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**SCHOOL-AGE CHILDREN'S PERCEPTION OF STRESS IN
THE HOSPITAL: A DRAW AND TELL STORY**

By

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BSN, Ursuline College, 1984

MSN, Kent State University, 1992

DISSERTATION

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ABSTRACT

The purpose of this study was to explore the perceptions of stress for hospitalized school-age child, seven to nine years of age, through a child-centered draw and tell technique. Over 3 million children are hospitalized every year (NACHRI, 2012). Hospitalization of children is reserved for increasingly complex care. Since the 1960's, it has been well known that hospitalization can be a traumatic experience for children (King & Ziegler, 1981; Thompson, 1986; Vernon, Foley, Simpowicz, & Schulman, 1965; Visintainer & Wolfer, 1975). This experience elicits feelings of fear, uncertainty, pain and discomfort that can affect a child's healing, behavior and health outcomes (Hopia, Tomlinson, Paavilainen, Paivi, 2004). Although the psychosocial impact of hospitalization is evident, it has not been fully explored from a child's perspective.

Thirty child participants in a large Midwest children's hospital were interviewed

through a child-centered ‘draw and tell’ technique (Driessnack, 2006) to elicit their perceptions of stress in the context of hospitalization. Interpretive description approach was applied (Thorne, 2008). The results of this study revealed 14 themes for building a conceptualized framework. Five important messages from children are communicated to professional caregivers in the hospital: a) stress for children is expressed through their fears, worries, discomforts and sadness; b) children should be listened to, as they have something important to say; c) children want to know what is expected of them and be informed of what they need to do; d) children identify simple things health care providers can do to help them during hospitalization e) the ultimate relief of stress for children in the hospital is going home and children want to know a timeline what they need to do to go home. Discovering the meaning of stress for the hospitalized child launches a research trajectory addressing the remedies for psychosocial trauma for this population.

DEDICATION

This work is dedicated to all the precious, sweet children and their families who graciously participated in my study during the course of acute illness and hospitalization. Many of these children were in the midst of their fears, anxieties, and discomforts, and were willing to share their insights, drawings and feelings with me during a time of crisis in their lives. Their trust in me to disclose their intimate thoughts was a testimony to the nature of children who are willing to give voice to help others find their way through the difficult journey of hospitalization. To these wonderful children, their families and caregivers, I humbly dedicate this work. Without them, there would be no voice for children in this area of study.

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CHAPTER I

INTRODUCTION

Since the 1960's, it has been well known that hospitalization for children can be an extremely traumatic and stressful experience (King & Ziegler, 1981; Skipper & Leonard, 1968; Thompson, 1985; Visintainer & Wolfer, 1975). Children are required to submit their small bodies to adult control and restrictions, and are asked to 'hold still' for painful procedures they do not understand (Rollins, Drescher, & Kelleher, 2012). The stress of hospitalization for a child elicits feelings of fear, anxiety, insecurity, pain and discomfort that can affect a child's healing, behavior and health outcomes (Hopia, Tomlinson, Paavilainen, Astedt-Kurki, 2005). Enhanced technology and increased acuity of the hospitalized child exacerbates this stress. Understanding children's stress and psychological responses to hospitalization is essential in providing congruent care to this population (Vessey, 2003). Critical to this understanding is identifying antecedent events and mediating factors and their relationships to these responses, and designing interventions that help children have stress free, growth-promoting experiences while mitigating unhealthy responses (Wilson, Megel, Enenbach & Carlson, 2010; Vessey). To accomplish this, researchers need to explore children's views of hospitalization through their own voice. There is a paucity of research efforts addressing children's stress of hospitalization specifically from a child's point of view. This study explores the perceptions of stress for the hospitalized school-age child through a draw and tell, child-centered framework.

Background/Significance

Hospitalization is a landmark occurrence in the series of lifetime events for a child (Vessey, 2003). In the United States, over 3 million children are hospitalized every year and over 40% of these children are school-agers (National Association of Children's Hospitals and Related Institutions (NACHRI, n.d.). Hospitalization of children in the 21st century is reserved for increasingly complex care, where acute hospital stays in specialized children's hospitals, account for more than 40% of all inpatient stays (Forum on Child and Family Statistics, 2010). Child in-patient hospital visits account for \$10 billion of annual hospital costs for children (NACHRI). The stress of hospitalization on a child can lead to prolonged recovery, increased risk for infection and poor patient outcomes, increasing these hospital costs.

Until recently, knowledge of children's perceptions of their hospital experiences was based on studies using quantitative measure of children behavioral responses, or qualitative data from parents or nurses (Lindeke, Nakai, & Johnson, 2006; Schmidt, Bernaix, Koski, Weese, Chiappetta & Sandrik, 2007; Woodgate, 2001). There have been limited studies looking at hospitalized children's perceptions of stress (Carney et al, 2003; Coad, Coad, & Theibe, 2005; Knighting, Rowa-Dewar, Malcolm, & Gibson, 2010; Wilson, Megel, Enenbach, & Carlson, 2010). Current research emphasis for the hospitalized child has been on the impact of specific diseases or conditions of children such as traumatic injuries (Scheeringa, Wright, Hunt, & Zeanah, 2006; Sturms et al., 2005), cancer (Aksin & Moore, 2008; Miller, Jacob & Hockenberry, 2011); infectious disease (Leidy et al 2005); and diabetes (Garrison, Katon & Richardson, 2005). In addition, particular aspects of hospital environments that prompt physiological and

psychological stress for the hospitalized child have been studied (Board, 2005; Lambert, Coad, Hicks & Glacken, 2013; Linder & Christian, 2011; Nelson & Gold, 2012). Some scholars have explored the stress of hospitalization through the parents' and nurses' perceptions, leaving the child's voice silent (Espezel & Canam, 2003; Power & Franck, 2008). However, research suggests that parent's perceptions differ from those of children's (Hadley, Smith, Gallo, Angst, & Knafl, 2008; Schilling et al, 2007). Therefore, it is essential to determine what a child perceives and understands about the hospitalization experience from the child's point of view.

Although the psychosocial impact of hospitalization on school-age children is evident and has not been remedied, the problem has received little research effort in the past seven years. Given the current complex, technological, and dynamic nature of hospital environments, and the unresolved stressful, psychosocial impact of hospitalization on children, it is critical to resume the study of children in a hospital setting. In particular, it is vital to understand the stress from a child's point of view, so a child can be empowered and give voice to what will comfort and soothe them effectively during the hospitalization experience.

Specific Aim

The specific aim of this study is to explore school-age children's perceptions of stress in the hospital. Children ages seven to nine years interpret their perceptions through their own voice with a draw and tell technique.

Research Questions

The research questions for this study include: a) how do school-age children describe stress related to the experience of hospitalization? b) is stress of hospitalization

related to anxiety, fear, and discomfort or other factors? c) how do school-age children cope with stress during hospitalization? d) what does a child think a nurse can do to help a child with stress during hospitalization?

Definitions of Terms

Preliminary definitions that frame this study include the meanings of stress, coping, hospitalization, school-age, perceptions and children's voice.

Stress

For the purpose of this study, stress is defined as an adverse circumstance that disturbs, or is likely to disturb the normal physiological or psychological functioning of an individual and manifests in physical, mental or emotional disruption (Oxford English Dictionary, 2008). Stress in context is a personal experience that reflects a disturbed relationship between a person and a situation (Lazarus & Launier, 1978).

Coping

Coping is the process of dealing effectively with a difficult situation or disruption (Oxford English Dictionary, 2008). LaMontagen (1987) identifies a person's appraisal or evaluation of stress and then the proceeding coping or maladjustment depends on personal and situational factors that are unique to the individual. For a child, these could include: a) age and developmental level; b) parental attitudes and anxiety; c) hospital environment; d) separation and emotional deprivation; or e) anxiety and fear (Vessey, 2003).

Hospitalization

Hospitalization is defined as the period of time during which someone is in the hospital, (Oxford English Dictionary, 2008). A hospital is defined as an institution that

provides medical, surgical and nursing care for sick and injured people. Operationalized for this study, hospitalization is a child who is admitted to the hospital and has an in-patient stay for greater than eight hours and up to four weeks. Due to the current hospital regulations related to cost, 33% of children are hospitalized as observation patients and are in the hospital for less than 24 hours (Fieldston et al, 2013), so these children will be included in this study. At times, children with complications and acute illness with underlying chronic problems could be hospitalized for a lengthy period. These children will also be included in this study.

School-Age

School-age is a descriptor that depicts ‘of or relating to children who are at an age to be in school.’(Macquarie University, NSW, 2005). The law sets this parameter of age for children starting school attendance. The literature varies in the age span that is included in the school-age time continuum. For the purposes of this study, a school-age child is identified as a child between six and twelve years of age. For this study, the term school-age child is operationalized to be a child between seven and nine years of age.

Perception

Perception is the result of processing and organizing information about one’s environment and experiences received by the senses and interpreted as meaningful (Oxford English Dictionary, 2008). Children’s perceptions of hospitalization can bring a contextual discernment of their individualized experience through their developmental framework. Perception for the child is operationalized through a child’s drawing about the hospital and their words of interpretation describing their drawing.

Children's Voice

Voice is defined by Carlisle (2000) as an expression of a child's internal thoughts, feelings, and opinions to the outside world. Important considerations are that a child's voice is influenced by their experience in their world, by their immature physical bodies and by a culture that has particular expectations of the child (McPherson & Thorne, 2000). "Compounding these complexities, when nursing interacts with children, the context is often a strange and stressful environment and uncertainty, fear, illness, or injury may hamper the child's voice. As pediatric nurses and advocates for children, how do we know that the voice we claim to represent is that of the child?" (p.22).

Traditionally, researchers have deemed that children lack the verbal skills, conceptual abilities, recall and overall narrative competence to relay their experiences and emotions. Therefore, researchers rely on adult informants including parents, caregivers, nurses and other adults to convey the voice of the child (Runeson, Hallstrom, Elander, & Hermeren, 2002). Hearing the voices of children can reveal new knowledge regarding hospitalization of children (Sorsa, Ranta, Harikainen, & Paavilainen, 2006; Wilson, Megel, Enenbach & Carlson, 2010). Children's voice is operationalized by the child's drawing of their interpretation of the hospitalized experience, and then utilizing language to describe the drawing for the researcher.

Child Agency. An additional dimension of voice is the need for a child to be accepted and respected for their thoughts and feelings as a reflection of his or her reality at that time. The Oxford dictionary informs this dimension of voice as "the agency by which opinion is expressed" (Styles, 1964). From the idea of agency emerges the notion of power and action, as agency can be seen as the child's ability and opportunity to act on

his or her own behalf. When a child possesses the personal authority to express thoughts and feelings, their power and likelihood of getting their needs met is enhanced within a health care setting.

Research findings challenge those who are nursing children to confirm all aspects of the experience from the child's perspective. This could assist children to employ their personal powers to deal with their illness. "Investigating further children's experience of illness and care is a task of great importance....to eventually improve the possibility of comforting children facing various aspects of medical and health care." (Forsner, Jansson, & Sorlie, 2005, p. 162). To conduct valid studies, it is essential for researchers today to obtain a child's own perspective of what they think about the world and themselves (Christian, Pearce, Roberson, & Rothwell, 2010). A child will feel more understood, valued and cared for when nurses create an environment in which the thoughts and feelings of the child are valued and respected (McPherson & Thorne, 2000). Hill (2006) researched the agency and voice of children from the child's view and summarized the implications suggested from these small voices (Table 1).

Table 1.

Some Implications for (Adult) Researchers From what Children have Said

<u>Core Implication</u>	<u>Description</u>
Fairness	Ensure as many types of child and viewpoint as possible are included
Effectiveness	Try to ensure that the research or consultation will benefit children
Agency	Benefit from children's ideas about the best ways to explore their world
Choice	Maximize the opportunities for participants to choose forms of communication and levels of involvement they prefer
Openness	Be clear to about limitations to their participation and the results
Diversity	Use a range of methods and include all major perspectives
Satisfaction	Make the experience comfortable and when appropriate, good fun
<u>Respect</u>	<u>Recognize children's rights and opinion; minimize use of power</u>

Note. Adapted from Children's voices on ways of having a voice: Children's and young people's perspectives on methods used in research and consultation by M. Hill, 2006, *Childhood*, 13, p. 85.

In research with children, it is recommended for the researcher to identify the value placed on children's views, manage the relationship of the researcher as the trusted adult to the vulnerable child and maintain the integrity of social differences between the adult and child (Randall, 2012). Child agency is operationalized through techniques of interviewing that the researcher will utilize to validate and uphold the child's perspectives of their hospitalized experience.

Chapter Summary

Preliminary definitions of the terms stress, coping, hospitalization, perception, school-age, children's voice and child agency are proposed. Due to the nature of the emergent design and interpretive description for this study, the author engages in furthering the interpretation of these terms through data collection and analysis from a child's lens. Therefore, these terms hold a dynamic place in this study, with anticipation of the validation of this terminology as analysis unfolds.

CHAPTER 2

LITERATURE REVIEW

A review of the literature regarding stress, coping and comfort of the hospitalized child has revealed some significant findings. Clear areas of study identify hospitalization as a stressor correlated with fear, anxiety, and discomfort for children. Coping and comfort of hospitalized children are explored as a response to this stressor. Essential to the outlay of this study is an initial overview of the theoretical models and frameworks that inform and guide this research and analysis.

Theoretical Frameworks

The guiding theoretical underpinnings for this study include Magnusson's (1995) Developmental Science model that is the basis for Vessey's (2003) multifaceted model for the psychological experience of hospitalization for a child (Appendix A). Kolcaba's (2003) modified Comfort Theory (CT) that includes developmental and parent-child relationship variables, is a third congruent framework utilized to guide the beginning assumptions regarding children who are hospitalized. Finally, an overarching framework is my experience in pediatric nursing and care of children which I use as a guide for methodology, data collection and analysis.

Developmental Science

A developmental science framework provides a structure for this child-centered study. A developmental science perspective employs developmental, systems, and ecological frameworks (Bronfenbrenner, 1986; Magnusson, 1995) to capture the interactions between children and their environment with the interplay of developmental changes, stability and transition considered (Cairns, 2000). A developmental framework

is essential for understanding developmental mechanisms that influence the health of children and their adaptation to health problems (Miles & Holditch-Davis, 2003).

Knowledge of children's fears and perceptions of hospitalization implied from the work of major developmental theorists, such as Erikson (1968) and Piaget (1950), have been the foundation of pediatric nursing care. Some of the commonly assumed causes of stress for hospitalized children include separation from family, pain, intrusive procedures, loss of control, and fear of such experiences. Studies of children's perceptions of illness (Bibace & Walsh, 1980; Moss-Morris & Patterson, 1995) suggest a developmental paradigm assists in explaining children's understanding of illness and hospitalization. This same paradigm has helped nurses to develop specific interventions, such as age-appropriate play, family participation in care and pain management strategies (Schmidt, Bernaix, Koski, Weese, Chiappetta & Sandrik, 2007).

Vessey's Model of a Child's Psychosocial Responses to Hospitalization

Vessey (2003) utilizes a developmental science framework and identifies the major intervening variables shown to affect a child's psychological response to hospitalization. These variables include age, separation, length of hospitalization, hospital milieu, type and severity of illness and symptomatology, previous adaptive capacity, perceptions of the experience, parent-child relationships, and parental equilibrium (Vessey, 2003). Numerous trans-disciplinary studies informed this model, and support multifaceted variables related to a child's psychosocial responses to hospitalization. To enhance this model and capture temporal and holistic components, parental response, culture, and a child's prior experiences could be additional variables to consider.

Kolcaba's Comfort Theory (CT)

A third theory that is relevant to the care of the hospitalized child is the Comfort Theory (CT) (Kolcaba, 2003). A central theme of nursing care for the hospitalized child is to relieve stress, anxiety and fear for children, and enhance comfort and healing (Christian, 2011). Kolcaba (2004) explains that the purpose of the CT is to support a philosophy of care whereby holistic comfort needs of patients and families are identified and addressed. With modifications, this theory is an optimal holistic framework in the analysis of data for this study with children.

Kolcaba (2003) defines comfort as “the immediate experience of being strengthened by having needs for relief, ease, and transcendence met in four contexts (physical, psychospiritual, sociocultural and environmental). In her formal concept analysis of comfort, Kolcaba (1991) explains that the definition is derived from psychology, psychiatry, medicine, ergonomics and nursing. Kolcaba (1994, 2001) describes the three states of comfort: (a) relief is the experience of having a specific comfort need met, (b) ease is the state of calm or contentment, and (c) renewal as the state at which one rises above problems and pain. Renewal was later changed to transcendence, crediting the term to Paterson and Zderad (1988).

Kolcaba (1994, 2001) describes the four contexts of comfort as: (a) physical comfort, pertaining to bodily sensations and homeostatic mechanisms; (b) psychospiritual comfort, encompassing the internal awareness of self that includes esteem, sexuality, meaning in one's life, and a relationship with a higher order or being; (c) sociocultural comfort pertaining to interpersonal, family, cultural, financial, informational and societal relationships; and (d) environmental comfort, attending to the external background of

human experience which includes light, noise, ambience, color, temperature, and natural versus synthetic elements. These holistic aspects of comfort (Kolcaba, 1992; 1995) are congruent with the physical, psychological, social, cultural and environmental parameters related to stress of the hospitalized child. Mirrored to the multifaceted realms of stress are possible ways to soothe a child within a comfort paradigm.

Modifications of Kolcaba's Theory. The major emphasis of research with CT has been with adults (Appendix B; Comfort Line, 2010). One study applied the CT to the hospitalized child (Kolcaba & DiMarco, 2005) without modification. However, the special needs of the child population mandate essential modifications that include a developmental context to comfort and capturing the child/parent relationship in the process and product of comfort to create a congruent framework for research regarding children.

Developmental aspect added to holistic comfort. For children, the achievement of comfort includes the multi-dimensional contexts that Kolcaba (2003) proposes, but needs a specific developmental context added. Children have specific developmental needs at different ages that will affect the process and the product of comfort. In addition, the CT has incomplete congruency with the concept of holistic comfort defined by Kolcaba (2003) as “the immediate state of being strengthened through having the human needs for relief, ease, and transcendence addressed in four contexts of experience (physical, psychospiritual, sociocultural, and environmental)” (p. 251). Transcendence is a need that may only apply to the children who have a developmental capacity to achieve this state. Addressing the full scope of the developmental state that the child is experiencing would include expanding or refining the outcome of transcendence. In

cases when a child is unable to achieve transcendence, another outcome that is developmentally inclusive would be more appropriate for their state of comfort. By adding the developmental context and reevaluating transcendence, the congruency of the CT for this study is evident.

Parent/guardian relationship related to comfort. In light of the process of comfort for the child, the relationship of the parent and or guardian is a vital piece for inclusion. Although the current CT proposes that nursing interventions for comfort are the venue to achieve comfort for adults, a key aspect for children is the parent or guardian as the vehicle to achieve comfort (Piiarra, Sugiura, Champion, Donnelly & Cole, 2005). Therefore, an additional modification of the CT would include the interrelationship of parent/guardian as a vehicle to comfort for the child.

This study is sensitized to three key theoretical frameworks, and a nursing lens is laced throughout this study, that guides decision-making in the research process. The strength of the nursing experience with children is an overarching influence which results in significant process oriented outcomes for children in this study.

Children in the Hospital

Significant areas of study regarding children in the hospital and stress are categorically outlined to include: a) hospitalization as a stressor; b) fear; c) anxiety; d) discomfort of the hospitalized child. A summary identifies changes that have improved the hospital stay for children, and gives rationale for the vital necessity of continued research in this domain.

Hospitalization as a Stressor

Several researchers have identified stress related to hospitalization for children through specific experiences that occur during that time. Children described the stressor of hospitalization disrupting their usual routine, going to school, being with their families and friends and playing games (Haiat, Bar-Mor, & Shochat, 2003; Sartain, Clarke, & Heyman, 2000). Painful procedures, especially those involving needles are universally regarded as negative stressors for hospitalized children (Bossert, 1994; Coyne, 2006; Forsner, Jansson, & Sorlie, 2005; Lindeke, Nakai & Johnson, 2006; Melnyk, 2000). When children narrated about their stress and illness during hospitalization, contrasting verbs immersed including scared, sad and hurt versus confident, cozy and playful (Forsner, Jansson, & Sorlie).

Post-Hospitalization Disturbances. An early study by McClowry (1991) suggested school-age children ages eight to twelve had significant behavioral disturbances after being hospitalized. More recent studies identify Post-Traumatic Stress Disorder (PTSD) for children after hospital stays (Depp Cline, Wilson, & Thompson Prout, 2011; Nelson & Gold, 2012). Although PTSD is identified, and hospitalization is a catalyst, no clear remedies to effectively prevent and treat this stress disorder, and mitigate the negative effects that result after a child has been hospitalized.

Fear During Hospitalization

Fear is defined as a potent, biologically driven, motivated state where a single threat guides behavior (Bay & Algase, 1999). Fear is typically a defensive response to a perceived threat or the result of exposure to a single cue presented in the environment that is reminiscent of the original fear experience. Very little is known about hospital

related fear identified by children themselves. Earlier studies about children's fear and hospitalization report findings through adult informants and suggest 19%-68% of children were afraid of injections and needles (Kettwich et al., 2007; Majstorovic & Veerkamp, 2004). Parents reported fears of pain, strangers, separation from primary caregiver, difficulty breathing, blood samples, nursing procedures, and the fear of being held still (Gozal, Drenger, Levin, Kadari, & Gozal, 2004; Gullone, 2000; Nicastro & Whetsell, 1999; Snyder, 2004). When threatened during hospitalization, researchers found that children wanted their parents nearby to feel safe, and preferred the things and people with which they were familiar (Runeson, Hallstrom, Elander and Hermeren, 2002).

Anxiety During Hospitalization

Although fear and anxiety are often used interchangeably in the literature, anxiety is uniquely different from fear. Anxiety is defined as an elevated sense of uneasiness to a possible threat, which is not consistent with the expected event (Bay & Algase, 1999). This feeling results in a mismatch between the next likely event and the actual event. Anxiety is often equated to the fear of the unknown. There is early evidence in the literature regarding anxiety and hospitalization from the child's point of view through their drawings (Board, 2005; Brewer, Gleditsch, Syblik, Tietjens & Vacik, 2006; Clatworthy, Simon & Tiedeman, 1999a, 1999b; Tiedeman & Clatworthy, 1990). Drawings were analyzed through a projective assessment to measure the child's states of anxiety in these studies. A Child Drawing Hospital Instrument (Clatworthy, 1981) measured anxiety objectively by analysis of the drawings. The intention of this instrument was to produce a non-threatening, developmentally sound, easily administered

and scientifically scored mechanism that enhanced the fun for the child research participant (Clatworthy, Simon & Tiedeman, 1999a, 1999b). Other scholars have utilized facilitative drawing techniques with interviews to assess anxiety in hospitalized children (Matsumori, 2005; Smith & Callery, 2005; Wennstrom, Hallberg, & Bergh, 2008). These studies suggested a wide range of anxiety responses in children related to the stress of hospitalization.

A critical integrative review of multiple instruments claiming to measure both anxiety and fear of hospitalized children was recently conducted (Foster & Park, 2012). The researchers suggested that tremendous efforts towards measuring anxiety and fear of hospitalized children are evident with only five instruments supporting adequate reliability and validity. Foster and Park identify quantitative measurement of these emotional reactions is challenged by the complex nature of the distress and discomfort for children, and that fear and anxiety potentiate not only pain but multiple symptoms of overall distress and discomfort. They suggest vital research needs to continue to support children's communication and interpretation of what they feel.

Discomfort During Hospitalization

Pain and discomfort is an identified stressor for a child in the hospital (Carney et al, 2003; Kortessluoma, Punamaki, & Nikkonen, 2008). Relief of pain and discomfort for children has improved over the last 20 years with the introduction of pharmaceutical measures to relieve children's pain and enhance comfort. Multiple tools have been developed to measure the distress in children (Ambuel, Hamlett, & Marx, 1992, Johanssen & Kokinsky, 2009; McConahay, Bryson, & Bulloch, 2006) so adequate treatment of pain and discomfort could improve for the child in the hospital. In clinical

practice, nurses have framed their care and often their comfort for patients in a pain paradigm that is evidenced through tools, national guidelines and quality assurance programming in hospitals (Oakes, Anghelescu, Windsor, & Barnhill, 2008). Nurses contract with parents to achieve this goal in a pediatric health care setting (Brady, 2009; Pruitt, Johnson, Elliot, & Polley, 2008; Schmidt, Bernaix, Koski, Weese, Chiappetta, & Sandrik, 2007). The majority of studies regarding children's pain have been done utilizing quantitative means to assess, measure, and interpret their discomfort (Table 2). Additionally, pain, discomfort and comfort have been consistently assessed through the parent's or nurse's point of view (Claar, Guite, Kaczynski & Logan, 2010; Claar, Simons & Logan, 2008; Ford & Turner, 2001; and Forgeron et al, 2009). Consistent in the findings from these studies are the incongruences with an adult's view versus a child's perception. In Table 2, a summary of the current research and clinical advancement regarding pain and comfort of children is highlighted.

Table 2.
Synthesis of Recent Literature: Pain and Comfort in Children

<i>Topic: Pain</i>	<i>Authors</i>	<i>Significance</i>
Post-op Pain Scale for Brazilian infants and children	Alves, Carvalho, Wagner, Castoldi, Becker & Silva (2008)	Validation of quantitative measures for pain of infants and children.
Children's Pain Behavior and Development	Breau & Camfield (2010)	Examination of pain and development congruency
Information Systems to Improve Pain	Bruce & Franck(2005)	Utilization of the world-web for pain advancement
Parent's Perceptions of Child's Pain and Distress	Caes, Vervoort, Eccleston, Vandenhende, & Goubert (2011)	Parental catastrophizing about child's pain/facial expressions.
Use of the Shotblocker for Immunization pain	Cobb & Cohen (2009)	RCT for relieving immunization distress with the Shotblocker
Pediatric Pain: Contextual Issues	Cohen (2007)	The context of pain and significance; Where is pain.

Pediatric Pain at end of Life	Collins & Frager (2006)	Dying children and pain management; Critical issues
Children's Perceptions of Pain	Esteve & Marquina-Aponte (2012)	Children's pain perceptions transition from concrete to complex related to developmental age.
Cultural and Ethnicity Influences on Children's Pain	Finley (2009); Fortier, Anderson and Kain (2009)	Assessment of pain in children studied suggesting cultural and ethnicity differences in findings.
Development of Language for Expression of Pain in Children	Franck, Noble, & Lioffi (2010)	Language development to assist young children in expression of pain with minor illnesses and injuries.
End-of-life Pain Management	Friedrichsdorf & Collins (2007)	Pharmacologic/non-pharmacologic parameters of pain management for end of life
Nurses' Characteristic, Inferences and Stereotyping of Children's Pain	Griffin, Polit & Byrne (2007) Griffin, Polit, & Byrne (2008)	Nurses' characteristic, Inferences and stereotyping of children's pain: How it affects care.
Parental Perceptions	Haralstad, Sorum, Eide, Natvig, & Helseth (2011)	Pain in children and adolescents and its impact on daily life; parents' perceptions.
Non-Pharmacologic Pain Relief	He et al (2010); He et al (2011); He, Polkki, Vehvilainen-Julkenen & Pietila (2005); He vehvilainen-Julkenen, Polkki & Pietila(2010); Hong-Gu, Tat-Leang, Riawati, Rajammal, Vehvilainen-Julkenen, & Polkki (2010);	Chinese nurses' use of non-pharmacologic pain relief in children's post-operative pain relief. Massage, thermal regulation, imagery, and positive reinforcement and demographics of nurses using them.
Parental Satisfaction	Hong, Murphy & Connolly (2008)	Parent's perceived satisfaction of pain management PICU patients
Parent/Caregiver Response to Pain	Huguet, Miro & Nieto (2007)	Validation of the IRPEDNA for parents
Reducing Needle stick Pain	Jeffs, Wright, Scott, Kaye, Green & Huett (2011)	Evidence-based practice approach to reduce children's needle stick pain.

Psychological Interventions for Chronic Pediatric Pain	Kashikar-Zuck (2010)	Meta-analysis positive outcomes psychologically based therapies for pediatric chronic pain
Pain Management Interventions for Parents in the Emergency Room (ER)	LeMay et al (2010)	RCT regarding pain management technique to reduce pain for children in ER
Managing Cancer Pain	McCarthy, Chammas, Wilimas, Alaoui, Harif (2004)	Cancer pain in children in Morocco.
Children are Not Little Adults	McGrath (2005)	Differences in children for pain and comfort management
Measurement Advancement: The Color Analog Scale	McConahay, Bryson, & Bulloch (2006); McConahay, Bryson & Bulloch (2007)	Advancement in defining mild, moderate, to severe pain in children in the ER with the Color Analog Scale.
Narratives of Children with Chronic Pain	Meidrum, Tsao, & Zeiter (2009)	Chronic pain and treatment outcomes gleaned through narratives.
Rating Scale Research and Analgesia	Melby, McBride & McAfee (2011)	Acute pain relief studies with children, analgesia, rating scales.
Wound Dressings and Pain	Nilsson & Renning (2012)	Pain management during wound dressings in children.
Pediatric Pain in Cancer Patients: QA	Oakes, Anghelescu, Windsor, & Barnhill (2008)	QA program to improve pain management of cancer patients
The Primal Face of Pain for the Child	Schiavenato (2008)	Pain complex/Facial Expressions unreliable.
Children's Expectations of Pain...Following Tonsillectomy	Sutters et al (2007)	Children's expectations about pain medications and experience with non-pharmacologic pain management.
Nurses' Perceptions: Cognitive Representations	Van Hulle-Vincent (2007)	Nurses' perceptions Kaplan's theory
Nurses' Perceptions of Pain and PIV's	Papa & Zempsky (2010)	Nurse and patient satisfaction related to peripheral intravenous therapy for children.

Nurses' Responses to Vignettes on pain; Improving Assessment Skills	Van Hulle Vincent & Dreyers (2004); Vincent & Gaddy (2009); Johnston et al (2007):	Nurses' attitudes regarding pain; Administering analgesics for children; Improving assessment with coaching
Children's Ratings of Pain and Children's Memories of Pain	VonBaeyer et al (2009); VonBaeyer, Marche, Rocha, Salmon (2004)	Response biases in children when rating pain; Evidence of memory for children with pain.

Topic: Comfort	Authors	Significance
Theory Driven Improvements Care and Comfort of the Hospitalized Child	Alsop-Shields & Mohay(2001)	Bowlby and Robertson theory; crusaders for improvements.
Comfort Seeking/Genders	Buss, Brooker, & Leuty (2008)	Differences between boys & girls and comfort seeking behaviors
Meaning of Comfort/Cancer	Cantrell & Matula (2009)	Perceptions of adolescents and adult survivors of pediatric cancer and retrospective meaning of comfort
Physiologic Correlates of Comfort	Foster, Yucha, Zuk & Vojir(2003)	Correlates explored in healthy children
How to Calm and Comfort	Hong, Miller & Church (2006)	Educational/psychological experts anecdotal of how to comfort children
Comfort Journey Memoir	Hood (2008)	A mother's memoir of a comfort journey in grief.
Tools for Measure COMFORT & FLACC	Johansson & Kokinsky (2009)	Quantitative use of tools that claim to measure comfort and pain PICU
Comforting nurse: The Patients' perceptions	Jouybari, Oskouei, Ahmadi (2005)	Exploring patients' experiences and perceptions of comfort
Comfort Theory Applied to Pediatrics	Kolcaba & DiMarco (2005)	A Case study application of Kolcaba's Theory on a post-op peds.
Comfort and the Built Environment	Kowaltowski, Filho, Labaki, Mikami, Pina, & Bernardi (2004)	Educational context of comfort for children/built environment theory
Comfort through Environmental Focus	Linder & Christian (2011)	Sound, light, and temperature in the environment of nighttime care for children with cancer
Comfort of the Unaccompanied Hospitalized Child	Livesley (2005)	Landmark exploration regarding comfort of those children unaccompanied by parents to the hospital.
Parental Presence and Comfort	Piira, Sugiura, Champion, Donnelly, & Cole (2005)	Parental presence and outcomes of comfort
Comfort in Raising Children with Chronic Conditions	Rehm & Bradley (2005)	Social safety and comfort for families raising children with chronic conditions.

Comfort Philosophy in a Pediatric Institution	Schechter (2008)	Institutional parameters for the context of comfort in a pediatric setting.
Verbal and Tactile Comfort	Triplett & Arneson (1979)	Seminal attempts for alleviation of distress of the hospitalized child.

Although findings suggest progress in some relief of pain for children, and improved care, children continue to experience moderate to severe, unrelieved pain and discomfort during hospitalization (Johnston, Gagnon, Pepler & Bourgalt, 2005; Manworren, 2007; Olmsted, Scott and Austin, 2010; Schechter, 2008; Stevens, et al 2012). This unrelieved pain is a significant stressor for the hospitalized child. In addition, it is apparent that children’s views differ from those of their parents, and it is important to assess pain from a child’s point of view.

The Constellation of Coping and Comfort for Children

Within the constellation of stress and hospitalization for the child, a complimentary coping and comfort research has evolved to ease the detrimental effects for the child.

Comfort. The comfort of a child through hospitalization is a major concern for parents and nurses. Comfort has been eloquently described by scholars through an adult lens (Bottorf, 1991; McIlveen & Morse, 1995; Morse 1983, 2000b; Morse, Bottorff & Hutchinson, 1994; Seifert, 2002) and researched with adult patients (Asa, Katie, Arne, & Bengt, 2008; Evans & Hallet, 2007; Newson, 2008; Nuccio & Nuccio, 2009; Roche-Faye & Dowling, 2009; Tutton & Seers, 2004; Waldrop & Kirkendall, 2009). Surprisingly, there is a paucity of research exploring the meaning of comfort for the hospitalized child

(Angstrom-Brannstrom, Norberg & Jansson, 2008; Cantrell & Matula, 2009 & Kolcaba & DiMarco, 2005; Woodgate & Kristjanson, 1996).

Encouraging in the recent literature on comfort, is a growing exploration for the meaning of comfort for children through education, psychology, and preventative health contexts (Abbe et al, 2007; Angstrom-Brannstrom, Norberg, & Jansson, 2008). One study by Cantrell and Matula (2009) explores the meaning of comfort. This is a retrospective study illuminating perceptions of adolescents and young adults who formerly had experiences with pediatric cancer. Findings suggest that comfort during cancer treatment was of prime concern. Pioneer studies on gender and comfort seeking behaviors (Buss, Brooker & Leuty, 2008) and comfort in a built environment (Kowaltowski et al, 2004) align with exploratory studies looking at comfort to remedy stress in the hospitalized child.

The Essence of the Parent-Child Relationship. It has been well established that a critical part of a child's coping ability while in the hospital setting is the parent/guardian presence (Dudley & Carr, 2004; Pederson, 1994; Piira, Sugiura, Champion, Donnelly, & Cole, 2005; Stephens, Barkey & Hall, 1999). Some early studies have documented comfort as having its roots in the parent-child relationship (Cote, Morse, & James, 1991; Herterich, 2005; Morse; 1983; Morse, 1992). A recent series of work that examines the parent-child relationship (Pridham, Lutz, erson, Riesch, & Becker, 2010) suggests that the moment-to-moment interaction between a parent and child, and the challenges and opportunities that arise through this interaction is the cornerstone of how a child perceives and makes sense of his/her world. Researchers have indicated that this relationship and parental presence may be the greatest source of

comfort for a child during the stress of hospitalization (Mangurten, Scott, Guzzetta, Clark, Vinson, & Sperry 2006; Pruitt, Johnson, Elliott, & Polley 2008; Stratton, 2004). One study concludes that parents are the best medicine to manage children's pain (Franck, 2007).

Although there is evidence in the literature of advancements in pain management and comfort of the hospitalized children, the majority of studies have been conducted from a quantitative lens. In addition, the essence of pain and discomfort for the child has been assessed through the parents' or nurses' frame of reference, leaving the child's voice silent. When children were asked about their perceptions, a heavy reliance on the use of standardized external measures, questionnaires and surveys were utilized. These methods preclude the child from constructing and reporting their own reality, as reality is already defined by a predetermined set of responses (Woodgate, 2001).

Chapter Summary

Knowledge regarding stress, fear, anxiety and discomfort experienced by hospitalized children, and the significance of coping, comfort and the parent/child relationship, have directed changes to occur in the hospitalized setting. Health care providers have attempted to improve the hospitalization experience for children. These improvements include a more child and family-centered environment, liberalized hospital visitation, parental rooming-in, shortened hospital stays, inclusion of Child Life programs and pet therapy in the attempt to decrease the stress of the hospitalized child (Gardner, Woollett, Daly, & Richardson, 2009; Jolley & Shields, 2009; Kaminski, Pallino & Wish, 2002; Lambert, Glacken & McCarron, 2011; Urbanski & Lazenby, 2012). However, the current stress of hospitalization now encompasses higher acuity levels, increased use of

technology and repeated and extended hospital stays for children with illness (Rempel, 2004; Wilson, Megel, Enenbach & Carlson, 2010). In addition, very few studies have addressed the current state of stress for the hospitalized child from the child's point of view (Carney et al, 2003; Coad, Coad, & Theibe, 2005; Knighting, Rowa-Dewar, Malcolm; Kearney & Gibson, 2010; Pelander & Leino-Kilpi, 2010; Wilson, Megel, Enenbach, & Carlson). Therefore, it is imperative that nurse researchers explore the perceptions of children regarding stress in the current hospital environment to base nursing interventions on sound truths from a child's view.

CHAPTER 3

METHODOLOGY

Qualitative research describes and builds theories about human behavior, with emphasis on the implicit meanings of the participants' words and actions (Denzin & Lincoln, 2003). Qualitative methods are intended to help researchers understand the meanings participants assign to their everyday lives and to elucidate participants' understanding of social and psychological processes underlying their behaviors (Denzin & Lincoln). One qualitative method, interpretive description, is applied to explore perceptions of school-age children's experiences during hospitalization. A detailed overview of design, human subjects protection and planned data collection and analysis techniques for child participants in this study is described.

Design

The design for this inquiry was a non-categorical, qualitative research approach, interpretive description, outlined by Thorne, Reimer-Kirkham and MacDonald-Eames (1997). The essence of this approach is the description of a child's experience through the analysis of the child's interpretation of that experience; that being the child's perceptions of stress while in a hospitalized setting. The analysis constitutes an interpretation of the experience to understand its meaning. The rationale for choosing this method is that it is appropriate for answering the research question, as it is grounded in an interpretive orientation that allows for shared realities, but also acknowledges the constructed and contextual nature of the individual child's experience (Thorne, 2013). Including children in the dialogue about their direct experience regarding a phenomenon has the potential to inform caregivers of the implications and outcomes of these

experiences for young children (Dockett & Perry, 2003). Thorne et al (1997) suggest that interpretive description meets the applied practice needs of nursing and, in particular attends to acknowledgement of the aggregate without negating the individual. This process can enhance individualization in practice, aiding the provision of accurate and congruent care to the hospitalized school-age child. This study design illuminates findings that contribute to the understanding of how school-age children, who are acutely ill in the hospital, perceive stress, and identify possibilities for child-defined nursing interactions that could remedy and comfort a child through this experience.

Setting

The setting for this study was a 28-bed acute pediatric medical-surgical school-age unit in a large urban children's hospital in Northeast Ohio. It was anticipated that this unit would yield the targeted number of participants. A second 22-bed acute pediatric medical-surgical infant through adolescent floor was utilized for data collection. The hospital is a 253-bed free standing children's hospital that serves a multi-state region with an integrated system in 80 locations serving infants, children and teens, handling 600,000 in-patient and out-patient visits per year (Children's Hospital Medical Center of Akron (CHMCA), 2013). The first unit admits patients with acute medical and surgical conditions for children ages six through twelve years of age. The second unit admits patients from infancy through adolescent who have medical- surgical conditions.

Sample

A convenient sample of children seven through nine years of age who were hospitalized, was utilized for this study to allow for exploration of maximum variation in the phenomenon studied through participant selection (Lincoln & Guba, 1985;

Sandelowski, 1995b). Participants who met criteria, were evaluated by the researcher within the context of their illness to feel well enough to draw and give information relevant to the study aims. As suggested by Thorne (2008), participant selection was aimed at enabling understanding of the general and the particular both within and across themes. Thorne proposes identifying a main grouping and condition of participants that will ensure inclusion in the study and eventual findings that have potential of “ringing true or seeming reasonable to the intended audience” (Thorne, p. 91). School-age children from age seven to nine years were recruited in the study because they typically have the ability to read and understand simple explanations, have the motivation to draw a picture, and have the social skills to answer questions asked by adults (Stare, 2011). Although an age range was targeted, each child was treated as an individual, with unique and different experiences (Morgan, 2005).

Inclusion and Exclusion Criteria for Child Participants. The participants for this study were selected for initial recruitment with attention to the following inclusion criteria: a) children between the ages of seven years and nine years (84 months and 119 months); b) fluent in the English language; c) hospitalized for an acute medical or surgical condition; d) have the ability to utilize dominant writing hand for drawing a picture; and e) intact vision, hearing and speech as reported by parent. The focus for this study was children admitted to these units for acute medical or surgical conditions, between the ages seven to nine years of age without known cognitive or developmental delays.

Exclusion criteria for this study included: a) children with a reported developmental delay; b) children with a diagnosed mental health or behavioral disorder;

c) children in protective custody/foster care; d) children who are hospitalized for intentional trauma (child abuse); e) children who do not speak English; and f) children who are severely ill or with impending death. Rationale for the exclusion criteria for this initial study was to eliminate the possibility of developmental, behavioral or trauma related issues interfering with the child's ability to draw and tell about their experience. Patients with neurological disorders admitted to this second unit did not meeting the inclusion criteria for the study. Although the exclusion criteria was listed for this initial study exclude some children's voices, the excluded children in this study have important messages that are beyond the limits of this study, but will be captured in future research studies.

Inclusion and Exclusion Criteria for Parent Participants. Inclusion criteria for the parents were to have at least one parent of the child participate who is the legal guardian of the child. Inclusion criteria for the legal guardian was as follows: a) fluent in the English language, and b) the ability to read and write to complete the consent, HIPAA authorization, and demographic questionnaire. Exclusion criteria followed included: a) a parent who was not a legal guardian of the child and b) any parent being investigated by social service for neglect or abuse of the child.

Sample Size. The sample size for this study was 30 child/parent dyads. The estimated sample size needed for this study was between 30 and 60 child/parent dyads. For this study, it was anticipated that 150 participants would be approached for participation in the study, and a minimum of twenty percent of those approached would be recruited for full study participation (20% of 150 is 30 participants). Morse (2000a) identifies the following factors for consideration when estimating sample size: a) scope

of the study; b) nature of the topic; c) quality of the data; d) study design; and e) use of shadowed data. The scope of this study was moderate in breadth and depth, looking at a specific phenomenon of stress; within a specific population, school-age children, ages seven to nine; and within a limited context, hospitalization. The nature of the topic was obvious and clear, so the picture drawn by the child with their story narrated would be easily obtainable. However, each child's temperament and accessible expression in drawing and telling was unique. In addition, in the process of interviewing children, parent gatekeepers were anticipated that may limit access to the interviews and drawings of children.

The quality of the data was of some consideration for this study, as child participants varied in their ability to express their thoughts and feelings regarding the topic. It was anticipated that some children would take more time, be less distracted, have more experience, and be more willing to share their perceptions, which would affect the quality of the data. In addition, due to the child participant experiencing an acute illness or surgery during the time of data collection, it was anticipated that pain, discomfort, and anxiety of the hospitalized child could affect the type of expression and interpretations. The study design was limited to one interview, and a single draw and tell process for each participant, thereby possibly requiring more participants when considering sample size. Finally, the use of shadowed data was utilized, as children share experiences of stress and hospitalization related to their friends or family members' experience. The use of these data provided a range of experiences and the domain of stress and hospitalization beyond a child's single experience.

Feasibility of projected sample size. The number of participants that would meet criteria and are admitted on a monthly basis was not available for predetermination. According to predicted statistics of past admissions to the unit regarding age, diagnosis, and length of stay, there was a possible interface with 250 patients meeting inclusion per month on the first unit (Personal Communication, Admissions Bed Coordinator, August 30, 2013). It was accurately anticipated that there were at least 300 child/parent dyads who meet inclusion criteria available for recruitment to the study over the three month period anticipated for data collection.

Human Subjects Protection

The study was reviewed and approved through the University of New Mexico's Health Science Center Human Research Protection Office (HRPO) and the Akron Children's Hospital Institutional Review Board (IRB) in August of 2013 (Appendices N-R). A modification was approved several months into the study, during data analysis, which addressed key credentialing parameters of the members of the clinical check group involved in the analysis of the data who may not have been on the initial application reviews for human subject protection (Appendix S).

Consent and Assent. Informed written consent was obtained from the parent and/or legal guardian of the child participant prior to the study participation (See Appendix C). In addition, informed assent was obtained from each child participant (See Appendix D). It was critical to uphold the ethically sound standard of giving children a clear informed choice of being a participant in research. It was vital for child participants to gain a clear explanation and voice understanding and full knowledge of their role as a research participant, separate from parental consent (Bray, 2007). I

designed a developmentally designed pictorial assent script (Bray) and utilized the script to help child participants visualize and understand the process of research and the meanings of confidentiality, assent, tape recording equipment, parent presence and participation, and voluntary withdrawal from the study (See Appendix F). Although a child initially gave assent to participate in this study, it was imperative that I was sensitive to any cues that the child gave towards not be a willing participant, or showing indicators of wanting to withdraw during data collection (Horstman, Aldiss, Richardson & Gibson, 2008). In addition, Skanfors (2009) recommends researchers working with children should employ an ‘ethical radar’ throughout the research process. If a child initially gave assent, the process should be viewed as ongoing, and warranting regular review rather than a on-off process. I was vigilant throughout the assent and data collection process of this concept, advocating for informed assent throughout the study.

Careful choice of data collection methods with children was imperative to respect children’s participation rights (Powell & Smith, 2009). Children are more likely to respond openly and honestly if they feel respected and safe. This process usually depends on the skill of the researcher putting them at ease, minimizing the distance between the adult and the child, and establishing shared interests and dialogue which put the child in the position of the expert (Freeman & Mathison, 2009; Gollop, 2000). Assurances and tangible choices were in place to reduce power imbalances, and build a relationship with the child and their family to preserve children’s participation rights.

Personal Health Information Consent. In addition to a specific informed consent from the parent, an “Authorization for Release of Medical Information for Research” was given and explained to parents (See Appendix E). I offered explicit

information that I was not accessing the direct electronic medical record of the child, but rather collecting demographic data from the parent to be utilized for description of the aggregate sample. Following this explanation, the parent/legal guardian was given time to have their questions answered, and if they consented, they complied to sign the authorization.

Participation Incentives for Child Participants. There was a paucity of research guidelines regarding the appropriate amount, types and schedules of incentive recommended with young child participants in research studies. Lobo (2007) and DeSantis (2007) frankly debate the needed balance between remuneration and coercion regarding payment to vulnerable child participants in research. Researchers emphasized: a) developmentally appropriate rewards (Driessnack, 2012) and b) safeguards to avoid the incentives resulting in coercion (Rice & Broome, 2004). For this study, children were given a choice of different art bags filled with developmentally appropriate art tools including crayons, pencils, markers, paper, scissors, stickers and stencils. This compensation addressed developmental congruency and sensitivity to the avoidance of a coercive incentive.

Participation Incentive for Parent Participants. The parents were given a choice between a five dollar coffee/tea card for the gourmet coffee cart in the welcome lobby, or a five dollar gift card for the gift shop. This small incentive acknowledged the work of the parent in the study and encouraged the parent to take a break during the stressful hospital stay.

Recruitment

The leadership team on the in-patient medical-surgical units was informative and directive with assistance in planning for successful recruitment of participants. There was a multi-disciplinary, family-centered team meeting that took place every morning on the units where the cases of in-patient children were reviewed. The team consisted of the Clinical Coordinator (nurse who is in charge of the unit resources that day), the social worker, the chaplain, the dietician, the hospitalist (physician in charge of the medical needs of the patients on the unit), the case manager, child life specialist and other team members as needed. Through a student research contract between the University of New Mexico and Children's Hospital, I gained access to attend these meetings for planned recruitment. When my schedule would allow, I planned to receive an overview of the patient population on the units from the Clinical Coordinator or relief charge nurse to identify which patients met inclusion criteria for the study.

Marketing for Recruitment. To maintain an ongoing communication regarding recruitment, a flyer was placed in the admission packets for children between seven and nine years of age to notify families that the study is taking place (See Appendix I). Another strategic flyer was placed on the playroom door where parents frequently interact with their child and the health care team (See Appendix I). This spot for the flyer also attracted those children who were feeling well enough to go to the playroom, and would also be able to participate in the study.

Procedure for Data Collection

Demographic Questionnaire for Parents. A demographic questionnaire to be completed by the parents about their child and family demographics was developed. The

parents would be asked to complete a demographic questionnaire regarding their child and family (Appendix G). The questionnaire assessed the following: a) child's age in years and months; b) gender; c) grade in school; d) ethnicity; e) what brought the child to the hospital; f) how long the child's been hospitalized; g) what things the parent was worried about regarding their child's hospital stay; h) if it was the first time their child was hospitalized; i) reasons for past hospitalizations; j) special doctors the child sees; k) things the parent is worried about regarding their child's stay; l) number of siblings, ages and gender; m) who will be visiting the child while he is in the hospital; n) what they think is most stressful for the child during hospitalization; o) what comforts their child during hospitalization; and p) anything else they would like to tell me about their child. The parent questionnaire was utilized to collect specific demographic data about the child and family, and to become sensitized to the parent's interpretation of stress for the hospitalized school-age child. The full analysis of the parent questionnaire is beyond the scope of this study, and with approval from the dissertation committee and consent of the parents, the open-ended questions submitted by the parents will be examined through a secondary analysis for a future study. This option was included and explained to the parent on initial consent.

The Mosaic Approach for Children in Research. A Mosaic approach (Clark & Moss, 2001) was utilized to explore the perceptions of stress of the hospitalized school-age children for this study. This approach employed methodology for children that incorporated their strengths, rather than weaknesses (Clark, 2004). A combination of data collection techniques was utilized including a drawing and an oral retelling as a joint representation of the lived experience of stress.

Draw, Write and Tell Technique for Children. Children may know and feel more than they are able to describe, therefore using drawings combined with writing and interview can be a powerful way of accessing their accounts (Pridmore & Bendelow, 1995; Piko & Bak, 2006). A draw and write technique (Pridmore & Bendelow) has shown to be an effective way to elicit children's views within health care settings (Driessnack, 2006; Franck, Sheikh, & Oulton, 2008; Horstman & Bradding, 2002; Oakley, Bendelow, Barnes, Buchanan, & Husain, 1995). In addition, Driessnack suggests that the draw and tell technique for illuminating a child's experience may be one of the "most cost-effective, portable, and relevant ways of accessing and privileging" (p.1432) the voices of children in any arena. For this study, the child was asked to draw a picture of a child in the hospital setting.

Children's drawing as a form of narrative. A growing body of literature advocates the use of narrative inquiry when conducting research with children (Engel, 1999; 2005; Lancaster & Kirby, 2010; Maybin, 2006; Harcourt, Perry & Waller, 2011). Children's interviews coupled with an activity that decreases the stress of pointed interview questions, is a valued technique to gain insight into a child's experience of their world (Engel, 2005; Freeman & Mathison, 2009). Piaget (1954) proposed that children have thoughts and experiences worth knowing about, and tend to be very different from an adult interpreted view. Conducting this type of inquiry with children captures the social and cultural context through which children view their world (Dockett & Perry, 2005). It provides a researcher with an opportunity to view the child's experience from their own perspective, acknowledging the child as an expert in their own life (Clark & Moss, 2001). Capturing children's perceptions regarding their experiences within the

context of the health care setting was of specific interest for this study (Dreissnack & Furukawa, 2012). The child's narrative and picture gives a window into the perception of the child's view about hospitalization. Giving a child voice through a multiple expressive media of drawing and telling has the potential to shift the focus from adult-determined interests and agendas and redirect them, and generate new child determined hypotheses (Pound, 1999).

Drawings are useful tools for research with children as they provide the child with a familiar and non-threatening activity. The child can change and add to the drawing as they choose, and as drawings take time, a quick response is not demanded (Einarsdottir, 2007). These artistic expressions are a powerful medium to elicit thoughts, feelings and experiences of children and often tell stories to accompany their drawings (Ehrlen, 2009). From drawings, a memory or experience that the child may not be able to verbally express, often emerges, and provides a greater richness of thought and expression for the child.

Drawing and telling technique. Interviewing children and collecting children's drawings are well-established individual data collection tools; the two techniques together provide a holistic approach to enriching the individual child narrative (MacDonald, 2009). The process of drawing and telling gives the child a shared meaning of the two modes (Wright, 2007). The children in this study were asked to tell a story about their drawing to reveal their understanding in a different but complementary way (Smith & MacDondald, n.d.). Emphasis was placed on listening and attentively watching the child while they drew, instead of trying to analyze their drawing, as the child's narratives and interpretation of their drawing can give a window into their perceptions, as

compared to a researcher's interpretation of the drawing (Clark, 2005; Einarsdottir, 2007; Punch, 2002; Veale, 2005). The story was audiotaped for later transcription and analysis. In this way, the coinciding data analysis became a process whereby the meanings were co-constructed by the researcher and the child.

Immediate benefits for the child participant with draw and tell technique. The draw and tell method of data collection for this study supports an additional immediate benefit to the child participants in the study. This method is a form of emotional storytelling that engages a child to express his or her feelings regarding a stressful situation, such as hospitalization. Expressing feelings can assist children in coping by providing an opportunity for them to work through, reflect and find meaning in their experiences (Rollins, Drescher & Kelleher, 2012). Dealt with openly and honestly, difficult feelings lose some of their strength. For example, programs intended to promote expression of feelings have achieved positive results on psychosocial measures in grieving children (Heiney, Dunaway, & Webster, 1995), children whose parent or grandparent has cancer (Heiney, & Lesensne, 1996), child who witnessed violence (Rollins, 1997), children with leukemia undergoing painful procedures (Favara-Scacco, Smirne, Schiliro & DiCataldo, 2001), and school-aged children of alcoholics (Emshoff & Anyan, 1991). The process of drawing and then narrating perceptions of stress in the hospital potentially gave the child participants in this study the immediate benefit of working through their feelings regarding hospitalization.

Collection of Data with Child. After consent from the parent and assent from the child was obtained, a mutually optimum time for data collection was negotiated with the child, parent and the bedside nurse. The elements for drawing and recording were

brought to the patient's room. The parent and family were given the option to stay during the data collection to ensure comfort for the child, and were asked to avoid participating and asked not to prompt the child during drawing and telling. Although current research available (Gardner & Randall, 2012) suggests that parental presence during interview type data collection could interfere with the child true voice, a child's need for comfort and security in a hospital setting overrides dismissing the parents during collection of data for this study. Most parents and families opted to stay with their child. In addition, siblings could be attracted to the process of drawing with their hospitalized sibling. This is particularly the case for a younger sibling. Therefore, I planned to offer the sibling drawing materials and a piece of paper to maintain family-centered inclusiveness in the process of data collection.

Privacy. Privacy for the data collection process was attended to by planning to interview the child participants in their private rooms. The ideal situation was to have no other health care team members in the room except for the nurse researcher, child participant and parent(s). However, due to the unpredictable nature of hospitalization, there were anticipated interruptions to the private research study process. When an interruption would occur, data collection would be stopped momentarily until the room was private again. I recorded field notes, documenting the time and specific nature of these interruptions and possible effects on the child during data collection.

Choices for Child Participants. Multiple choices for the child participants were planned throughout the data collection process to empower the child, and engage them throughout the study. Children were given the choice of where to sit, a choice of a plain

white or manila 8 X 11 inch paper, as well as a choice of drawing instruments that ranged from new colored pencils, new thin colored markers, or a new box of crayons.

The blank surface of paper framed by the outer edges provided a secure and clear boundary, and a familiar, receptive and passive medium for expression (Sieden, 2001). Drawing instruments can be viewed as aggressive and exist on a continuum from fluid to controlled, with finger paint and pastels at the fluid end and pencils at the controlled end (Robbins, 1994; Seiden). A pencil is the most common controlled instrument used for marking, and markers and crayons are viewed as no-nonsense tools that are more decisive, committed and unable to be erased. Color is individual, culturally based and often used arbitrarily by children (Malchiodi, 1998). For this study, the children had a choice of drawing media on the controlled end of the continuum, so they remained privileged in terms of control (Dreissnick, 2006).

Each child was given the opportunity to see and manipulate the audio recorder prior to the start of data collection. They were given the choice of pushing the 'On' button when we started the audiotape, and the 'Stop' button when they said they were done. The child was given specific instructions on what they were expected to do, and then guidelines for the prompting of explanation of their drawing ensued as part of the draw and tell technique. Interview prompts and guidelines for the process of draw and tell were utilized to ensure comfort of the child during data collection and to elicit optimum thoughts, feelings, and perceptions of the participant (Appendix H).

Reflective Journal and Field Notes for Decision Making

As a pediatric nurse for thirty years, I brought strong clinical knowledge and some preconceived notions into the research process. That being said, a meticulous reflective

journal, field notes before and after each participant data collection, and specific analytic reasoning notes were recorded to track and enhance the decision- making process throughout the collection and analysis process. I was mindful of the truth value during data collection and analysis to ensure that research bias and over enthusiasm did not systematically skew the findings. It is recommended by Thorne (2008) that the interpretations be brought back to participants for critical consideration, but for this study, due to lack of access of the participants after hospital discharge, that process was not feasible. Sandelowski (2002) cautions researchers regarding member checking for some participants. For children at this age, it was not be advised, due to the possibility of the child forgetting what they said, or feeling compelled to agree with my interpretations, due to my adult status. Member validation processes were less useful for the validation of my own interpretations of the child's perceptions in this study (Sandelowski). To ensure critical consideration of the interpretations, a thoughtful clinical check process with pediatric clinical experts occurred during data collection, analysis and theme formation, outlined in the credibility section of data analysis.

Data Analysis

The specific aim of this study was to explore school-age children's perceptions of stress in the hospital through an interview draw and tell technique. The research questions included: 1) how do school-age children describe stress related to the experience of hospitalization? b) is stress of hospitalization related to anxiety, fear, and discomfort or other factors? c) how do school-age children cope with stress during hospitalization? and d) what does a child think a nurse can do to help a child with stress during hospitalization? These research questions were answered through the data

analysis of interviews, drawings and observations of the child in the hospital environment.

The data analysis was ongoing throughout the data collection process using a process of inductive analysis (Lincoln & Guba, 1985). The cumulative analytic findings informed and guided the ongoing data collection process, enabling the construction of the interpretive description. Verification strategies of concurrent data collection and analysis and constant comparative and iterative analysis served to locate the findings (Strauss & Corbin, 1990) and explained the interpretive description (Thorne, Reimer Kirkham & O'Flynn-Magee, 2004). Data collected on the parent demographic surveys was coded and entered into SPSS to obtain descriptive statistics of the sample; with open-ended questions interpreted in themes for secondary analysis.

Coding and Decision Making

The software program that was utilized for organization and retrieval of data was MAXQDA (MAXQDA 11, 2013). Determination of coding and how the codes shaped the interpretations unfolded as the data collection and analysis ensued, and expected conceptual clarity occurred. Thorne (2008) advocates for an initial “broad-based and “generic” coding scheme” (p. 147), until the researcher moves a significant distance down an analytic path that can clearly define the explicit and fine-tuned coding schemata. As Thorne suggested, the coding tool and software was used cautiously, as critical evaluation of the process was completed at each phase of analysis.

Threats to Meaningful Interpretations

Inductive analysis with interpretive description is a journey that can lead to certain threats to the final, meaningful interpretation (Thorne & Darbyshire, 2005). I was

vigilant to protect against a) premature closure; b) misinterpreting frequency; and c) over-inscription of self.

Premature Closure. An avoidance of premature closure with the formation of conclusions from the initial meaningful interpretations and early fittings of conceptual connections during data analysis was anticipated (Thorne, 2008). If the data fit too quickly in the thematic scheme, I considered the possibility of the relationship of my clinical knowledge and review of literature that could prematurely create this early connection, and limit a broader and more meaningful interpretation (Kearney, 2001). I was able to avoid this process by the delayed of coding and sorting, as Thorne (2013) advised. I took time to conceptualize and thoughtfully make connections to the concepts the children were speaking about related to stress of hospitalization.

Misinterpreting Frequency. Several interpretive errors can occur in the data analysis related to frequency, which I contemplatively monitored. The first was the possibility of things occurring very frequently and mislabeling them as relevant and important due to their frequency (Thorne, 2008). The second possible error was identifying a particularly graphic instance, and assuming that it happened frequently, even though it failed to appear in other cases. And finally, interpreting that because something was not revealed, that it does not exist. This was the most challenging pitfall regarding misinterpretation of frequencies, as it illuminated the possibility that the data set has not revealed all the possible variations that could lead to a robust interpretation.

Over-Inscription of Self. Inherent in the data collection and analysis process of children and parents in the hospital setting was the intense engagement of human interaction that occurred. Studying the perceptions of children, and the intimate

relationships that formed in this process, led to the possibility of being too self-absorbed in the process, detracting from the credibility of the findings. The term offered by Sandelowski and Barroso (2002) to describe this enmeshment is 'hyper-reflexivity'. I monitored, journal, and discussed this threat with my dissertation chair to avoid the possibility of enmeshment. I anticipated that at times this would be extremely difficult; as the nature of talking to and working with sick children and their families captured and held a certain intimacy in the relationship formed, especially in light of the topic of stress and coping that was the center of the discussions.

Credibility

To ensure credibility of the products of this interpretive description research, it was imperative to anticipate the need for strong evaluative criteria. Thorne (2008) upholds the general principles typically applied across the qualitative research continuum. She recommends four evaluative criteria that include: a) epistemological integrity; b) representative credibility; and c) analytic logic.

Epistemological Integrity. To meet epistemological integrity, this research process demonstrated a defensible sequenced thought process from the assumptions regarding the nature of the knowledge, through the methodological guidelines of decision making during the process of data collection and analysis (Thorne, 2008). This integrity began with research questions consistent with the epistemological standpoint of interpretation that carried through to analysis. Consideration of the child's interpretation of stress in the hospital was the center of this research, with decisions and analysis made precisely following an interpretive description. Epistemological integrity was strengthened by my rich pediatric nursing knowledge and evidenced by my nursing

practiced with a 30-year span. Working with children and families in a variety of health care venues brought integrity to the methodological framework that is assumed with interpretive description (Thorne, 2013).

Representative Credibility. Anticipated congruency for representative credibility was maintained by upholding the theoretical claims that resulted from the children who were sampled. For this study, only one interaction and collection of data from each child was conducted through the draw and tell technique. To confirm substantive completeness, demonstrated value for a triangulation of data sources is recommended (Breitmayer, Ayres, & Knafl, 1993; Sandelowski, 1995a). Since not all knowledge is reducible to language, and a child may not be able to express in words the multiplicity of their sensorial experiences (Bagnoli, 2009), data was collected through a variety of sources beyond the interview. Through the child's voice and drawing as well as my knowledge and observation of the child and his/her family in the hospital, information was gained beyond a single angle of vision (Thorne, 2008). In addition, I was a key instrument in the process of data collection, and utilized all senses including smells, sounds, sights and emotional culture of the child's environment (Sandelowski, 2002). I also engaged a thoughtful clinical check team of pediatric experts that enhanced credibility in the study.

Field notes both during and after the data collection with the child were meticulous and recorded the embodiment of my mind and soul to evidence this angle of vision, thereby enhancing substantive completeness and representative credibility.

Analytic Logic. Attention to analytic logic illuminated my thinking process and was evidenced through an audit trail, an explicit pathway of reasoning (Erlandson, Harris,

Skipper, & Allen, 1993; Lincoln & Guba, 1985) as the data were collected and analyzed. The value of thick description was resounded in the anticipated reports, grounded in interpretive claims of verbatim accounts from the data (Thorne, 2008).

Chapter Summary

The methodology of interpretive description was applied to explore perceptions of school-age children's experiences during hospitalization. Although a detailed overview of design, human subjects protection, data collection and analysis techniques for the child and parent participants is outlined, the emergent nature of this design directed avoidance of premature closure of the possible changes that would occur and enrich the actualization of implementation. Strict attention to the threats to meaningful interpretations and the guidelines for credibility were utilized to direct the analysis and forecast a significant contribution to this area of research.

CHAPTER 4

FINDINGS AND INTERPRETIVE THEMES

Chapter four presents a) a description of the context of the findings; b) the tangible procedures for recruitment, collection and analysis; c) an overview of the sample demographics; and d) the 14 interpretive themes with subthemes that developed from the analysis. Full engagement in the analysis was implemented through development and use of a thoughtful clinical check team that supported credibility and interpretive authority. The resulting themes were organized according to the initial research questions offered in this work, however, some of the concepts, child thoughts and interpretive outcomes overlap and tend to have fluid borders due to the nature of this qualitative inquiry. A matrix (Appendix M) provided a summary guide to the themes and subthemes described. The themes served as building blocks for the conceptual summary of the interpretive messages from children directed to professional caregivers in a hospitalized setting. Throughout this chapter, all names of child participants are aliases and not the actual names of the participants.

Context

In the process of interpretive description, my goal was to generate knowledge that captures the commonalities of the perceived experience of stress for the hospitalized child and at the same time, allow for contemplation regarding an individual child's view of this experience. The context of this study was hospitalization and understanding the child's viewpoint within this context. I, as a nurse could then advise other professional caregivers of children on how to make informed decisions about the encounters with children in this context. Children who are hospitalized are placed in vulnerable,

dependent positions, with very little control over what happens to them within the context of care, and adult decision makers of that care and treatment. By empowering children to speak about their experiences, we as caregivers are summoned to pause and listen to their concerns and responses to this environment and context of care.

Privacy

All interactions with participant dyads including recruitment, parental consent, child assent, and data collection took place in the child's private hospital room. All the patient rooms on both units are private, as to ensure confidentiality during data collection and minimize unnecessary interruptions. The child participants in this study were very enthusiastic about participating, and helping other children who were hospitalized, and experiencing something similar to what they were experiencing in the present moment.

Empowerment of the Child

Within the context of this study, parents, in general, responded very positively to the involvement of their child's input within a process that could improve the hospitalization experience. Due to the nature of this process, on several occasions parents consented and wanted their child to be a part of the study, but when assent was requested from the child participant, the child opted out of participation. To continue the theme of empowerment of children throughout this study, positive feedback was given to the child regarding the choice of 'No', clarifying that there are so many things in the hospital that they had no choice over, and this was one thing that they could say 'No' to, and continue to feel respected and valued within the context of their hospitalized setting.

Recruitment and Data Collection

I utilized a screening tool for recruitment (See Appendix J) to streamline the evaluation of potential participants. Prior to the access and attendance at the family-centered team meetings, I ensured awareness and education for the leadership team and the nursing staff through presentations at staff meetings and leadership meetings (Appendix L). When I was unable to attend the rounds because of scheduling conflict, primarily on evenings and weekends, I screened for possible recruitment of participants utilizing the screening tool, with a discussion with the Clinical Coordinator (CC) or relief charge nurse. I collaborated with these individuals and reviewed the patients on the unit, and assessed inclusion criteria. In addition, I provided a study notebook placed at the main nursing station of each unit, which provided clear explanation of the background, purpose, methods and process of the study and included clear contact information.

Once study participants were identified, I spoke with individual bedside nurses to confirm inclusion criteria congruency and verification of a legal guardian/parent at the bedside. I discussed with the nurse the child's schedule for the day, and accommodation of data collection time. Occasionally, individual nurses would need a review of the study particulars. Although education was done before the study began, I did not anticipate the float nurses, student nurses and nurses who work very infrequently would be engaged as gatekeepers in the study, and would need real time education before I collected data on their assigned patient. I remedied this by educating them with a brief summary and provided them with a one-page education sheet of the information about my study (Appendix K) before data collection began.

Upon entering a patient's rooms, I introduced myself to the child, parent/legal guardian and the family and explained the purpose of the study. I gave them a marketing flyer with information on the study, and told them I would return to the room shortly to see if they were interested in participation. If the parent and child verbalized interest in the study, I confirmed a time for data collection that would be convenient for the child's schedule around treatments, procedures and medications. I confirmed this time with the bedside nurse. The study was explained in more detail to the parent/legal guardian, with risks and benefits emphasized. Questions were answered, and then the parent/legal guardian signed the consent form that described the study and the expectations of the study procedure. In addition, the authorization of the use of medical HIPAA information was explained and given to the parent for a signature. After initial written consent was obtained from the parent, then a more simple educational process of informed assent through a pictorial explanation (Appendix F) proceeded to gain informed, written assent of the child (See Appendix D). After consent was obtained from the parent and assent from the child, I asked the parent to complete a demographic questionnaire and then proceeded with the draw and tell audio taped interview for the child participant.

Although I planned to interface with a minimum of 150 parent/child dyads who met the inclusion criteria, the actual interface of parent/child dyads was 45, with 30 meeting criteria and participating in the study. The positive response by parents and children willing to participate in the study was surprising, and possibly attributed to staff education, the nature of partnered recruitment with staff, the low risk perceived by parents who consented, and the fun perceived by child participants in this study.

Choices were given methodically to each child participant to enhance their power and control during data collection. The child was given the choice to sit in their hospital bed or in the chair at the bedside if their medical condition permitted. In both cases, the bedside table was utilized for a writing surface at a comfortable height for the child. Some children preferred to write on top of a small cardboard surface, as the bedside table was too high for comfortably drawing, so they were given that option. Children were also given the choice of signing their assent form in cursive signature or printed signature. Children were shown the paper choices and drawing tools, and asked to choose which ones they preferred. Some children asked for assistance with putting the caps back on their markers, and were accommodated. They also manipulated the switches on the tape recorder for the 'Start' and 'Stop' process, and were given the option of telling me when they were done with their drawing so I would know when to start the discussion. Finally, children were given the choice of the art bag designs that offered different colors for child preference after the interview was completed.

Data Analysis Procedures

During this fascinating inquiry of the inductive interpretive description, I was inspired to acquire an aptitude for what May (1994) terms as "magic." I was attuned to the threats of meaningful interpretations and followed the evaluative credibility criteria, and set my sights on an analysis that was high caliber. An overview of the interview transcription process, engagement in analysis, and dialogue with the thoughtful clinical check is outlined to inform the process of interpretive theme formation and conceptual summary.

Transcription of Interviews

The audiotaped data from the draw and tell interview with the child was transcribed verbatim. I transcribed all of the interviews to deeply attend to what the language contained, including the nuances, words, phrases, and pauses (Thorne, 2008). Due to the number of interviews, I initially decided to hire a transcriptionist to transcribe the interviews to enhance accuracy and objective outcome of the interpretation of the interviews. Ultimately, I was able to transcribe all the interviews, which assisted in the initial immersion into the data. I also found the narrative of what occurred during the interpretive words of the interviews was captured very accurately by this transcription process. Thoughtful, repetitive reading of each transcription was completed to become intimately familiar with the data, beginning at the start of data collection and continuing through the end, to compare and interpret the findings.

I was able to transcribe the data within 24 hours of collection, as I found that to be an ideal time frame for accurate memory detail of what I observed during the interview, and the interview flow of the child, the family and the occurrences before, during and after the interviews. In retrospect, the fact that I conducted the transcription independently enhanced my immersion in the culture of hospitalization that the child was experiencing. The details of observation and the occurrences during data collection in a hospital setting were unique depending on the atmosphere of the hospital units on the day of data collection. Each day brought nuances of activity levels on the unit, stress levels of the nursing staff, and varying levels of acuity of patients. An occasional medical response team was called, which was an emergency code-like situation. This event occurred simultaneous to the comparatively quiet draw-and-tell research process.

Data were analyzed through a constant comparison method. Repeated immersion in the transcribed data, as well as reflection on the drawings was done prior to beginning coding. This process enhanced the accuracy of classification and creation of linkages between the child's words and concepts. Although the drawings were utilized primarily as a tool for expression for the child, their pictures were an integrated part of the audiotaped analysis. I read and reread the transcribed interview data simultaneous to reviewing the child's drawing. The goal attained was to read through the transcripts with the objective of immersion in the data, and become aware of the life world of the child participants through their stories. I synthesized, theorized and re-contextualized rather than sampled, sorted and coded the data, following the interpretive description method of data analysis recommended by Thorne (2008).

Full Engagement for Analysis

The analysis consisted of engagement in both the real abstractions of theorizing and earth bound concrete realities of the practice context to produce sound and usable knowledge (Thorne, 2008). I entered the study with the theoretical scaffolding sensitized to the psychological responses of the hospitalized child (Vessey, 2003) and a modified Comfort Theory (Kolcaba, 2003). To fully engage in the inductive reasoning, I moved beyond the initial understanding of stress of the hospitalized child, toward an abstracted new and meaningful interpretation (Thorne, Riemer Kirkham, & O'Flynn-Magee, 2004) to validate and illuminate the meaning of stress for the hospitalized school-age child, from their point of view. Further strategic periods of immersion in the field were interspersed with periods of immersion in the data, as this was ideally suited for this research context and process. The results were a refinement of the inquiry, testing of the

developing conceptualizations and challenging of the abstractions that emerged with the planned theoretical sampling. The theoretical sampling was enhanced with the input of the clinical check team, as they identified and confirmed some of the typical responses, and then suggested some of the issues I had not seen through the collection and analysis. This also occurred as I interpreted data simultaneously in a private setting and collected data in the hospital setting. On the basis of this analysis, an interpretive description was generated of what school-age children perceived as stressful in the hospital.

Prior to the initial coding, I constructed multiple concept maps as well as utilized a large white board to help visualize the connection of concepts and meaning of the children's messages. Analytic guidance on the process of coding of data, sorting them into patterns, testing those patterns for relationships and conceptualizing those into findings was guided by Dr. Lobo, the clinical experts, and authors within the interpretive description methodology (Thorne, 2008, 2013; Thorne, Reimer Kirkham & O'Flynn-Magee, 2004). Although during analysis, there were some themes that seemed to occur consistently, there were many times that I reflected and separated from the data. This allowed for a fresh perspective, and avoided misinterpreting frequency, and most importantly, to avoided anticipating similar patterns during the consecutive interviews.

The software program MAXQDA was utilized to analyze data towards the end of data analysis for sorting and coding patterns and themes (MAXQDA 11, 2013). I purchased the program and utilized five video tutorials to train myself on the software, but found that I needed to re-educate myself during the analysis process to utilize the software effectively. The software provided an ability to encrypt the data, which was a requirement for the human subjects protection. The software was user friendly, and was

an excellent tool for choosing and retrieving key quotes from child participants that supported the interpreted themes and final conceptual summary.

Thoughtful Clinical Check Team. To validate and support the interpretations that emerged during data collection and analysis, I formed a thoughtful clinical check team at a large Midwest children's hospital. This team of expert practitioners provided a perspective that was formed on the basis of experienced pediatric clinicians engaging with many hospitalized children over time. The essence of their input was to integrate their perspective with the interpretive descriptions of the child's perspectives with the outcome of sensitizing and informing the people who provide care to the hospitalized child, my intended audience for this research (Thorne, 2008). A thoughtful clinical test provided a form of triangulation with respect to examination of the data, and enhanced the power of the findings. The meeting for this examination took place after 19 cases of the 30 cases were collected and analyzed, and then again toward the end of analysis to assist with fine-tuning and solidifying the interpretive themes.

The team consisted of a) Aris Eliades, the Associate Director of the Research Institute at Children's Hospital, who is a doctoral prepared children's researcher with over 30 years of pediatric clinical experience with the school-age population; b) Betsy Kendrick, the lead nurse practitioner in the Pain Management Center at Children's hospital; a mastered prepared nurse with 30 years of experience with hospitalized school-agers, and a 15 year expertise in pain, anxiety and comfort of children who are receiving acute medical and surgical care in the hospital; and c) Laura Leiedecker, a Child Life Specialist, with 15 years of attending to the psychosocial, developmental and emotional needs of school-age children in the hospital.

My interpretations of the data were shared and discussed at the mid point and at the end of data collection and analysis to validate meaning, and to prompt what other types of theoretical sampling I was missing in my data interpretation. This engagement was audiotaped and was summarized in the findings section of this presentation. The team offered tremendous input in the comparative analysis of the cases and suggested a few things that may be missing, that they often saw in this context. This process was extremely helpful in anticipating the possible threats to meaningful interpretations in this study.

Researcher Support for Credibility. By utilizing the team of clinical experts for thoughtful clinical checks, I enhanced and validated my interpretations of the data. The team reviewed my initial alignment of thought pattern, allowed for alternative explanations of my initial interpretations, and informed my ongoing and future thoughts to outlay the analysis. These expert clinicians aided to fine-tune the analysis, and helped me to avoid platitudes and simplistic representation of issues and concepts I was seeing. At times I was overwhelmed by the data, listening to children's stories about hospitalization and experiencing their drawing and telling. This team was extremely helpful in being peer supports to me, as I felt analysis fatigue and needed emotional support that was required when doing research with sick children and anxious parents.

Interpretive Authority. I was accountable for the credibility of the findings in this study and anticipated upholding the evaluative guidelines to ensure this process. I was guided by an incredibly knowledgeable, experienced research dissertation committee, and supported by the thoughtful clinical check team. This guidance supported this research effort, so I could consistently ensure the claims that represented

individual subjective truths from the child's perspective. Built into this study was the verification of these truths as Dr. Thorne and Dr. Lobo were instrumental in their ongoing review and input during the data analysis process. Although I claimed interpretive authority as I contemplated and crystallized the final themes, I was doubtful at times that I was interpreting the truths of what the children were telling me during this study. I believed interpretive authority was built over time, as I developed in the clinical research context and became more expert at listening and interpreting children's thoughts and perceptions. I believe this development will be ongoing, as I continue the process of dissemination of the findings for this study, and utilize my authority in future studies.

Demographic Descriptive

The sample size was 30 child/parent dyads. Sample size related to methodology and recruitment statistics were reviewed. The demographic data from the parent questionnaires was summarized in Table 1, 2 and 3 respectively. A narrative of key demographic data highlighted important interpretations regarding the sample.

Sample Size Related to Interpretive Description Methodology

According to Thorne (2008), there are not firm rules constituting the right sample size for an interpretive descriptive study. When considering key factors for sample size, the amount of usable data from the draw and tell interviews could yield small amounts of data per interview. To obtain the richness of data required for qualitative analysis for this study, interpretations numbering somewhere between 30 and 60 was forecasted. In estimating a lower limit of 30 to allow for a range of interpretation of children of different ages, gender, and hospital experiences that will provide an intensive, in-depth interpretation. An upper limit of 60 was warranted to allow exploration of an

unanticipated theoretical variable that commanded expanded data collection. The process of simultaneous data collection, interpretation and analysis assisted in determining a stopping point for the number of parent/child dyad participants. The sample size of 30 was deemed adequate, as the data from child interviews was rich and complete, as discussed with the dissertation committee members and the thoughtful clinical check team.

Recruitment Data

There were a total of 45 parents and children approached and recruited. Fifteen of the 45 did not participate. Of the 15, five of the parents consented yes, but of those five, the child denied assent. Ten other dyads were recruited and opted not to be participants related to multiple issues that included imminent discharge, child not feeling well enough, or the transport of a child off the floor for testing. There was an unanticipated ease of recruitment for this study that was attributed to nursing and child life involvement, professional health team support and knowledge of the study, as well as the low risk nature of participation as perceived by the parents who consented to the study.

Demographic Tables

Three tables summarize the demographic information regarding the sample. Table 1 outlays the key demographic and family information about the child participants. Table 2 summarizes the information regarding hospitalization and includes length of hospital stay, differentiation of diagnosis and hospitalization experience and visitors. Table 3 describes case-by-case information with pseudo names of actual participants. A description and interpretation of the demographic picture of the sample follows the table presentations.

Table 1. *Demographic Characteristics of the Participants*

Characteristics	<i>N</i>	<i>% Totals</i>
Age, years		
7 (<i>M</i> : 7 yrs. 2 mo.)	16	53.3
8 (<i>M</i> : 8 yrs. 6 mo.)	4	13.3
9 (<i>M</i> : 9 yrs. 2 mo.)	10	33.3
Gender		
Male	18	60.0
Female	12	40.0
Ethnicity		
White, non-Hispanic	23	76.7
African American	6	20.0
Hispanic	1	3.3
Legal Guardian		
Mother	26	86.7
Father	3	10.0
Grandmother	1	3.3
Grade in School		
1 st	7	23.3
2 nd	9	30.0
3 rd	5	16.7
4 th	9	30.0
Siblings		
0	1	3.3
1	6	20.0
2	14	46.7
3	9	30.0

Table 2. *Hospitalization Descriptive for Child Participants*

Characteristics	N	%
Days in Hospital		
< 1	3	10.0
1	6	20.0
2	9	30.0
3	5	16.7
4	2	6.7
5 or greater	5	16.7
Previous Hospitalization		
Yes	18	60.0
No	12	40.0
Types of Hospitalizations		
Surgical	15	50.0
Medical	15	50.0
Appendicitis	9	30.0
Asthma	6	20.0
Infection (I&D*)	4	13.3
Other Infection (**)	3	10.0
Brain Tumor	1	3.3
Chronic Neurological Disorder	1	3.3
Heart Arrhythmia	1	3.3
Tonsillectomy Bleed	1	3.3
Abdominal Pain/Rule Out Crohn's	1	3.3
Juvenile Idiopathic Arthritis/Fever	1	3.3
Henoch-Schonlein Purpura (HSP)	1	3.3
Diaphragm Repair	1	3.3
Sees Medical Specialist		
Yes	17	56.7
No	13	43.3
Visitors during Hospitalization		
Yes	30	100
3 or greater	30	100

*I&D is Incision and Drainage equated to surgery

**Pneumonia, Gastroenteritis, Osteomyelitis/Septic Arthritis

Table 3. *All Participants by Name and Demographics*

NAME*	Age	Gender	Ethnicity	Reason for Hospitalization**	Length of Hospitalization
Sarah	8 years, 4 months	Female	White	Appendicitis	4 days 21 hours
Sammy	9 years	Male	White	Appendicitis	9 days
Tom	7 years	Male	White	Pneumonia	2 days
Molly	9 years, 4 months	Female	White	HSP	6 days
Tim	7 years, 11 months	Male	White	Asthma	24 hours
Victor	9 years, 9 months	Male	White	Infection in Left Hand	6 hours
Ann	9 years	Female	African American	Appendicitis	2 days
Jade	9 years	Female	African American	Asthma/Pneumonia	2 days
Jeff	7 years, 5 months	Male	White	Emergency Appendectomy/ Rupture	2 days
Cassy	7 years	Female	White	Stomach Virus	2 days, 20 hours
Nick	7 years, 3 months	Male	Hispanic	Appendicitis	1 day, 3 hours
Mary	8 years, 6 months	Female	White	Osteomyelitis Septic Arthritis	2 days
Chad	7 years, 4 months	Male	White	Had tumor removed from left side of brain	1 day
Susi	8 years, 8 months	Female	White	Flare up of a chronic neurologic problem	3 days
Charlie	7 years, 8 months	Male	White	Infection in Finger	1 day
Lily	7 years, 6 months	Female	White	Appendix removed	2 days

NAME*	Age	Gender	Ethnicity	Reported Reason for Hospitalization	Length of hospitalization
Jimmy	7 years, 1 month	Male	White	Had abscess after going to the dentist	3 days, 7 hours
Ricky	7 years	Male	African American	Asthma	2 days
Bobby	7 years, 6 months	Male	African American	Asthma	20 hours
Gary	9 years	Male	White	Asthma	1 day
Mona	9 years	Female	African American	Appendenxious***	5 days
Keith	9 years	Male	White	Heart Arrythmias***	2 days
Jared	7 years	Male	African American	An appendacitis	7 days
Howie	7 yrs	Male	White	Had abscest on neck area	3 days
Xavier	8 yrs, 7 months	Male	White	Appendicitis dehydration	3 days
Ariel	7 years	Female	White	Had a hole in her diaphragm and had it repaired	47 days
Bianca	9 years 10 months	Female	White	Complications from tonsillectomy	1 day
Harry	7 years	Male	White	Asthma	12 hours
Kelly	9 years 5 months	Female	White	Unknown Fever JIA	2 days
Blaze	7 years	Male	White	3 years of abdominal pain, nausea and vomiting and rectal bleed	4 days

*All names listed are pseudo names of participants

**Reason for hospitalization reported by parent

***Identified word spelled by parent

Child Age and Gender

Early school-age children seven, eight and nine years of age were a part of this purposive sample. Parents were asked their child's age in years and months. Of the thirty children in the sample, over half of the sample, 16 (53.3%) were seven-year-olds, which was one consideration in analysis of the data related to their ability to draw and articulate their thoughts and feelings. Ten (33.3%) participants were age nine, and this age group complimented the data with enhanced abilities to communicate and offer their thoughts and feelings in words and drawings. Four children (13.3%) were eight years of age. The means of each age group were as follows: a) seven year cohort had a mean of 7 years and 2 months of age; b) eight year cohort had a mean of 8 years and 6 months; and c) the nine year cohort had a mean of 9 years and 2 months. These data were calculated from parent report on the questionnaire and not by birthdate. Therefore, the accuracy of the ages is based on the assumption that the parents reported the age in years and months. Overall, the children in the age group of seven and nine year olds, were on the younger continuum of seven and nine years of age. The eight year olds were on average, eight and a half years of age.

In addition to the sample being younger, there were far more boys (60%) than girls (40%), which was a consideration regarding gender sensitive perceptions.

Ethnicity

The majority of children in the sample were white, non-Hispanic ethnicity (76.7%). Six of the children (20%) were African-American, and only one child was Hispanic (3.3%). The study setting, a northeast Ohio hospital, serves a 17 county area,

and reflects the state of Ohio with ethnicity percentages of 82% white, non-Hispanic, 11.6% African-American, 2.6% Hispanic, 1.5% Asian and American Indian/Alaskan Native at 0.2% (U.S. Department of Commerce, 2013). Although Asian and American Indian/Alaskan Native participants were not represented, the ethnicities in the sample mirrored those in Ohio, with a greater percentage of African Americans represented in this sample.

Family Demographics

Legal guardians of children recruited for this study consisted of 26 (86.7%) mothers, 3 (10%) fathers, and 1 (3.3%) grandmother. This sample mirrored the greater population of children in the hospital, as typically more mothers than fathers stay with their child during hospitalization (Sanjari et al, 2009). Only one child participant out of 30 did not have a sibling, with over half reporting two or more siblings. One demographic issue that was not differentiated was the essence of the blended family. Many of the parents and child participants in the study anecdotally reported having step-parents and step-brothers and sisters, although this was not specifically asked about on the parent questionnaire. A blended family is a common scenario in today's family make-up, with statistics suggesting that 49% of children live in blended families with at least one step-parent and step sibling (Kreider, 2007).

Characteristics Related to Hospitalization

Days in Hospital. Parents reported length of time in the hospital and previous hospitalizations. Over half of the children were hospitalized for at least two days (60%), which mirrored the median and mode of the sample at two days. Five children (16.7%) had lengthier hospitalizations greater than five days. The mean number of days in the

hospital was 4.2 days, and for this sample was skewed, as one child was hospitalized for 47 days. Without the outlier of 47 days, the mean length of stay was 2.5 days in the hospital for this sample of participants.

Reasons for Hospitalization. Half (50%) of the participants were hospitalized for a medical condition and half (50%) were admitted for surgery. The reasons for hospitalization varied, however, nine (30%) of children were there for appendectomies, and six (20%) were there for asthma, which were unusually large percentages as comparable to the population at this hospital. Children were hospitalized with 14 different medical and surgical conditions, which supported a wide range of perspectives related to the type of care they received while hospitalized. In addition, over half of the children (60%) were hospitalized before, which related to over half of them (56.7%) seeing a specialist for their health care for this hospitalization. By parent report, almost half, 14 of the 30 (47%) of the children were diagnosed with a chronic disease.

Visitors. Thirty of the children, 100% of the sample had three or more visitors during hospitalization. This was a critical demographic that was related to some of the issues children spoke to regarding stress and coping while hospitalized.

Interpretive Themes

The interpretive themes were organized by research questions and themes and subthemes are presented in a matrix in Figure 1. The four research questions presented were: a) how do school-age children describe stress related to the experience of hospitalization? b) is stress of hospitalization related to anxiety, fear, and discomfort, or other factors? c) how do school-age children cope with stress during hospitalization? and d) what does a child think a nurse can do to help a child with stress during

hospitalization? The interpreted themes were informed by the child's interview and the process of them drawing and telling about their hospital experience, as well as the observations of the child, parent and family during the interview process.

The interpreted themes presented were supported with quotes to represent the truth and the beauty of the child's voice, and to get as close as possible to their human experience of hospitalization throughout this analysis (Sandelowski, 1994). Not all of the themes were supported with direct quotes due to the nature of a young child's expression, which is often fragmented and unclear. Thematic representations were also cited in the drawings completed by participants. This chapter concludes with a summary of comments about the developing themes that were discussed by the thoughtful clinical check group and informed the final analysis. The 14 themes presented and supported by the clinical check team were the building blocks for the conceptual framework and concluding thoughts that summarized the power of perception of stress in the hospital from a child's lens.

A matrix method (Averill, 2002) assisted in organizing the thematic process noted in Figure 1. An extended matrix with interpretive summaries is listed in Appendix M.

Figure 1. *Matrix of Themes and Subthemes: Four Research Questions*

<p><u>STRESS THROUGH CHILDREN’S EYES</u></p> <p>(How do school-age children describe stress related to the experience of hospitalization?)</p>	<p><u>THE RELATIONSHIP OF CONCEPTS</u></p> <p>(Is stress of hospitalization related to anxiety, fear, and discomfort, or other factors?)</p>	<p><u>COPING</u></p> <p>(How do school-age children cope with stress during hospitalization?)</p>	<p><u>WHAT CAN ‘WE’ DO TO HELP?</u></p> <p>(What does a child think a nurse can do to help a child with stress during hospitalization?)</p>
<p><u>THEMES AND SUBTHEMES</u></p>	<p><u>THEMES AND SUBTHEMES</u></p>	<p><u>THEMES AND SUBTHEMES</u></p>	<p><u>THEMES AND SUBTHEMES</u></p>
<p><u>My ‘story’ is the essence of today</u> .I am unique and have something important to say. .It’s chaotic on admission and onset of illness.</p> <p><u>My meanings are different than yours</u> .Children empowered to speak and interpret</p> <p><u>There is no place like home.</u> .What I would rather be doing</p> <p><u>I can’t always say what I am thinking and feeling</u></p>	<p><u>The things I worry about and what might happen</u></p> <p><u>I am afraid of shots, IV’s and surgery</u></p> <p><u>Discomforts: Things that hurt</u> .Things I don’t like, but can tolerate.</p> <p><u>What is expected of me?</u></p>	<p><u>My family is the most important</u> .Family who stay with me.</p> <p><u>I can transcend the hospital stresses</u></p> <p>.Food is a comfort for me.</p> <p><u>Fantasy is a part of the way I think.</u> .My wish</p>	<p><u>The ‘We’ is many more people than nurses.</u> .It matters what you do to me. .It matters how you make me feel.</p> <p><u>Honesty is the best policy: When will I go home?</u></p> <p><u>There are simple things you can do to help me!</u></p>

Research Question 1: Stress Through a Child’s Eyes

The first question was “How do school-age children describe stress related to the experience of hospitalization?” The data that informed the themes for this question

included children's descriptions about why they were hospitalized; comparison of concepts defined in the literature with the child's meanings, comparison of home to hospital; and finally, interpretations of things that children did not say that were observed. Four themes emerged from the analysis of data for research question 1: a) my story is simple and essence of today; b) my meanings are different than yours; c) there is no place like home; and d) I can't always say what I am thinking and feeling.

Theme 1: My Story is Simple and the Essence of Today. The child participants talked about their experiences in the hospital primarily by citation of things that happened to them today, and most stories were simplistic. Although adults are able to tell a story of experience over several days, weeks, or months, children have a tendency to talk about the here and now. Children's view of stress in the hospital were captured in the essence of today when they said: "Well,she got an IV out, and it hurt....it made her sad." (Jade, Age 9, lines 75 -79) and "... he was getting surgery because he was not acting very good! (Jeff, Age 7, lines 52-53). For some children their perception of gaining things or losing things was part of the essence of the story. One little boy who had an appendectomy reported, "I got an appendigs." (Nick, Age 7, line 51) and another little boy with a septic finger said, "they had to take my nail off because I got shut by a door and my brother had flip flops on and I put my hand there so he wouldn't smash his foot" (Charlie, Age 7, lines 62-68). A simplistic understanding of their hospitalization was revealed when one boy said, "Oh, they took something out and once they took it out of my body, that made me feel better" (Howie, Age 7, lines 126-128). This participant was hospitalized for an abscess under his chin that was drained and he perceived this process to be the most stressful part of his hospitalization. Two

subthemes that were interpreted from the essences of child stories included: a) I am unique and have something important to say; and b) it's chaos on admission and onset of illness.

Subtheme 1: I am unique and have something important to say. Although the general themes of the child's stories revealed their initial stress and the specifics of what was happening now, there were several specific nuances that emerged from interviews that emphasized the uniqueness of each child. Every child interviewed had something important to say. Some children told a story about another child who was sick, and referred their stress to depersonalize their story. One boy who was in for an appendicitis said, "Well, he was playing football with his brother, and he tripped over a rock and broke his legs." (Sammy, Age 9, lines 17-18). He portrayed this boy in a wheel chair (Appendix T, Case 2). Another boy who was admitted with asthma said, "Well, he was more like a 'she' and her throat was hurting and she kept on throwing up like crazy" (Tom, Age 7, lines 57-58). When asked about the reason why he was in the hospital, one boy stated, "I don't know....I wasn't there" (Tim, Age 7, line 114).

The nuances of each child were captured in their initial stories. One little girl with a chronic neurological disorder who came in for an exacerbation was able to speak in a detailed chronological rendition about her illness:

Yeah, umm, it all began on May 18th. I was diagnosed with 'XX' and umm, I was blind, and I went to the hospital and they made me better.....and then I had a flare up again, and I was blind and I went to the hospital, again...and then when I had another flare up when I went to the hospital.....

That was a little one, umm, it began on Monday or Tuesday. (Susi, Age 8, lines

73-85)

Subtheme 2: *It's chaotic on admission and onset of illness.* Some children revealed their angst through the stressful events that led up to their hospital admission with the onset of their illness. One boy with asthma reported, “Yeah, I just kept coughing over and over and over and my Dad said, are you OK?, Nope, and then we took the helicopter to the hospital.” (Tim, Age 7, lines 218-220). One participant who had a large bleed after a tonsillectomy reported,

I just had my tonsils out...and then last night, I went to bed and then I woke up, and there was blood all over the floor, and all over my favorite blanket. Then my mom came in and saw it and took one look at me and one look at the floor, and said, come on, you are going back to the hospital...get in the car! (Bianca, Age 9, lines 110-119)

Another boy with asthma animatedly reported his stressful admission, ‘Well, I started coughing...and it got really bad, so my mom called grandpa and they brought me to the hospital, and they gave me a breathing treatment...I had to take six of them last night.’ (Harry, Age 7, lines 124-126, 147)

Theme 2: *My Meanings are Different than Yours.* In this study, there were clear definitions of concepts described at the first phase of the design that identified what I believed to be concepts of stress, anxiety, fear, discomfort, pain, and coping. It was illuminated through the interviews that children spoke about things that made them feel ‘sad’ and those could be in the overlapping categories of the concepts listed. The main question and concept that directed this study was the concept of stress, and nowhere in

the interviews did any of the children use the word stress. Rather, they spoke about things they did not like, issues that bothered them and things that made them sad.

Theme 3: There is No Place Like Home. The third theme within the context of identifying stress for children was that being away from home was stressful. This was a theme that began with identification of what was stressful for children in the hospital, and then continued as a threaded theme through coping and interventions for the hospitalized child. During the interview process, as I consistently addressed different topics with the child's experience in the hospital, it was intriguing that most of the conclusions were that they were either missing things from home or were worried about people and things at home. The act of reflection about home life itself--their normal routine, their friends and family, pets, school, parties and playtime, brought on a dichotomous stress. The dichotomy was the reflection of home for hospitalized children could be positive, and help them transcend, but also could be a negative stress, bringing on worry, sadness and concern about things they missed.

Several children identified this stress. One boy said, "I don't like being in the hospital or talkin about it cuz it makes me feel sad, as I am not playing and doing things like I was at home" (Chad, Age 7, lines 219-220); Another girl discussed the routine she missed while being in the hospital when she stated, "While you are here, you don't get to eat....you don't get to do the thing you get to do everyday....like going out and playing in the snow, and playing with friends....stuff like that (Bianca, Age 9, lines 204-206); and one little girl identified the essence of missing people and pets from home as she stated,

I keep thinking that when I get better, I can go home....and if you have a pet and if you have family who couldn't come, you can say hi to your family...I miss my

dog, her name is Lily and she is a golden retriever! (Susi, Age 8, lines 172-182).

Subtheme 1: What I would rather be doing. Many children talked about what they would rather be doing instead of being in the hospital. These things were mostly associated with their home routine. One boy stated, “If I was home...I would probably be riding my dirt bike....if I was feeling better! (Tom, lines 96-100). Another girl said she would like to “...go out and play in the snow...playing with friends....stuff like that! (Bianca, Age 9, lines 210-211). Another boy spoke about school and said, “One good thing is you don’t have to go to school, but right now I want to go to school! (Chad, Age 7, line 247). One little girl stated she would rather be home. She was interviewed just before Christmas and showed me a paper chain countdown for the approaching holiday and said, “when I get to go home....it’s almost Christmas!...17 more days, and I made this” (Ariel, Age 7, lines 213-218).

Theme 4: I Can’t Always Say what I am Thinking and Feeling. Many times during the interviews when children were asked about things they did not like in the hospital, the answers were that they did not know, or they just did not respond, but just looked down, looked away or buried themselves in a teddy bear or hid under their blanket. These interactions and observations did not have specific words or quotes, but rather were interpreted as there may be hidden thoughts and feelings related to stress that children could not express. These may have been thoughts and feelings that could be expressed at another time, or could be so upsetting from the child’s point of view, that they may not have wanted to disclose them. These hidden thoughts and feelings were interpreted as something that were present, but not revealed in their words. Many of my observations during the interviews identified a child looking sad, but not saying words

about the sadness. There was an aura of hesitancy to express their feelings, and my interpretations and intuitions concluded they might not have wanted to tell me, as I was essentially a ‘stranger’ to them. Often times, you can disclose the darkest feelings to someone who knows you, and I yearned for a follow up with the children who seemed to have hidden thoughts and feelings, but were not going to express those on the day I was interviewing.

Summary. Children described stress of hospitalization through the stories they told about admission and onset of their illness as well as the daily occurrences in the hospital. The individual children expressed different messages in unique ways through their stories. Children did not use the word stress, but were empowered to articulate what was difficult for them when they were hospitalized. The stress of thinking about and being away from home brought a host of angst for children while they were hospitalized. There were also several moments with children that silence and hiding under blankets possibly revealed that there were some things they could not express in the interview process.

Research Question 2: Relationship of Concepts

The second research question was ‘Is stress of hospitalization related to anxiety, fear, and discomfort, or other factors?’ Four themes were identified related to these concepts and included: a) the things I worry about and what might happen; b) I am afraid of shots, IV’s and surgery; and c) discomforts: things that hurt; and d) what is expected of me?

Theme 1: The Things I Worry About and What Might Happen. The child participants identified many things that were unknown to them that they did not like and

elicited worry for them. There was a stress in the unknown, and unpredictable occurrences were reflected in their concerns. The unknown of when they might have a procedure or “shot”, and different people they missed or were worried about was consistently expressed by children. One boy reflected,

I was worried I couldn't see my friends...but I was very worried about getting a shot...yeah, and I got one at CVS like a month ago and I was brave then, but I am worried now...I was worried when they were talkin about takin off my nail, and I was like, 'are they really going to take off my nail?...and I was very worried about that! (Charlie, Age 7, lines 233-253)

Another boy named consecutively, “I am worried about by dog and cat and my brother and Dad...and my grandma and grandpa” (Tom, Age 7, lines 162-167).

Theme 2: I am Afraid of Shots, IV's and Surgery. There were clear recognized fears for children. In this sample of children at ages seven through nine, whether they had been hospitalized or not, they have had experiences in the health care setting with “shots” or injections. Some children called them “pokies”, or “ouchies” or “boo boos”, but most children at this age called them “shots.” They were fearful of getting a “shot”, as they claimed firm understanding of what a “shot” was and that it was something they did not want. One little girl drew a syringe that was as big as the child she drew in the picture (See Appendix T, Case 10). Syringes with needles were prominent in several pictures, and reflected children's constant vigilance regarding who would give them an injection (Appendix T, Case 6, 13,23, and 25). Children at this age came in with previous knowledge and a variety of perceptions about the process and understanding of “shots” related to their immunization experience. Also, due to the need

for increases in booster immunizations, most children in this age group had recent experiences with a “shot” in a clinic type setting. Many children spoke about “shots” and assimilated their negative experiences.

Intravenous (IV) catheters were also a specific fear related to the concept of “shots”, and some children spoke about them being one and the same. One boy stated “I don’t like IV’s....they make me sad, last night I thought I was going to have to get an IV, but I didn’t!” (Tim, Age 7, lines 64-65). Many children did not associate the IV’s with fear of pain, but rather they were scared of the lines. Many of the drawings had small children attached to very prominent long IV lines (Appendix T, Case 1, 5, 7 and 29). One boy stated, “There were some strange people and strange wires....and he was like very, very nervous!”(Sammy, Age 9, lines 38-43). Half of the children were admitted to the hospital for some type of surgical procedure. Many specifically said they were afraid of surgery. Interestingly, some said that although they were afraid of surgery, it did made them feel better when it was over.

Theme 3: Discomforts: Things that Hurt. Many children identified issues surrounding pain and things that hurt while they were in the hospital. Also, children complained during the interview that their surgical sites were where they had pain, and those with extremity or abdominal surgery were able to point to those areas. Children seemed to be able to handle the pain and discomfort, and interestingly, many children associated pain medicine with relief of their pain. Pain has been studied with children at this age, and it seemed that for the children in this study, it was something that could be remedied, and did not take the center stage of conversation in the interviews.

Subtheme 1: Things I don't like, but can tolerate. As mentioned previously, “shots”, IV's and surgeries were mentioned throughout the interview process as things associated with what they did not like. Although they did not like them, when they expressed their feelings about things they did not like, there was an overwhelming sense of acceptance of some things in the hospital that they did not like, but could tolerate. Children's resilience was amazing, and again brought out in this study. One girl talked about repeated measures to place an intravenous line when she said,

“They had to put that up here...and they tried to put it in and they didn't get it...and then they had to pull it out!...I never liked that and was sad... and I even screamed...I got six pokies downstairs! (Mary, Age 8, lines 155-167)

Theme 4: What is Expected of Me? Many children spoke to the issue that people talked to their parents, but did not speak with them. Therefore, they did not know what was expected of them. They spoke about this in the context of procedures and daily medical processes, but also identified that they did not know when they were going home. Although most of the children mentioned going home, not one child was able to verbalize what they needed to do to go home. The process of longing to go home inherently caused them stress. Many children mentioned precursory events that they hoped would happen and would ultimately result in them going home.

Summary. When considering the relationship of the concepts of stress related to anxiety, fear, and discomfort, most children identified things that were worrisome, things that they feared would happen, and things that caused them hurt or pain. Discomfort seemed manageable with medicine and other remedies that helped with pain. When children spoke about what they did not like, and what was stressful to them, they were

more focused on what was expected of them for procedures and most importantly what they needed to do to go home.

Research Question 3: Managing the Stress...Is it Coping?

The third question, ‘How do school-age children cope with stress during hospitalization?’ was addressed through three main themes interpreted from the data that included: a) my family is the most important; b) I can transcend the hospital stresses for a moment; and c) fantasy is a part of the way I think.

Theme 1: My Family is the Most Important. Families were a critical part of the child’s experience in the hospital, and were mentioned by the children in several ways as part of what helped them to feel better. Many children proudly named all the visitors they had, “Grandma Vicky, Grandma Ann, Aunt Janet, Aunt Sharon, Aunt Mona, Aunt Gertie, Grandpa, cousins Brock, Brodie, PJ, Barbara and Keith, (Sammy, Age 9, line 72-75); and another child said it really made her feel better when visitors came and said, “My dad, mom, grandma, cousins, and my pastor and his wife even came to me!” (Ann, Age 9, lines 77-82). One child’s emphasis of their entire drawing was the family presence they felt in the hospital (Appendix T, Case 25). A subtheme that emerged in this area was the specific comfort issues of family who stayed in the room with them during hospitalization.

Subtheme 1: Family who stay with me. Many of the children drew a family member or pet in their picture (Appendix T, Case 4, 9, 14,15, & 25). Children consistently identified that someone being by the bedside with them helped them to feel better. Some children spoke about brothers or sisters who could not come to the hospital for reasons such as schooling, transportation, and avoidance of the infection the child

participant was enduring. Most of the time, not being able to see a sibling was something that they missed. However, some children spoke about not having siblings there and seemed to enjoy having the undivided attention of mom, dad or whoever was at the bedside.

One boy spoke about being shocked to see people when he said, “I had some visitors....my uncles came to visit me and I was shocked to them, cuz it had been a really long time since I saw them” (Tom, Age 7, line 145-147). Other children mentioned family members they had not seen in a while, and it revealed the phenomenon that when children are hospitalized, it often prompted family who may have not visited, to come and see a child who is sick. Children also liked when family and friends brought gifts, as one boy said, “People come to see me and bring me presents” (Jeff, Age 7, line 93-94).

In many of the interviews, there were siblings in the room that entertained their brother or sister by playing games, coloring with them, or just sitting watching a movie together. During the interview process, I had four situations where a younger brother was present, and wanted to engage in the interview process. In all four situations, I offered the sibling drawing material, as they yearned to do what their older brother or sister was doing. To place direct, focused attention on the participant, I allowed the sibling to engage in a complete parallel drawing process. In many cases, however, I talked to the sibling who had comments and questions during the interview as well as the child participant. This was not an ideal situation, however, was part of the child’s world and hospitalization experience. I had mixed emotions about the sibling interfaces, and my thoughts were that this was just a glimpse of home life for a child who was in the hospital. Although they were sick, it may be one of the isolated times they would be

getting undivided attention from their parents. Siblings who were high maintenance for the parents and who were present in the hospital, brought about a normalcy to the child, like home, whether positive or challenging.

Theme 2: I can Transcend the Hospital Stresses for a Moment. Interestingly, children were able to identify several things, places and events that helped them transcend the stress of hospitalization. The things that children mentioned most often were play related events, and those were in the capacity of specifically the playroom or games in their room. There were several participants that spoke about television, computers or technology, tablets, iPod touches and hand held games. These were noticeable in several drawings by child participants (Appendix T, Case 9, 13, 16, 24, 28, and 29). Many of the things that children mentioned help them to cope momentarily and seem to help them transcend the stresses that occurred during their hospitalization experience. Two subthemes developed in this area were: a) Where I go and what I do (pets, crafts, play, and more); and b) food is a comfort for me.

Subtheme 1: Where I go and What I do (Pets, Crafts, Play, and More)

Children mentioned a full repertoire of services and fun activities during the interviews. These were identified as helping them to feel better. They spoke of the ball machine, pool table, the gift shop, baking cookies, the fish tank, and the most loved was the pet therapy. One boy's complete drawing was his experience at the gift shop (Appendix T, Case 15). He was delighted that his older brother had given him money to spend at the gift shop. In this hospital, pet therapy, called the Doggie Brigade, was a daily visit from different therapy dogs who would come to the bedside with their owners, and allow children to pet them, give them treats, and comfort them. Several children mentioned the

pet therapy, and two children included them in their pictures (Appendix T, Case 4; Case 28). Many children liked the crafts, music, dancing and the art therapy sessions they were able to attend. They also mentioned visitors that provide fun things like the bracelet lady, the glamor cart and the cookie baking volunteer. Interestingly, although these were identified as things that children really liked about being in the hospital, they seemed to be only momentarily relieved of their stress during these activities.

Subtheme 2: Food is a comfort for me. When children were asked what made them feel better, they consistently spoke about food. These discussions were in the context of food they liked in the hospital, foods they longed for, and fantasy foods that were symbolic of the greatest fantasy in their worlds. One girl spoke about her greatest wish in the hospital, “My one wish would be to have some strawberries, and they are not on the menu!”(Ann, Age 9, line 136); and one boy stated, “I really like eating the lunch here...a burger and French fries, and some ice cream... and I get my own tray and go into the kitchen and get my own chocolate milk.”(Tim, Age 7, lines 170-180). In addition to having the food he liked, it helped him to cope and have control of the choices and independence related to the food in the hospital setting. One boy wanted to magically turn the hospital and his hand with an intravenous line into his favorite food so he could eat it as he stated, “I wish the hospital would all be made of cookies...and vanilla ice cream! I would eat my hand all up like this! (Chad, Age 7, lines 191-196). Food and drink appeared in several of the drawings as things that were significant to children during hospitalization (Appendix T, Case 3, 6, 14, and 19).

Theme 3: Fantasy is a Part of the Way I Think. During many interviews, children spoke about fantasy and some had many stories to tell. A child’s unbounded

fantasy gave room for pleasant, transcending thoughts and a sensorium of flight of ideas, which is the delightful, expected nature of children. Whether we discussed unpleasant issues or fun things they enjoyed doing, frequently the automatic and reactionary fantasy thoughts interjected, and seemed to help a child cope with the crisis surrounding them. These fantasy thoughts seemed to aid them in telling their story. One boy drew about ‘Creepers’ in his picture. He identified these characters in a video game he frequently played, and he mirrored these to the health care workers (Appendix T, Case 13). Children also drew helicopters and airplanes in their pictures, and I wondered if they were symbolic of ways they could escape from the hospital, and go home (Appendix T, Case 18, 24, and 30). One little girl told a detailed story about her rabbit at home, and how he was so cute and cuddly, and that he had jellybean poops in all different flavors. This was a great example of perceptions of reality that were mixed with fantasy in a child’s expressions.

Subtheme 1: My wish. Children spoke about what they wished for in the hospital and the wishes were very simple, very real and positive life fantasies about hospitalization. Some simple yet grand wishes were voiced: ”I wish everyone would heal and get better real quick!” (Keith, Age 9, lines 187-192) and “...to make kids get better that were really sick....so they could go back home to their families! (Charlie, Age 7, line 339-340); “I wish that kids that were in with me got to go to the playroom!” (Ricky, Age 7, lines 188-189); and “that all the parents would be there with them!” (Bobby, Age 7, line 121). Other wishes were more tangible as one girl stated, “I wish a Labrador or a Retriever would visit.” (Kelly, Age 9, lines 180-181). One little boy who

could not have visitors, longed for the real wish, “that I could spend time with my family inside the hospital.” (Blaze, Age 7, lines 208-209).

Other wishes carried the longing to go home or be cured, and were profound statements such as, “I wish all children would feel better...and their pain goes away so they can go home!” (Lily, Age 7, lines 143-151); “I would like to have more than one doctor....more doctors would be able to do a lot of things a lot faster...then you get to go home a little quicker, (Xavier, Age 8, lines 257-262); “I wish for like.... the scientists to find like a cure for XX....I wish that everyday! (Susi, Age 8, lines 152-153); and “I wish that every time a kid goes home, that they will always stay strong!” (Mona, Age 9, lines 134-135).

Summary. Children mentioned many things that helped them cope in the hospital. The most consistent theme was family, with moms, dads, siblings, and friends mentioned. They identified some momentary transcendence from stress when they spoke to the many things they can ‘do’ in the hospital that they liked. These included: going to the playroom, doggie visits, baking cookies, doing crafts; singing, listening to music, watching movies; playing games (video and others). Some children made friends in the hospital. Fantasy thinking was a strong theme for children when they talked about coping and what they wished would happen. Children had flight of ideas that were verbalized and drawn.

Research Question 4: Things We Can Do to Help.

The fourth research question was what does a child think a nurse can do to help a child with stress during hospitalization? Three main themes interpreted included: a) the

‘we’ is many more people than nurses; b) honesty about is the best policy: When can I go home; and c) there are simple things you can do to help me.

Theme 1: The ‘We’ is Many More People than Nurses. Throughout the interview process, it was clear to me the differentiation of the health care team members. However, to a child of seven, eight and nine years of age, it was not always clearly deciphered. The theme interpreted was that the ‘we’ for the child participants consisted of anyone who came in to their room, or was a part of their hospital experience. Whether children spoke about the experiences of their transport to the hospital, their admission, their surgery or tests, they did not identify specific roles as clearly as what it was they were having done to them. Two subthemes emerged from this main theme: a) it matters what you do to me; and b) it matters how you make me feel.

Subtheme 1: It matters what you do to me. Expressions and stories that children told about the people that interacted with them focused on their need for information about what these people were going to do to them when they entered their room, versus the importance of who they were. Interestingly, very few children who were interviewed seemed to notice the difference between a physician, surgeon, attending, resident, student nurse, housekeeper, or volunteer grandmother. Rather, they were more concerned about what they were going to do to them and why they were in their room. Children were insulated from the hierarchy and credentials of the health care team, and had more of an awareness of why a member of the health care team was talking to them or their parents. Also they were concerned about what was going to be done to them or where they were going to be taken.

Subtheme 2: It matters how you make me feel. One of the subthemes that was clear from observing and interviewing children in this study, was it really mattered to children how you made them feel. They talked a lot about things different health care team members did for them that made them feel better. Those included being polite, speaking kindly, giving them a medicine that helped them, and even giving them a shot that made them feel better. An important message that seemed to ring true consistently for children was when they were hospitalized, they were searching to feel better. They want to get better from surgeries, medical procedures, and illness. We as professional caregivers have a large influence on how we made children feel while they were in the hospital. This was a simple critical perception of how they viewed all team members.

Theme 2: Honesty is the Best Policy: When can I go Home? This theme had an overlapping essence regarding what we can do to help children with hospitalization. Many children spoke to the lack of knowing about when they will go home, and also, again, what they needed to accomplish to go home. One of the issues I interpreted as a nurse, was an overwhelming sense of hesitation with telling a child when they will go home, because what if it did not happen? It seemed that the drivers of care, whether they be surgeons, physicians, nurses, or therapists, had a clear hesitation with being honest with children about when we expected of them and what they needed to do before they could go home. As previously mentioned, many children noticed that we talked to their parents about the plan, but we did not talk with them, directly. This was especially evident for this age range of children. There may be the sense of hesitancy as health professionals deny the self-efficacy and competency as well as the flexibility a child may have to adjust if the planned day of discharge does not happen. However, a child

between seven and nine years of age demonstrates competency in the ability to be flexible if a teacher changes a deadline, or if a parent reschedules a family event. Therefore, a child may have the ability to understand and endure a tentative day, time and acknowledgement of things needed to accomplish before discharge. Honestly including children in the conversation about when they will go home, and the things they need to accomplish before they go home, could empower them, and help them through the stress of hospitalization.

Theme 3: There are Simple Things You can do to Help Me. I came in with some preconceived notions that the child participants would provide me with new and possibly innovative interventions that we should do as nurses and caregivers for easing their stress during hospitalization. For many reasons, I thought these would be more complex and even costly interventions to help children who are hospitalized. The children in my study gave such clarity and insight to the fact that the things that really helped were simple and could be done by a highly trained physician or nurse as well as a nurse's aid, transporter or volunteer. On occasion, a child mentioned the nurses specifically and one girl stated, 'the nurses are very cool and nice...the nurses really help me to calm me down and help you do things...they always rub my hand and tell me it's going to be OK' (Mona, Age 9, lines 56-60). One child said the thing that helped the most while she was in the hospital was a hug from the nurses. Other children mentioned things like speaking to them kindly, and holding their hand was something that helped them get through difficult things. One child emphasized that when she had to have her blood drawn, the most comforting thing was to have a band-aid, and not everyone remembered to give her one.

Summary. Children identified what they thought a nurse could do to help them with stress in the hospital. A nurse was perceived by a child as one person in the pool of many people who interfaced with them while they were hospitalized. Children did not always differentiate as readily who professional caregivers were or what their credentials or role was, but rather they were interested in what you did to them and how you would make them feel. Honesty about home going was very important to children, and they wanted to know what they had to do to get to that goal. Finally, children identified simple things that health care providers could do to help them to feel better.

Thoughtful Clinical Check Group Reflection on Interpretations

A clinical check group was utilized to discuss and reflect upon the initial interpretations and tentative themes summarized at midpoint of data collection and analysis phase, and then again at the final stages of data collection and analysis. The purpose of this review was to check credibility with the interpretations, and to interface with the audience that was most critical within the parameters of interpretive description methodology. The discussions were audiotaped and transcribed to capture the detail and nuances during the discussions. The insights from these knowledgeable clinicians were phenomenal, and resulted in several suggestions addressing stress of the hospitalized child. I outlay the process and outcome of a summary of their thoughts in response to the initial interpretations and then the final themes.

Initial Interpretations. Two weeks before the initial meeting, I sent out a summary of findings to the clinical check group by email. This group consisted of a pediatric nurse researcher, Aris Eliades, a Pain Management Clinical Nurse Specialist (CNS), Betsy Kendrick, and a Child Life Specialist, Laura Leiendecker, from a large

Midwestern pediatric hospital. Included in this summary was a brief overview of the study purpose, the methods, and my objectives for obtaining the clinical group's insights. First, I presented a demographic summary, to give them an understanding of the types and ages of patients that opted to be participants in the study. I also spoke very briefly to my initial theoretical frameworks, and asked that these be suspended in the judgment and interpretation of the initial themes.

Secondly, I summarized several tentative interpretive themes in large, umbrella-like categories, emphasizing that these were tentative, and hence even the categorical nature of the summary could be in question from a child's point of view. The themes were identified under broad headings of stress, coping and child indicated remedies for stress. I also reviewed with the clinicians the pictures, and pointed out some of the nuances and interesting aspects of the drawings. For each of the initial categorized sections of data, I explained what I interpreted the children were telling me, through the interviews and observations. I paused after each of the summaries to entertain thoughts, questions, and validation of what I was finding. I was emphatic about the tentativeness of the thoughts, and implored the group to give their insights as they reflected on their vast experience with stress of the hospitalized child.

Stress. The group discussed several issues regarding school and homework, making friends, and the feelings related to stress. Interestingly, many impressions were discussed about feelings of sadness, loneliness, embarrassment, worry, bravery, and different lifelines for children who are hospitalized. Betsy, from the Pain Center, contributed many thoughts about expressions and words of sadness reported repeatedly by all ages of children in the pain clinic and those hospitalized with pain management

needs. She also brought the feeling of anger into the discussion, and I responded that the words and expressions of anger were not consistently apparent in my interviews; however, one child did use the word ‘mad’ when people blocked his TV view in the hospital. Betsy confirmed that what she saw with expressions of children regarding pain also seemed to merge with the expressions of stress with hospitalization. There was quite an overlap of concepts that were so closely linked to each other, namely discomfort, anxiety and fear. The others in the group agreed, and we discussed how the adult lens somewhat interferes and isolates the concepts of stress, anxiety, fear, discomfort and pain, and for a child, these may overlap and not be expressed consistently in these terms. The discussion ensued with the importance of clarity of these concepts, and then a question emerged from Betsy when she said, “so what?”, as we know that there were some blurring of these feelings and concepts, but was the most important question “what are they?” versus “what can we do to relieve them?”

Coping. I summarized the section of interpretation about coping, and an in depth discussion ensued regarding topics of strengths and limitations in the hospital, services for children, and the home going communications and processes that occurred in the hospital. We discussed very pointedly about how we as health care team members believed we were doing things to help children cope with the stress of hospitalizations. The conversation addressed those tangible programs that included preparation of children for procedures and surgeries, pet therapy, baking cookies, crafts, music, art therapy, environmental aesthetics, etc. Many of the items and programs discussed had intentions of helping children to cope, and the outcome goal of decreasing stress. An emphasized theme that children reported in a variety of ways was their longing to go home. This was

illuminated through their discussions about what they would rather be doing, what they wished they could do in the hospital, and what they missed. Although many of the tangible interventions and sensitivities to the process of coping were mentioned by the children, such as pet therapy and the playroom, those could only offer immediate transcendence and off set the ultimate longing to go home.

Aris and Laura brought some interesting thoughts about the normal home going routines in the hospital. A mirrored reflection and discussion took place regarding adult hospital systems preparing for patient discharge upon admission to the hospital. At times, in children's settings, we are not as attuned and attentive to this 'end game' so to speak, and have more a "wait and see" mentality. However, there are medical model pathways for certain diagnosis that place a slice of clarity on the medical and pharmacologic steps necessary for a child to be deemed recovered enough to manage their disease process at home. Aris and Betsy very honestly pointed out that we are not doing a good job preparing children for what to expect in the hospital, and what they need to do to go home. This discussion was humbling, as we talked about the multiple significant efforts made as health providers of children to assist them in recovery and optimum health. We also projected that many of the things we did currently were with the intention of helping a child cope. With the anticipated influenza season beginning, some of the interventions and services could be very limited when a child is in isolation.

What can Nurses Do. Discussion ensued regarding the issues surrounding interventions for stress, and what the children believed we could do to help them. I interpreted the finding to the group, as the 'we' was not just nurses, as children seven to nine do not seem to clearly identify the differences between and among the multiple

professionals that care for them. Alternatively, they knew if someone comes into their room, they may do something to them, and it is important for them to be prepared, to know what their job is. It is critical how you make them feel. Betsy, the CNS spoke to this lack of differentiation of roles very eloquently. She interfaced the validation with management of care and discharge questions she receives on a daily basis from children. She said frequently the parent stopped the child from asking questions, and told them that ‘she is the pain lady’ and we need to ask someone else those questions about home going. She is typically a consultant in a patient case, and not the driver of care, but her testimony confirmed that children are seeking this information from anyone that is willing to share it with them.

Final Engagement. A second engagement with the clinical check group was done upon completion of data collection. A matrix of tentative themes were shared with the group, and discussion was lively on the results. The members confirmed many of the tentative themes, and, as nurses do, wanted to move on to the interventions that would improve the child’s coping in the hospital. Each member said that the study findings caused them to pause about their future interactions with children at this age, as they offered some conclusions and confessions about their current interactions with them, and how going forward they would be more sensitized to listening to them, talking to and including them in the plan of care. Also differentiating the daily expectations for children and communicating more clearly about steps for going home and discharge were of prime importance for this team of experts.

Further discussion arose about the possibility of a laminated chart that each child could have in their room to identify the steps and the stars they may get for meeting the

competencies for home going. The experts decided that although children come in with different diagnosis, needs for medical treatment and surgeries, their goals for discharge are similar and relate to their activities of daily living, and returning to some normalcy in their lives. Certain competency of liquid and food intake, oral transition of pain medication, mobility, and then other things like being fever free, infection improving, or adjustment to certain medications or treatments before going home. The clinical group also confirmed that the dissemination of this information was important to not only the nursing staff, but also to other professional caregivers who interface with children.

One final take away was the noisy hospital rooms. We discussed the fact that a new tower was being built for the hospital, and there was the ability of all three members to make suggestions about building structure and comfort for children. They planned on giving this feedback to the architects for the possibility of enhanced insulation and sound proof or sound limiting rooms to enhance patient and family comfort.

Conceptual Summary of Children's Messages

The 14 themes and the synthesis of rich discussion and validation of the themes with the thoughtful clinical check team served as building blocks for the conceptual summary of the interpretive messages from children. These messages were directed to nurses and all professional caregivers in a hospitalized setting. An interpretive description of these messages to the targeted audience included: a) stress for children is expressed through their fears, worries, discomforts and sadness; b) children should be listened to, as they have something important to say; c) children want to know what is expected of them and be informed of what they need to do; d) children identify simple things health care providers can do to help them during hospitalization e) the ultimate

relief of stress for children in the hospital is going home and children want to know a timeline what they need to do to go home.

Chapter Summary

A demographic analysis and interpretive themes, subthemes and a thoughtful clinical check team summary were articulated in this chapter. The power of perception was evident in the interpretive themes summarized and the conceptual messages the children communicated to professional caregivers in a hospitalized setting. The child's lens and view of their stress, coping and remedies informed the interpretive descriptive findings for this study. This powerful perception of the child shakes up, turns things around, upside down and backwards, and overrides the adult lens of what was stressful for a hospitalized child. This movement that took place enlightened a more accurate truth of the meaning of stress through a child's eyes.

CHAPTER 5

DISCUSSION AND CONCLUSION

This chapter outlays the a) summary of the interpretive findings; b) comparison of the findings to relevant literature; c) relevancy of theoretical frameworks; d) strengths and limitations; e) significance of the study; and f) implications for care of the hospitalized child and future research. Imperative in this final chapter is the acknowledgement of the importance of listening and hearing the voice of the child. In addition, the limitations in this study inform future implications for clinical care and research with children's insights.

Summary of Interpretive Findings

The findings of this study revealed several important interpretations regarding stress of the child in the hospital. The children in this study revealed several key themes critical to consider in the care of the child in the hospital. These themes were the building blocks of the conceptualized messages children were portraying in the interviews, and then confirmed by the clinical check team. A hospitalized child's perception of stress was rooted in their need to know what is expected of them in the hospital. The most important questions they asked were 'when will I go home?' and 'what do I have to do to go home from the hospital?' In light of these questions, the ultimate remedy and relief of their stress was to inform them of these issues, so they can cope with the discomforts, pains, and anxiety related to hospitalization, knowing that they will have relief and go home.

The important directive this gives to nursing caregivers of children in hospitals is first and foremost we must listen to children, as they have something very important to

say. Secondly, we must talk with children, and succinctly inform them of the tangible steps of their journey to home going. Finally, amid the multiple interpretive messages that children gave regarding their stress, namely that they did not call stress by name, but rather described things they did not like. Their perception about the professional caregiver was that it was not important who you are, whether it be a nurse, physician, therapist or housekeeper, but so important from their view, as how you made them feel while they are hospitalized. Although simple messages, they inform future studies that could expand the understanding of stress in the hospitalized child.

Comparison of Findings in Relevant Literature

Although children in younger school-age range of seven, eight and nine years of age had responses to interview questions that were shorter and perhaps less eloquent; they revealed descriptive, insightful information regarding their perceptions of stress, coping and related interventions that eased the experience of hospitalization. Very few recent studies were available that gave insight to children who are hospitalized and the nature of their stress. This could be related to the challenges of design and implementing research with the complications of parental consent and assent in a stressful, hospital environment. A few key studies are compared in this presentation, and this reflection illuminates the need for future research in this area.

Stress and Coping for the Hospitalized Child

There have been limited studies looking at hospitalized children's perceptions (Carney et al, 2003; Coad, Coad, & Theibe, 2005; Knighting, Rowa-Dewar, Malcolm, Kearney & Gibson, 2010; Wilson, Megel, Enenbach, & Carlson, 2010). These studies were with children after they were hospitalized or with older children and revealed some

congruency with the current study findings. When children were asked about stress of hospitalization, children described the experience to be disruptive to their usual routine, going to school, being with their families and friends and playing games (Haiat, Bar-Mor, & Shochat, 2003; Sartain, Clarke, & Heyman, 2000). Children also described things they did not like, and issues that caused, pain and discomfort such as intravenous lines, injections and surgeries. When children narrated about their stress and illness during hospitalization, contrasting verbs emerged including scared, sad and hurt versus confident, cozy and playful (Forsner, Jansson, & Sorlie, 2005). Many of the interpretive themes described in this study mirrored these findings. The two themes that were new and not found in the current literature were first the iterative relationship of the stress children endure regarding knowledge and understanding about home going, and expectations related to the competency needed to achieve a home going status. Secondly, children emphasized that people who interfaced with them in the hospital consistently spoke with their parents and not directly to them throughout the hospital experience.

What Can Nurses Do

In this study, interpretive themes regarding what children said a nurse can do to help relieve stress in the hospital revealed that children believed there were simple, specific things that helped. Things like a kind word, holding a hand, reassuring stroke, giving a hug, and putting ice on where it hurts were interventions that children tangibly identified. There is a paucity of studies that ask children specifically what helps them when they are hospitalized. One researcher interviewed children and the results suggested similar findings about specific things nurses could do to relieve anxiety, fear

and discomfort (Schmidt et al, 2007). Things children reported that helped included listening more, being sensitive to patients and saying it was alright if a child was scared.

An area that was illuminated by this study is the lack of differentiation of the role of the nurse versus the other health care team members. One researcher interviewed hospitalized children about their descriptions of a ‘good nurse’ (Brady, 2009). Themes that were suggested and described about a ‘good nurse’ included that she or he provided good communication, competence, safety, and kindness. Therefore, it speaks to the need to assist all professional caregivers interfacing with children in the hospital to be aware of how a child perceives them, and what they can do to ease their stress while hospitalized.

Relevancy of Theoretical Frameworks

This study was initially designed and sensitized to three theoretical frameworks including: a) Magnusson’s (1995) Developmental Science model, b) Vessey’s (2003) multifaceted model for the psychological responses of a child to hospitalization (Appendix A) and c) Kolcaba’s (2003) modified Comfort Theory (CT) with an integrated developmental and parent-child relationship components. After being placed in the vision of how a child experiences stress and coping in the hospitalized setting, an evolution of understanding of these related frameworks is discussed.

Developmental Science

Understanding a child’s age and developmental stage within the context of how they perceive hospitalization was important and the interpretive themes in this study gave solid validation to this awareness. I came to understand first hand the differences between the specific ages of seven, eight and nine year olds in my interactions with the research participants. Although Magnusson (1995) speaks to the specific developmental

patterns of school-age children, I saw specific evidence of their strengths and challenges at each developmental age and stage. Seven year olds are still mastering the ability to write, draw, and articulate their words and feelings. They struggled at times, to portray their meanings of stress related to hospitalization. At seven years of age, they are just beginning to adhere to the structure of schoolwork, expectations, and mastering completion of projects. I noticed that their attention span was shorter at times, and their ability to have flight of ideas and enhanced fantasy in their thoughts was more vivid in this age group. Unfortunately, I spoke with only four eight year-olds, so the detailed essence of their thought, abilities and challenges were not as clear. The eight year-olds in my study seemed to be more mature, and articulated their thoughts and drew pictures that captured more advanced stages of cognitive thought, and could be compared quite adequately to the nine year olds in my study. I realized towards the end of my data collection and analysis that I began to understand nine year-olds, and were able to engage them in more detail during the interview process. As a group, they could articulate their thoughts and feelings quite extensively, and were still very willing to sit and draw a picture. Many of the nine year-old participants took a very methodical approach to drawing and discussion of their feelings and stress of hospitalization. I realized as the study evolved, I could anticipate more in depth engagement with them related to their maturity and communication skills. That being said, adapting to the developmental lens of research participants in the early school-age years was extremely critical for the work of accessing child's perceptions, and is warranted in future studies.

One clear theme that resounded with all the children was their need to feel that they were following directions, saying the right things, drawing the right way, and

performing to my expectations. Within their world of interactions with adults, mainly parents and teachers, this developmental role of a daughter or son or student was part of their view and participation in this research project. I was reminded of this throughout the data collection process, and wanted the children to be more free spirited about their expression. However, holding true to their developmental age and stage and their developmental role in life at this time, they were limited by their perceived expectations I had of them, due to the nature of my adult, authority status, and their need to please and be successful in the tasks I was expecting them to accomplish.

Vessey's Psychological Responses to Stress

Three main realms of Vessey's (2003) model included biological factors, maturational factors and ecological factors. Although differences in each child were apparent in biological factors included the pathophysiology of disease, child temperament and individual stress response, these difference were difficult to differentiate within the realm of this study, and the limited time spent with each child for the interview. However, the maturational factors and the ecological factors were critical in relationship to how the child responded to their stress of hospitalization.

Maturational Factors. Maturational factors Vessey (2003) discusses in her work include the developmental frame of reference the child views their hospitalized state and consideration of perception of threat, prior experiences, preparation and coping. In my study, all of these factors were captured and identified by the study participants as a whole, although the individual maturation differences of children were apparent. I had 18 children in the study that had prior hospitalizations, therefore their expectations,

experiences and preparation could be possibly deemed at a higher level than the 12 who were experiencing their first hospitalization.

Ecological Factors. Ecological factors included family, siblings, pets, the hospital environment, and therapies to support children in the hospital environment were all related to the child's perceptions of their hospital experience, and were important in the interviews with children. The ecological factors seemed to capture the most important entities that helped children cope with hospitalization in this study.

Kolcaba's Comfort Theory

Kolcaba's Comfort theory has been studied through an adult lens and relativity. This was evident by the research completed utilizing this theory (Appendix B). One study applied the theory through a pediatric case study of one hospitalized child and suggested relevancy (DeMarco & Kolcaba, 2005). The one component of Kolcaba's comfort framework that I was questioning could relate to the child realm was the ability to transcend stress, pain, and worry. Consistently throughout the interviews, I could see the concept of transcendence align with the child's response, and coping with the stress of hospitalization. These were only moments of transcendence that were temporary escapes from the negative things that were happening. Most transcending moments came through a specific activity the child could do or was related to an interaction with another person or animal. The product of a comforted child and the process of comforting a child in the hospital was addressed in the final question of this study. Interpretive themes of what children perceive as helping them in the hospital included the wide range of family, friends, dogs, play, therapies, and all caregivers who interact with them during their stay.

A significant message communicated by children was the most comforting thing for them was the identification and assurance of home going.

The theoretical frameworks that I was sensitized to for this study were addressed from a strong nursing epistemology. Many of the decisions made about the design, implementation and interpretive analysis were based on my own knowledge of nursing care of children and families. The essence of this strong theoretical framework integrated into the work of the scholars regarding development, psychological stress, and comfort, informed this study and contributed to the success in finding the truths through a child's voice.

Strengths and Limitations of the Study

There were several strengths and limitations of this study with suggested remedies for future work. The strengths are outlined with attention to the study design, ease of recruitment of participants, and the thoughtful clinical check input. The limitations are presented addressing the sample and setting, the design, and the limits of a novice researcher.

Strengths

Study Design and Assent Tool. The detailed design of data collection that empowered the child to establish rapport, make choices, and be engaged in the interview process through the medium of drawing were strengths of this study. This design yielded intimate storytelling by the child.

The process of assent and consent set the tone for the research. The use of the pictorial assent tool was part of the engagement of the child participant, and assisted in establishing rapport. I found that the intimacy of storytelling about my study brought an

immediate bonding with the participant and the researcher. When I reflected on this process, it was clear to me that many times the person who reads to a child is usually a close family member or friend, and it is usually at a quiet, calm environment, at a pleasant time frame within a child's day. Children ages seven to nine are at ideal ages to read the pictorial assent tool, and engage in understanding, as they are at the beginning stages of the nuance and excitement of reading independently, but still enjoy being read to in many circumstances. The strategies to empower children and the utilization of a study specific pictorial assent tool enhanced the engagement of child participants in this study. An additional benefit of the assent tool was the adjacent parent listening in during the assent process. It created a reaffirmation of parental consent and simple explanation of all the parts of the study to the parent. The process demonstrated a respect for their child's clear understanding and agreement to participate, hence enhancing the trusting relationship that I formed with the parent/child dyad.

Ease of Recruitment. A clear strength of this study was the ease of recruitment of participants. There were 45 parent/child dyads recruited and 30 consented as full participants. Within the 15 who did not participate, several of those parents consented, but then the child was discharged to go home. In addition, there were five occasions that parents consented yes, but the child did not want to participate, and I encouraged the children who did not want to be in the study, to make their voice known. As, I believe there is very little the child has consent/assent to during hospitalization, and if they wanted to say 'No' to my study, they had the right and were encouraged to decline participation.

Ease of recruitment was also attributed to the education, encouragement and appreciation to the nursing staff and leadership teams on both units. The nurses became very vigilant for opportunities for parent/child participants when I was there collecting data, and often times assisted me in an explanation or reinforcement with the family or parent in the room. The head nurse managers on both units infused information about the study into their staff emails, and notices on the bulletin boards and communication books.

Thoughtful Clinical Check Input. An apparent strength in this study was the engagement of a thoughtful clinical check group as a valuable validation of the themes for the intended audience of this work. This audience was the professional caregivers of children in the hospital. To associate the significance of the findings to clinical application was an important part of the methodology, interpretive description, in this study. The conclusions and suggested interventions by this group regarding children's perceptions of stress, coping, communication and home going planning, and focus supports the strength in this study of engaging with a clinical check group during data analysis.

Limitations

Sample and Setting. The sample of 30 child participants was a limitation of this study, as more perceptions of children in the designated age groups could have offered more insight to the research questions posed. One clear limitation was that the participants were children who were hospitalized, which meant that their physical and psychosocial demeanor could have been altered due to the medical or surgical condition. In other words, they may not have felt good which could have affected the quality of reported perceptions. Within this context, I captured children's perceptions within the

essence of their experience, as they could recall pains, comforts and their initial impressions of experiences, but may not have felt well enough to have lengthy conversations that were comprehensive of their total experience. Although the sample was diverse in reasons for admissions, with the sample split in half with medical and surgical ailments, there were a concentrated number of children with appendectomies and asthma, which could have narrowed the perceptive view of the interpretive themes with the nature of their common experience with hospitalization. Cultural and ethnic diversity is not fully captured in this sample. Although the numbers of Amish, Native American, and Asians are smaller in this area of the United States, these factions were not represented in my sample. To capture the perceptions of children from a rich, cultural lens, it will be necessary to replicate this study, with posed inclusion criteria to enhance the cultural diversity.

The setting for this study was primarily one medical-surgical pediatric unit, although three of the participants are sampled from the second medical-surgical unit. The sample was from one hospital, in one geographic area in the Midwest United States area, which again, limits the scope of experiences to perceptions of children from that particular hospital. Each hospital designs protocols of care to support children in that specific hospital. Although the hospital chosen for this study had several strengths in the type of environment and services offered to children to support a positive experience, there were several areas of weakness and gaps in care, that are typically apparent for any single hospital.

Another limitation regarding the setting or overall experience of a child in the hospital was that I sampled children during their stay on a particular unit. Most children

who experience hospitalization enter through an emergency room or hospital transport experience that leads to a stay in the medical-surgical environment. Also, children may have an intensive care unit (ICU) experience in the midst of the journey from admission to discharge. The emergency, transport, and ICU settings and experiences were not part of this study, although some children reflected on these experiences.

Novice Researcher. A clear limitation in this study was my own lack of experience with interviewing children within a research protocol. Although I have interacted with children for 30 years within my pediatric nursing role, my specific skills are more developed in interviewing parents upon admissions, care and discharge, versus speaking specifically to children in a semi-structured interview fashion. This process was humbling for as I empowered the children to have choices and drive the conversations during the interviews, there were times when I felt out of focus due to the nature of talking with children who had flight of ideas, fantasy, and off topic comments and remarks related to their experience. At times I felt torn between accessing their thoughts about the topic of the research and just having a nice conversation. Looking at things from an adult point of view was a definite disadvantage in my response, questioning and inquiry for child participants. This limitation may have restricted all the nuances that could be captured with a more child-like lens, and the ability to “walk in their shoes.” In addition, my experience and pre-conceived notions of what they might say may have also inhibited a natural free flow of ideas from these children.

One final issue that was challenging as a novice researcher was not working with a team of researchers who was side by side with me to collect and analyze data. Therefore the essence of my angle of vision was not shared with others on a day-to-day

basis during data collection and analysis. I clearly saw the value of working with a partner or a team. This would be valuable to enhance this credibility.

Design. The design of this study was to interview children in the hospital, and maintain their comforts within this setting during the interview process. Therefore, parents, family, and siblings were able to stay during the drawing and interviewing. Parents were asked not to prompt the children with ideas or their own impressions. In most cases, having family in the room was a comfort to the child, however, in three of the cases, the parents prompted the child's answers. Although parents were reminded at the beginning to not prompt their child's answers, it seemed there may have been the inclination of a parent is to offer information and help their child to perform better during the interview. Another limitation related to the parents being present during the interviews was the possibility of child participants not wanting to fully share their feelings of stress. Many children recognize and feel the discomfort and anxiety their parents are already experiencing due to the illness and hospitalization episode. Their attempts to protect their parents from more stress could result in not being able to fully express their true thoughts and feelings. This could have directly affected the observations I interpreted as hidden thoughts and feelings that may have been expressed if the parents were close by but not present in the room.

Also, in four of the cases, the siblings, who were all younger brothers of the participants, were fully engaged in the drawing and interview process, which may have limited or altered the isolated thoughts, feelings and responses child participant. Family-centered care is practiced in today's hospital environment (Shields, Pratt & Hunter, 2006), which means that there is great deal of activity happening in a child's hospital

room that could interfere with the child's thought process and expression. One of the ways to remedy this in the design of the study would possibly be to have children interviewed in a nearby room, where they could easily access the comfort of their family.

The other limitation of the study design was there was a one-time interaction with children. I walked away from each interview wanting to know more about the child's continued recovery, home going experience, and then events that transitioned at home that led to the child reaching a normalcy in routine, post hospitalization. Although my interpretation of the expression of stress for children was outlined in the themes presented, there were ways children showed and communicated hidden thoughts and feelings about the stress of hospitalization that they could not reveal to me on the day of interview. A follow-up interview in the home setting would have been a way to validate their perceptions of stress, and possibly elaborate on their full view of the experience.

Finally, a limitation was a study designed by me, an adult, with adult impressions and views. Although I consulted several children when I created the pictorial assent tool, the interview guide, and the process of drawing and telling, I did not have a consistent focus group of children validating all points of the study from start to finish. Close, sequenced input from children for the design of this study may have informed a child friendlier process as well as improved the wording and process of interviewing for better outcome data. Also, as an adult, at times it seemed that children perceived that there were right and wrong answers to my questions, as they would if a teacher or parent were asking the questions. Many children asked permission for drawing certain things, or in a certain fashion, which may have inhibited their natural creativity in drawing and telling. A possible remedy for this would be to have adjunct focus groups of children that could

enhance their ability to be supported as children, and be in a peer leveled environment, versus a performance like environment. However, having many sick, hospitalized children in one room to conduct a focus group, may not have worked for a hospital environment due to infection control and HIPAA issues, however, this could be done at a post hospitalization time frame.

Significance of the Study

The findings of this study inform and remind professional caregivers of hospitalized children of issues that are important from a child's viewpoint. Although not new, it is critical that we were reminded that children want to be listened to and have something important to say. However, the emphasis by many of the children in different phases of their perceptions of stress in the hospital gleaned some nuances that are significant for future care of children and future research work. First, children used different words that could signify they are experiencing stress. One of those particular words was sadness, as it seems to be an umbrella for worry, anxiety, fear and discomfort. Also, children at the ages of seven through nine years did not perceive professional roles clearly in the hospital setting. But rather, they perceived an adult being someone that may do something to them. In light of that perception, if you are a nurse, a physician, a therapist, or a housekeeper, it is critical to tell children what you are doing, and let them know what you expect their job is when you are 'doing' to them. In addition, due to the lack of differentiation of roles, it matters most how you make a child feel while you are interacting with them, rather than who you are and what your credentials may be.

The overriding significant message that was interpreted from children in this study is the clarity regarding home going. Children want to know when they are going

home and what they have to do to go home. Going home was the ultimate remedy for the stress they experienced during hospitalization. Not knowing when and how they will go home compounds the worry and sadness they experienced in the hospital.

Children's perceptions of stress in the hospital truly humble the adult caregiver. We are directed to listen, communicate clearly with them, and help them to feel safe and comforted to relieve their sadness. Although many programs and child-friendly activities have been created for children to momentarily transcend their stress during hospitalization, children continue to give voice to simple and basic things that can be given and done to help them cope. Holding their hand, speaking words of kindness, giving them a hug, and not forgetting the Band-Aid are simple gestures that help a child cope with the stress of hospitalization.

Finally, one of the most significant tangible outcomes of this study was that it has informed the beginning of a clinical project with pediatric health experts for the creation of a communication tool for children regarding discharge to home. A team is being formed for the project that will include a variety of health care team members, children, family and community to enhance the quality and outcome of the project. The initial design of the tool discussed is a laminated board with the patient's name, picture symbols for the things children need to accomplish before home going, and finally, sparkly star stickers to place adjacent to the symbols as children achieve these accomplishments. This project will be designed and discussed with children, their families, and all health professionals that engage with school-age children to enhance the versatility, understanding and health outcome for the child and family. One of the outcome goals will be to relieve stress of the hospitalized school-age child.

Implications

Implications for Nursing Care of Children. There are several implications for nursing care of children in the hospital related to what a child perceives as stressful. First, the nurse can speak more clearly regarding preparation for each action and procedure that a child may undergo during hospitalization. Also, a clear plan for the day contracted with children would assist in relieving a child's fear of the unknown. The emphasis on the concept of home going illuminates a triad of needs that are implied by the children in this study. First, children need to know what is expected of them to go home. Secondly, these issues need to be clearly communicated, possibly through pictures and words that are posted in the room so all caregivers can be giving a consistent message to the child. Finally, a child would like to know when they are going home. For many children, returning to the comforts, the routines and the people who are at home, could be the ultimate relief of their stress during hospitalization.

Implications for Research. There are several implications for research that have been prompted by this initial qualitative interpretive study. First, more children need to be interviewed to continue to validate and expand on the initial interpretive themes regarding stress and coping. Secondly, a wider span of ages could be engaged to increase the voice of children of all ages regarding their perceptions of stress, and what we as caregivers can do to assist them. Also, excluded from this study are children with mental, cognitive and emotional challenges that call for newer methods to assess their feelings of stress and needs for coping. Parents are important partners in the relief of the stress of the child in the hospital. Therefore, a more thorough understanding of the stress of parents as well as sibling, family functioning and stress in the hospitalized setting will

inform caregivers of the stress endured through a family lens. Finally, child-centered and child participatory research would assist in a more congruent design and accurate assessment of child language, perceptions and interpretations. A child created interview tool, and other suggested art medium for children to express themselves could lend to a clearer understanding of a child's stress in the hospital.

Chapter Summary

This chapter outlays the a) summary of the interpretive findings; b) comparison of the findings to relevant literature; c) relevancy of theoretical frameworks; d) strengths and limitations of the study; e) significance of the study; and f) implications for care of the hospitalized child and future research. In addition, this chapter presents a critical summary of significance and methodological suggestions informing future implications for clinical interventions and study of children in the hospital. Imperative in this final chapter is the acknowledgement of the uniqueness of each child, and the importance of listening and hearing the voice of the child. Incrementally done with each child on every day during hospitalization, we can empower children to give voice to their needs, and improve the care of children in the hospital.

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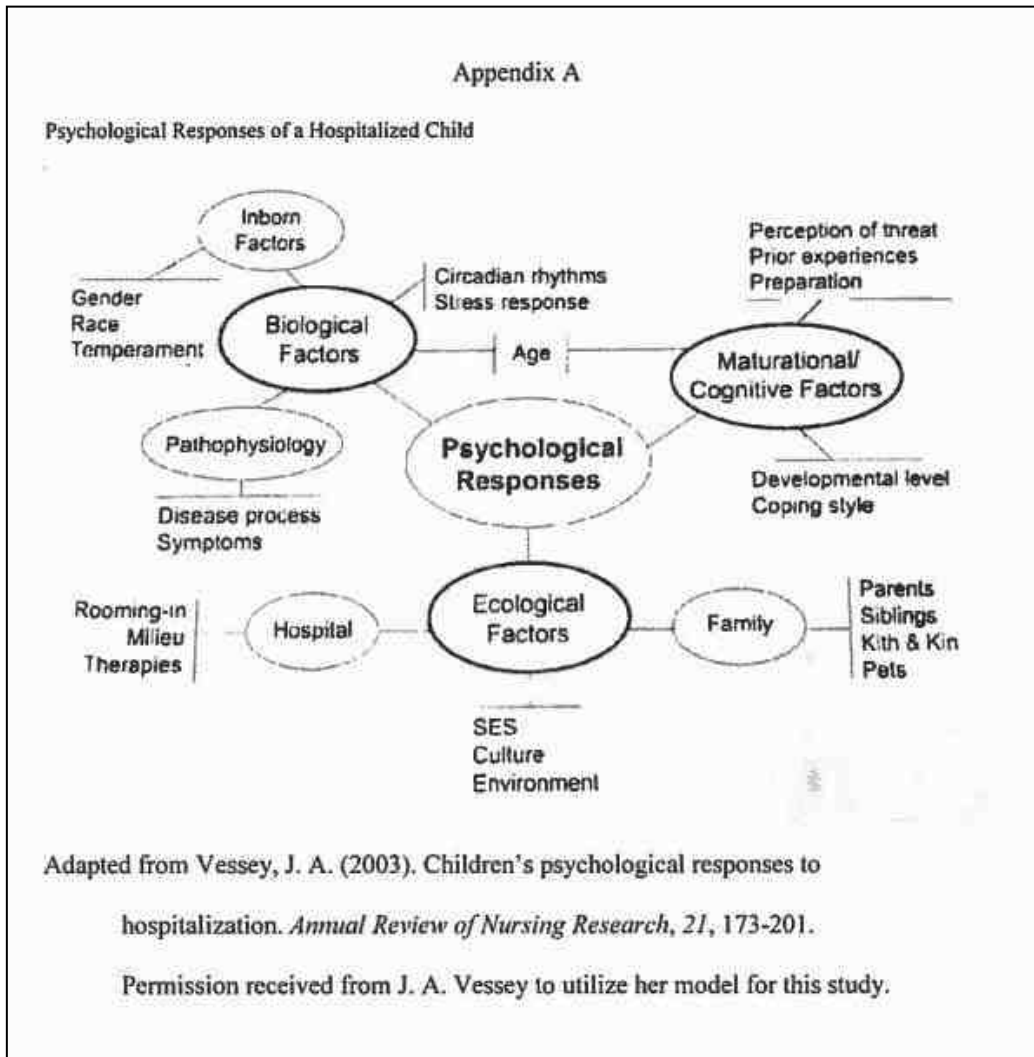
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Appendices



Adapted from Vessey, J. A. (2003). Children's psychological responses to

hospitalization. *Annual Review of Nursing Research*, 21, 173-201.

Permission received from J. A. Vessey to utilize her model for this study.

Appendix B

Table 3
Utilization of the Comfort Theory

Date	Area	Author	Usage
1996	Practice	Kolcaba & Fisher	Comfort care as an advanced directive
1996	Research	Kolcaba & Wykle	Comfort research around the world
1999	Research	Kolcaba & Fox	Guided imagery and comfort for breast cancer patients
2000	Research	Kolcaba & Steiner	Empirical evidence for holistic comfort
2000	Practice	Panno, Kolcaba & Holder	Acute care for elders; holistic model
2000	Practice/Research	Dowd, Kolcaba, & Steiner	Cognitive strategies for bladder control and comfort
2000	Practice	Koehn	CAM and holistic theory of comfort for labor and delivery patients
2001	Practice	Walden, Sudia-Robinson, Carrier	Comfort care for infants in the neonatal intensive care unit at end of life
2002	Practice	Kolcaba & Wilson	Comfort Care in perianesthesia nursing
2002	Research	Walker	Comfort work of nurses through patient narratives
2003	Practice	Kolcaba & Kolcaba	Fiduciary decision-making using comfort care
2003	Practice	Wilkin	Caring in intensive care practice
2004	Research	Al-Hassan & Hweidi	The perceived needs of Jordanian families of hospitalized, critically ill patients
2004	Practice/Research	Kolcaba, Dowd, Steiner & Mitzel	Hand massage for comfort in hospice patients
2005	Research	Herterich	Choosing to care: Male and female nurse experiences of comforting in the emergency department
2005	Practice	Kolcaba & DiMarco	Comfort theory and application to pediatric nursing
2005	Research	Wilby	Cancer patients' descriptions of comforting and discomforting nursing actions
2006	Research	Kolcaba, Schirm & Steiner	Hand massage for home residents
2006	Practice/Research	Dowd, Kolcaba & Steiner	Healing touch and comfort
2006	Practice	Kolcaba, Tilton, Drouin	Comfort theory in a practice environment
2006	Research	Wagner, Byrne & Kolcaba	Warming patients and comfort in preoperative patients
2007	Research	Bland	Critical ethnography on comfort aged care

2007	Research	Bortolusso, Boscolo & Zampieron	Survey about the comfort level (sic) according to Kolcaba on a sample of oncologic patients (Italian)
2007	Research/Education	Dowd, Kolcaba, Steiner & Fashinpaour	Healing touch and coaching for comfort of college students
2007	Research	Evans & Hallet	Living with dying: A hermeneutic phenomenological study of the work of hospice nurses
2007	Education/Theory	Goodwin, Sener, & Steiner	A novel theory for nursing education
2007	Research/Practice	Alves-Apostolo, Kolcaba, Cruz-Mendes & Calvario-Antunes	Development and evaluation of the Psychiatric In-Patient Comfort Scale (PICS)
2009	Practice/Research	Apostolo & Kolcaba	The effects of guided imagery on comfort, depression, anxiety and stress of psychiatric in-patients with depressive disorders.
2009	Practice	March & McCormick	Theory directed health care: An institution wide approach
2010	Practice	Lin (2010)	Strong commentary on comfort emphasized in nursing care and when promoting comfort becomes an important core value of nursing, the belief that nurses will gain more respect from their patients, the families of patients, and colleagues in the field of medicine.

Appendix C

Children's Hospital Medical Center of Akron Consent to Participate in Research

"School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story"

You are being asked to participate in a study that is being done by Susan M. Wechter, who is a Certified Pediatric Nurse Practitioner and Doctoral Student at the University of New Mexico's College of Nursing. This research is studying school-age children's perceptions of stress, coping and comfort in the hospital.

You are being asked to participate in this study because your child is a school-age child between the ages of 7 and 9 experiencing hospitalization. 30-60 people will take part in this study at Children's Hospital Medical Center of Akron (CHMCA). No other hospitals will participate across the United States.


The study is an unfunded dissertation.

This form will explain the research study, and will also explain the possible risks as well as the possible benefits to you. We encourage you to talk with your family and friends before you decide to take part in this research study. If you have any questions, please ask the researcher, Susan Wechter.

What will happen if I decide to participate?

If you agree to participate, the following things will happen:

You will be asked to sign this consent form and a HIPAA authorization form. You will also be asked to complete a survey regarding information about you, your child and your family. Your child will be asked to draw a picture of a child in the hospital and tell a story about the picture. The child will be tape recorded during this procedure, and the researcher will ask to keep your child's picture for the study.

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If you decide not to participate in the study, it will not change the care that you and your child will receive from the doctors and nurses in the hospital. If you do decide to be in the study, you can change your mind at any time. The care you and your child will receive in the hospital will not change if you change your mind or if you do not want to join this study.

How long will I be in this study?

Participation in this study will take a total of 1 to 2 hours over a period of 1 day. Most children complete the drawing and telling in less than one hour.

What are the risks of being in this study?

There are minimal risks for you and your child to be involved in this study. The possible risk for your child will be that drawing and telling about their experience of hospitalization could bring about feelings of anxiety, fear and emotional distress. The researcher will monitor the child closely for these responses and provide support to the child during the entire interview/draw and tell procedure and, if needed, will provide follow-up support through the bedside nurse and Child Life Specialists. If your child reveals anything that could be related to child neglect or abuse, safety measures for the child will be taken to care for your child.

For more information about risks and side effects, ask the investigator.

What are the benefits to being in this study?

Having your child draw a picture and tell the story about their time in the hospital could give your child an immediate benefit. This technique of storytelling helps a child to express his or her feelings regarding a stressful situation, such as hospitalization, and can help them cope by allowing them to talk about, work through and reflect on their experiences. Dealt with openly and honestly, difficult feelings lose some of their strength, and can help a child's stress and improve their comfort.

What other choices do I have if I do not want to be in this study?

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If you do not want to be in the study, there are no other choices or alternative treatments or interventions related to this research.

How will my information be kept confidential?

We will take measures to protect the security of all your personal information, but we cannot guarantee confidentiality of all study data.


Information contained in your study records is used by the study staff. The University of New Mexico Health Sciences Center Human Research Review Committee (HRRC) that oversees human subject research, and CHMCA's Institutional Review Board (IRB) may be permitted to access your records. There may be times when we are required by law to share your information. However, your name will not be used in any published reports about this study.

All information that you share and your child shares will be kept confidential for the purpose of the research. No identifying information will be recorded regarding you or your child, and all information that you and your child share with the researcher will only be shared with the dissertation committee and clinical experts when evaluating the findings. All data will be locked in a file cabinet only accessible to the nurse researcher. All electronic data will be password protected only accessible to the researcher and her research consultants.

What are the costs of taking part in this study?

There is no cost for you to participate in this study.

What will happen if me or my child is injured or become sick because I took part in this study?

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In the event that you have an injury or illness that is caused by you or your child's participation in this study, reimbursement for all related costs of care will be sought from your insurer, managed care plan, or other benefits program. If you do not have insurance, you may be responsible for these costs. You will also be responsible for any associated co-payments or deductibles required by your insurance.

It is important for you to tell the investigator immediately if you have been injured or become sick because of taking part in this study. If you have any questions about these issues, or believe that you have been treated carelessly in the study, please contact the Human Research Review Committee (HRRC) at the University of New Mexico Health Sciences Center, Albuquerque, New Mexico 87131, (505) 272-1129 or CHMCA IRB Office at 330-543-3691 for more information.

Will I be paid for taking part in this study?


Compensation for a parent will be your choice of a 5 dollar coffee card from the gourmet coffee cart in the lobby or a 5 dollar gift card from the gift shop. Compensation for your child will be his/her choice of an art bag filled with crayons, markers, paper, notebook, safety scissors, stickers and stencils that can be used to entertain him/her while in the hospital.

How will I know if you learn something new that may change my mind about participating?

You will be informed of any significant new findings that become available during the course of the study, such as changes in the risks or benefits resulting from participating in the research or new alternatives to participation that might change your mind about participating.

Can I stop being in the study once I begin?

Your participation in this study is completely voluntary. You have the right to stop participation at any point in this study. If you stop, it will not affect your future health care or other services for you and your child.

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It is possible, that you or your child could be withdrawn from the study without your consent. Those circumstances would be if the child became too ill to participate or if information was disclosed by you or the child that he/she is being harmed in any way.

Whom can I call with questions or complaints about this study?

If you have any questions, concerns or complaints at any time about the research study, Susan Wechter at 330-354-7782 or Marie Lobo at 505-272-2637, her associates will be glad to answer them.

If you need to reach someone after business hours regarding the study, please call 330-354-7782 and ask for Susan Wechter.


If you would like to speak with someone other than the research team, you may call the University of New Mexico Health Sciences Center Human Research Review Committee (UNMHSC HRRC) at (505) 272-1129 and/or Children's Hospital Medical Center of Akron Institutional Review Board at 330-354-3691.

Whom can I call with questions about my rights as a research participant?

If you have questions regarding your rights as a research participant, you may call the UNMHSC HRRC at (505) 272-1129. The HRRC is a group of people from UNM and the community who provide independent oversight of safety and ethical issues related to research involving human participants. For more information, you may also access the HRRC website at <http://hsc.unm.edu/som/research/hrrc/>

CONSENT

You are making a decision whether to participate (or to have your child participate) in this study. Your signature below indicates that you/your child read the information provided (or the information was read to you/your

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child). By signing this consent form, you are not waiving any of your (your child's) legal rights as a research participant.

I have had an opportunity to ask questions and all questions have been answered to my satisfaction. By signing this consent form, I agree to participate (or let my child participate) in this study. A copy of this consent form will be provided to you.

Name of Parent/Child's Legal Guardian: _____

Signature of Parent/Child's Legal Guardian _____

Date _____

INVESTIGATOR SIGNATURE

I have explained the research to the participant and answered all of his/her questions. I believe that he/she understands the information described in this consent form and freely consents to participate.


Name of Investigator/ Research Team Member (type or print):

Signature: _____ Date: _____

Protocol
Title/No:
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Appendix D

Children's Hospital Medical Center of Akron
ASSENT TO PARTICIPATE IN RESEARCH

Title of Study: School-age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story

First, your parents said I could talk with you. They told me your age. They have told me why you are in the hospital.

I want to know what it is like for you to be in the hospital. I am a nurse and I want to know what I can do better when I take care of you. I want to know what you like. I want to know what you don't like. I want you to tell me what makes you feel better.

I will ask you to draw a picture of a child in the hospital. You will get to choose the paper, pencil, crayons or markers you would like to use.

You can choose where you would like to draw your picture. You can sit in your bed or chair in your room. Your parents can be with you while you are drawing your picture and talking to me.

I will ask you to tell me the story of your picture. I will tape record your story. I can listen to the tape when I look at your picture. I may ask you questions about your picture. I would like to keep your picture. I am going to write about your picture for a school project. I will never use your name when I talk about your picture and your story.

I will be asking other children your age to draw pictures and tell their story, too. I will use this to help nurses take the best care of children in the hospital. You do not have to be in this study. You can stop at any time. The doctors and nurses won't care if you change your mind. They will not care if you do not want to do this.

Print Your Name: _____

Sign Your Name: _____ Date: _____

Witness Name: _____ /Signature: _____ Date: _____

Protocol Title and
Number: #13-409 Lobo

CHMCA IRB

JUL 03 2013

HRPO #: 13-409

Page 1 of 1

Version: 08/23/2013

APPROVED: 08/13/2013

OFFICIAL USE ONLY

EXPIRES: 08/12/2014



UNM | Human Research Protections Office

The University of New Mexico Institutional Review Board (HRRC/MCIRB)

Appendix E

AKRON CHILDREN'S HOSPITAL
One Perkins Square • Akron, Ohio 44308-1062

Information Sheet for "Authorization for Release of Medical Information for Research" (Use and/or Disclosure of Protected Health Information for Research Study)

What is the purpose of this form?

You/your child has been asked to participate in a research study and you have agreed.

Study title: "School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story"

Person in Charge of the Study: Susan M. Wechter, PhDc, RN, PNP-BC

Purpose: In order to perform the study, the researchers need to use and share some of your/your child's personal health information. Starting on the 14th of April 2003, federal privacy laws require that the study doctor explain to you/your child in detail what information will be obtained during the study, how that information will be used and with whom it will be shared. Please carefully review the information below. If you agree that researchers can use your/your child's personal health information for the study, you must sign and date the last page of this form.

Organization/Study Sponsor: Children's Hospital Medical Center of Akron and The University of New Mexico

What personal health information do the researchers want to use?

The study doctors or staff will collect information for the study from medical records, examinations, observations and forms or questions that you/your child may have completed. This information may identify you/your child by name, date of birth or other identifying information. The information used for the purposes of the study that may be released may include:

- History and diagnosis of the condition to be studied
- Current and previous treatments that you/your child received
- Other medical conditions that may affect the management of the condition to be studied
- Laboratory, radiology and any test results that have been used to determine if you/your child may participate in the study
- Results used to assess response to and the safety of study
- Physical findings, vital signs and clinical notes from your/your child's care during the study
- Follow-up information about your/your child's health, course of the condition and any late effects from the study

Who will receive and be able to use your/your child's personal health information?

As part of the research, your/your child's personal health information may be given to the following entities. These entities may also review your/your child's original records to assure that the information submitted is accurate.

Entities (list):

- Akron Children's Hospital and study investigators
- The University of New Mexico and its representatives, partners, and agents
- The Food and Drug Administration (FDA) and other regulatory/governmental agencies within and outside of the United States
- The Office for Human Research Protections (OHRP)
- The Akron Children's Hospital Institutional Review Board (IRB), a committee that reviews all human research

The researchers and sponsors will keep all patient information private in accordance with applicable law. Only those working with the researchers and sponsors will have access to your/your child's information. Personal health information will not be given to others except as authorized or required by law. However, once your/your child's information is given to other organizations that are not required to follow federal privacy law, the researchers and sponsors cannot assure that the information remains protected.

AKRON CHILDREN'S HOSPITAL
One Perkins Square • Akron, Ohio 44308-1062

Information Sheet for "Authorization for Release of Medical Information for Research"
(Use and/or Disclosure of Protected Health Information for Research Study)

What happens if you do not sign this form?

If you do not sign this form, you/your child will not be able to take part in the research study. Your refusal to allow your/your child's personal health information to be shared for research now or at any time in the future will not cause you/your child to lose any benefits, medical treatment or legal rights to which you/your child is otherwise entitled.

If you sign this form, does it mean you have been entered in the research study?

No, you enter the research study only when you have had the study completely explained to you and you have signed a separate informed consent/permission. This form is only intended to inform you about research-related use and disclosure of your/your child's health information.

What happens if you refuse to continue or let your child continue in the study or want to revoke (withdraw) your authorization?

You can change your mind about the study at any time and revoke your authorization. If this happens, you must revoke your authorization in writing. Beginning on the date that you revoke your authorization, no new protected health information will be used for research. However, researchers may continue to use the health information that was provided before you revoked your authorization. If you signed this form and enter the research study, but change your mind and revoke your authorization, you will also be removed from the research study at that time.

To revoke your authorization, please contact the person below. He/she will make sure your written request to revoke your authorization is processed correctly.

Name of Contact Person (Study Doctor or designee): Aris Beuglos Eliades, PhD, RN, CNS

Address: Akron Children's Hospital
One Perkins Square
Akron, Ohio 44308-1062

Phone: (330) 543-3193 Fax: (330) 543-3166

How long does this authorization last?

This authorization has no expiration date. However, as stated above, you can change your mind and revoke this authorization at any time.

What are your/your child's rights regarding your protected health information?

- You have the right to refuse to sign this authorization.
- You have the right to review and/or copy records of your protected health information.
- You do not have the right to review and/or copy records kept by the sponsor or other researchers associated with this research study.

RECEIVED
by the IRB
JUL 03 2013
Rm



**AUTHORIZATION for
RELEASE of MEDICAL
INFORMATION for RESEARCH**

Protocol Title/Number: Protocol School-Age Child Percepticon Draw & Tell

A Patient Name (Please Print) Last _____ First _____ Middle _____
 Date of Birth _____ MR# _____
 Address _____
 Street _____ City _____ State _____ Zip _____

B The undersigned authorizes the use or disclosure of the above named individual's health information by Akron Children's Hospital or its subsidiaries (Children's) as described below:

1. Use/Disclose information to the Person(s) and/or Organization(s) listed below and on the attached Information Sheet*:

Name: Susan M. Wechter, PhD, RN, PNP-BC, the co-investigators and study team for the dissertation on behalf of the University of New Mexico, College of Nursing,

Address MSC09 5350
1 University of New Mexico Albuquerque, New Mexico 87131-0001
 Street City State Zip

*See attached Information Sheet for a complete listing of the entities with whom information will be shared.

C 2. Purpose of Use of Disclosure:
 At request of patient Research Database or Repository Billing/Payment Other Other : Research, development and regulatory activities related to the study

3. Treatment during clinical trial is CONDITIONED UPON THE SIGNING OF THIS AUTHORIZATION:
 Check One: Yes No

D 4. Type of information to be used or disclosed:

<input checked="" type="checkbox"/> Complete medical record	<input checked="" type="checkbox"/> Consultation Reports	<input checked="" type="checkbox"/> Pathology Reports
<input checked="" type="checkbox"/> History & Physical	<input checked="" type="checkbox"/> Diagnostic Imaging Reports	<input type="checkbox"/> Photographs/videotapes
<input checked="" type="checkbox"/> Progress Notes	<input checked="" type="checkbox"/> Lab Reports	<input checked="" type="checkbox"/> Diagnosis & Treatment Codes
<input checked="" type="checkbox"/> Discharge Summary	<input checked="" type="checkbox"/> Radiology Reports/Films	<input type="checkbox"/> Other _____

5. Treatment date(s) _____ Duration of research study _____

E Unless revoked, this authorization will expire at the end of the research study or on the following date or event: no expiration date

I understand that the information in my health record may include information relating to sexually transmitted disease, acquired immunodeficiency syndrome (AIDS), or human immunodeficiency virus (HIV). It may also include information about behavioral or mental health services, and treatment for alcohol and drug abuse.

I understand that if the person(s) or class (es) of persons in Sections B 1 are not health care providers, health plans or health care clearing houses covered by the Federal privacy regulations, the protected health information they receive may be further used or disclosed by them and may not be protected any longer by the Federal privacy regulations.

I understand that this Authorization may be revoked at any time, except to the extent that Children's has taken action in reliance on this Authorization. Notify in writing, the Privacy Officer, Akron Children's Hospital, One Perkins Square, Akron, OH 44308. I understand that Children's can use and disclose health information obtained prior to the effective date of such revocation to maintain the integrity of the research data.

I understand that access to my health information may be restricted for the duration of the research study. However, once the study has concluded at all sites, I can inspect and obtain a copy of this information.

Signature of Patient or Parent/Legal Guardian _____ Date _____

If this Authorization is signed by the Parent/Legal Guardian, please specify the relationship to the patient/authority to sign on behalf of the individual: _____

Signature of Witness _____ Date _____

Appendix F

Pictorial Assent Tool for Explaining Assent to Children

PICTURE	STORY
 A portrait photograph of a woman with short brown hair, wearing a light-colored jacket over a blue top. The photo is framed with a thick black border.	<p>Hi, My Name is Sue Wechter</p> <p>I am a nurse who takes care of children. I am a student in school, too.</p>
 A photograph of a stack of several books on a library shelf. The background shows more bookshelves filled with books. The photo is framed with a thick black border.  The logo for the University of New Mexico (UNM), featuring a red arch over the letters "UNM".	<p>I am doing a school project that is called research.</p>



My project is about children your age who are in the hospital.

I want to know what I can do better when I take care of you.



I will ask you to draw a picture of a child in the hospital.





BED

You can choose where you would like to draw your picture. You can sit in your bed....



CHAIR

Or in the chair in your room.



Your parents can be with you while you are drawing your picture and talking to me.



I will ask you to tell me the story of your picture.



I want to know what you like.

I want to know what you don't like.



You will get to choose the paper, pencil, crayons or markers you would like to use.



I will tape record your story. I will listen to the tape when I look at your picture.



I may ask you questions about your picture.



I will be taking notes while you talk to me so I can remember important things about you and your picture.



I would like to keep your picture and write about your picture and story for my research school report.



I will not use your name when I talk about your story and picture.



I will be asking other children your age to draw pictures and tell their story, too.



I will use these pictures and stories to help nurses take better care of children in the hospital.



You do not have to be in this study.



You can stop any time. The doctors and nurses won't care if you change your mind. They will not care if you do not want to do this.



If you would like to draw a picture and tell me the story,
I will ask you to print your name on a form to say it is OK.

Do you have any questions?

Appendix G

Parent Questionnaire

Please Complete The Following Information on You and Your Child:

Person Completing this Questionnaire: (Please Circle): Mom Dad
Other: _____

1. Child's Age: _____ Years: _____ Months: _____

2. Child's Gender: (Please Circle) Male Female

3. Child's Grade in School: (Please Circle) 1st 2nd 3rd

Other: _____

4. Child's Ethnicity: (Please Circle):

African American
Hispanic
White, Non-Hispanic
Asian
American Indian
Other: _____

5. Why has your child been hospitalized? _____

6. How long has your child been in the hospital? Days: _____ Hours: _____

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7. What things are you worried about regarding your child's hospital stay?

8. Is this the first time your child has been hospitalized? (Please Circle)

Yes No

9. If No, please list the reasons your child has been hospitalized in the past:

10. List any special doctors that your child sees:

11. Does the child have brothers or sisters? (Please Circle) Yes No

Please list each sibling's age and gender:

AGE	MALE or FEMALE

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12. Who will be visiting your child while he/she is in the hospital?

13. What do you think is most stressful for your child during hospitalization?

14. What do you think comforts your child during hospitalization?

15. Is there anything else you would like to tell me about your child?

Thank You for Completing this Survey!!

Readability Statistics:

Flesch Reading Ease: 74.8% Flesch-Kincaid Grade Level: 5.2

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2248

Appendix H

Interview/Drawing Prompts for Children in the Hospital

2249 The following are ideas, possible questions and prompts for the draw and write process
2250 for data collection.

2251 "Draw a picture of a child in the hospital" Some things to think about while you are
2252 drawing.....

- 2253 1. What could be the reason the child in the hospital?
- 2254 2. What happens to the child while he/she is in the hospital?
- 2255 3. What things does the child like about the hospital?
- 2256 4. What are the things the child does not like about the hospital?
- 2257 5. What is different from the hospital than home?
- 2258 6. "If your friend was coming into the hospital, what things would you tell them
2259 about?" ?Might start with this question....
- 2260 (Wilson et al (2010))

2261 Some prompts for telling about their picture.

- 2262 1. You did nice work drawing a picture of a child in the hospital. Can you tell me
2263 about your picture?
- 2264 2. What is happening in your picture?
- 2265 3. How do you think the child feels in your picture?
- 2266 4. What is the *best* thing about being in the hospital?
- 2267 5. What is the *worst* thing about being in the hospital?
- 2268 6. If you had *one wish that could come true*, how would you change the hospital to
2269 make it a nicer place for children?
- 2270 7. If you had to tell the nurse how to take care of a child in the hospital, what would
2271 you tell him/her?
- 2272 8. You are doing such a good job drawing; you are doing such a good job talking
2273 about your picture.

2274
2275

2276 Checklist for Interviewing Children (Caplan & Bursch, 2013)

- 2277 • Interview child separately from the parent if possible
- 2278 • Use literal concrete language
- 2279 • Speak in simple sentences without clauses to ask short focused questions
- 2280 • Word questions at the appropriate developmental level and use words the child
2281 understands
- 2282 • Use 'What' and 'How' questions

2 25 2013

- 2283 • Avoid 'Yes/No', "When", "How long", "How often", and "Why"
- 2284 • Leave sensitive topics to later in the interview when rapport is strengthened
- 2285 • Allow the child to continue to engage in an activity (drawing) that does not
- 2286 demand the child's full attention
- 2287 • Carefully listen to the child and ask for the child's help if you do not understand
- 2288 • Let the child know that he is doing a good job or is a good talker periodically
- 2289 during the interview if the child is, in fact, talking
- 2290 • When the child does not answer a question, reformulate the question or provide a
- 2291 choice of response options
- 2292 • Express empathy for the child's difficulties and problems
- 2293 • When possible, "normalize" negative feelings to encourage the child to talk about
- 2294 them.
- 2295

A STUDY ON CHILDREN'S PERCEPTIONS OF THE HOSPITAL



CHILDREN WILL DRAW AND TELL THEIR STORY

Is your child between the ages of 7 and 9 years?

Are you interested in having your child participate in a research project on children's understanding of the hospital?

Susan Wechter, is a Nurse, and a doctoral student at the University of New Mexico, College of Nursing. As part of her school work she is studying children's understanding of stress and coping in the hospital. Children will be asked to draw a picture. Then they will be asked to tell the story about their picture.


Parents must sign a consent form for their child to be included in the study. Children will also have to agree to participate. They can stop at any time.

If you are interested in having your child help in this study, please tell your child's nurse.

If you would like more information about this study, please call Susan Wechter @330-543-7782

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08/23/2013

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APPROVED: 08/13/2013	OFFICIAL USE ONLY	EXPIRES: 08/12/2014
 UNM Human Research Protections Office The University of New Mexico Institutional Review Board (HRRC/MCIRB)		

Appendix J

Screening Tool for Participant Recruitment

Recruitment Study Number: _____ **Date:** _____

Child Screen:

1. Child between ages seven years and nine years (84-119 months) _____
2. Fluent in the English language. _____
3. Reason for hospitalization is acute medical or surgical condition. _____
4. Child with ability to utilize dominant writing hand for drawing. _____
5. Child with intact vision, hearing and speech. _____
6. Child without developmental delay. _____
7. Child not in protective custody or foster care. _____
8. Child not hospitalized for intentional trauma. _____
9. Child not severely ill or with impending death. _____

Parent Screen:

1. Parent is legal guardian for the child. _____
2. Parent is fluent in English language. _____
3. Parent not being investigated for intentional trauma or child endangerment. _____

Protocol: #13-409 Lobo "School-age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story"



Appendix K

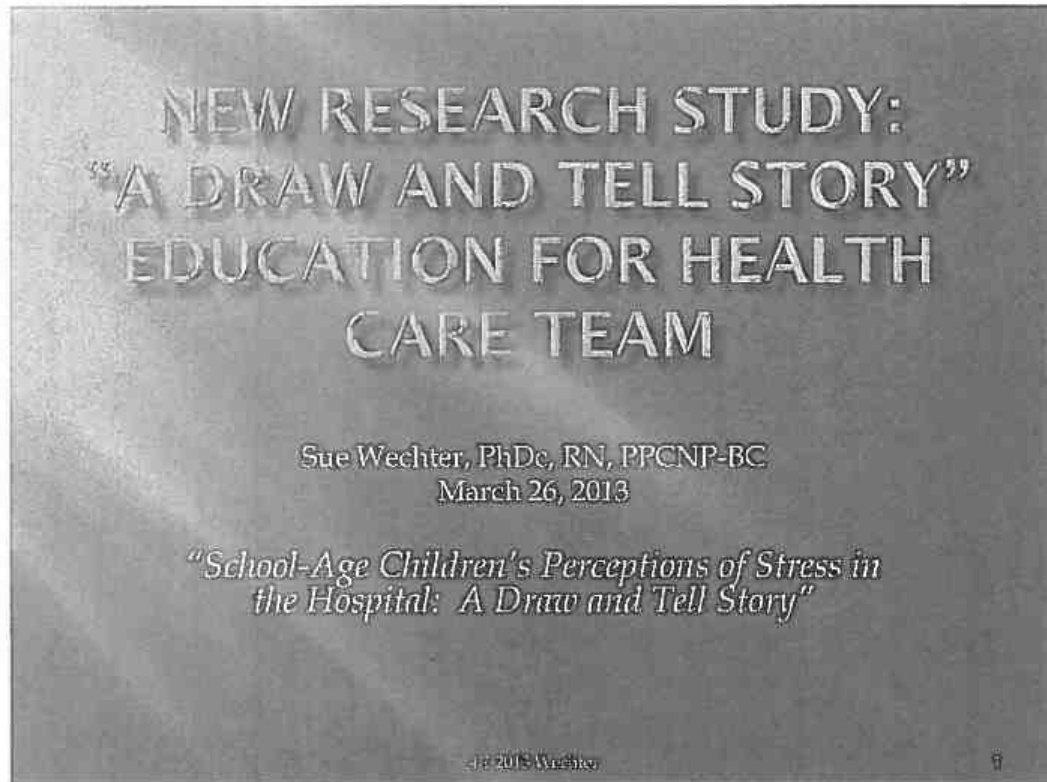
Research: School-Age Children's Perceptions of the Hospital

Sue Wechter: Cell: 330-354-7782

Nursing Student, University of New Mexico

<p>What: Study to investigate children's perceptions of stress, coping and comfort in the hospital from <i>their point of view</i>. The method is a qualitative inquiry called interpretive description. Data is collected through taped interviews and children drawing a picture of a child in the hospital with parents completing a questionnaire.</p>
<p>Where: 7100 and 6100 units at Children's Hospital Main Campus</p>
<p>Who: Children: 7, 8, and 9 years old; Fluent English; medical or surgical condition; ability to write with dominant writing hand; intact vision, hearing, speech. (Exclusions: developmental delay; protective custody; intentional trauma; severely ill, impending death.) Parents: legal guardian, fluent English. (Exclusion: investigated for intentional trauma or child endangerment.) Ideally recruiting 150-300 dyads to get 30-60 active participants. Assents/Consents will be used. IRB approval through CHMCA and UNM</p>
<p>When: Data collection Sept. through Nov.; Contract Expires 7/14</p>
<p>Why: To discover what children perceive about being hospitalized and identify the best ways to relieve pain, anxiety, and fear and comfort them in optimal ways to promote healing, earlier discharge, less post-traumatic stress for dyads.</p>
<p>I Need Your Help:</p> <ol style="list-style-type: none">1. <i>Identifying children who meet inclusion criteria</i><ul style="list-style-type: none">• I may be attending the clinical coordinator report (6a, 6p 71; 7a, 7p, 61)• I may call in to the unit to ask if anyone meets criteria for my study• I may attend FCC rounds2. <i>Assisting with finding a good time to collect data in the room and helping to decrease interruptions when possible. This will take about 1 hour</i>
<p>Incentives: Children: receive a full art kit with colored pencils, crayons, markers, paper, stencils and stickers. Parents: Receive gift card from coffee cart or gift shop.</p>

Thank you in advance for all of your support and assistance as I consider all of you vital to my study and advancing the knowledge of comfort for hospitalized children!!



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Purpose

Explore school-age children's perceptions of stress in the hospital.

Children seven, eight and nine years of age will interpret their perceptions through their own voice with a draw and tell technique.

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Significance

- ❑ 3 million children are hospitalized every year.
- ❑ Today's hospitals...complexity, technology, and acuity.
- ❑ Psychosocial impact of hospitalization for children has not been remedied.
- ❑ The stress of hospitalization elicits fear, anxiety, pain, and discomfort that can affect the child's healing, behavior and health outcomes (6).
- ❑ Vital to understand stress from a child's point of view to empower the child and give voice to what will comfort and soothe them effectively during hospitalization.

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Theoretical Frameworks

This study is sensitized to the following frameworks:

- ▣ Developmental Science (7)
- ▣ Vessey's Model of a Child's Psychosocial Responses to Hospitalization (8)
- ▣ Kolcaba's Comfort Theory (9)

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Setting/Sample/Recruitment

- ▣ Setting: Children's Hospital Medical Center of Akron, School-Age Units
- ▣ Sample: 30-60 child/parent dyads
- ▣ Recruitment Plan: Education of Health Care Team; Family-Centered Rounds, Consent and Assent; 250-300 possible recruitments

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Parent Survey

Parent Questionnaire

Please complete the following information on you and your child:

- Person completing this questionnaire (Please Circle): Mom Dad Other _____
1. Child's Age _____ Years _____ Months _____
2. Child's Gender (Please Circle) Male Female
3. Child's Grade in School (Please Circle) 1st 2nd 3rd 4th
4. Child's Ethnicity (Please Circle): African-American Hispanic White, non-Hispanic
Asian American Indian
- Other (Please describe): _____
5. Why is your child in the hospital?

6. How long has your child been in the hospital? Days: _____ Hours: _____
7. What things are you worried about regarding your child's hospital stay?

8. Is this the first time your child has been hospitalized? Please Circle Yes No

Questions?



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References

5. Hopia, Tomlinson, Paavilainen, Astedt-Kurki, 2005; Rollins, Drescher, & Kelleher, 2012.
6. Carney et al, 2003; Coad, Coad, & Theibe, 2005; Knighting, Rowa-Dewar, Malcom; Kearney & Gibson, 2010; Wilson, Megel, Enenbach, & Carlson, 2010.
7. Magnusson (1995).
8. (Vessey, 2003).
9. Kolcaba (2003).
10. Thorne, Reimer-Kirkham and MacDonald-Eames (1997); Thorne, 2008.

Figure 1. Matrix of Themes and Subthemes: Four Research Questions

<p><u>STRESS THROUGH CHILDREN'S EYES</u></p> <p>(How do school-age children describe stress related to the experience of hospitalization?)</p>	<p><u>THE RELATIONSHIP OF CONCEPTS</u></p> <p>(Is stress of hospitalization related to anxiety, fear, and discomfort, or other factors?)</p>	<p><u>COPING</u></p> <p>(How do school-age children cope with stress during hospitalization?)</p>	<p><u>WHAT CAN 'WE' DO TO HELP?</u></p> <p>(What does a child think a nurse can do to help a child with stress during hospitalization?)</p>
<p><u>THEMES AND SUBTHEMES</u></p> <p><u>.My 'story' is the essence of today</u> .I am unique and have something important to say. .It's chaos on admission and onset of illness.</p> <p><u>.My meanings are different than yours</u> .Children empowered to speak and interpret</p> <p><u>.There is no place like home.</u> .What I would rather be doing</p> <p><u>.I can't always say what I am thinking and feeling.</u></p>	<p><u>.The things I worry about and what might happen</u></p> <p><u>.I am afraid of shots, IV's and surgery</u></p> <p><u>.Discomforts: Things that hurt</u> .Things I do not like, but can tolerate.</p> <p><u>.What is expected of me?</u></p>	<p><u>.My family is the most important</u> .Family who stay with me.</p> <p><u>.I can transcend the hospital stresses</u> .Food is a comfort for me.</p> <p><u>.Fantasy is a part of the way I think.</u> .My wish</p>	<p><u>The 'We' is many more people than nurses.</u> .It matters what you do to me. .It matters how you make me feel.</p> <p><u>.Honesty is the best policy: When will I go home?</u></p> <p><u>.There are simple things you can do to help me!</u></p>
<p><i>Summary: When children tell their stories, it is usually about what is happening now, or in the last day. Many tell things about themselves, but some personify a new child. There is reported chaos upon admission and onset of acute illness, but then things get better. Each child has special things to say because they are each unique. When talking about stress, they use many terms, and at this age cannot articulate 'stress' in adult terminology, but they know what bothers them. They speak about things they miss and would rather be doing. Being away from home is very stressful. Many children do not talk about or deny that there is any stress in hospitalization, but their pictures and non-verbal</i></p>	<p><i>Summary: There seems to be many unknowns that cause concern and worry. Children identify known fears of IV's, shots and surgery. Discomforts and hurts are mentioned, but they do not take priority in the interviewing and storytelling, but rather are identified as something that happened that they didn't like, but were able to work through. The word sad is used almost universally within the circle of concepts surrounding fear, anxiety and pain. Children emphasize that they want to be listened to and they want to know what they</i></p>	<p><i>Summary: Children mention many things that help them cope in the hospital. The most consistent theme is family, with moms, dads, siblings, and others mentioned. They identify some momentary transcendence from stress when they speak to the many things they can 'do' in the hospital that they like. These include: going to the playroom, doggie visits, baking cookies, doing crafts; singing, listening to music, watching</i></p>	<p><i>Summary: When helping a child in the hospital, it doesn't matter what your title is, or your credentials. Most importantly children want to know 'what you may do to them' and what can they expect from you? They want to be listened to and addressed as a person. It matters how you make them feel. There is an overlapping theme of honesty. Tell me what I have to do now, later, and tomorrow, so that I can go home, as that is the ultimately relief of my stress in the hospital. There are simple things that nurses and other health care team members can do to help children in the hospital such as give a Band-Aid, hold a hand,</i></p>

Appendix M

<i>communication speak to possible hidden feelings.</i>	<i>have to do to go home. They consistently report that people talk to their parents but not to them.</i>	<i>movies; playing games (video and others). Some children make friends in the hospital. Fantasy thinking is a strong theme for children when they talk about coping and what they wish would happen. Children have flight of ideas that are verbalized and drawn.</i>	<i>give a hug, and/or just speak kindly.</i>
---	---	--	--

New Study

Use this form to submit a new project

Contact Information

Principal Investigator: Marie Lobo, PhD, RN, FAAN
 MLobo@salud.unm.edu
 Name/Email

Coordinator: Susan M. Wechter, PhDc, RN
 SWechter@salud.unm.edu
 Name/Email

Basic Information

1. * **Title of study:**
 School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story
2. * **Short title:**
 Children's Perceptions of Stress
3. * **Brief description:**
 The purpose of this study is to explore school-age children's perceptions of stress in the hospital. Children at ages seven to nine years will interpret their perceptions of being in the hospital through their own voice with a draw and tell technique.
 The research questions for this study include: a) how do school-age children describe stress related to the experience of hospitalization? b) is stress of hospitalization related to anxiety, fear, and pain? c) how do school-age children cope with stress during hospitalization? d) what can a nurse do to help a child with stress during hospitalization?
4. * **Identify the campus:**
 UNM
 UNMHSC
 Other: _____
5. * **Is the PI a UNM student or visiting faculty?** Yes No
 If "Yes", please identify the faculty advisor

Name	Email	Department
------	-------	------------

6. * **Is this CTSC Research?** Yes No
 If "Yes", please indicate the RFA Date: _____
7. * **Is this VA Research?** Yes No
 If "Yes", please answer the following:
 Does the PI hold joint appointment? Yes No
 Indicate where the research will take place: (check all that apply)
 UNM
 VA
8. * **Is this a Facilitated Review?** Yes No
 If "Yes", please answer the following:
 Is this the first time the study is opened with UNMHSC HRRc? Yes No

If "No", when was this study previously opened? _____

Funding Sources

Identify each organization supplying funding for the study:

Name of Funding Source Funding Source ID Grant Office ID

None

Study Team Members

Identify each additional person involved in the design, conduct, or reporting of the research:

Name & Email	Role on Project:				Involved in Consent?	Training Complete?
	Co-Investigator	Data Analyst	Research Assistant	Statistician		
Susan M. Wechter, SWechter@salud.unm.edu	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Cindy Mendelson CFMendelson@salud.unm.edu	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Beth Tigges BTigges@salud.unm.edu	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Sally Thorne Sally.Thorne@nursing.ubc.ca	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

External Sites

Complete for each external site at which the investigator will conduct or oversee the protocol

Site name	Contact name	Contact phone or email	Will site's IRB review the protocol?		Will site rely on this institution's IRB ¹ ?	
			Yes	No	Yes	No
Children's Hospital Medical Center of Akron	Aris Eliades	AEliades@chmca.org	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

¹ Not allowed for Veterans Administration (VA) research

			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
			<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Drugs, Biologics, Dietary Supplements, and Foods

List all:

- Unapproved drugs/biologics being used in the protocol
- Approved drugs/ biologics whose use is specified in the protocol²
- Foods or dietary supplements whose use is specified in the protocol³

Generic Name	Brand Name	
None		
		Submit a package insert or investigator brochure for each listed drug
Protocol is being conducted:	<input type="checkbox"/> Under IND#(s):	Submit evidence of IND#(s) ³
	<input type="checkbox"/> Without IND#	
Who holds the IND?	<input type="checkbox"/> Sponsor	
	<input type="checkbox"/> Investigator	Submit approved IND application(s) (Form 1571) and FDA approval letter(s) for IND#(s)
	<input type="checkbox"/> Other, Specify:	

Devices

List all:

- Devices being evaluated for safety or effectiveness:
- Humanitarian Use Devices (HUD)

Name		
None		
		Submit product labeling for each item listed
Protocol is being conducted:	<input type="checkbox"/> Under IDE#(s):	Provide the #(s) below: Submit evidence of IDE#(s) or HDE#(s) ⁴
	<input type="checkbox"/> Under HDE#(s):	
	<input type="checkbox"/> Under abbreviated IDE requirements	Submit an explanation of why the device is a non-significant risk.
	<input type="checkbox"/> None of the above	
Who holds the IDE?	<input type="checkbox"/> Sponsor	
	<input type="checkbox"/> Investigator	Submit approved IDE application(s) and FDA approval letter(s) for IDE#(s)
	<input type="checkbox"/> Other, Specify:	

² "Specified in the protocol" means that the protocol requires one or more subjects to use the drug, biologic, dietary supplement, or food as part of study participation, regardless of whether its use is standard of care. For example, if the protocol indicates that "subjects in group 1 will take 650 mg of aspirin in response to a headache" the use of aspirin is specified by the protocol. If the protocol indicates that "subjects in group 1 may take 650 mg of aspirin in response to a headache" the use of aspirin is not specified by the protocol.

³ Acceptable evidence includes: Sponsor protocol with the IND#, communication from the sponsor documenting the IND#, or FDA approval letter indicating IND#

⁴ Acceptable evidence includes: Sponsor protocol with the IDE#/HDE#, communication from the sponsor documenting the IDE#/HDE#, or FDA approval letter indicating IDE#/HDE#

Attach supporting documents:

Document

- *Protocol (i.e. Investigator-Initiated or Sponsor)
- *Departmental Scientific Review Form
- *Curriculum Vitae (CV)
- *Certificate of Completion for required human subjects training (HRP / CITI / NIH) for each study investigator
- *UNMHSC Conflict of Interest Form(s) or UNM FCOI Cover Sheet for each study investigator
- Written materials meant to be seen or heard by subjects:
 - Evaluation instruments and surveys
 - Advertisements (printed, audio, and video)
 - Recruitment materials and scripts
 - Consent documents (The IRB does not require an informed consent document for HUD use.)
 - If consent will not be documented in writing, a script of information to be provided orally to subjects
 - Foreign language versions of the above
- DHHS grant application, DHHS protocol, and DHHS-approved sample consent document
- For Department of Energy (DOE) research, a completed "Checklist for IRBs to Use in Verifying that HS Research Protocols are In Compliance with Department of Energy (DOE) Requirements"
- HRPO Attachments:
 - Drug Attachment
 - Biological Specimens Attachment
 - Radiation Safety Attachment
 - HRPO Sponsorship Fee Form
 - Study Team Members Attachment
- Official Letters of Support/Approval from an outside entity such as Albuquerque Public Schools (APS), American Indian/ Alaskan Native (AI/AN) Tribes
- For Veteran's Affairs (VA) Research, FL 151-266 & FL 151-267
- Conflict of Interest Disclosure Decision Memo
- UNMHSC CTSC Resources Form

Statement of Principal Investigator

- I have completed the CITI or HRP training (or an equivalent) research ethics training.
- I will personally conduct or supervise this research in accordance with state law, Good Clinical Practices and regulations presented in the Code of Federal Regulations (CFR) Title 21 Parts 50, 56, 312 and 812 / Title 45 Part 46 and Title 45 Parts 160-184 (the HIPAA Privacy Rule).
- I agree to conduct the research in accordance with the three basic ethical principles of the Belmont report (Respect for Persons, Beneficence, and Justice)
- I agree to seek and obtain prior written approval from UNM HRPO for any changes/amendments to this research including, any changes in procedures, study risks, co-investigators, etc.
- I will maintain records of this research according to federal and state regulations and guidelines, including keeping a copy of this application for the investigator's records. If this application is approved, I agree to maintain copies of all HRPO correspondence for at least 3 years after the completion of the study, or, if it is VA research according to NMVAHCS retention schedule; or longer if required by study sponsor.
- I agree to promptly report any adverse events or unanticipated problems involving risks to participants or others in the course of this study in accordance with the UNM HRPO policy.
- I understand that this research, once approved, is subject to continuing review and approval by UNM HRPO (applies unless the HRPO provides written determination that research is exempt). I agree to maintain active study approval; I will not conduct any research activities if there is a lapse in approval. In order to maintain active approval, I agree to submit to the UNM HRPO complete requests for continuation at least forty-five (45) days prior to the study expiration date. Once the study is complete, I agree to submit a complete request for closure to the HRPO promptly and at least forty-five (45) days prior to the study expiration date.

I certify that the statements herein are true, complete, and accurate to the best of my knowledge, and accept the obligation to comply with all applicable federal regulations and state laws, institutional policies and procedures, and the requirements and determinations of the UNM Human Research Protections Office (HRPO) with respect to this research.

Signature of Principal Investigator

Date

Appendix O

PROTOCOL TITLE: School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story

1) Protocol Title

"School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story"

2) IRB Review History*

An IRB review is being done through Children's Hospital Medical Center of Akron IRB in April of 2013; The IRB contact is Aris Eliades, Associate Director, Rebecca D. Considine Research Institute; Director, Nursing Research; she can be reached by email at: aeliades@chmca.org and phone at: 330-543-3193

3) Objectives*

The purpose of this study is to explore school-age children's perceptions of stress in the hospital. Children ages seven to nine years will interpret their perceptions through their own voice with a draw and tell technique. The research questions include: a) how do school-age children describe stress related to the experience of hospitalization? b) is stress of hospitalization related to anxiety, fear, pain, or other factors? c) how do school-age children cope with stress during hospitalization? d) what does a child think a nurse can do to help a child with stress during hospitalization?

4) Background*

Hospitalization is a significant occurrence in the series of lifetime events for a child (1). Since the 1960's the knowledge base about stress for the hospitalized child has been cultivated (2). The knowledge base is built primarily from quantitative studies (3) and some studies from the viewpoint of the parents and nurse (4). Limited studies have been done from the perception of the child's viewpoint (5).

There are 3 million children hospitalized each year, and 40% of them are school-age range, the population of target for this study (6). Child in-patient hospital visits account for \$10 billion of annual hospital costs for children. The stress of hospitalization on a child can lead to prolonged recovery, increased risk for infection and poor patient outcomes, increasing these hospital costs. Hospitalization today changed with increased complexity, technology, and acuity related to the context of this event. The stress of hospitalization elicits fear, anxiety, pain, and discomfort that can affect the child's healing, behavior and health outcomes (7). This psychosocial impact of hospitalization has not been remedied. It is vital to understand stress from a child's point of view to empower the child to give voice to what they believe will comfort and soothe them effectively during hospitalization.

5) Inclusion and Exclusion Criteria*

Inclusion and Exclusion Criteria for Child Participants. The participants will be selected, attending to the following inclusion criteria: a) children between the ages of seven years and nine years (84 months and 119 months); b) either male or

PROTOCOL TITLE: School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story

female; c) Fluent in the English language; d) hospitalized for an acute medical or surgical condition; e) ability to utilize dominant writing hand for drawing a picture; and f) intact vision, hearing and speech. Exclusion criteria for this study will include: a) children with developmental delay; b) children with a mental health or behavioral disorder; c) children in protective custody/foster care; d) children who are hospitalized for intentional trauma (child abuse).

Inclusion and Exclusion Criteria for Parent Participants. Parent inclusion criteria will be at least one parent of the child who is the legal guardian of the child. Inclusion criteria would be: a) fluent in the English language; b) the ability to read and write to complete the consent, HIPPA authorization, and demographic questionnaire (verbal explanation of these forms could be done if the parent had difficulty reading or writing); c) the parent will meet the legal guardian criteria by showing their formal picture ID matched with the legal guardian name identified in the electronic medical record. Exclusion criteria will be: a) not a legal guardian of the child; and b) any parent being investigated by social service for neglect or abuse of the child.

6) Study-Wide Number of Subjects*

The estimated sample size for this study is between 30 and 60 child/parent dyads. The lower limit of 30 will allow for a range of interpretation of children of different ages, gender, and hospital experiences that will provide an intensive, in-depth interpretation. The upper limit of 60 allows for exploration of an unanticipated theoretical variable that commands expanded data collection, and to offer expanded interpretations for anticipated child informants who provide thin data due to less expression because of the nature and unique temperament of the child in the context of the hospital setting.

7) Study-Wide Recruitment Methods*

This is a single site study at Children's Hospital Medical Center of Akron. Estimated recruitment will be between 150 and 300 child/parent dyads with a 20% as consented participants. A marketing flyer will be placed on the unit at the nursing station and also in the admission packets of children admitted to the study setting units (see attached). The participants will be recruited from two inpatient units, one unit is a 28 bed acute pediatric medical-surgical school-age unit, and the other is a 22-bed acute pediatric medical-surgical unit housing infants through children 18 years of age. Both units have interdisciplinary, family-centered care rounds that take place every morning reviewing the cases and plans for care for the children on these units. I will gain access to these rounds and identify children and parents meeting inclusion criteria. I will talk with the legal guardian of the child, describing the study, to see if there is interest. If there is interest in participating, I will contract with the family, child, and bedside nurse a convenient time to gain consent, assent, and to collect data.

8) Study Timelines*

The duration of time for the child and parent to be involved in the study would be approximately 2 hours. The first half hour will be spent explaining the study and obtaining consent, HIPAA authorization and assent from the child. It is expected

PROTOCOL TITE: School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story

that the demographic questionnaire for the parents and the child drawing a picture and telling a story will take approximately 1 to 2 hours. The interaction with the child/parent dyad will be a single data collection period.

It is anticipated that data collection will occur over a period of six to nine months considering access to those children and parents meeting inclusion criteria.

Data collection will take place from June of 2013 through November of 2013 but could take up to nine months depending on participant recruitment with end point being February of 2014.

9) Study Endpoints*

There is only a primary data collection for this study with expectations of data collection to be completed by February of 2014.

10) Procedures Involved*

All nursing staff and health care team members will be educated about this study through in-service education provided live, electronically and through a communication board on the unit. A study protocol handbook will be available at the nurse's station, a central location in the hospital, for referral of information and questions from the health care team regarding the study. This education will be coordinated through Aris Eliades who is the Associate Director and Director of Nursing Research of the Rebecca D. Considine Center at Children's Hospital Medical Center of Akron, the liaison to the hospital for all clinical research.

After consents, HIPPA consent, and assent (using a pictorial assent tool) from the child is obtained, and a mutual good time for data collection will be negotiated with the child, parent and bedside nurse. The parents will be asked to complete a demographic questionnaire (Appendix E). Element for writing will be presented to the child for them to choose their writing utensils and paper. The child can choose to sit in their chair or hospital bed during data collection. Parents will stay during data collection to ensure comfort and security for the child, although they will be asked not to prompt their child during data collection.

The child will be asked to draw a picture of a child in the hospital, and tell the story about their picture. The techniques will include a drawing and an oral retelling as a joint representation of the lived experience of stress and hospitalization. Children may know and feel more than they are able to describe, therefore using drawings combined with writing and interview can be a powerful way of accessing their accounts (8). The draw and tell process will be tape recorded. The design for this inquiry will be a non-categorical, qualitative research approach, interpretive description (9). This approach is the description of a child's experience through the analysis of the child's interpretation of that experience; that being the child's perceptions of stress while in a hospitalized setting. The analysis constitutes an interpretation of the experience to understand its meaning. Including children in the dialogue about their direct experience regarding a phenomenon, has the potential to inform caregivers of the implications and outcomes of these experiences for young children (10).

PROTOCOL TITLE: School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story

Protection of participants related to risk: The study involves minimal risk to the parent/child participants. However, the child will be drawing and narrating their experience of hospitalization which could elicit feelings of anxiety, fear and emotional distress. The researcher will monitor the child and parent closely for these responses and provide support to the child and parent during the entire interview/draw and tell procedure and will provide follow-up support through the bedside nurse, Child Life Specialists, Clinical Nurse Specialist and if warranted a Psychiatric Nurse Practitioner. If the child reveals anything that could be possible child neglect or abuse, safety measures for the child will be taken immediately by notification to the Social Service department, and activation of the Care Center protocol at the hospital site of the study which will give a multidisciplinary assessment, treatment and follow-up for any child deemed at risk.

11) Data and Specimen Banking*

All interviews will be audio-taped. All data on tapes will be transcribed verbatim onto a password protected Word Document before analysis. All tapes will be stored in a locked file in the researcher's private office. Data from parent questionnaires will be coded and stored in an electronic code sheet that is password protected on researcher's laptop. All data will be stored for three years then destroyed.

12) Data Management*

Data analysis: SPSS will be utilized for descriptive statistics from the data obtained from the parent questionnaires; Initial transcription of the audiotapes will occur and repeated immersion in the data will take place through repetitive reads and reflection on drawings of the child data. Constant comparison will be utilized comparing each interview transcription with the interview following. Field notes will be taken throughout the data collection. Thoughtful clinical tests will be periodically completed with experts in the field of hospitalized school-age children, reviewing the interpretations of the data found. This data monitoring group will include a doctoral prepared Clinical Nurse Specialist, a master's prepared Pain Management Nurse Practitioner, and a Child Life Specialist team who manages hospitalized school-age children at Children's Hospital Medical Center of Akron.

MAXQDA software will be utilized to help code the data and interpret the themes. A Themes will be reviewed by dissertation committee members to ensure accuracy and credibility. All data analyzed will be done electronically through a password protected laptop owned by the PI. Tapes of interviews, drawings and questionnaires will be stored in a locked file in the PI's office with PI's sole key access. The only persons who will be reviewing the data analysis is the dissertation committee members. Otherwise, the PI will have sole access to the electronic, paper and tape files.

13) Provisions to Monitor the Data to Ensure the Safety of Subjects*

The study involves minimal risk to the parent/child participants. However,

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The child will be drawing and narrating their experience of hospitalization which could elicit feelings of anxiety, fear and emotional distress. The researcher will monitor the child closely for these responses and provide support to the child during the entire interview/draw and tell procedure and will provide follow-up support through the bedside nurse, Child Life Specialists, and if warranted a Psychiatric Nurse Practitioner. If the child reveals anything that could be possible child neglect or abuse, safety measures for the child will be taken immediately by notification to the Social Service department, and activation of the Care Center protocol at the hospital site of the study which will give a multidisciplinary assessment, treatment and follow-up for any child deemed at risk.

14) Withdrawal of Subjects*

Anticipating circumstances of withdrawal: If the child cannot complete the drawing and interview due to exacerbation of their illness or an unanticipated hospital procedure or test that would interfere with data collection, then they will be immediately withdrawn from the interview. If the parent has any concerns about the child's condition during the data collection process and would like the child withdrawn from the research, their request will be honored, and the child's needs will be cared for.

Orderly termination: The child and parent are terminated from the study at the end of data collection, or at any time during data collection that the parent or child would request to be terminated from the study, including after the data is collected.

Partial withdrawal: There may be a situation where the child/parent cannot finish the data collection due to a hospital interruption. If the parent and child agrees, data will be collected at another time.

15) Risks to Subjects*

There are minimal risks foreseeable to the child and parent for this research. The risk of disclosing personal information by both the child and parent is consistently a risk in this type of study. Data will be collected in patient's private hospital room to protect privacy issues. To address anonymity and confidentiality, data will be given an objective identifier number to be stored and if data is disseminated, pseudo names will be utilized for direct quotes of participants.

16) Potential Benefits to Subjects*

There are potential immediate benefits to the child participant. The method used for the study is a form of emotional storytelling that engages the child to express his/her feelings regarding a stressful situation such as hospitalization. This has been shown to provide opportunity to work through, reflect and find meaning in their experience helping intense feelings lose some strength (12). Potential benefits for the parents would be to hear the process of their child drawing and telling about their hospital experience, thereby receiving a deeper understanding of the psychosocial impact of hospitalization for their child, and then identifying immediate ways for them to comfort their child.

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Otherwise, no direct benefits to the study participants would be available.

17) Vulnerable Populations*

Children between ages 7 and 9 will be asked to participate in this study. A CHECKLIST: children HRP 416 was completed for this study. Children will have a pictorial assent process explaining the study, and a written informed consent will be done by the parent/legal guardian, and a written informed assent will be done by the child (see attached documents). Also, a HIPPA Authorization will be obtained from the parent/legal guardian.

18) Multi-Site Research*

N/A

19) Community-Based Participatory Research*

N/A

20) Sharing of Results with Subjects*

Results of the study will not be shared with the participants as the encounter will only be in the hospital setting. If parents or children request information about the results of the study, those participants will be followed up with to present written results.

21) Setting

The setting for this study will be a 28-bed and 22 bed acute pediatric medical-surgical units in a large urban children's hospital in Northeast Ohio. The hospital is a 253-bed free standing children's hospital that serves a multi-state region with an integrated system in 80 locations serving infants, children and teens, handling 600,000 patient visits per year. The units admit patients with acute medical and surgical conditions for children ages newborn through 18 years of age. For this study, the focus will be on children admitted to these units for acute medical or surgical conditions, between the ages seven to nine years of age. Data collection will take place in a private patient hospital room.

22) Resources Available

The PI, Marie Lobo, who is overseeing the study has had over 40 years of experience with research with children in the acute hospital settings. The study coordinator and the sole data collector, Susan Wechter, is a registered nurse, certified Pediatric Nurse Practitioner, and Masters prepared, PhD candidate in nursing and has 30 years of experience in pediatric health care. The study is supported through the process of data collection, analysis and dissemination by the dissertation committee consisting of Marie Lobo, Cindy Mendelson, Elizabeth Tigges and Sally Thorne. In addition, the resources available to through data collection to the study coordinator and sole data collector at Children's Hospital Medical Center of Akron is consultation with the Associate Director of the Research Institute, Aris Eliades, as well as supportive resources for child participants for any needed medical or psychosocial support including the head

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nurse manager, clinical coordinator, nursing staff, child life staff, social service, hospitalists and psychiatric clinical nurse specialists.

23) Prior Approvals

Approval through University of New Mexico HRPO as well as the Children's Hospital Medical Center of Akron IRB will be completed before the study begins.

24) Recruitment Methods

Sample/Recruitment: Purposive sampling will be utilized for this study to select the participants to allow for exploration of maximum variation in the phenomenon studied through participant selection (13). There is a multi-disciplinary team meeting that takes place every morning on the unit where the cases of in-patient children are reviewed. The team consists of the Clinical Coordinator (nurse who is in charge of the unit resources that day), the social worker, the chaplain, the dietician, the hospitalist (physician in charge of the unit), the case manager, child life specialist and other team members as needed. The study coordinator will gain access to this meeting daily to overview of the patient population on the unit can be assessed to identify which patients meet inclusion criteria for the study. Prior to this access, the researcher will ensure education for the leadership team (see Procedure section).

Once study participants are identified that meet inclusion criteria, I will collaborate with the bedside nurses for access to the patient and parent to discuss their schedule for the day, and accommodation of data collection time. I will introduce myself to the parent/legal guardian and the family and explain the purpose of the study. The parent/legal guardian will be given a consent form that describes the study and the expectations of the study procedure. After initial written consent is given by the parent, then the education and process of informed assent through a pictorial explanation to gain proper assent of the child will ensue (See attached assent tools). After consent and assent is obtained, I will contract with the child and parent for a convenient time for the draw and tell interview to be completed.

25) Local Number of Subject

The targeted number of participants which will be child/parent dyads will be 30 to 60. It is anticipated that between 250 to 300 child/parent participants will be screened to meet criteria with the goal of 20% consenting and assenting to be participants in the study. The possible deterrents of consent and assent to participate could be the condition of the child, past experiences with research that were not favorable, protection of the child by the parent against unnecessary interaction or stress, parental anxiety, or unanticipated reasons for parents to deny access to the child.

26) Confidentiality

Not a multicenter study, however, confidentiality will be maintained through careful handling of tapes, data, hand drawn pictures, and anonymous dissemination of data, with no disclosure of personal information. All electronic

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data will be stored in a password protected electronic format. All paper data (pictures) and tapes will be stored in a locked file only accessible to the researchers.

27) Provisions to Protect the Privacy Interests of Subjects

Privacy interests: Attention will be paid to maintaining privacy during the study procedure with the child and parent. All parents and children will be interacted with in the privacy of the single patient/child's hospital room. Disclosure of information on the parent questionnaire and the child draw and tell interview will be done only with the PI who will be collecting all of the data. I will ensure that the only people in the child's room during data collection will be the myself, the parent, child and possibly other family members (siblings) at the parent's consent.

Putting the child and parent subjects at ease: Careful choice of data collection methods with children is imperative in order to respect children's participation rights (14). Children are more likely to respond openly and honestly if they feel respected and safe, and this usually depends on the skill of the researcher putting them at ease, minimizing the distance between the adult and the child, and establishing shared interests and a dialogue, and putting the child in the position of the expert (15). Attempts will be made to reduce power imbalances, and time taken to build relationships with children and their families. Multiple choices will be given to the child to empower them during the data collection including choice of where to sit and draw, choice of paper, choice of writing utensils and the ability to manipulated the tape recorder before the data collection and turn on and off the tape recorder.

28) Compensation for Research-Related Injury

Only minimal risk is anticipated with this study and research related injury is not anticipated. However, incentives to participate are being offered as a gesture of thank you for participation. (see below regarding guards against coercion)

Participation Incentives for Child. There is a paucity of research guidelines that exist about the appropriate amount, types and schedules of incentive to be used with young child participants in research studies. Emphasis is placed in the available literature regarding: a) developmentally appropriate rewards (16) and b) safeguards related to avoidance of incentives being coercive (17). For this study, children will be offered an art bag filled with developmentally appropriate art tools including markers, pencils, paper, stickers, scissors, and stencils. This compensation will address developmental congruency and be sensitive to the avoidance of a coercive incentive.

Participation Incentive for Parents. The parents will be given a choice of a five dollar coffee/tea card for the gourmet coffee cart in the welcome lobby of the hospital or a five dollar gift card for the hospital gift shop. This small incentive acknowledges the work of the parent in the study and encourages the parent to take a break during the stressful hospital stay.

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29) Economic Burden to Subjects

The participants will not be incurring any costs for participation in this research.

30) Consent Process

Consent and assent will be obtained prior to the study beginning (See Appendix A, B, C & D). I will obtain an informed consent and HIPAA authorization and assents. I will identify those participants meeting criteria in family-centered rounding in the morning, and then go to the patient (child's) room, introduce themselves to the parent and child, and introduce the study to the parent and child. If the child and parent are interested, then the process of the study will be described. The study description and consent/assent process will take approximately 30 minutes for each child/parent dyad.

Informed written consent will be obtained from one parent and/or legal guardian of the child participant prior to the study participation (See attached). In addition, informed assent will be obtained from each child participant (See attached). For the assent process, a picture tutorial will be utilized with the child explaining the study and equipment including the tape recorder, drawing materials, and process of study from beginning to end. In addition to study specific informed consent from the parent, an Information Sheet for "Authorization for Release of Medical Information for Research" (see attached). Following this explanation, the parent/legal guardian will be requested to sign an 'Authorization for Release of Medical Information for Research (See Appendix D).

Non-English speaking participants will not be included in this initial study.

31) Process to Document Consent in Writing

Written consent and written assent will be documented according to the HRP protocols. (See Attached)

32) HIPAA Authorization

A HIPAA information sheet will be given and explained to parents and a HIPAA Authorization will be obtained from the parent/legal guardian of the child. (See Attached)

Appendix P -



*Human Research Review Committee
Human Research Protections Office*

August 22, 2013

Marie Lobo (Principal Investigator)
mlobo@salud.unm.edu

Susan Wechter (Student Investigator)
swechter@salud.unm.edu

Dear Dr. Lobo:

On 8/13/2013, the HRRC reviewed the following submission:

Type of Review: Initial Study
Title of Study: School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story
Investigator: Marie Lobo (Principal Investigator)
Susan Wechter (Student Investigator)
Study ID: 13-409

Documents Reviewed:

- Protocol v 08/02/2013
- UNM HSC Consent v 08/02/2013
- UNM HSC Assent v 08/02/2013
- HIPPA v 08/02/2013
- Parent Questionnaire v 08/02/2013
- Screening Tool 08/02/2013
- Children's Hospital Medical Center of Akron Contract submitted 08/14/2013
- Departmental Review Form v 08/02/2013
- IRB Approval Letter v 07/05/2013
- Authorization for Release of Information v 06/18/2013
- Assent Picture Tutorial v 06/18/2013
- Draw and tell Education for Staff v 08/01/2013
- Flyer for Marketing v 06/18/2013

Review Category: EXPEDITED: CATEGORIES (5) Data, documents, records, or
specimens
Determinations/Waivers: Children

The HRRC approved the study from 8/13/2013 to 8/12/2014 inclusive. Before 8/12/2014 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review with required explanations. You can submit a continuing review by navigating to the active study and clicking Create Modification / CR.

If continuing review approval is not granted before the expiration date of 8/12/2014, approval of this study expires on that date.

To document consent, use the consent documents that were approved and stamped by the IRB. Go to the Documents tab to download them.

This determination applies only to the activities described in the submission and does not apply should any changes be made to these documents. If changes are being considered and there are questions about whether HRRC review is needed, please submit a study modification to the HRRC for a determination. A change in the research may disqualify this research from the current review category. You can create a modification by clicking Create Modification / CR within the study.

In conducting this study, you are required to follow the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library.

Sincerely,



Mark Holdsworth, PharmD
Executive Chair



Appendix Q

**AKRON CHILDREN'S HOSPITAL
INSTITUTIONAL REVIEW BOARD
RESEARCH PROPOSAL APPLICATION**

1. Title of Protocol:
"School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story"
2. Investigators involved in the Protocol (All investigators and co-investigators must submit or have on file a certificate of required training):
<http://ohrp.nihtraining.com/users/login.php>

Principal Investigator: Susan Wechter	Signature: <i>Susan Wechter</i>
Department/Division: Nursing	Phone: 330-354-7782
Co-Investigator(s): Marie Lobo, PhD, RN, FAAN Cindy Mendelson, PhD, RN	Signature: <i>Marie Lobo</i>
Beth Tigges, PhD, RN, PNP-BC	<i>Beth Tigges</i>
Sally Thorne, PhD, RN, FAAN	<i>Sally Thorne</i>

*write it in that it is, betsy - bina will be. >

3. How will the study be funded? Attach a budget
This study has no outside source of funding and is funded by the PI
4. Are any non-CHMCA faculty or facilities involved?
 No Yes
If yes, please list:
University of New Mexico, College of Nursing, Albuquerque, NM (Marie Lobo, Cindy Mendelson, and Beth Tigges, faculty), and University of British Columbia (Sally Thorne, Dean of College of Nursing)
An IRB review is being done through the University of New Mexico's Human Research Protection Office in April of 2013.
5. Do any of the investigators have an interest in a drug or device to be studied that might lead to a conflict of interest?
 No Yes

If Yes, please detail:

6. What is the purpose of the research? The specific aim of this study is to explore school-age children's perceptions of stress in the hospital. Children ages seven to nine years will interpret their perceptions through their own voice with a draw and tell technique.
7. a. What experimental drugs and devices will be used?
- None
- b. If a drug is used, is there an IND number? Yes ___ No ___, if not explain. N/A
- Question: consult - FDA Drug Information Branch – HFD-210
Center for Drug Evaluation and Research
Food and Drug Administration
5600 Fishers Lane
Rockville, Maryland 20857
301-827-4573
- c. If a device is used, is there an IDE? Yes ___ No ___, if not why does the investigator consider the device NSR. N/A
- Question: consult – Program Operations Staff (HFZ-403)
Office of Device Evaluation
Center for Devices and Radiological Health
Food and Drug Administration
9200 Corporate Blvd.
Rockville, Maryland 20850
301-594-1190
8. What procedures (including venipuncture) will be undertaken for the purposes of this research?
- No invasive procedures will be utilized. Data will be collected through having the children draw a picture of a child in the hospital and tell their story about their picture. A parent will complete a parent questionnaire (See Appendix D).
9. Summarize the foreseeable risks and discomforts (include both physical and social risk such as loss of confidentiality).
- The study involves minimal risk to the parent/child participants. However, the child will be drawing and talking about their experience of hospitalization which could elicit feelings of anxiety, fear and emotional distress.

The researcher will monitor the child closely for these responses and provide support to the child during the entire interview. The PI is a certified pediatric nurse practitioner (PNP) with 30 years of experience working with school-age children in the in-patient and out-patient health care setting and the PI is a former CHMCA employee who worked as a PNP and advanced practice nurse, and is familiar with the rules and resources available. She has a strong background and ability to identify children in distress and support them. The PI will provide follow-up support for the child and family if needed through the bedside nurse, Child Life-Specialist, and if warranted a pediatric clinical nurse specialist and/or psychiatric clinical nurse specialist. If the child reveals anything that could be possible child neglect or abuse, safety measures for the child will be taken immediately by notification to the Social Service department, and activation of the Care Center protocol at the hospital site of the study, which will give a multidisciplinary assessment, treatment and follow-up for any child deemed at risk.

Although minimal risks are foreseeable to the child and parent for this research, disclosing personal information by both the child and parent is consistently a risk in this type of study. Close attention will be paid to the informed consent (Appendix A) and informed assent process (Appendix C) with added education through a pictorial review. Also, data will be collected in patient's private hospital room to protect privacy issues. If the data collection is interrupted by the health care team or others entering the room, data collection will stop during the interruption. To address anonymity and confidentiality, data will be given an objective identifier number to be stored in a locked file only accessible to the PI. When data are disseminated, pseudo names will be utilized for direct information summarized or direct quotes utilized of participants.

10. Summarize the expected benefits to the subject and others.

There are potential immediate benefits to the child participant. The method used for this study is a form of storytelling that engages the child to express his/her feelings regarding a stressful situation such as hospitalization. This has been shown to provide opportunity to work through, reflect and find meaning in the child's experience, helping intense feelings to lose some strength (12). Potential benefits for the parents would be to hear the process of their child drawing and telling about their hospital experience, thereby receiving a deeper understanding of the psychosocial impact of hospitalization for their child, and then identifying immediate ways for them to comfort their child.

Otherwise, no direct benefits to the study participants would be available.

11. What steps are being taken to minimize risk?

The researcher will take steps to develop rapport with the child and inform the child thoroughly about what to expect, providing a safe emotional environment for disclosure. The child will be given multiple choices to help empower the child. These choices include choice of drawing materials, place to sit, and parental presence etc.

The study involves minimal risk to the parent/child participants. However, the child will be drawing and telling about their experience of hospitalization which could elicit feelings of anxiety, fear and emotional distress. The researcher will monitor the child closely for these responses and provide support to the child during the entire interview. The PI is a certified pediatric nurse practitioner (PNP) with 30 years of experience working with school-age children in the in-patient and out-patient health care setting and the PI is a former CHMCA employee who worked as a PNP and advanced practice nurse, and is familiar with the rules and resources available. She has a strong background and ability to identify children in distress and support them.

The PI will provide follow-up support for the child and family if needed through the bedside nurse, Child Life-Specialist, and if warranted a pediatric clinical nurse specialist and/or psychiatric clinical nurse specialist. If the child reveals anything that could be possible child neglect or abuse, safety measures for the child will be taken immediately by notification to the Social Service department, and activation of the Care Center protocol at the hospital site of the study, which will give a multidisciplinary assessment, treatment and follow-up for any child deemed at risk.

12. What alternatives exist to the experimental procedures?

There are no alternatives in this qualitative inquiry, and the parent and child have the opportunity to accept or decline participation.

13. Who are the subjects to be studied? (List inclusions and exclusions)

Type and number of experimental subjects and contacts: The estimated sample size for this study is between 30 and 60 child/parent dyads. The anticipated number of contacts for recruitment is between 250 and 300 child/parent dyads to obtain a sample of 20% of those who meet criteria. The lower limit of 30 will allow for a range of interpretation of children of different ages, gender, and hospital experiences that will provide an intensive, in-depth interpretation. The upper limit of 60 allows for exploration of an unanticipated theoretical variable that commands expanded data collection, and to offer expanded interpretations for anticipated child informants who provide thin data due to less expression because of the nature and unique temperament of the child in the context of the hospital setting.

Selection of subjects: Inclusion and Exclusion Criteria for Child Participants. The participants will be selected, attending to the following inclusion criteria: a) children between the ages of seven years and nine years (84 months and 119 months); b) fluent in the English language; c) hospitalized for an acute medical or surgical condition (chronically ill children with acute exacerbation of illness will be included); d) ability to utilize dominant writing hand for drawing a picture; and e) intact vision, hearing and speech as reported by parent. Exclusion criteria for this study will include: a) children with reported developmental delay; b) children with a diagnosed mental health or behavioral disorder; c) children in protective custody/foster care; d) children who are hospitalized for intentional trauma (child abuse); e) children who are severely ill or with impending death.

Inclusion and Exclusion Criteria for Parent Participants. Parent inclusion criteria will be at least one parent of the child who is the legal guardian of the child. Inclusion criteria would be: a) fluent in the English language; b) the ability to read and write to complete the consent, HIPAA authorization, and demographic questionnaire (verbal explanation of these forms could be done if the parent had difficulty reading or writing); c) the parent will meet the legal guardian criteria by showing their formal picture ID matched with the legal guardian name identified in the electronic medical record. Exclusion criteria will be: a) not a legal guardian of the child; and b) any parent being investigated by social service for neglect or abuse of the child and c) parent unable to speak or understand English.

14. What method(s) will be employed to select or recruit subjects?

This is a single site study at Children's Hospital Medical Center of Akron. Estimated recruitment will be between 150 to 300 child/parent dyads with a 20% as consented participants. A marketing flyer will be placed on each of the units at the nursing station and also in the admission packets of children admitted to the study setting units (See Appendix F). The participants will be recruited

[Type text]

from two inpatient units, one unit is a 24 bed acute pediatric medical-surgical school-age unit, and the other is a 20-bed acute pediatric medical-surgical unit housing infants through children 18 years of age. Both units have interdisciplinary, family-centered care rounds that take place every morning reviewing the cases and plans for care for the children on these units. I will gain access to these rounds and identify children and parents meeting inclusion criteria. I will talk with the legal guardian of the child, describing the study, to see if there is interest. If there is interest in participating, I will contract with the family, child, and bedside nurse a convenient time to gain consent, assent, and to collect data.

15. How many subjects will be in the study? 30-60 child/parent dyads

16. Population to be studied (check all that apply):

- Male Only
- Minors
- Female Only
- Disabled or Mentally Retarded
- Male and Female
- Other (explain) _____
- Pregnant Women/Fetus/Nonviable neonate _____

If vulnerable subject (for example: minors, pregnant women, or disabled/retarded individuals) will be included, how are the additional requirements met?

Children between ages 7 and 9 will be asked to participate in this study. Children will have a pictorial assent process explaining the study, and a written informed assent (See Appendix C) And a written informed consent will be done by the parent (See Appendix A) or Legal guardian and a an information sheet, as well as an Authorization for Release of Medical information will be reviewed and signed by the parent (See Appendix B.)

17. How will you ensure that the subjects understand the risks of participation in the study (check all that apply):

- Informed consent will be obtained
- An assent will be obtained (include a copy of Readability Statistics - Flesch-Kincaid Grade Level) (See Appendix C)
- Waiver of consent is requested (please document why)
- Delayed consent (emergency research) is requested (please document why) and obtain and complete extra documentation such as plans for community consultation
- No assent is needed (please specify why)

[Type text]

18. How will subject confidentiality be protected?

Confidentiality will be maintained through careful handling of tapes, data, drawings, and Anonymous dissemination of data, with no disclosure of personal information.

All electronic data will be stored in a password protected electronic format on a personal Laptop of the PI. All paper data/drawings will be stored in a locked file in the PI's office only accessible to the PI and the research team. Drawings utilized in presentation will remain anonymous.

19. How will you address HIPAA requirements?

One parent/legal guardian will be provided a HIPAA information sheet with the Study information and be asked to sign Authorization for Release of Medical Information for Research (See Appendix B)

20. Will data be recorded in such a manner that subjects remain identifiable?

Yes No

If yes: initially throughout project after project

21. How will the safety of subjects be assured?

As individuals (safety monitoring on each individual subject)?

As a cohort, check and complete A, B or C below:

A. If the study is a Phase III randomized clinical trial, a data safety monitoring committee is required and a charter must be attached.

B. For other trials, IRB may still require a data safety monitoring committee or allow an alternative safety program. Please supply answers to all of the following if an alternative safety program is proposed.

1. Who is the designated safety monitor?
2. What relationship does the monitor have to the study sponsor?
3. Is the monitor able to independently act to recommend changes and stopping of the trial?
4. Does the monitor perform review of subjects to assure they meet inclusion/exclusion criteria prior to application of research interventions?
5. Is there a well defined monitoring of reported severe unexpected events and severe expected adverse events frequency such that they are appropriately reported to sponsors, federal agencies, investigators and IRBs?
6. Are reports of adverse events provided with analysis and context?
7. Are there appropriate stopping rules with interim analyses at appropriate frequencies to allow for stopping or modifying the

study in a prompt manner? Please specify.

8. Does the monitor review and approve any proposed changes to assure they are consistent with optimal safety of the study?

C. The study is minimal risk and only requires technical safety measures as noted:

The child will be drawing and telling their story about their experience of hospitalization which could elicit feelings of anxiety, fear and emotional distress. The researcher will monitor the child closely for these responses and provide support to the child during the entire interview. The PI is a certified pediatric nurse practitioner and advanced practice nurse who has worked with children for 30 years; She has a strong background to assess and support a child or parent in distress. The PI will provide follow-up support for the child and family if needed through the bedside nurse, Child Life-Specialist, and if warranted a pediatric clinical nurse specialist and/or psychiatric clinical nurse specialist. If the child reveals anything that could be possible child neglect or abuse, safety measures for the child will be taken immediately by notification to the Social Service department, and activation of the Care Center protocol at the hospital site of the study, which will give a multidisciplinary assessment, treatment and follow-up for any child deemed at risk.

22. Will the subjects be offered any compensation? Yes No

If yes, please detail:

Only minimal risk is anticipated with this study and research related injury is not anticipated. However, incentives to participate are being offered as a gesture of thank you for participation. (see below regarding guards against coercion)

Participation Incentives for Child. There is a paucity of research guidelines that exist about the appropriate amount, types and schedules of incentive to be used with young child participants in research studies. Emphasis is placed in the available literature regarding: a) developmentally appropriate rewards (17) and b) safeguards related to avoidance of incentives being coercive (18). For this study, children will be offered an art bag filled with developmentally appropriate art tools including markers, pencils, paper, stickers, scissors, and stencils. This compensation will address developmental congruency and be sensitive to the avoidance of a coercive incentive.

Participation Incentive for Parents. The parents will be given a choice of a \$5 dollar coffee/tea card for the gourmet coffee cart in the welcome lobby of the hospital or a \$5 dollar card for the hospital gift shop. This small incentive acknowledges the work of the parent in the study and encourages the parent to take a break during the stressful hospital stay.

23. Will any recruitment materials be used? Yes No If yes, please attach. (See Appendix F)

24. What is the duration of the subjects' participation? 1-2 hours at A single interval.

25. Support of your Departmental Chairman/Research Director

Signature: _____

Date: _____

26. Indicate Cooperating Departments:

Responsible Signature(s)

Pharmacy

Laboratory

Radiology

Nursing Research Center

Information Services

Other (List)

27. Date of Application:

April 1, 2013

Please attach appropriate HIPAA, informed consent and assent documents, a complete budget for this application, a complete research protocol and investigator's brochure if provided. Incomplete submissions will be returned.

See Attached Research Protocol with Consent, HIPAA information sheet and HIPAA Authorization, Pictorial Assent Tool and Assent Form, Parent Questionnaire, Educational Slide show, and Marketing Flyer.

Appendix R



Akron Children's Hospital - FWA #00000917 - Expiration Date 1/10/17
IORG #0001126 - Expiration Date 1/10/15

July 15, 2013

Susan Wechter, PhDc
The Rebecca D. Considine Research Institute
Akron Children's Hospital
One Perkins Square
Akron, OH 44308

Re: School Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story
Introduction

IRB No: 130704

Dear Dr. Wechter:

The IRB Chair received a letter from Deborah Giebner dated July 9, 2013 and the revised consent, assent and HIPAA documents with the changes requested in its letter dated July 5, 2013. The study was approved as of July 3, 2013 (the date of initial review) pending receipt of the revised documents which have been received and reviewed.

The study is minimal risk. It is granted expedited approval under Subpart D 46.404 (21 CFR 50.51) subject to the following:

1. Approval is for one year 3 July 2013 to 2 July 2014 and ends unless appropriately renewed.
2. Any serious incidents or events associated with the study be promptly reported to the IRB.
3. No changes will be made to the conduct of the study unless they are first reviewed and approved by the IRB.
4. That IRB approval does not preclude the need for other institutional approval.
5. All individuals participating in this study must provide the IRB evidence of completion of the Protecting Human Research Participants on-line training course prior to any involvement in the study. This can be found at <http://phrp.nihtraining.com/users/login.php>

Sincerely,

A handwritten signature in cursive script that reads "Robert W. Novak".

Robert W. Novak, M.D.
Chairman, Institutional Review Board

RWN/hs

Appendix S



Human Research Review Committee
Human Research Protections Office

January 7, 2014

Marie Lobo
mlobo@salud.unm.edu

Dear Dr. Marie Lobo:

On 1/6/2014, the HRRC reviewed the following submission:

Type of Review: Modification
Title of Study: School-Age Children's Perceptions of Stress in the Hospital: A Draw and Tell Story
Investigator: Marie Lobo
Study ID: 13-409
Funding: None
Grant ID: None
IND, IDE, or HDE: None

Submission Summary: Modification request received 11/11/2013: Addition of investigators Laura Leifendecker, Aris Eliades and Sally Thorne.

Documents Reviewed: • Acknowledgement of Conflict of Interest documents and human subject protection training for added investigators.

Review Category: EXPEDITED: CATEGORIES (5) Data, documents, records, or specimens

Determinations/Waivers: Children

The HRRC approved the study Modification from 1/6/2014 to 8/12/2014 inclusive. Before 8/12/2014 or within 30 days of study closure, whichever is earlier, you are to submit a continuing review with required explanations. You can submit a continuing review by navigating to the active study and clicking Create Modification / CR.

If continuing review approval is not granted before the expiration date of 8/12/2014, approval of this study expires on that date.

This determination applies only to the activities described in the submission and does not apply should any changes be made to these documents. If changes are being considered and there are questions about whether HRRC review is needed, please submit a study modification to the HRRC for a determination. A change in the research may disqualify this research from the current review category. You can create a modification by clicking Create Modification / CR within the study.

In conducting this study, you are required to follow the Investigator Manual (HRP-103), which can be found by navigating to the IRB Library.

Sincerely,



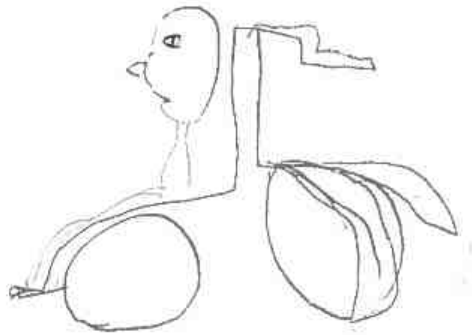
Mark Holdsworth, PharmD
Executive Chair

Appendix T- Children's Drawings

Case 1



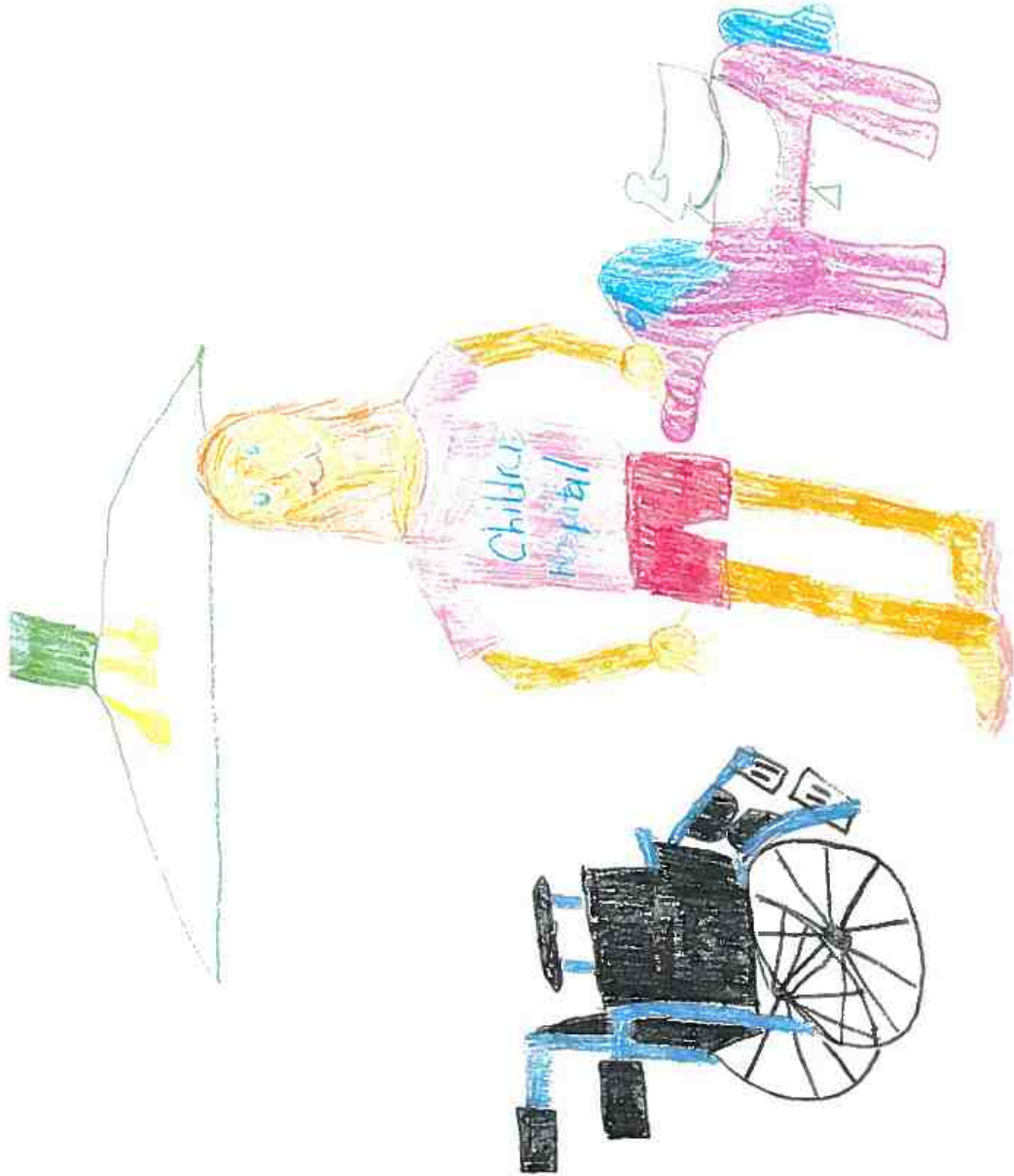
Case 2



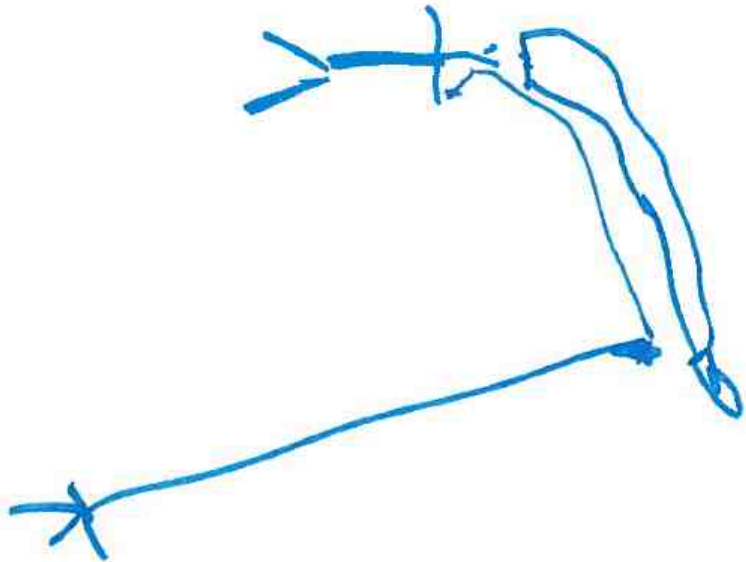


I like the food and I
don't like sitting in the bed.

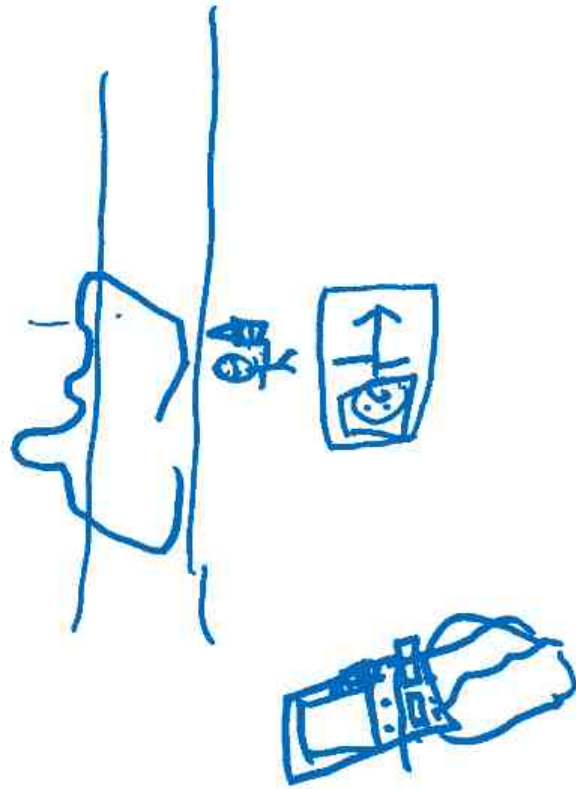
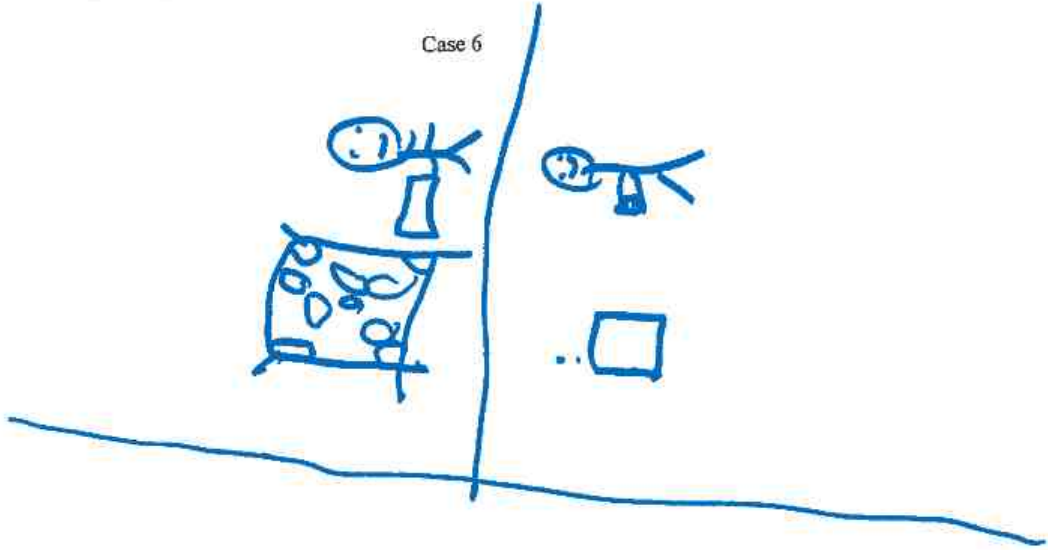
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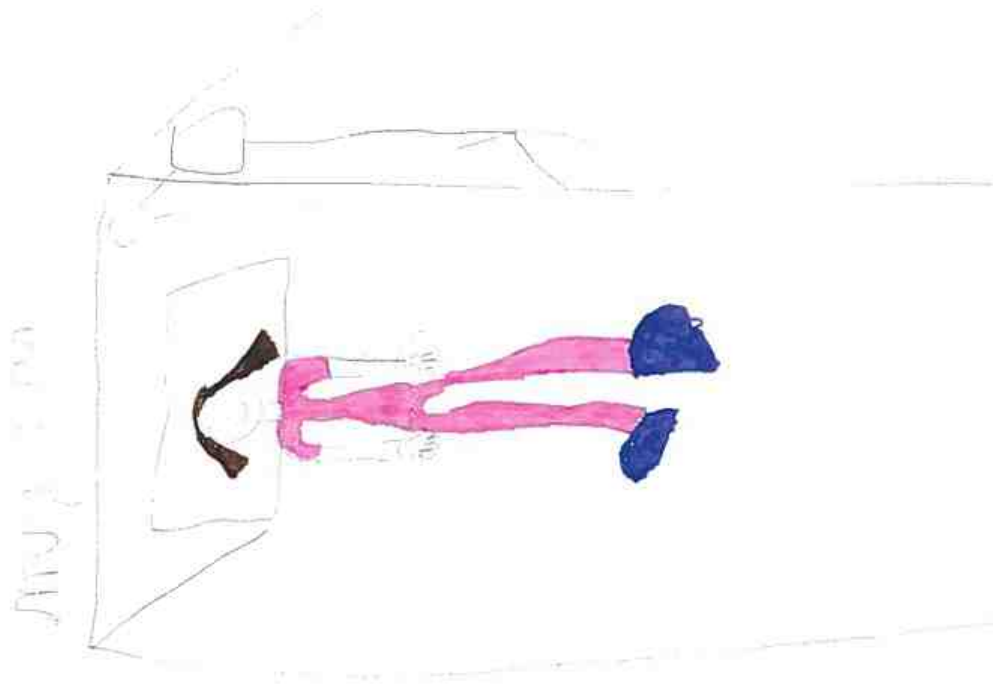
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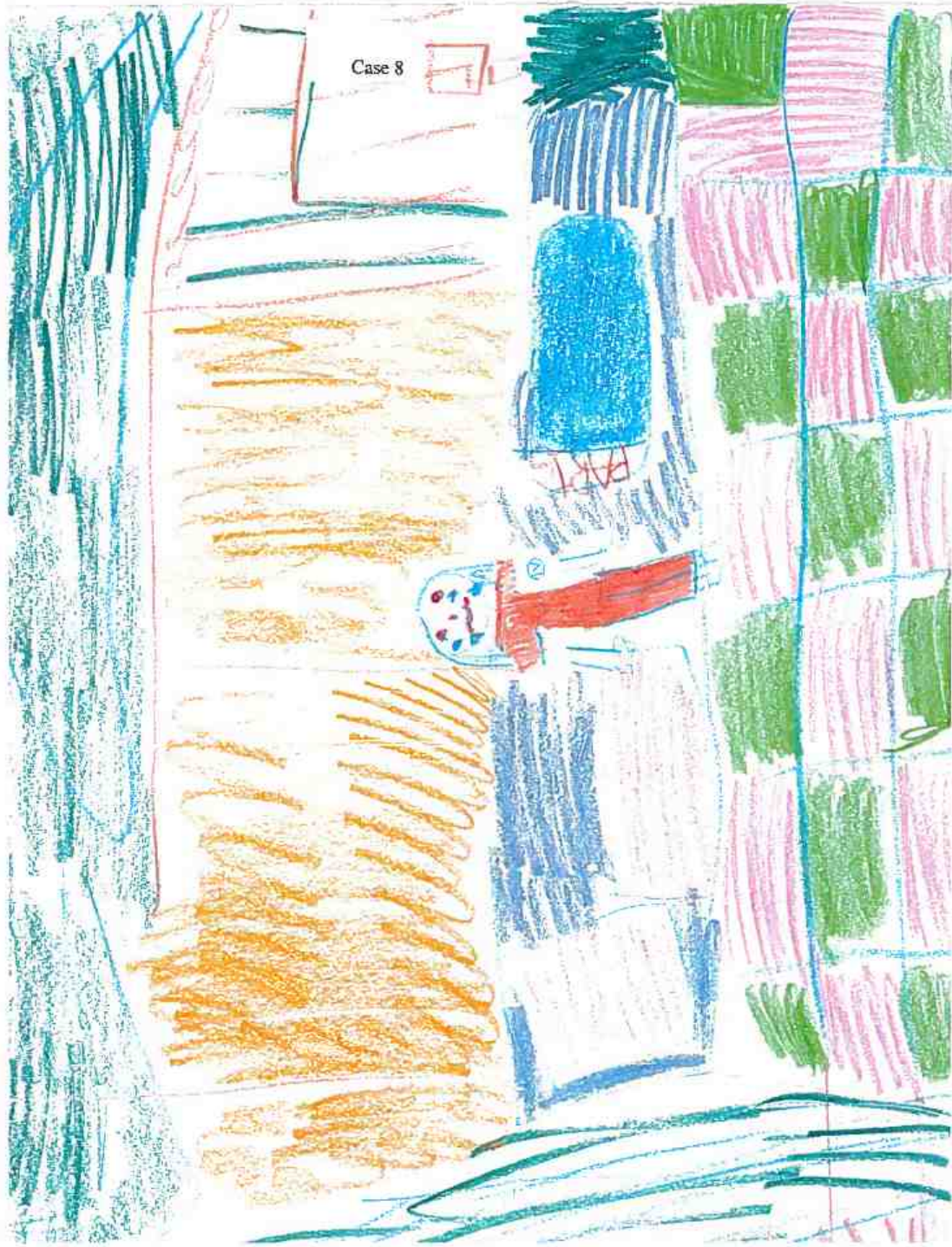


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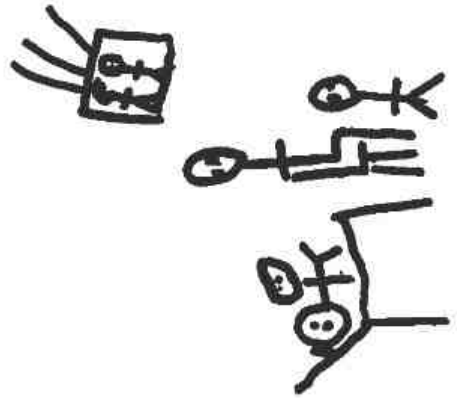


Case 7

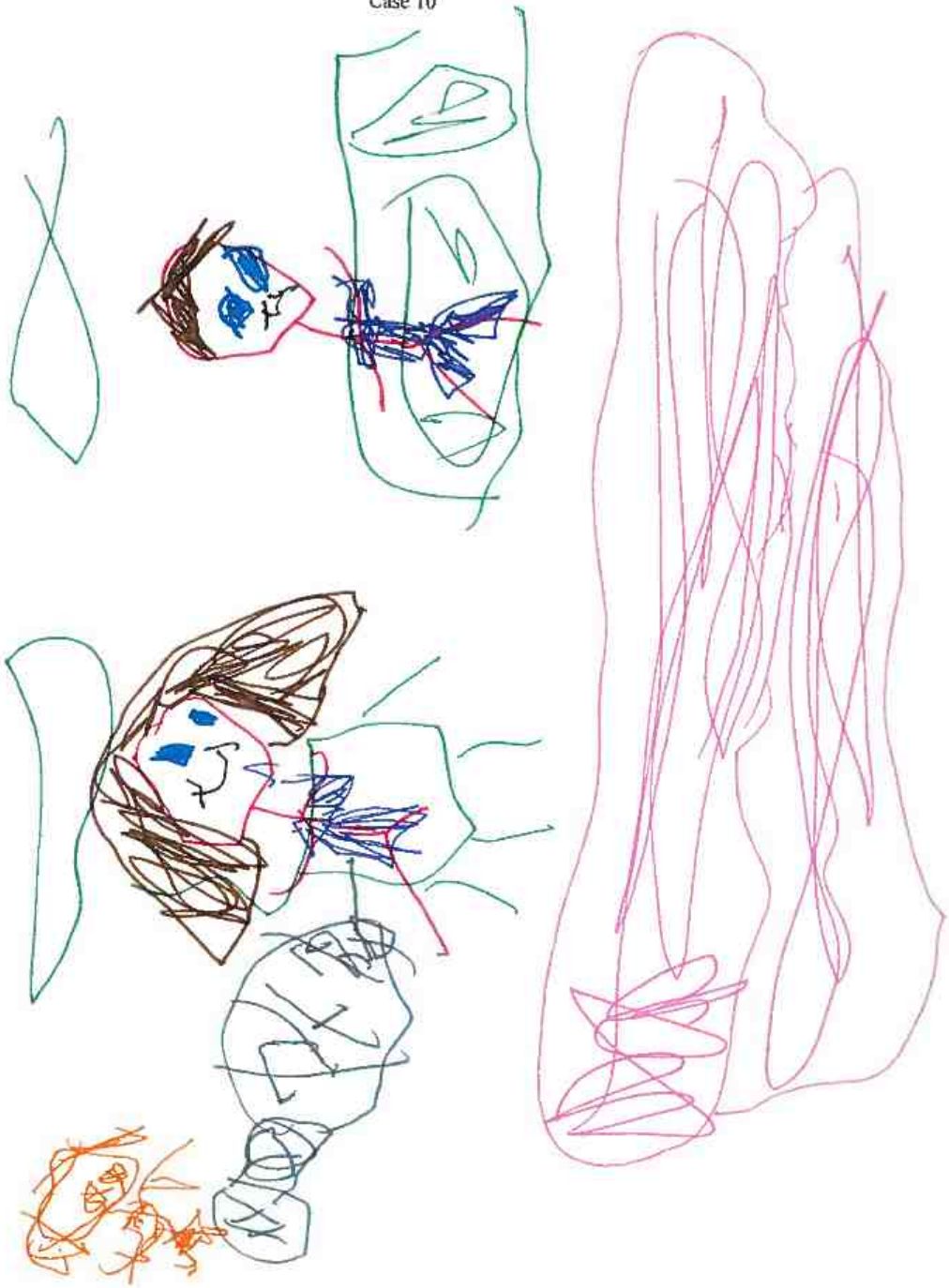




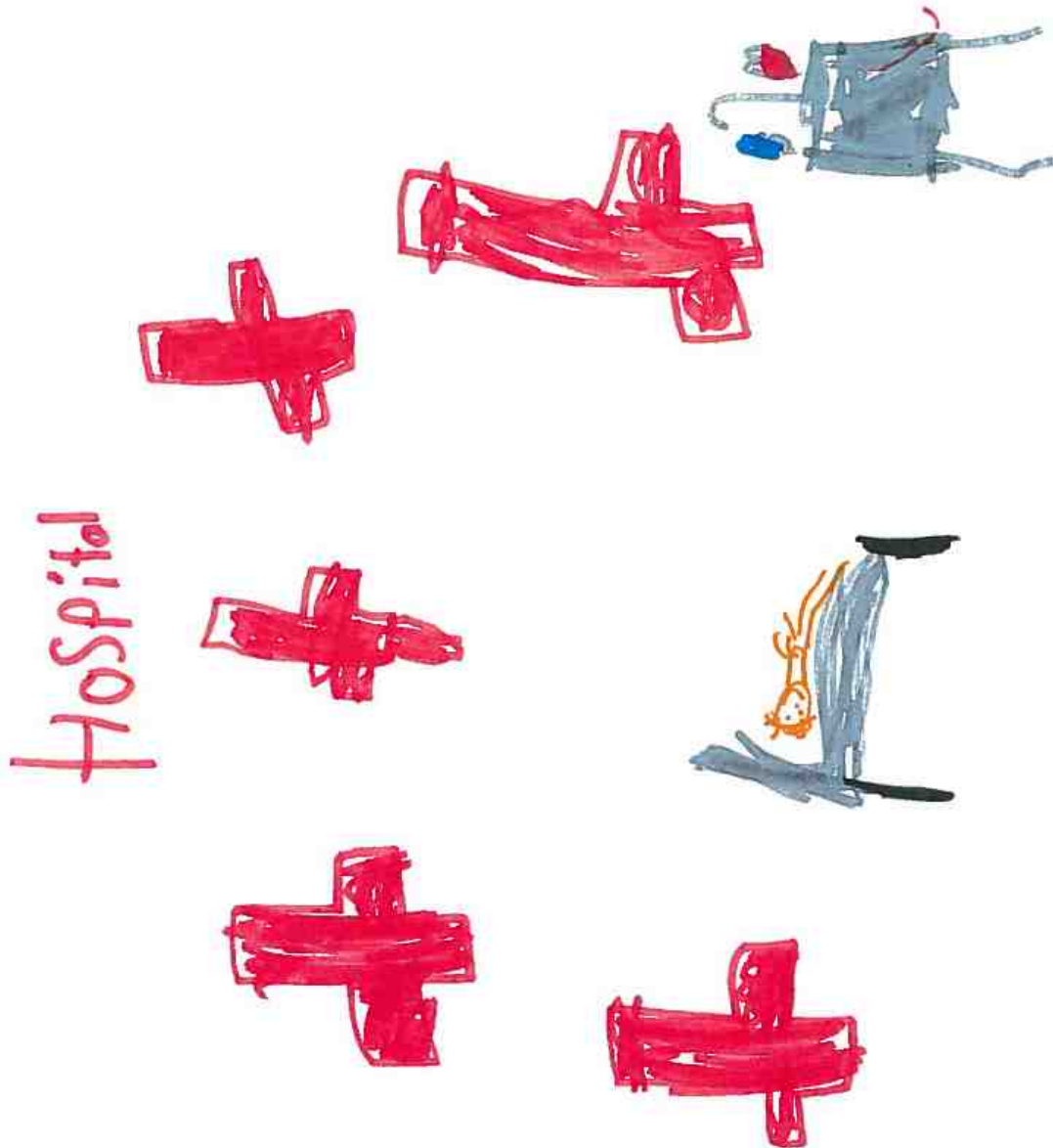
Case 9



Case 10

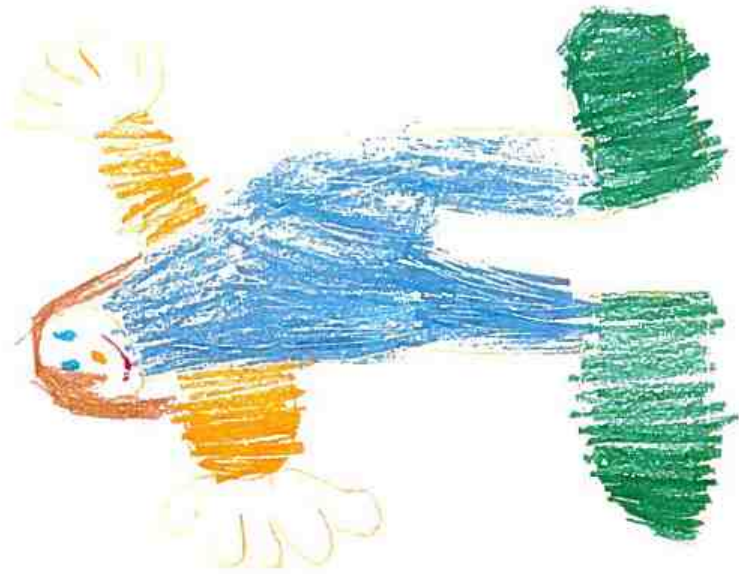


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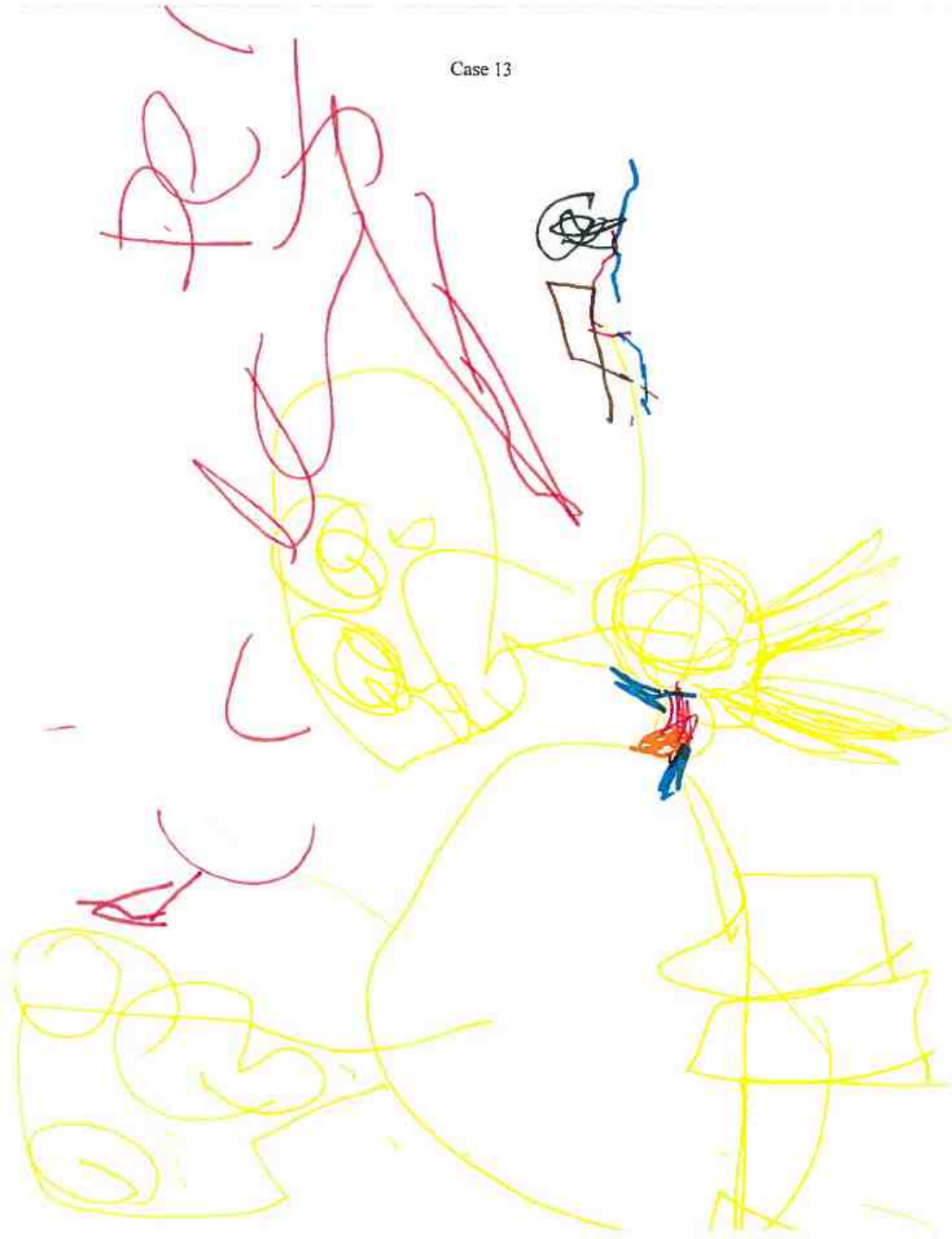


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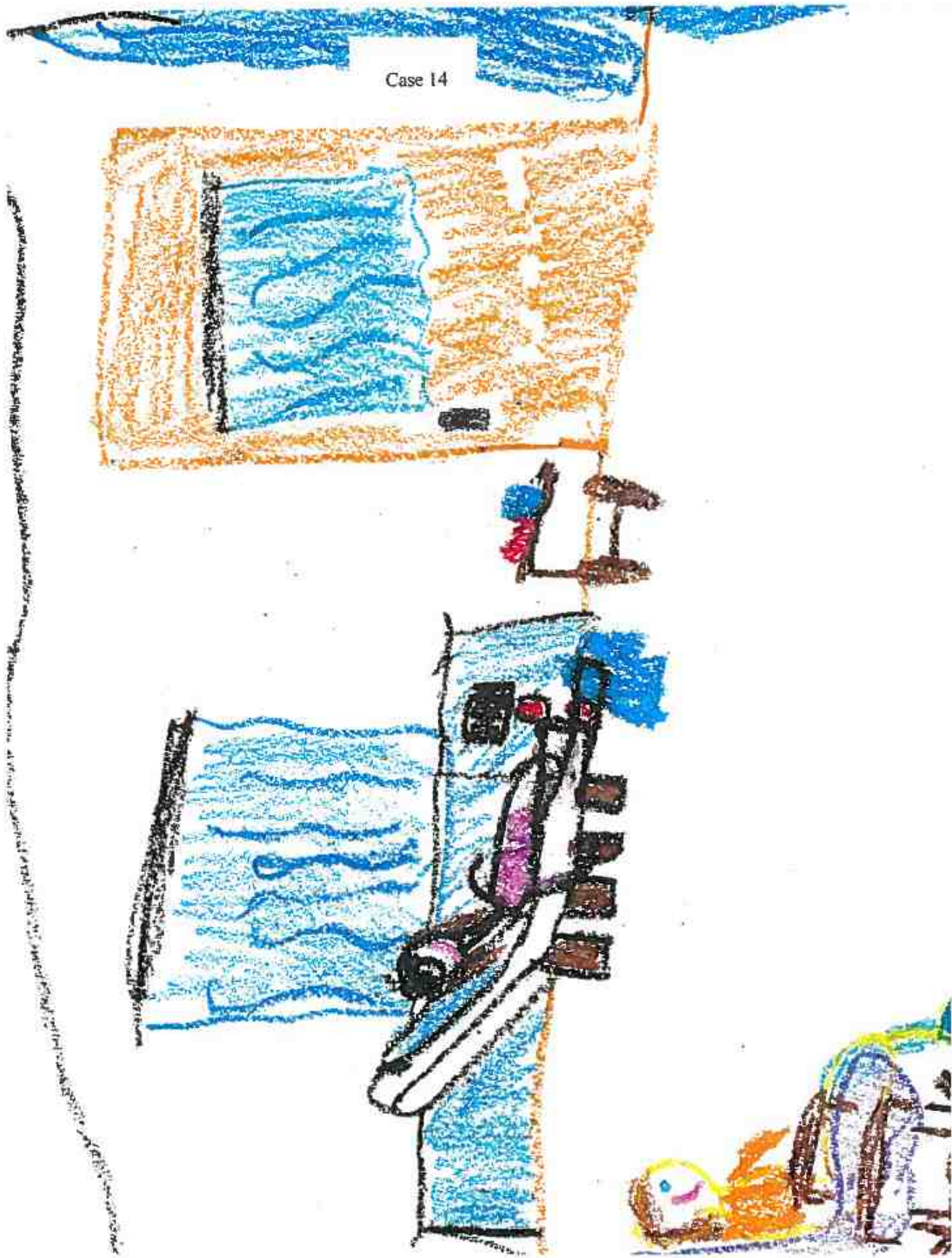
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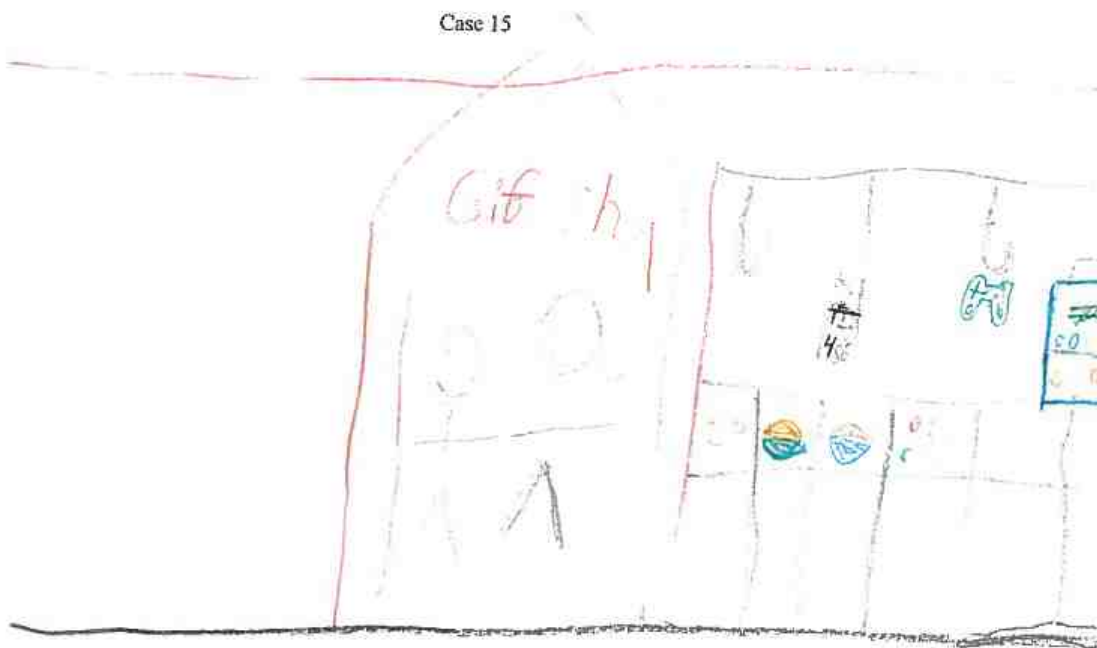
Case 13



Case 14



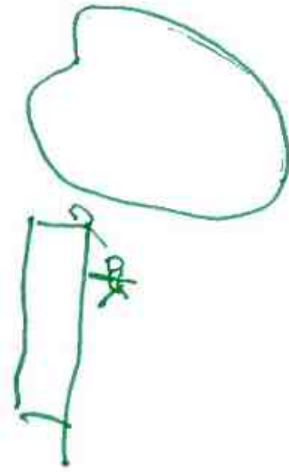
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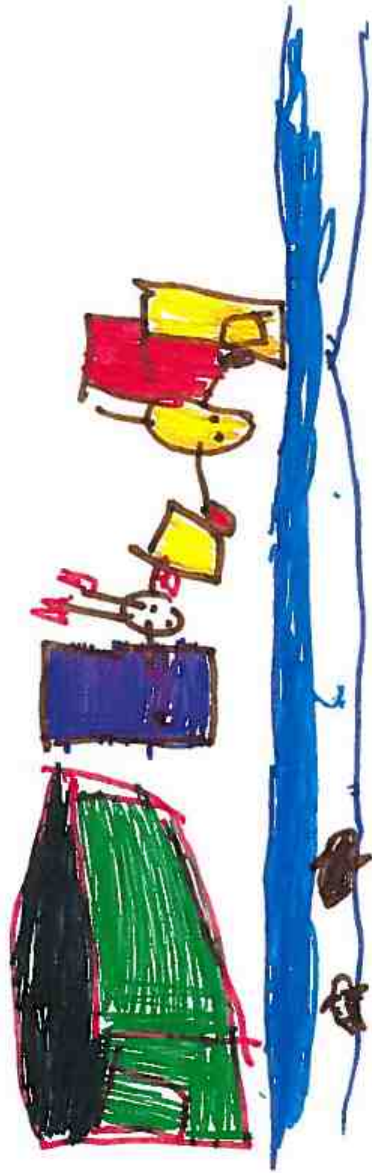


Case 16

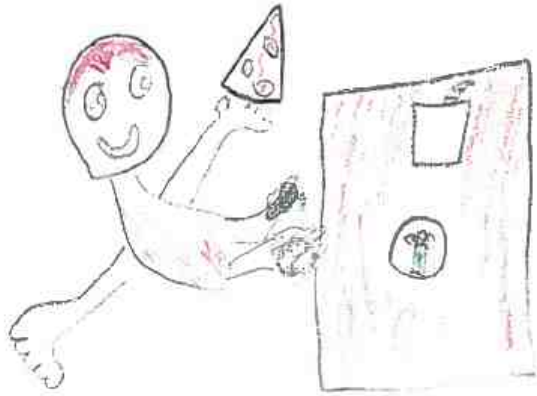


Case 17





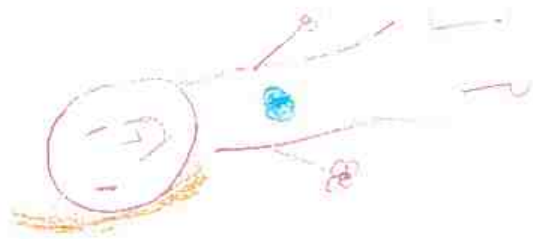
Case 19



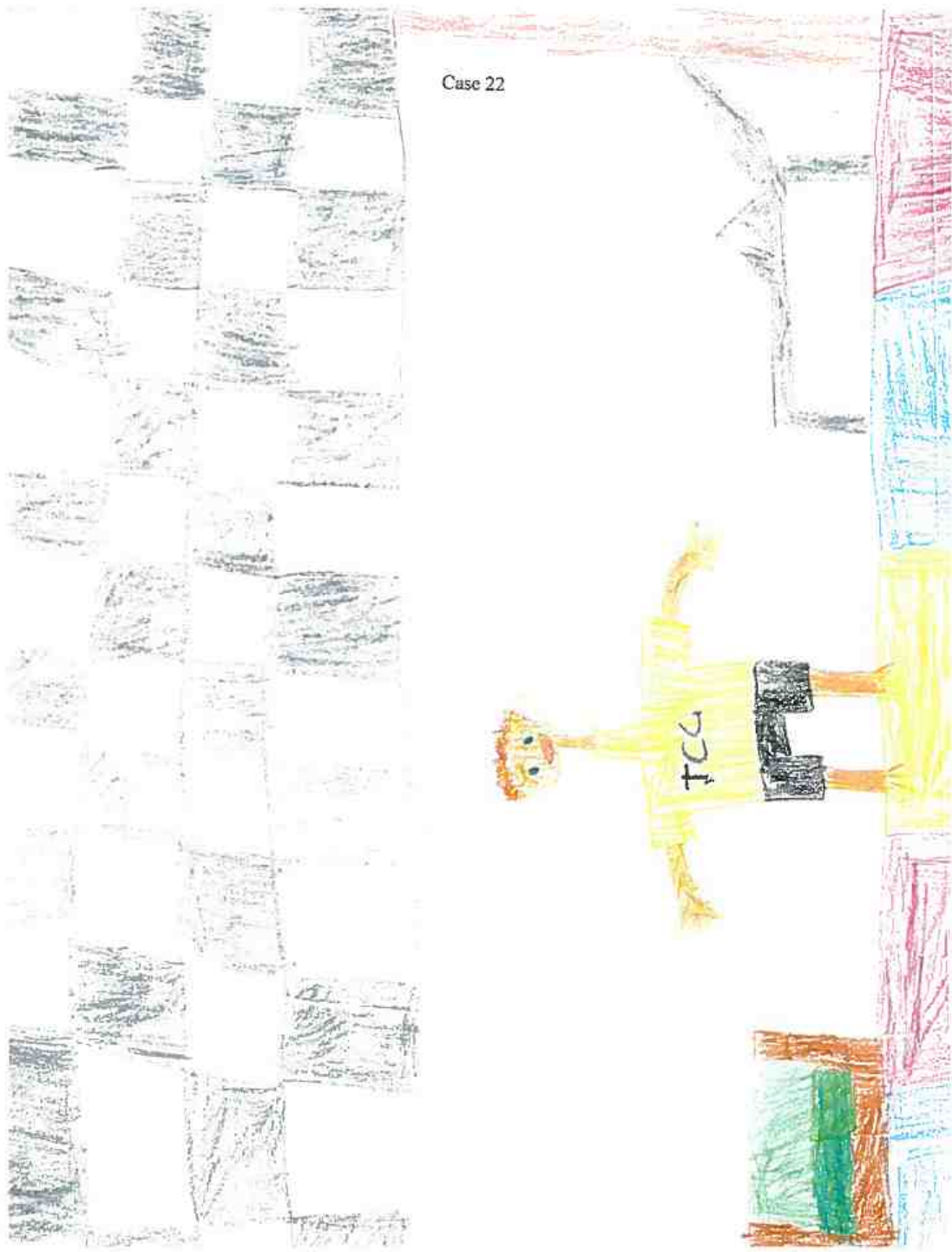
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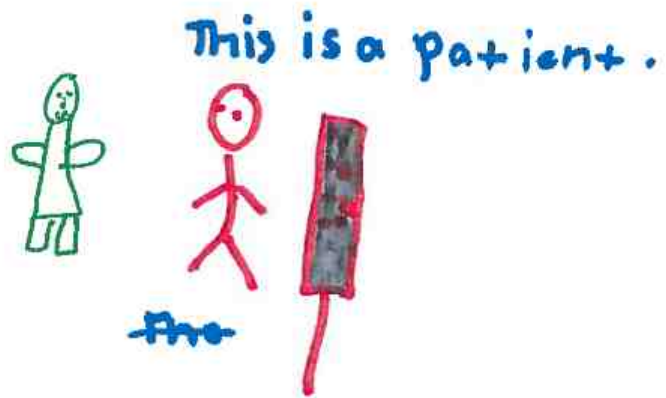
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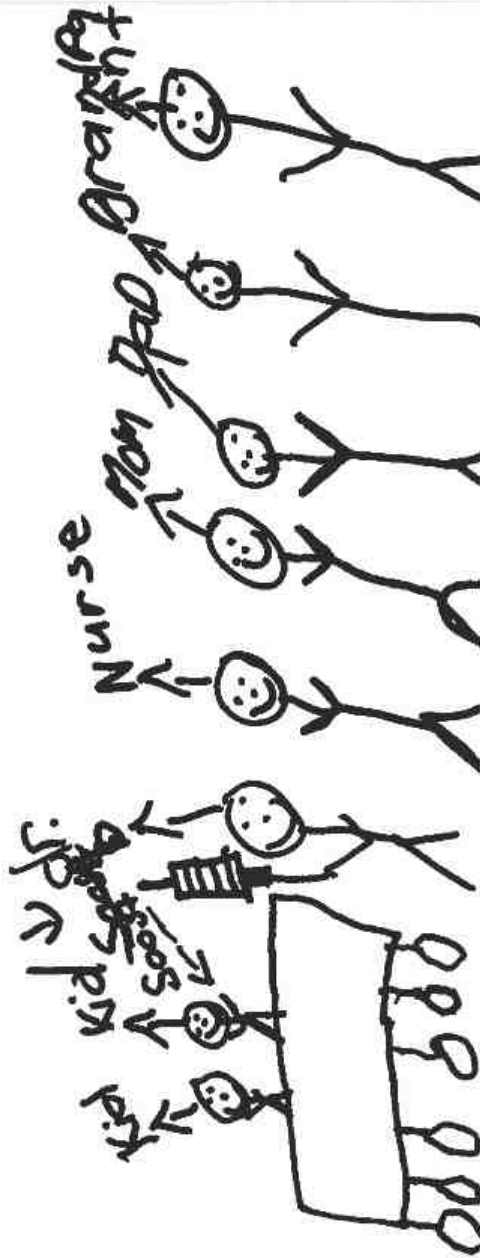
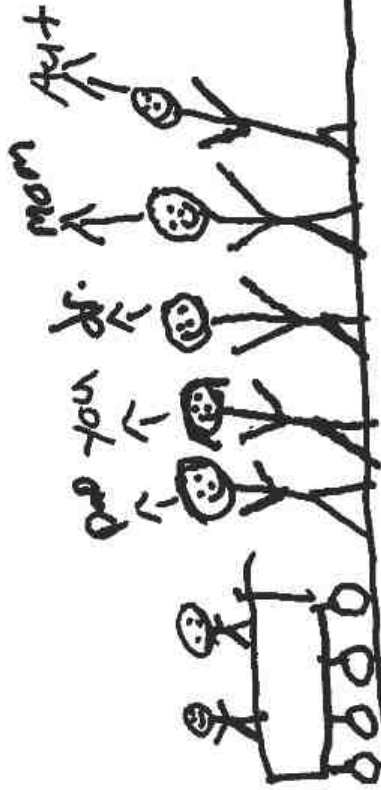
Case 22



Case 23

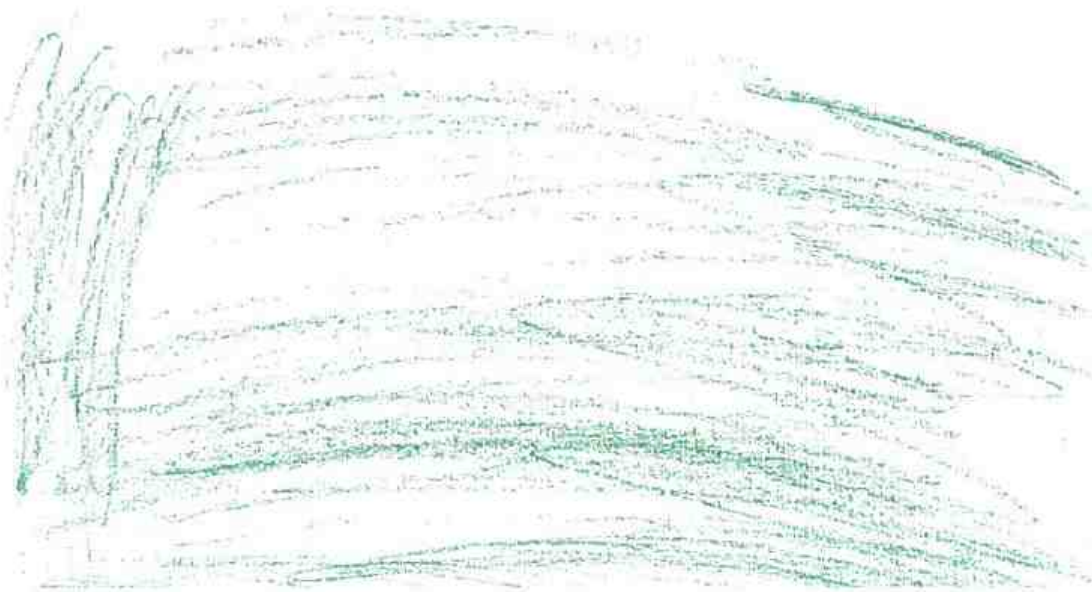


Case 25

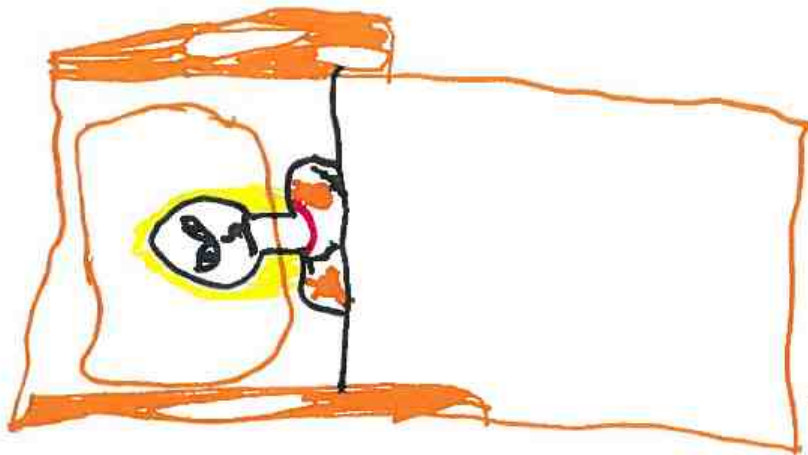




Case 26



Case 27



Case 28



Case 29



