuring the survey so participants do not skip questions



could also potentially promote completed surveys or encourage participants to complete full sections instead of having questions left unanswered throughout the survey.

This study provides information that is not only valuable to the field of child life but also the healthcare system in general. The utilization of child life preparatory services has shown positive outcomes for more than just patients; and the more that research like this is utilized, the more positive outcomes can be identified in other areas. For those who work directly in patient care, CCLSs can be a resource to them and utilizing preparation services can potentially make their task much easier if patients become more cooperative. The more that preparatory interventions are studied, the more information can be shared on their efficacy and the positive outcomes that may occur for all individuals involved.

## REFERENCES

- Association of child life professionals. (2018). Retrieved from: [www.childlife.org/about-aclp/purpose-mission-values/official-documents/codes-and-guidelines-for-professional-conduct](http://www.childlife.org/about-aclp/purpose-mission-values/official-documents/codes-and-guidelines-for-professional-conduct)
- Bartlett, F.C., (1932). *Remembering: A study in experimental and social psychology*. New York, NY, US: Cambridge University Press.
- Boerner, K. E., Gillespie, J. M., McLaughlin, E. N., Kuttner, L., & Chambers, C. T. (2014). Implementation of evidence-based psychological interventions for pediatric needle pain. *Clinical Practice in Pediatric Psychology*, 2(3), 224-235. doi:10.1037/cpp0000074
- Brown, N. J., David, M., Cuttle, L., Kimble, R. M., Rodger, S., & Higashi, H. (2015). Cost-effectiveness of a nonpharmacological intervention in pediatric burn care. *Value in Health*, 18(5), 631-637. doi:10.1016/j.jval.2015.04.011
- Cohen, L. L., & MacLaren, J. E. (2007). Breaking down the barriers to pediatric procedural preparation. *Clinical Psychology: Science & Practice*, 14(2), 144-148. doi:10.1111/j.1468-2850.2007.00073.x
- Cox, A. D., Virus-Ortega, J., Julio, F., & Martin, T. (2016). Establishing motion control in children with autism and intellectual disability: Applications for anatomical and functional MRI. *Journal of Applied Behavior Analysis*, 50(1), 8-26. doi:10.1002/jaba.351
- Crawford, C., & Raven, K. (2002). Play preparation for children with special needs. *Paediatric Nursing*. 14(8), 27

- DeMore, M., Cataldo, M., Tierney, E., & Slifer, K. (2009). Behavioral approaches to training developmentally disabled children for an Overnight EEG procedure. *Journal of Developmental & Physical Disabilities*, 21(4), 245-251. doi:10.1007/s10882-009-9139-7
- Grissom, S., Boles, J., Bailey, K., Cantrell, K., Kennedy, A., Sykes, A., & Mandrell, B. N. (2016). Play-based procedural preparation and support intervention for cranial radiation. *Supportive Care in Cancer*, 24(6), 2421-2427. doi:10.1007/s00520-015-3040-y
- IBM Corp. (2016). IBM SPSS Statistics for Windows, Version 24.0. Armonk, NY: IBM Corp.
- Jaaniste, T., Hayes, B., & von Baeyer, C. L. (2007). Providing children with information about forthcoming medical procedures: A review and synthesis. *Clinical Psychology: Science & Practice*, 14(2), 124-143. doi:10.1111/j.1468-2850.2007.00072.x
- Miró, J., Huguet, A., Jensen, M. (2014). Pain beliefs predict pain intensity and pain status in children: Usefulness of the pediatric version of the survey of pain attitudes. *Pain Med*, 15 (6): 887-897. doi: 10.1111/pme.12316
- Nguyen, T. N., Nilsson, S., Hellström, A., & Bengtson, A. (2010). Music therapy to reduce pain and anxiety in children with cancer undergoing lumbar puncture: A randomized clinical trial. *Journal of Pediatric Oncology Nursing*, 27(3), 146-155. doi:10.1177/1043454209355983
- Ortiz, G. S., O'Connor, T., Carey, J., Vella, A., Paul, A., Rode, D., & Weinberg, A. (2017). Impact of a child life and music therapy procedural support intervention

on parental perception of their child's distress during intravenous placement.

*Pediatric Emergency Care*. doi:10.1097/PEC.0000000000001065

Piaget, J. (1936). *Origins of intelligence in the child*, London: Routledge & Kegan Paul.

Qualtrics. (2018). Qualtrics, April 2018. Provo, UT. Retrieved from:

[www.qualtrics.com/](http://www.qualtrics.com/)

Rothman, S., Gonen, A., Vodonos, A., Novack, V., & Shelef, I. (2016). Does preparation of children before MRI reduce the need for anesthesia? Prospective randomized control trial. *Pediatric Radiology*, 46(11), 1599-1605. doi:10.1007/s00247-016-3651-6

Slifer, K. J., Hankinson, J. C., Zettler, M. A., Frutchey, R. A., Hendricks, M. C., Ward, C. M., & Reesman, J. (2011). Distraction, exposure therapy, counterconditioning, and topical anesthetic for acute pain management during needle sticks in children with intellectual and developmental disabilities. *Clinical Pediatrics*, 50(8), 688-697. doi:10.1177/0009922811398959

Srouji, R., Ratnapalan, S., & Schneeweiss, S. (2010). Pain in children: Assessment and nonpharmacological management. *International Journal of Pediatrics*, 1-11. doi:10.1155/2010/474838

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

Tomkins, S.S., (1978). Script Theory: Differential magnification of affects. Nebraska symposium on motivation, 26, 201-236.

## APPENDIX A: RECRUITMENT EMAIL

Hello Everyone!

My name is Emily R. Bellino and I am a graduate student The University of North Carolina at Charlotte. I am working on my thesis regarding IV preparation and how all children are included in the preparation process. I am looking for CCLS's to complete and 10-15 minute online survey! The survey can be taken as many times as you would like in accordance with the number of IV preparations you preform. A minimum of four responses is requested and all information provided is greatly appreciated!

Here is the link to the survey:

[https://unccprojectmosaic.az1.qualtrics.com/jfe/form/SV\\_82hQru9UtiHdAUJ](https://unccprojectmosaic.az1.qualtrics.com/jfe/form/SV_82hQru9UtiHdAUJ)

I greatly appreciate your time!

Sincerely,

Emily R. Bellino  
[ebellino@uncc.edu](mailto:ebellino@uncc.edu)

## APPENDIX B: INFORMED CONSENT

**Department of Special Education and Child Development**

9201 University City Blvd, Charlotte, NC 28223-0001

t/ 704.687.8828 f/ 704.687.1625 [www.uncc.edu](http://www.uncc.edu)

Title: The Effects of IV Preparation on Children's Perception of Pain and Coping Outcomes

Principal Investigator: Emily R. Bellino, M.Ed. student at The University of North Carolina at Charlotte under the supervision of Dr. JaneDiane Smith

**Project Purpose:** The purpose of this study is to garner more information about the IV procedure preparation process in the pediatric population. The hope is to discover what the common procedural preparation practice is for IV preparation and what can be done to include children with disabilities in this practice.

Eligibility for this study is limited to Certified Child Life Specialists at children's hospitals throughout the United States. The participants will be asked to complete a survey regarding their practices for IV preparation with pediatric patients with and without disabilities (e.g., visual, auditory, speech/ language, motor/physical, developmental/ intellectual, other please explain). Data collection for each participant will be open for one month and the survey will take between 10 to 15 minutes per entry. The CCLS will be asked to complete the survey a minimum of four times (no more than a one hour commitment) over the course of the month. There are no foreseeable discomforts to participating in the study. The knowledge gained from this study could potentially benefit society with more information regarding effective IV preparation for the pediatric population. There will be no compensation for participation in the study. Participation is voluntary. The decision to participate in this study is completely up to the participants discretion. If a participant decides to be in the study, they may stop at any time. A participant will not be treated any differently if they decide not to participate in the study or if they stop once they have started.

Absolute confidentiality of data provided through the Internet cannot be guaranteed due to the limited protections of Internet access. Participants must be sure to close all browsers when finished so no one will be able to see what you have been doing. Only the principal investigator will have the login information to be able to access the data. Any identifiable information collected as part of this study will remain confidential to the extent possible and will only be disclosed with a participant's permission or as required by law.

UNC Charlotte wants to make sure that all participants are treated in a fair and respectful manner. Contact the Office of Research Compliance at 704-687-1871 or [uncc-irb@uncc.edu](mailto:uncc-irb@uncc.edu) if there are any questions about treatment as a study participant. If participants have any questions about the actual project or study, please contact Emily R. Bellino (717-524-6895, [ebellino@uncc.edu](mailto:ebellino@uncc.edu)) or Dr. JaneDiane Smith (704-687-8850, [jdianesm@uncc.edu](mailto:jdianesm@uncc.edu))

**ELECTRONIC CONSENT:** Please select a choice below. Participants may print a copy of this consent form for their records. Clicking on the "Agree" button indicates that

- You have read the above information
- You voluntarily agree to participate
- You are 18 years of age or older

☐ Agree    ☐ Disagree

## APPENDIX C: SURVEY

## The Effects of IV Preparation on Children's Perception of Pain and Coping Outcomes

### Survey for Child Life Specialists

---

-Consent page.

The goal of this survey is to garner more information about IV preparations. Participants are being asked to fill out the survey at least once. However, if they choose to do so, they may fill out the survey as many times as they are able. Filling out the survey more than once is completely optional and up to the discretion of the participant.

-If you've taken this survey before, click continue, if you have NOT taken this survey before, click begin.

#### Demographics of Specialist (please fill out once):

Departments worked in:

Years in the field:

Educational Background (major, program area, specialized training, additional trainings throughout career):

Do you provide preparatory services for children with disabilities (role play, modeling, medical play, etc.) and if so, what types of populations of children with disabilities and their families do you provide services for?

#### Part 1 (Please fill out this section once):

1) How many IV preparations do you provide per week (on average)?

1-5  
5-10  
10-15  
15+

2) How often do you encounter children with disabilities (on average)?

Very often (weekly)  
Often (monthly)  
Rarely (every other month)  
Never

- a. How comfortable are you working with children with disabilities?  
Not comfortable (1) Somewhat comfortable (2) Neither comfortable or uncomfortable (3) Somewhat comfortable (4) Extremely comfortable (5)
- 3) At your establishment, is there a standard protocol for IV preparation or do you use a variety of techniques when providing IV preparation for children with and without disabilities?
- a: Protocol  
b: Variety

- a. How do you handle “frequent flyer” patients?

a: Same preparation every time  
b: No preparation after first time  
c: Depends on the situation  
d: Other, please explain

- a. Do you utilize pre and posttest assessments (e.g., pain scales)?
- Yes  
No  
Other, please explain

The following questions are to be answered regarding the patient who received IV Preparation:

**Demographics of Patient:**

What was the admission setting/ background of the patient?

Came in through the emergency room  
Admitted directly onto pediatric floor  
Other, please explain

Chronological Age of the Child:

- a. 0-18months



- b. 18- 36 months
- c. 3- 7years old
- d. 7-11 years old
- e. 11-13 years old
- f. 13+

Developmental Age of Child:

- g. 0-18months
- h. 18- 36 months
- i. 3- 7years old
- j. 7-11 years old
- k. 11-13 years old
- l. 13+

Awareness of presence of disability (if any, check all that apply):

- a. Visual
- b. Auditory
- c. Speech/ Language
- d. Motor/ Physical
- e. Developmental/ Intellectual
- f. None that I'm aware of
- g. None
- h. Other, please explain

Reason for Admission:

- a. Acute care
- b. Chronic care
- c. Other, please explain

Parent present during preparation (circle one): Yes/ No

The following questions should be answered in regards to your reflection on a previous IV preparation experience.

- 4) Approach to Preparation (Check all that apply):
  - a. Modeling procedure (e.g., demonstration of IV)
  - b. Video/graphic (e.g., video of IV)
  - c. Interactive medical play (e.g., Activity with doll or stuffed animal)
  - d. Diversion/ Distraction Techniques (e.g., Games, bubbles, iPad)
  - e. Role play
  - f. Other, please explain

a. Reason for choosing specific preparation (check all that apply):

- a. Protocol
- b. Easiest/ quickest given situation
- c. Requested by family and/or staff
- d. Based on CCLS's observation/ assessment
- e. Based on prior knowledge of individual child
- f. Other, explain

b. What materials did you use (Check all that apply)?

- a. Videos, graphics, technology
- b. Dolls
- c. Stuffed animals
- d. Distraction tools (e.g., Bubbles, pinwheels)
- e. Medical equipment

c. Based on your knowledge and the information available to you, are you aware if this patient has received a preparation for an IV in the past?  
(Y/N)

5)

a. Rate the child's perceived **anxiety level** before preparation (please circle one): (1) Not anxious/scared at all (2) Very little fear/anxiety observed (3) Obvious uneasiness/ fear observed (4) Extremely anxious/ fearful, physically showing fear (5) Completely uncooperative/ inconsolable

b. Rate the child's perceived **pain level** based on your observation before preparation (please circle one): (1) Mild pain anticipated (2) Tolerable pain anticipated (3) Child is expecting procedure to be distressing and painful (4) Child expecting intense pain (5) Child is expecting severe, intolerable pain

6) Assessment of the intervention:

a. What outcomes resulted from the IV preparation? Check all that apply.

- a. Lower pain level (perceived)

- b. Managed anxiety/ fear well
- c. Used coping strategies
- d. No medication needed
- e. Held still
- f. Other, please explain

b. Did child interact with you or the materials during the preparation?

Interacted with CCLS

Interacted with materials

Interacted with materials and the specialist

7) Did you need to make any alterations to the preparation based on the individual developmental level/needs and/or disabilities of this child (check all that apply)?

- a. Language alteration
- b. Material alteration
- c. Prep more than once
- d. Increment training (e.g., introducing procedure step by step)
- e. Combination of approaches
- f. Other, please explain
- g. No alteration

8) How did the child's delay (if any) influence how they were prepped?