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Child Pain Matters: A Training Protocol for General Nursing Staff in an Infusion Center on Procedural Anxiety in Pediatric Patients with Crohn's Disease and Ulcerative Colitis.

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By

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Abstract

Procedural anxiety is a broad concept that encompasses fear, distress, and pain. Anxiety is the most critical factor affecting pain perception. There is a growing body of literature suggesting that early pain might have long-term consequences. There is also research evidence that has linked inadequately managed pain in the pediatric population to negative behavioral and physiological consequences later in life. Pediatric patients with inflammatory bowel disease (IBD) refers to Crohn's disease and Ulcerative Colitis. These chronic conditions often require multiple and repeated medical procedures that may cause pediatric patients to experience procedural anxiety. Needle related procedures are any procedures involving the use of needles for medical purposes such as immunization, venipuncture, IV insertions, intramuscular, or subcutaneous injections. The literature and relevant theories are discussed. A proposed training protocol for nursing staff in an infusion center is presented and this author created resource handouts for nurses, parents, and caregivers. A social narrative written by this author is presented. Also included are distraction card easel prototypes developed by this author to be used as a distraction technique to reduce procedural anxiety. An illustrative case study is presented to show the application of psychological interventions in reducing procedural anxiety. The future utility of the protocol, adapting to individual differences, and future directions are discussed.

Keywords: Procedural anxiety, pediatric, Inflammatory Bowel Disease (IBD), social narrative, distraction, needle related procedures, comfort positions, procedural support.

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To all the children, I see you, I hear you, and I will spend my career advocating for you- your pain matters, your comfort matters, your growth matters, your voice matters, your joy, and your healing matters; especially to me.

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Section I: Introduction

Definition of the Problem and Statement of Significance

The interaction between psychological functioning and biological factors is well-documented with evidence available to guide the evaluation and treatment of pediatric conditions. A new diagnosis of Inflammatory Bowel Disease (IBD) (which includes Crohn's disease and Ulcerative Colitis) occurs approximately 25 % in childhood or adolescence years (Easterlin et al., 2020b). Pediatric patients with IBD are at an increased risk of developing depression and anxiety, experience poor health-related quality of life, attempted suicide, and experience difficulties with social and school functioning (Easterlin et al., 2020b). These pediatric patients often face repeated medical procedures that they find to be distressing and anxiety producing. While the literature supports the efficacy of utilizing and implementing non-pharmacological interventions to treat children with procedural anxiety; there is still a lack of wide application of these interventions due to factors such as limited staff availability, limited resources and funding, and limited staff with knowledge of the implementation of these interventions. The American Pain Society and American Academy of Pediatrics state that one of the keys to managing pain and distress in children is procedural preparation (Abrams et al., 2016). The primary purpose of procedural preparation interventions is to increase a child's coping ability and sense of control, enhance self-efficacy, medical adherence, decrease distress, fear, and pain (Abrams et al.,2016).

Training pediatric medical staff in behavioral pain management strategies such as distraction is noted in recent research (Slifer et al., 2011). Research has shown that there is short- and long-term effects of painful experiences, medical trauma, and painful memories of medical procedures. In fact, memories of painful experiences are an important factor in predicting pain

for subsequent procedures and a tendency to avoid medical situations that can carry into adulthood, impact medical adherence, and avoidance of medical care (Rocha et al., 2009). Children who are not adequately prepared for health interventions are more likely to have poor experiences as well as increased anxiety and upset feelings (Bray et al., 2019). Furthermore, pediatric pain that is inadequately addressed may lead to "conditioned anxiety," heightened pain intolerance, increased distress, and anxiety (Abrams et al., 2016). Additionally, negative medical procedure encounters and experiences can result in children having a delayed recovery, being fearful of healthcare professionals, and failing to attend follow-up care (Bray et al., 2019). In the U.S 20% of children under 18 years of age have special health care needs (Easterlin et al., 2020a). Further, children and youth with special health care needs may be exposed to traumatizing situations in medical settings (Easterlin et al., 2020a). Therefore, it is important to provide training and implementation of interventions to address procedural anxiety in pediatric patients.

Purpose and Organization

This project includes three principal sections. The first is a Literature Review: research pertaining to Procedural Anxiety, and Non-pharmacological interventions. This section will provide the reader with an overview of the research on procedural anxiety and relevant theories on understanding and conceptualizing procedural anxiety, distress, anticipatory anxiety, and interventions that can be used to address procedural anxiety in the pediatric population. In addition, the reader will gain an overview of the inflammatory bowel diseases and pharmacological interventions, more specifically Crohn's disease and Ulcerative Colitis. The purpose of this review is to provide a comprehensive overview of the literature and demonstrate

how non-pharmacological interventions (behavioral and psychological interventions) can be implemented and clinically utilized with children and adolescents.

The second section will primarily focus on a training protocol for nurses in an infusion center. A general description of the training protocol will be provided to provide an understanding of the key components considered in developing the training. Resource handouts for health care professionals and parents will be provided and can be used in healthcare settings to disseminate resources and helpful guidelines in addressing procedural anxiety. Moreover, prototypes of distraction cards will be presented and discussed as a tool to use in healthcare settings to address procedural anxiety. In addition, a social narrative developed for the infusion center is presented. Finally, collaboration with multidisciplinary teams will be addressed.

Lastly, the reader will be presented with a discussion of a de-identified pediatric case study and application of behavioral and psychological interventions utilized to address procedural anxiety in a child. Further, the case study will demonstrate the considerations of individual factors and adaptability of treatment approaches amended to the needs and individual differences and factors to consider in developing a treatment plan with patients. An evaluation of the training protocol and distraction prototypes will be discussed as well as the limitations and future directions for the training protocol and prototypes.

Section II: Literature Review

Methods of Literature Search

The primary search tool for this literature review was the Academic Search Ultimate database. Search terms included but were not limited to the following: procedural anxiety, procedural pain, medical distress, needle-related procedures, children, pediatrics, pediatric pain, procedural distress, distraction, reassurance, Crohn's disease, and Ulcerative Colitis. Published journal articles, peer reviewed research studies, other academic papers such as systematic reviews and metanalyses were utilized. In addition, information from reputable organizations, websites, and pediatric psychology books were utilized.

Introduction to Procedural Anxiety

Children go to a physician or dentist many times during their childhood and even the most benign procedures can be experienced as stressful and anxiety producing by the child and parent (Frank et al., 1995). There are more than three million children that are hospitalized in the United States every year (Chrisler et al. 2021). Children who experience frequent hospitalizations are at a greater risk of developing behavioral problems. Even further, in one study it was found that one-year post discharge that hospitalized children reported increased feelings of anxiety, fear, and post-traumatic stress symptoms (Chrisler et al., 2021). This highlights the importance of addressing the psychosocial and emotional impacts of hospitalization on children (Chrisler et al., 2021). Among the worst fears that children describe during hospitalizations are fears related to injections, needles, nursing procedures, and pain (Salmela et al., 2011). Medical procedures including those that involve needles are reported to be the second most commonly occurring fear in children (Diener et al., 2019). In fact, it is more common than a fear of the dark, thunderstorms, heights, or water (Diener et al., 2019). Children

who undergo even relatively minor medical procedures often experience anxiety and stress in the hospital (Chrisler et al. 2021). Procedural anxiety is referred to as a broad concept to encompass anxiety, fear, and distress (Nunns et al., 2018). Anxiety is the most critical factor affecting perception of pain (Diaz-Rodriguez et al., 2021).

Anxiety, fear, and distress can be defined differently, yet in a large number of studies. the terms are used synonymously to describe procedural anxiety (Nunns et al., 2018). Fear and anxiety are distinct constructs with higher inter-correlation and therefore are used interchangeably in the pediatric pain literature (Bearden, Feinstein, & Cohen, 2012). Anxiety can be defined as an internal emotion characterized by feelings of tension, worry, and activation of the autonomic nervous system (Nunns et al.,2018). Medical fears are defined as fears linked "to any experience that involves medical personnel or procedures involved in the process of evaluating or modifying health status in traditional health care settings" (Fox et al., 2016). Anticipatory fear is characterized by exaggerated perceptions of threat and danger and is closely linked to anxiety in children (Fox et al., 2016). Distress can be defined as an umbrella term that encompasses the functional impairment related to specific stressors or for the various responses to those stressors (Nunns et al., 2018). The literature indicates children continue to experience negative psychosocial outcomes after discharge from the hospital that include developmental delays related to feelings of fear, agitation, sadness, and apprehension (Chrisler et al., 2021). There is evidence that supports the linkages among temperament and anticipatory distress regarding immunizations and temperament and memory for pain (Rocha, Marche, & Von Baeyer, 2009). In one study, it was indicated that children are fairly accurate and reliable in recalling their pain (Rocha, Marche, & Von Baeyer, 2009). Children who self-report high levels of trait anxiety behaviors (such as feeling fearful) appear to be more likely to distort their

memory of pain and would benefit from interventions targeted at procedural anxiety (Rocha, Marcha, Von Baeyer, 2009). The anxiety and pain that children experience during hospitalizations and procedures can trigger intense emotional distress which, in effect, increases anxiety and fear of painful sensations, which can magnify the sensory experience and further worsen the intensity of pain (Diaz-Rodriguez et al., 2021). This can generalize to fear of any procedures and avoidance of medical care at a later age (Diaz-Rodriguez et al., 2021). Research suggests that children with anxious dispositions may have more difficulty forgetting pain- related experiences. This can lead to poor coping with subsequent procedures as a result of focusing on the negative aspects of the procedure (Rocha, Marche, Von Baeyer, 2009). Further, children with higher trait anxiety may require special treatment interventions such as distraction type interventions (Rocha, Marche, & Von Baeyer, 2009).

One study found that 61% on non-sedated children experienced serious or severe distress while undergoing a cystourethrogram (a fluoroscopic study of the urinary tract that involved catheterization) (Fox et al., 2016). Further, the distress they experienced may linger and manifest itself in other negative ways such as sleep disturbance, bedwetting, and other behavioral problems in the days and weeks following the cystourethrogram (Fox et al., 2016). Medical trauma can result from receiving a serious diagnosis and experiencing painful or distressing procedures (Easterlin et al., 2020a). In fact, 25-30% of medically ill children develop posttraumatic stress symptoms and 10-20% meet criteria for posttraumatic stress disorder (Easterlin et al., 2020a). Long term effects of painful and traumatic healthcare experiences in childhood can lead to increased medical fear, pain, and avoidance of medical care during adulthood (Chrisler et al., 2021). Specifically, children and youth with special health care needs are already at an increased risk of co-occurring long term psychological and behavioral

conditions (Easterlin et al., 2020a). An experience of a hospital- related fear might be so traumatic that it influences the normal development of the child (Salmela, Aronen, & Salantera, 2011). As a matter of fact, doctors and nursing staff report feeling overwhelmed with trying to balance addressing medical priorities of care and providing comfort to patients and their families (Chrisler et al., 2021). Even further, doctors are more often concerned with the efficacy of medical care than with communication with patients. There is a need for the medical system to address the psychological needs of children and their families with having additional social and therapeutic support specialists that can improve the hospitalization experience of pediatric patients and their families (Chrisler et al., 2021). In fact, incorporating psychologists into the healthcare team could help disseminate and hone these techniques (Easterlin, 2020b).

Anxiety and Specific Medical Procedures

Evidence suggests that fears of injections and operations are among the most common medical fears reported by healthy children (Fox et al., 2016). Needle-related procedures are defined as any procedure involving the use of needles for medical purposes, such as immunization, venipuncture, IV insertions, intramuscular or subcutaneous injections (Ballard et al., 2019). In one study, 63% of children and 24% of parents endorsed a fear of needles (McMurtry, 2013). Unmanaged needle pain can lead to exaggerated negative memories of procedures (McMurtry, 2013). Painful procedures can prevent children from wanting to undergo further procedures or to overact (Canbulat et al., 2018). Anxiety can exacerbate the perceived intensity of pain and lead to behaviors that can impede the performance of the procedure (Morrow et al., 2018). Many children are afraid of needles and negative emotions such as fear can increase pain perception (McMurtry, 2013). In fact, painful experiences begin with injection procedures (Canbulat et al., 2018). Children with both an acute and chronic condition that are

admitted to a hospital may undergo procedures such as venepuncture and intravenous cannula (Morrow et al., 2018). However, it is important to consider that pain is only one component contributing to procedural anxiety (Nunns et al., 2018). In fact, in a sample of children and adolescent cancer patients, it was found that procedural anxiety was considered the most negative burden on quality of life (Nunns et al., 2018). Even further, in one study children rated receiving a needle (referring to IV or injection) as one of their most feared medical events (Sparks et al., 2007). In addition, needle procedures are not only the most common but also an important source of pain and distress for children in healthcare settings (Inal & Kelleci, 2012b). Furthermore, a prospective cross-sectional survey at a large U.S Children's hospital indicated that needle pokes, such as those associated with Intravenous Cannula Insertions (IVs) are the most common source of pain in hospitalized children (Diener et al., 2019). In fact, children in the aforementioned study referred to needle pokes as the "worse pain" they experienced (Diener et al., 2019).

The management of procedural pain in children is suboptimal and may be explained by clinician's lack of familiarity with options of pain management or perceived barriers such as time constraint (Morrow et al., 2018). Traditional pain interventions may be less effective for patients with a severe fear of needles (Diener et al., 2019). In fact, procedural anxiety can exacerbate the perceived intensity of pain and lead to behaviors that can impede the performance of the procedure (Morrow et al., 2018). There is a bidirectional relationship between fear and pain perception in that fear increases the perception of pain and in effect, painful events become more feared (Diener et al., 2019). In fact, needle fears may actually increase with age and is prevalent in children (Diener et al., 2019). The demonstrated relationship between medical fears and

children's anxiety and pain during immunizations and venipunctures is supported by research (Fox et al., 2016).

Principal Theories

Gate Control Theory of Pain

Melzack and Wall's Gate Control Theory (1965) posits that anxiety may enhance pain by opening sensory "gates" that allow more input into the central nervous system (Bearden et al., 2012). Further, this theory states that pain perception is modulated by both internal and external factors (Cohen & MacLaren ,2007). It also proposes that the amount of attention given to a painful stimulus affects an individual's attention to it (Smith et al., 2020). Additionally, multiple resource theory suggests that as humans we have a limited capacity to attend to pain, while processing it. Therefore, rerouting and diverting mental attention away from a harmful stimulus through a distraction technique would impact the perception of pain (Smith et al., 2020).

Gate control theory suggests that pain is transmitted from the peripheral nervous system to the central nervous system where it is modulated by a "gating system" in the dorsal horn of the spinal cord (Inal & Kelleci, 2012). The gate control theory of pain offers a biological understanding of pain processing and understanding the role of the nervous system is central to this theory (Williams & Zahka, 2017). For example, two individuals can experience the exact same painful thing; however, they may have different reactions. According to Melzack and Wall (1965), there is a process of communication between the spinal cord and the brain that functions like a gate opening and closing. Additionally, pain signals have to pass through the gate in order to get to the brain (Williams, & Zahka, 2017). If the gate is open, then all of the pain signals pass through and a person will experience the full amount of pain that is being communicated. On the

other hand, if the gate is closed then the pain signals will not pass through and do not succeed in carrying their message to the brain, despite that pain signals being present in the body (Williams & Zahka, 2017). Furthermore, it is possible for the gate to be partially opened or closed and pain perception changes based on the extent that pain signals get through the gate.

There are several different factors that affect the position of the gate. Among these factors are attention to the signal, emotional state, cognitive processes, autonomic nervous system involvement, and contextual factors (such as social support and specific situations). In fact, all the aforementioned factors can affect the position of the gate and change the pain experience, even when the stimulus is exactly the same (Williams & Zahka, 2017). Understanding this theory is significant in understanding the individual differences in pain perception and the factors that affect the position of the gate. Furthermore, it is important to understand all the factors that affect the position of the gate for children as it is central to intervention and coping skills training (William, & Zahka, 2017).

Williams and Zahka (2017) suggest a script that can be used to explain gate control theory of pain to children and adolescents. The following is an excerpt of the script used to explain the theory to children and adolescents:

> Basically, when pain signals arrive to the brain, they have to pass through something like a gate, just like you find across a road. Now in our bodies, it is not a real physical barrier- it is more like a series of chemical and nerve impulses between the spinal cord and the brain, for our purposes we will think about it as an actual gate that can open and close. (Williams & Zakha, 2017, p.53)

Explaining to children how the gate opens and closes gives them an understanding of how their body works and how perceptions of pain impact them. Moreover, the goal is to educate them on the control they can exercise in learning how to close the gate on unhelpful pain signals (Williams & Zahka, 2017). There is data that links children's anxiety and procedural pain (Bearden et al., 2012. For instance, one explanation is that children's anxiety heightens their physiological awareness to sensitivity to painful stimuli (Bearden et al., 2012).

Williams and Zahka (2017) suggest the following script to further explain what opens and closes the gate:

> There are some situations, thoughts, feelings, and actions that are more likely to open the gate, like paying a lot of attention to pain, the fight-or-flight response being turned on, feeling nervous or upset, and stressful experiences at school, with friends, or in your family. And there are a lot of situations, thoughts, feelings, and actions that close the gate, like taking your attention away from the pain signal through distraction, turning on relaxation response, and getting the right kind of support from school, family, and friends that improves function. (Williams, & Zakha, 2017, p.53)

Gate control theory is used as part of an intervention treatment such as learning relaxation skills to close the pain gate. Thinking about something else changes attention to symptoms and slows down the ANS and closes the pain gate (Williams & Zahka, 2017).

Biopsychosocial model

The biopsychosocial model states that regardless of the etiology, that somatic symptoms are influenced by a child's emotional and behavioral responses along with the context in which

children live (Williams & Zahka, 2012). The biopsychosocial model goes further than the biomedical model in that it connects the mind and body so that any kind of symptoms arise from both mental and physical processes (Williams & Zahka, 2017). This leads to a more integrated view of somatic symptoms. This model suggests that there are interactions between psychological functioning, biological factors, and inflammation that are mediated through the gut-brain axis theory (Abrams et al., 2016). Treatment of inflammatory bowel diseases requires a multidisciplinary approach that targets both pharmacological interventions and psychosocial supports (Ciubara et al., 2014). The biopsychosocial model includes parental education, family therapy, cognitive behavior therapy, and relaxation techniques to help the child gain skills in managing the symptoms (Ciubara et al., 2014). In the application of the biopsychosocial model, it is essential to communicate with the child and family that their symptoms are real and not just in their head. Even more, it is important for the clinician to believe that the child's symptoms are real and communicate in the first meeting that their symptoms are biologically based, distressing, impairing, and not in their head (Williams & Zahka, 2017).

Health care professionals who consider the multiple causes and treatment for symptoms that include physical, social, emotional, and behavioral factors for all types of symptoms would be operating within the biopsychosocial model. In fact, the biopsychosocial framework improves understanding of any illness for both children and their families (Williams & Zahka, 2017). The biopsychosocial model provides a "conceptual framework from which to understand and treat symptoms that start and continue in the absence of injury or disease. It provides a rationale and support for explanations and treatments that direct their focus on the non-medical reasons why people may feel ill (Williams & Zahka, 2017)." The biopsychosocial model has become an essential aspect of medical treatment and assessment (Williams & Zahka, 2017).

A biopsychosocial assessment includes providing education to the child and their family on the biology of symptoms. The education session is the bridge between the assessment and treatment phases. The autonomic nervous system (ANS) plays a central role in physiological responses. The Autonomic nervous system connects the brain to the internal organs and regulates critical everyday functions such as circulation, respiration, and digestion (Williams & Zahka, 2017). Further the ANS has three branches known as the sympathetic system and parasympathetic, and the enteric nervous system. There are two of the three branches that are relevant to physiological responses. The sympathetic branch controls the "fight-or flight" response which increases heart rate, breathing and muscle tension (Williams & Zahka, 2017). The parasympathetic branch controls the "rest and digest" response which relaxes the body, decreases heart rate, and muscle tension (Williams & Zahka, 2017). The extent to which an individual experiences sympathetic and parasympathetic activity has a direct impact on their physical symptoms and even more so, in the case of somatic symptoms in children. Cases in which the ANS stays activated and the perceived stressor or threat are gone, it often causes a perpetuation of symptoms like increased heart rate or muscle tension. An analogy to explain this that can be used with children, would be a comparison between a fire alarm system and how their nervous system works. When there is detection of smoke, the fire alarm rings, and it is analogous to the sympathetic system activating in the face of a threat or stressor. Just as the alarm continues to ring after the smoke is gone; do does the ANS, which continues to be activated in the absence of any threats. However, in the case of chronic activation, an individual will need to learn ways to turn on the relaxation response known as the "rest and digest" response (Williams & Zakha, 2012). For instance, a child who is anxious is more likely to attenuate to aspects of a situation

that is worrisome, as a result of being in an activated ANS state and in effect, this maintains fear and leads to exacerbated somatic symptoms (Williams & Zahka, 2017).

An understanding of the connection between the ANS and somatic symptoms and emotions enables a child to understand that the ANS responses are part of a normal process, and they can learn how to take control of it (Williams & Zahka, 2012). Further, another analogy to explain this, that can be used with children, is the analogy of how pedals on a car function to make it accelerate of slow down. Similar to a car, the body has two pedals that control the speed. Just like a gas pedal is used to speed up a car; similarly, the sympathetic nervous system controls the fight or flight response. In the body, when the fight or flight response is activated, this is analogous to hitting the gas pedal. There are chemicals such as adrenaline and other chemicals that are released in the body to make the body go faster (Williams & Zahka, 2012). This reaction is felt in the body by heart rate and breathing increases, digestion slows down, and muscles tense up. The digestion slows down to divert energy to the parts of the body that need to act (Williams & Zahka, 2017). This process is functional when there is uncertain and dangerous situations. Similar to when a car speeds up to pass a truck on the highway (Williams, & Zahka, 2012).

As with the car analogy, the car brakes are analogous to the parasympathetic nervous systems which controls the rest and digest response. When the danger has passed, or the excitement has subsided then we need to slow down again. This is achieved in a car by pressing on the brakes (Williams, & Zahka, 2017). The rest and digest response in the body does the same thing as car brakes by slowing down the heart and respiration rate, turning on the digestion process again, and stopping the production of epinephrine (or adrenaline) so the body can relax (Williams, & Zahka, 2017). The rest and digest response is similar to parking the car in the garage for the night- its allows our body to restore and save energy for the next time it is needed.

The goal is to have a balance of activation and relaxation (Williams, & Zahka, 2017). The consequences of an overactivated nervous system are physical symptoms such as dizziness, nausea, headaches, muscle tension, feeling hot and sweaty, and jitteriness (Williams, & Zahka, 2012). These symptoms are maintained by an overactivated nervous system or similar to a car stuck on the gas pedal (Williams, & Zahka, 2017). The nervous system can get "stuck" on activation and forget how to press the brakes. A way to take control of this process is to learn to recognize when the body is stuck on the gas pedal and learn to press the brakes. This can be taught to children with techniques such as diaphragmatic breathing, cognitive -behavioral therapy techniques, and relaxation training to mention a few (Williams, & Zahka, 2017).

Anticipatory Anxiety and the Biopsychosocial model

Understanding the role of anticipatory anxiety in somatic symptom presentation and how it is linked to the process of anxiety and avoidance is critical in recognizing the intersection of all those factors (Williams, & Zahka, 2017). In terms of utilizing behavior theory in conceptualizing anxiety and somatic symptoms, negative reinforcement can be viewed as a mechanism for maintaining anticipatory anxiety and avoidance (Williams, & Zahka, 2017). A key component in addressing the recurring anxiety and avoidance and their link to somatic symptoms is retraining the brain to think differently (Williams, & Zahka, 2017). The cycle of anxiety and avoidance related to somatic symptoms is a response pattern that leads to temporary relief of anxiety, somatic symptoms; and reinforces negative thought processes, emotions, and physical responses that lead to avoidance (Williams, & Zahka, 2017). For example, a child who wakes up and fearing that they get nauseous in class again and vomit. This thought process may lead them to believe it will be a rough day which, in effect, increases somatic sensations, worry, and increases ANS arousal (Williams, & Zahka, 2017). This may lead them to actually feel what

they feared they might experience. Therefore, the child feels a need to escape, and if they are allowed to stay home and miss school, then this will lead to a temporary relief (Williams, & Zahka, 2017). These cognitive, emotional, and physiological responses are strengthened when children are positively reinforced for not doing something. For instance, they stay home from school and get to have an outing with a parent instead. Once the child understands how the ANS works, they can be taught that when they think of a fearful event that the same fight or flight response is activated. Their ANS can get stuck in the activated position and then make their body speed up and feel bad (Williams, & Zahka, 2017). This also relates to procedural anxiety. Cognitive behavior therapy can teach coping skills to calm the body down when it is activated while also learning how to think about a situation in a more helpful way (Williams, & Zahka, 2017).

Other Relevant Theories

Theory of Stress and Coping

Lazarus and Folkman's (1984) theory of stress and coping states that an individual's cognitive appraisal, stress, and coping is linked to one's sense of control over a threatening source to an individual's assessment of that threat (Abrams et al., 2016). Lazarus and Folkman (1984) postulated that if an individual is able to accurately assess the demands of an experience and make a cognitive appraisal about their abilities to cope with it then the more likely their coping will be effective (Boles, 2016). Procedural preparation is shown to reduce fears about unfamiliar and unknown things which helps children and their families to make accurate appraisals about stressors they may be faced with and allow them to utilize appropriate coping skills to manage them (Boles, 2016).

Information Provision Model

The information provision model posits that an individual's past experiences and their exposure to different information sources have an impact on their health-related schemata (Jaaniste et al., 2007). Schema theory states that an individual's appraisal and expectations of a medical situation is developed based on information from a variety of sources. For instance, children who have had several medical experiences as can be the case with children with chronic illness; they may develop more elaborate health related schemata (Jaaniste et al., 2007). Further, the self-regulation theory outlines the process by which an individual makes sense of a medical experience and how they tailor their coping responses based on their expectations (Jaaniste et al., 2007). Therefore, the information provision model integrates both the schemata theory and self-regulation theories. The activation of schemata will in effect shape the child's expectations and the child's approach to coping with the forthcoming procedure (Jaaniste et al., 2007). The self-regulation component of the information provision model focuses on how the child responds and acts upon their schemata and appraisal of a forthcoming procedure (Jaaniste et al., 2007). The application of this can be demonstrated with the example of a child who has to get an X-ray at a hospital. This may result in the activation of the child's schemata related to receiving needles in the case that the child has no prior experience in getting an X-ray and instead they associate needles with hospitals possibly because of their prior medical experiences (Jaaniste et al., 2007). In this case, procedural information may allow the child to recognize that they will not be getting any needles and that is not the helpful schema to be referring to (Jaaniste et al., 2007). Preparatory information that is provided to a child is likely to be incorporated into existing health related schemas or scripts and this provided preparatory information serves to refine, elaborate, extend, or correct existing schemas or scripts (Jaaniste et al., 2007). Children's health-related

schemata, their appraisal of a forthcoming procedure, and coping behavior all influence a variety of treatment outcomes (Jaaniste et al., 2007). Even further, these outcomes include distress levels, perceived pain intensity, and the ease with which the procedure is conducted (Jaaniste et al., 2007). This highlights the importance of appropriate and timely information provision to children in preparation of medical procedures.

Disability-Stress Coping Model

Wallander and Varni's (1992) findings suggest that children's adjustment or distress that is associated with disease or illness factors are impacted by the child's coping resources and their emotional functioning (Reed-Knight et al., 2018). The disability-stress coping model is a comprehensive model of adjustment for children managing a diagnosis with a chronic physical condition (Reed-Knight et al., 2018). There is some evidence that indicates that both anxiety and gastrointestinal (GI) symptom severity are associated with brain regions that are commonly activated in response to fear. This evidence suggests a potential mechanism by which negative emotions impact GI symptoms (Reed-Knight et al., 2018). Furthermore, psychoneuroimmunological research has demonstrated that chronic life stress is associated with immunosuppression and increases in inflammation. This suggests potential biological pathways by which stress may affect disease outcomes (Reed-Knight et al., 2018). The utilization of active and adaptive coping skills has been shown to buffer the relationship between perceived stress and poor emotional functioning in patients with chronic and immune-mediated disease (Reed-Knight et al., 2018).

In fact, it was found that with intervention that patients with Inflammatory bowel disease (IBD) such as Crohn's disease and Ulcerative colitis; rely more on passive coping strategies in comparison to a control group (Reed-Knight et al., 2018). Passive coping strategies refer to

coping strategies such a catastrophizing thought pattern, self-isolation, and disengaging from typical activities. Passive coping is an overall concern for the wellbeing of patients with IBD as these coping strategies are consistently associated with poorer outcomes compared with more adaptive coping skills (Reed-Knight et al., 2018). Additionally, a recent study identified specific psychosocial factors related to IBD; one of which was the presence of passive coping and depressive symptoms, which were associated with greater expression of pain-related distress (Reed-Knight et al., 2018). Family stress was also shown to be associated with poorer psychosocial functioning in youth with IBD across all domains studied (Reed-Knight et al., 2018). This highlights the importance of incorporating a biopsychosocial approach for understanding the pain experience in youth with IBD and it also suggests that family stress places children at a risk for expressed pain-related distress (Reed-Knight et al., 2018). The disability-stress model further supports adopting a biopsychosocial model and emphasizes the importance of addressing psychosocial factors to close the gap between disability and health (Reed-Knight et al., 2018).

Overview of Inflammatory Bowel Diseases

Inflammatory bowel disease (IBD) is characterized by chronic, relapsing gastrointestinal inflammation that results from dysregulation of the immune system (Easterlin et al., 2020; Roberts & Steele, 2018). Symptoms include abdominal pain, diarrhea, fatigue, and weight loss (Easterlin et al., 2020 b). Inflammatory bowel disease consists of two main types known as Crohn disease (CD) and Ulcerative Colitis (UC) (Roberts & Steele, 2018). Ulcerative colitis affects the colon whereas Crohn's disease can involve any component of the gastrointestinal tract from the mouth to the perianal area (Roberts & Steele, 2018). Approximately 5-10% of patients develop IBD during childhood or adolescence (Ghione et al., 2018). The mean age at diagnosis

was 10.3 years with 15 percent of patients receiving a diagnosis before six years old (Ghione et al., 2018). Inflammatory bowel disease diagnosed before six years old is termed "very early-onset IBD" (VEO-IBD). Children with VEO-IBD, particularly those with onset before two years of age, are more likely to have a more severe course compared to children who develop IBD later in life (Kelsen et al., 2020). Further, children with IBD are more likely to present with extensive intestinal involvement and have rapid clinical progression compared to adults (Van Limbergen et al, 2008). As such, Inflammatory bowel disease is stated to be an example of a condition in which patients are at risk of diminished health-related quality of life and long-term impairment that is partly related to repeated exposure to medical care (Easterlin et al., 2020). Inflammatory bowel disease is associated with pain and anxiety from the disease and from treatment such as repeated blood draws, colonoscopies, and medication side-effects (Easterlin et al., 2020).

Crohn's Disease and Ulcerative Colitis

Colitis (inflammation of the large intestine) is a painful condition that can occur in patients with either UC or CD (Roberts & Steele, 2018). Crohn's disease can occur in any part of the gastrointestinal tract and is marked by inflammation of the full thickness of the bowel wall with areas of intervening normal mucosa (Roberts & Steele, 2018). Ulcerative colitis is limited to inflammation of the large intestine and to superficial layers of the colonic mucosa (Roberts & Steele, 2018). Colitis usually presents as a subacute illness with diarrhea that is usually bloody, abdominal pain, fatigue, anemia, and weight loss (Monsen et al., 1990).

The onset of symptoms is usually insidious, but some children have a more fulminant presentation with severe abdominal pain, bloody diarrhea, tenesmus, and fever (Langholz et al., 1994). There are no specific diagnostic criteria for IBD. The diagnosis is typically established by a combination of clinical features and characteristic findings on imaging or endoscopy (Langholz

et al., 1994). Treatment of IBD depends on the severity of symptoms and degree of intestinal involvement at presentation. Attacks of IBD can last for weeks to months. Treatment helps to induce periods of long symptomatic remission, but intermittent exacerbations of disease can still occur (Langholz et al., 1994). Despite treatment, a certain proportion of patients develop IBD complications such as fistulas or abscesses and may require surgical intervention such as a colectomy (Allison et al., 2008).

Overview of Pharmacological Interventions

There is no "cure" for IBD; rather treatment approaches are aimed at managing effective symptoms relief, enhance daily living and minimize relapses (Roberts & Steele, 2018). This is accomplished with a conjunction of medications with behavioral interventions, which is found to provide the greatest symptom relief and less impairment (Roberts & Steele, 2018). Treatment is aimed at symptom control and prevention of disease progression and may involve oral and rectal medications, specific diets, and infusions of biologic agents (Easterlin at al., 2020b). Generally, there are five principal components of a program for management of IBD in children and adolescents, and they are the following: medications, surgery, nutritional rehabilitation/nutritional therapy, colorectal cancer screening, and psychosocial support (Roberts & Steele, 2018). Thus, treatment involve a muti-disciplinary effort. Treatment is aimed at symptom control and prevention of disease progression and may involve oral and rectal medications, specific diets, and infusions (Easterlin et al., 2020b). Inflammatory bowel disease treatment, such as Infliximab, often consists of frequent complex and time-consuming dosing schedules, sometimes in conjunction with other medications (Roberts & Steele, 2018). Overall, IBD medications often have unique dosing schedules that can be complex and time-consuming,

which poses a risk for medication adherence. In addition, patients can experience unpleasant side effects such as weight gain, facial swelling, and nausea (Roberts & Steele, 2018).

Pharmacological treatment often includes steroids to induce remission, which can cause weight gain, anxiety, and diabetes (Roberts & Steel, 2018). In addition, to the steroids, patients are often given immunomodulators to suppress the immune system and subsequently decrease inflammation (Roberts & Steele, 2018). Alternatively, patients can be given aminosalicylates that treat at the site of inflammation rather than altering the immune system to fight the inflammatory response (Roberts & Steele, 2018). The selection of drugs for induction and maintenance depends on age, disease severity, disease location, and clinical course (Van Rheenen et al., 2020). Infliximab (Remicaide) and Adalimumab (Humira) are the only immunosuppressive biologic agents approved for use in pediatric patients (Van Rheenen et al., 2020). Infliximab is an intravenous (IV) infusion whereas Humira is a subcutaneous injection self-administered over 2 weeks (Van Rheened et al., 2020). For mild disease initial therapy includes aminoalicylates that treat inflammation without suppressing the immune system (Roberts & Steele, 2018). In moderate to severe cases, Inflixmab, a monoclonal antibody against tumor necrosis factor-alpha, is commonly used first-line for pediatric patients. Infliximab is administered at an outpatient clinic for the chronic management of IBD at week 0, 2, and 6 followed by every 8 weeks (Van Rheenen et al., 2020). Infliximab side effects include infusion reactions, serious infections, blood abnormalities, and increased risk of malignancy. Dosing of Infliximab often involves measuring drug levels and, thus, can sometimes be more frequent than every 8 weeks (Singh et al., 2014). Furthermore, to decrease the development of drug antibodies to infliximab and help prolong response to therapy, pediatric patients are often also placed on concurrent oral immunomodulating therapies such as azathioprine or 6- mercaptopurine (Ungar et al., 2014).

Notably, the administration of the infliximab infusion requires frequent IV- placement or placement of a subcutaneous port (Easterlin et al., 2020b). Additionally, frequent blood draws are also required to monitor for drug side effects.

Needle pain management includes pharmacological and nonpharmacological approaches such as topical anesthetic creams and vapocoolant spray (Inal & Kelleci, 2012b). Topical and local anesthetics are the drugs of choice for procedures like intravenous access, and subcutaneous port access (Roberts & Steele, 2018). Topical anesthetics work by removing sensation from the skin (Roberts & Steele, 2018). Among the most studied of these is Eutectic Mixture of Local Anesthetics (EMLA) cream which is found to be effective in various procedures such as IV placement, lumbar punctures, subcutaneous port access, and immunization (Roberts & Steele, 2018). A noted barrier to using anesthetic creams is that is requires sufficient time and planning to implement (Diener et al., 2019). For instance, EMLA requires 60 minutes for adequate anesthesia (Roberts & Steele, 2018). On the other hand, LMX4 is a liposomal lidocaine cream-based formulation that is similar to EMLA; however, it provides anesthesia effects in approximately 30 minutes (Roberts & Steele, 2018). As an alternative, a J-Tip Needle-Free Injector delivers lidocaine subcutaneously for an IV start, which delivers anesthesia in less than 2-3 minutes, as compared to the 30 minutes, or longer, as in the case with EMLA anesthetic cream (Diener et al., 2019).

Vapocoolant sprays such as ethyl chloride and fluoromethane provide transient skin anesthesia in about 30 seconds (Roberts & Steele, 2018). However, comprehensive reviews of vapocoolants have shown that there is not sufficient support in the literature (Roberts & Steele, 2018). Furthermore, there is conflicting evidence on the efficacy of vapocoolants for injection

pain, and venous access procedures. In addition, some children consider the cold sensations to be unpleasant (Roberts & Steele, 2018).

Overview of Behavioral and Psychological Interventions

A study (Easterlin et al., 2020b) found that patients reported anxiety leading up to the IV-placement and reported pain with IV placement. In fact, for some of the participants the procedural and anticipatory anxiety began 1-2 days prior to their appointment and lasted until they got home after the procedure. In addition, the parents reported feeling helpless watching their child suffer through the IV-placement and reported they struggled to support their child during the procedure while managing their own anxiety (Easterlin et al., 2020b). Results from both experimental and correlational research studies have demonstrated that certain parental behaviors are associated with increased child distress and pain (e.g., apologizing, criticism, excessive reassurance), whereas others are associated with increased child coping (e.g., distraction, humor, suggestions to use coping strategies) (McMurty, 2013).

Comfort positions

Imagine a child hearing, “you need an IV,” “we are going to put a tube in your nose.” This is a common occurrence in pediatric hospitals and clinics. Anxiety surrounding being hurt has been identified as one of the greatest fears of children. Uncertainty about an invasive procedure limits a child’s ability to develop any control or use any coping skills and this can lead to increased feelings of helplessness and stress (Stephens et al., 1999). A child screaming and flailing to escape as several people hold them down on an exam table is another scenario that happens in pediatric hospitals. A child being restrained by multiple staff and held flat is frightening to children and results in less control and higher distress for a child (Sparks, Setlik, &

Luhman, 2007). Being held flat intensifies fear, and fear is known to increase pain perception (Sparks, Setlik, & Luhman, 2007). It is common for children to be observed crying and fighting when restrained in a flat position before any procedure has even started due to reacting to the anticipation of pain. Restraint is traumatic for children with neurological or developmental disorders and may have unwanted side effects such as vomiting (Slifer et al., 2011).

As mentioned previously, receiving a needle (IV or injection) is rated by children as one of their most feared medical events. Research has also found long-term traumatic memories for some children receiving painful medical procedures (Sparks, Setlik, & Luhman, 2007). Findings also indicate that it is traumatic for parents to watch their child receive painful medical procedures (Sparks, Setlik, & Luhman, 2007).

The position a child is in during IV and injections can have an impact on the comfort of the child and therefore, impact the success of a procedure. Comfort positioning helps parents and the healthcare team to minimize children's movement during stressful procedures such as IV starts, blood draws, NG placements, and injections (Duda, 2018). During a procedure, the experience of fear, lack of control, or a sense of helplessness can be impacted by the child's physical position. (Abrams, Muriel, & Wiener, 2016). Alternative positioning are recommended techniques to comfort children during stressful procedures (Sparks, Setlik, Luhman, 2007). There are different positions that a parent can implement to physically support a child as opposed to being restrained during the IV insertion (Duda, 2018). A child sitting up and being held by a parent is called a position of comfort and indicated as part of a recommended technique to comfort children experiencing stressful procedures (Sparks, Setlik, & Luhman, 2007). In fact, Stephens et al., (1999) have presented a model of care for children undergoing IV insertion (Stephens, Barkey, & Hall, 1999). The child sitting up and being held by the parent can be used

when the child has head and trunk control (between 3 and 5 months). In one variation the child is seated on the parent's lap with arms resting on the exam table (Sparks, Setlik, & Luhman, 2007). According to Stephens et al., (1999) children positioned this way are less upset and maintain a greater sense of control. In fact, it is stated, "Children who can see what is going on experience less anticipatory distress (Sparks, Setlik, and Luhman,2007)." Among the advantages of the upright positioning is that there is minimal body movement, large work area due to the child's body not taking up space on the table, and the child's movement being restricted by a comforting position of the parent (Stephens, Barkey, & Hall, 1999). It is even further recommended that one person hold the child while another holds the child's extremity being used for insertion (Sparks, Setlik, & Luhman, 2007). Kaher (2003) conducted a study to look at upright positioning and IV insertions in young children. The study included preschool (ages 3-5) and school age (ages 6-7) children during IV catheter insertions. Children in the study were randomly assigned to an upright or flat position, and distraction (bubble blowing) or no distraction group (Sparks, Setlik, & Luhman, 2007). The study results indicated a trend for preschool children to rate the IV insertion as less painful, and distress scores were lower in both groups (those with and without distraction) that were held upright (Sparks, Setlik, & Luhman, 2007). Even further, Kaher (2003) found that there was no difference in the time it took to start the IV or in the number of personnel needed for the procedure between the groups (Sparks, Setlik, & Luhman, 2007). Kaher (2003) found that nurses fear that this position would require extra help to immobilize the extremities was not corroborated in the study. Nurses often have concerns regarding safety and efficacy of parental holding and upright positioning. Sparks, Setlik, and Luhman (2007) conducted a study in a Level 1 trauma emergency department of a pediatric hospital in a large midwestern city. The total sample size comprised of 118 children ages 9 months to 47 months (Sparks, Setlik, &

Luhman, 2007). The children in the control group were positioned supine on the exam table with restraint provided by other staff as needed, at the discretion of the nurse (Sparks, Setlik, & Luhman, 2007). On the other hand, children in the experimental group were positioned upright and held by a parent or a family member. The child was either held on the parent's lap with the arm on the exam table or held sitting up on the exam table with the parent holding the child around the trunk (Sparks, Setlik, & Luhman, 2007). For both the groups, one family member had to be present during the procedure. The results showed that scores pre-procedure, procedure, and post-procedure were all significantly lower in the experimental group indicating less distress for children held by parents in an upright position (Sparks, Setlik, & Luhman, 2007). Moreover, the results showed that parents in the experimental group reported greater satisfaction with the procedure, and the difference was significant on the item concerning their satisfaction with the child's position for IV insertion (Sparks, Setlik, & Luhman, 2007). Children in the experimental group had significantly lower distress scores for the overall measure of distress for all periods of the procedure (Sparks, Setlik, & Luhman, 2007). Furthermore, the distress scores in children needing a second IV attempt were also lower in the group held upright by parents (Sparks, Setlik, & Luhman, 2007). Comfort positioning allows parents to hold their children in familiar positions of comfort. In these positions, children can cooperate and maintain a sense of control (Stephens, Barkey, & Hall, 1999). It is important to note that the positions of comfort can be applied to adolescents as well who may regress during stressful procedures (Stephens, Barkey, & Hall, 1999). Overall, the parental holding, and upright positioning decreases IV distress in young children, increases parental satisfaction, and does not significantly impact IV success (Sparks, Setlik, & Luhman, 2007). The positions of comfort also lessen the chance that the procedure will fail (Stephens, Barkey, & Hall, 1999). Hugging which is done in comfort positioning, limits the

child's movement while also is a positive and comforting act. A benefit of this position is that both arms stiffen in order to hug (Stephens, Barkey, & Hall, 1999). Overall, comfort positioning is a safe and simple technique that is a cost-effective technique that may help children and families cope with the frequent experience of having an IV inserted. In fact, it can be used in any setting, such as the Emergency department or pediatric hospitals and clinics (Sparks, Setlik, & Luhman, 2007).

Distraction Techniques

The most commonly and widely used nonpharmacological intervention for pain relief of children during painful medical procedures is distraction, which is consistent with the literature base (Morrow et al., 2018; Incel & Kelleci, 2012a). Distraction is an established and effective method for reducing both procedural anxiety and procedural pain (Morrow et al., 2018). Distraction interventions can be considered active when patients are fully engaged during the procedure and are using multiple senses such as breath exercises, interactive toys, and guided imagery (Abrams, Muriel, & Wiener, 2016). In active distraction children are encouraged to be involved in an action during the painful procedure such as virtual reality, controlled breathing, squeezing a soft ball, electronic games, and balloon inflation (Aydin, Sahiner, & Ciftci, 2016). Distraction interventions can be considered passive when the child remains focused on a stimulus such as reading, watching a movie, or listening to music (Abrams, Muriel, & Wiener, 2016). Distraction entails focusing a patient's attention on any other stimulant to attempt to control and reduce anxiety and pain (Incel & Kelleci, 2012a). Distraction redirects attention away from pain-inflicting stressors and positively influences a child's reaction to future procedures (Abrams, Muriel, & Wiener, 2016). In a study, it was found that children distracted by an interactive electronic tablet during intramuscular injections and port accesses reported

significantly less distress the second time the procedure took place compared to those who did not have the intervention (Abrams, Muriel, & Wiener, 2016). Distraction is commonly utilized during needlesticks. Distraction can also influence perceived pain perception (Abrams, Muriel, & Wiener, 2016). Distraction may serve a counterconditioning function. Counterconditioning is a behavior therapy technique based on respondent conditioning theory (Slifer et al., 2011).The results of a study support the effectiveness of a combined intervention consisting of exposure therapy during mock needle stick procedures, distraction, counterconditioning, and topical EMLA to reduce behavioral distress and promote cooperation during needlesticks in children with autism, pervasive developmental disorder, or ADHD with a history of failed needlesticks (Slifer et al., 2011). In a prospective and randomized controlled study of 123 children, the results showed that 96% of the children in the experimental group using Flippit cards as a distraction during venipuncture, reported less pain than their previous experience without the cards (Abrams, Muriel, & Wiener, 2016). Even further, in another study by Gupta et al. (2006) it was found that school children in the interventions group (they received balloon inflation and distraction) experienced less pain than children in the control group of the study during intravenous access procedures (as cited in Aydin, Sahiner, & Ciftci, 2016).

There is strong evidence that distraction is effective in reducing pain and distress that children experience during needle procedures (Aydin, Sahiner, & Ciftci, 2016). The rationale for the pain effects of distraction is the hypothesis that the brain has a limited capacity of focusing attention on stimulation. Therefore, if attention is diverted to focus on a distracting task, the little attention is left for attending to painful stimulation (Inal & Kellici, 2012a). Aydin et al. (2016) conducted a study that examined three distraction methods: squeezing a soft ball, balloon inflation, and distraction cards. The study examined how these three distraction methods

impacted pain and anxiety relief in children during phlebotomy. The sample study consisted of 120 children who needed a blood test (Aydin, Sahiner, & Ciftci, 2016). Results indicated that all three methods yielded pain and anxiety relief during phlebotomy with no statistically significant difference observed (Aydin, Sahiner, & Ciftci, 2016). However, although the pain was determined at a lower level in the distraction card group, it was not statistically significant, however it was clinically significant (Aydin, Sahiner, & Ciftci, 2016). Likewise, in this study, the parent and observer reported that their anxiety levels were low in the distraction group and although they were not found to be statistically significant; they were clinically significant (Aydin, Sahiner, & Ciftci, 2016). There are numerous studies that have reported the effectiveness of a variety of distraction methods used by parents and healthcare professionals to relieve procedural anxiety and medical procedure related pain and they have been found effective (Aydin, Sahiner, & Ciftci, 2016). Furthermore, Inal and Kelleci (2012), Canbulat et al. (2014), and Sahiner and Bal (2015) demonstrated that distraction cards (Flippits) were very effective in reducing procedural anxiety and pain in children during phlebotomy (as cited in Aydin, Sahiner, & Ciftci, 2016). In another study, children ages 6 to 12 were randomized into four groups (distraction cards, music, balloon inflation, and the control group) to compare the effect of distraction by applying distraction cards (Flippits), listening to music of a cartoon, and balloon inflation to reduce procedural anxiety and pain during phlebotomy (Sahiner & Bal, 2016). The study included 125 children and was conducted at a phlebotomy unit and a maternity unit at a children's hospital (Sahiner, & Bal, 2016). The results of this study indicated that the distraction group had significantly lower pain levels than the control group and all the distraction groups (music, balloon inflation) were also significantly lower than that of the control group (Sahiner & Bal, 2016). The results showed that all the forms of distraction included in the study significantly

reduced pain and anxiety perception. In addition, the results showed that procedural anxiety levels were also lower than the control group (Sahiner & Bal, 2016). Another important finding of this study is that balloon inflation significantly lowered procedural anxiety scores, therefore, proven to be an effective technique during painful procedure (Sahiner & Bal, 2016). As a result of the strength and anecdote regarding the effectiveness of distraction techniques in helping young patients cope with painful procedures, the current author designed and commissioned the creation of sets of distraction prototypes aimed at specific developmental age ranges (see these prototypes in Appendix A). These distraction prototypes are available for use by nurses accessing this training protocol and will also be used for additional research and member checking, and a pilot study by the current author as this line of research and product development continues.

Virtual Reality

Virtual reality (VR) is an advanced system that allows users to be fully immersed in a "virtual world" through a multimodal sensory experience that engages visual, auditory, and tactile (Gold & Maher, 2018). There are some plausible theories that can shed light on how VR facilitates analgesia (Smith et al., 2020). One school of thought suggest that VR enacts changes on a neurobiological level and facilitates analgesia in a manner similar to a drug (Smith et al., 2020). In one study during episodes of pain, VR is administered to patients and reduction of greater than 50 % is observed in the activity of the pain matric which corresponds with a decrease in patient reported pain ratings (Smith et al., 2020). The multiple resource theory suggests that humans have a finite capacity to provide attention towards pain. It is plausible that by rerouting or drawing these mental faculties away from the noxious stimulus through a mechanism such as virtual reality therapy that this would successfully attenuate the perception of

pain (Smith et al., 2020). Virtual reality has been utilized by nurses as a distraction tool in various pediatric healthcare settings as a tool to help children cope with procedural anxiety and pain related to medical procedures (Addab et al., 2021). Therapeutic virtual reality (VR) has emerged as a promising treatment for a range of pain and anxiety conditions and also has the potential to mitigate medical trauma (Easterlin et al., 2020a). Hoffman et al (2000) postulated that based on the cognitive-affective model of interruptive function of pain that the VR served to consume an individuals limited cognitive resource of attention and therefore outcompetes pain processing (as cited in Addab et al., 2021). Similary the gate control theory of pain proposes that the amount of attention given to painful stimulus affects the individual's interpretation of it (Smith et al., 2020). Virtual Reality distracts users from painful stimuli and moves them towards pleasant virtual world, which, reducing the pain experience (Addab et al., 2021). Virtual Reality draws heavily on the limited cognitive resource of attention, by drawing attention away from the "real world" stimuli and into the "virtual world" (Gold & Mahrer, 2019). The VR intervention blocks environmental cues and immerses the user in the virtual world (Addab et al., 2021). The new generation of head-mounted displays (HMDs) is now common technology that is more reasonably priced and user-friendly for a wide age range. It is not cost-prohibitive for research and clinical trials as in the past (Gold & Mahrer, 2018). In one study that was conducted in an outpatient phlebotomy setting at a pediatric hospital the patients were randomized to receive VR or standard of care (SOC) when undergoing routine blood draw (Gold & Mahrer, 2018). The findings indicated that VR significantly reduced acute procedural pain and anxiety compared to the SOC (Gold & Mahrer, 2018). Further, the study results found that VR is more effective for children with higher anxiety sensitivity (Gold & Mahrer, 2018). More specifically, the children using VR who were more distressed by physiological feelings of anxiety, experienced

significantly less anxiety compared with those patients with lower anxiety sensitivity or receiving SOC (Gold & Mahrer, 2018). Further, in pediatric burn patients, VR has shown to help manage pain and anxiety during dressing changes, decrease the length of dressing changes, help manage pain during physical therapy (Easterlin et al., 2020a). Smith at al (2020) conducted a systematic review of the current evidence for the efficacy of virtual reality as an analgesic in the management of acute pain (Smith et al., 2020). The findings of this review illustrated that there was a significant reduction of pain related to virtual reality therapy utilization in 67% of the studies (Smith at al., 2020). Furthermore, this systematic review demonstrated significantly reduced anxiety scores in individuals undergoing virtual reality therapy the treatment of anxiety disorders in comparison to those of control groups (Smith et al., 2020). It is also suggested that VR therapy generates positive emotions and improvements in mood which damped preprocedural anxiety (Smith et al., 2020). Additionally, this systematic review sheds light on the efficacy of utilizing virtual reality therapy for the reduction of acute pain and procedural anxiety within an inpatient setting (Smith et al., 2020). Addab et al (2021) conducted a literature review that included 77 studies. Overall, 12 studies found that VR combined with general analgesia can reduce the pain associated with burn wound care. When comparing VR distraction to standard of care procedures, 18 studies found that VR distraction showed a statistical significance reduction in procedural pain (Addab et al., 2021). There are eleven studies that reported that VR distraction significantly reduced procedural anxiety compared to the standard of care procedures. Further, three studies that investigated the ability of VR in reducing fear for the painful procedure found that children in the VR group experienced significantly less fear compared to children in the standard of care group (Addab et al., 2021). Studies that compared VR to standard of care resulted in 14 studies reporting that VR significantly reduced procedural

anxiety, stress, or fear in pediatric populations in randomized controlled trails (Addab et al., 2021). In another study examining VR with IBD patients treated with Vedolizumab it was found that the use of VR had a positive effect on the reduction of stress associated with vedolizumab treatment and could improve compliance (Lewandowski et al., 2021). While this study used adult participants receiving the infusion treatment of vedolizumab it demonstrates the efficacy of utilizing VR to reduce symptoms of depression and anxiety in chronic condition like IBD (Lewandowski et al., 2021). A systematic review of the efficacy of virtual reality as an analgesic indicates that to date, virtual reality therapy has been successfully used in several acute clinical contexts ranging from pediatric phlebotomy to dressing changes for burn and postcardiac surgery (Smith et al., 2020). In a qualitative study, pediatric patients and parents found virtual reality to be an acceptable option to help mitigate medical trauma during infusion procedures in targeted patients and their families (Easterlin et al., 2020a). The qualitative interview included 18 patient-guardian dyads at an outpatient infusion center for inflammatory bowel disease treatment. The interview explored how VR may change the infusions experience (Easterlin et al., 2020a). There are numerous studies that have demonstrated the efficacy of VR for decreasing pain, distress, anxiety, and in reducing time spent thinking about pain during burn management and wound care (Gold & Mahrer, 2018). The literature suggest that active virtual reality would facilitate a higher level of analgesia in comparison to that facilitated by passive virtual reality (Smith et al., 2020). It was also found that when VR is used in conjunction with analgesia methods that is more effective in reducing pain and distress that analgesia alone (Gold & Mahrer, 2018).

Among the limitations of using VR is that a majority of studies used an interactive VR game which may require the manipulation of controllers. This is a skill that may not be feasible

for children with cognitive delays or with certain medical procedures (Addab et al., 2021). In addition, another consideration is the experience of cybersickness (Easterlin et al. 2020a). The lack of synchronization is believed to cause cybersickness (Smith et al., 2020a). Cybersickness refers to side effects such as nausea, vomiting, eye strain, and dizziness (Smith et al., 2020). In a qualitative study, the potential challenges identified are VR side effects such as dizziness, nausea, limited mobility during the procedure, disorientation/immersion leading to shock upon IV placement, and lost opportunity to build coping skills (Easterlin et al., 2020a). Nurses, have the primary responsibility of administering the medical procedures and therefore they will play a crucial role in the implementation of VR (Addab et al., 2021). Nurses will need to be familiar with identifying signs of cybersickness, ideal time of dosing VR interventions based on the specific medical procedure, and efficiently disinfect equipment, and selecting VR interventions that have an adequate level of engagement and interactivity (Addab et al., 2021). Despite these limitations, the data show that VR helps to cope with anxiety, fear, and pain in some treatment regimens among children and adolescents and is considered by this pediatric population as a very positive and interesting experience (Lewandowski et al., 2021). Furthermore, during IV-placement, pediatric patients using VR had significantly lower pain scores than the control group (Easterlin at al., 2020a). Additionally, VR has shown to make blood draws and accessing of ports more pleasant for pediatric patients (Easterlin et al., 2020a).

Buzzy

Buzzy is a bee-shaped device consisting of a battery-operated vibrating motor attached to the removable ice wings to create a cold sensation. It was created by Dr. Amy Baxter who is a pediatric emergency physician and pain researcher in the U.S. (Ballard et al., 2019). Buzzy is a non-pharmacological pain control device that operates on the principles of the Gate Control

Theory (refer to Appendix C for an image of the Buzzy device). Buzzy is a rapid intervention specifically intended for pain management in children undergoing needle-related procedures (Ballard et al., 2019). Erdogan and Aytekin Ozdemir (2021) conducted a four-arm randomized controlled trial comparing VR distraction to distraction cards, Buzzy (vibration), and standard of care during venipuncture. They found that children using Buzzy during venipuncture experienced the least pain, followed by VR, distraction cards, and standard of care (as cited in Addab et al., 2021). One study conducted a randomized controlled trial that included 120 children aged 6 to 12 years undergoing blood specimen collection (Inal & Kelleci, 2012b). The purpose of the study was to examine the effect of external cold and vibration stimulation via Buzzy. The results indicated that the experimental group showed significantly lower pain and anxiety levels compared to the control group during the blood collection procedure. The use of Buzzy (see Appendix C for picture of Buzzy device) decreased perceived pain and reduced children's anxiety and blood specimen collection (Inal & Kelleci, 2012b). Buzzy is shown to be effective in reducing pain during blood sampling, IM injections, intravenous catheterization, and immunization (Sahiner et al, 2018).

In one study that included 120 children ages 6 to 12 years old and their parents, the results indicated that children in the external cold and vibration stimulation group had significantly lower pain levels by self-report, parent report, and observer report compared to the control group (Inal & Kelleci, 2012b). Further, the results that the external and vibration stimulation group had significantly lower intra-procedural anxiety levels by parent and observer report compared to the control group (Inal & Kelleci, 2012b). Utilizing Buzzy did not cause a significant different in the success of the blood specimen collection procedure. In fact, the experimental group (utilizing Buzzy) indicated that the current experience was less painful than

previous blood specimen procedures (Inal & Kelleci, 2012b). Ballard et al (2019) conducted a systematic review and meta-analysis examining the effectiveness of the Buzzy device combining cold and vibration for needle-related procedural pain in children (Ballard et al., 2019). A total of nine studies involving 1138 participants aged between 3 and 18 years old were included in the systematic review and sevem were suitable for meta-analysis. The results showed that Buzzy demonstrated a statistically significant effect on reducing self-reported procedural pain, observer-reported procedural pain and anxiety during needle-related procedures (Ballard at al., 2019).

The theoretical basis of Buzzy intervention originates from the Gate Control Theory. The non-painful stimulation such as vibration or cold, can reduce the pain signal transmitted from the periphery to the brain and intercepts the pain signal (Ballard et al., 2019). This occurs by activation of an inhibitory interneuron in the dorsal horn of the spinal cord that acts like a gate reducing the pain information transmitted to the brain (Ballard et al., 2019). The Buzzy device should be placed about 5cm above the insertion site by either attaching it to the arm or holding it in place manually (Ballard et al., 2019). The wider end of Buzzy is placed closest to pain with the head of buzzy closer to the patient's head during the procedure. The best numbing is directly distal from the center of Buzzy where the motor is (Ballard et al, 2019). It is important to note that Buzzy blocks sharp sensations, not light touch, so an anxious person may still feel distressed feeling dull pokes (Ballard et al., 2019).

Procedural Preparation

Interventions which provide procedural information, coping skills training, distraction, and/or parent coaching may offer promise for children undergoing invasive procedures (Fox et al., 2016). Explanation regarding the procedure and potential for discomfort may help alleviate

some of the anticipatory anxiety that children carry with them into the procedure room (Fox et al., 2016). The primary purpose of non-pharmacological procedural support interventions is to increase the child's coping ability and sense of control while reducing fear, distress, and pain (Abrams, Muriel, & Wiener, 2016). This demonstrates a need to assess and identify children with anxiety and medical fears such as worries about certain elements of a procedure or catastrophizing thoughts and provide preventive interventions and preparation programs for children undergoing procedures (Fox et al, 2016).

Research shows that children who are well-informed about their illness tend to adhere to treatment regimens more diligently and to have better disease outcomes than those that are less well-informed (Chilman-Blair, 2010). Advance preparation such as a hospital visit and educational video help to reduce children's preoperative anxiety (Rocha, Marche, & Von Baeyer, 2009). When it comes to procedural preparation there is a breakdown in communication with children due to time pressures (Chilman-Blair, 2010). For example, doctors will often not have enough time to adequately explain the illness in terms that a child will understand. Healthcare providers like doctors and nurses may use inappropriate medical jargon or at the other extreme they may provide an overly simplistic version of events devoid of factual data (Chilman-Blair, 2010). Doctors do not have the necessary training or time to provide adequate explanations to children, and the nurse is often the primary person that communicates information and support around a child's illness (Chilman-Blair, 2010). The clinical implication is that doctors and nurses need to be able to listen to children, respect their needs for procedural information and be prepared to provide that information in the right amount and in an age-appropriate way (Chilman-Blair, 2010). Diagnosis education and procedural preparation tools help psychosocial clinicians collaborate with children and families to develop a coping plan for the procedure

(Abrams, Muriel, & Wiener, 2016). While too much information can be a negative factor, so can too little information (Chilman-Blair, 2010). Role play and preparation techniques have also been found to increase understanding of what to expect during procedures, reduce fear in younger children, reduce anxiety in older children, and increase overall satisfaction (Abram, Muriel, & Wiener, 2016). In providing procedural information to children, it is essential to use age-appropriate language because children are more likely to understand language, they themselves use on a daily basis which emphasizes the importance of simplifying scientific terms (Chilman-Blair, 2010). For instance, telling children, "It won't hurt," does not decrease pain perception and erodes the trust between the patient and clinician if discomfort is felt. Generally, terms of reassurance, apologies, and criticisms have been shown to increase distress during procedures, while positive encouragement and validation can help to decrease stress (Abram, Muriel, & Wiener, 2016).

One of the major obstacles in procedural preparation is the lack of standardization and regulation (Chilman-Blair, 2010). Medical resources that are aimed at children and young people should be visually interesting while presenting facts in a fun manner (Chilman-Blair, 2010). Research has shown that children are more likely to understand and access health information if it is derived from their peers, uses language that they can identify with and is presented in a non-threatening manner (Chilman- Blair, 2010). Providing the opportunity to practice coping strategies through developmentally appropriate procedural education prior to surgery has been shown to minimize the child's and family's anxiety as well as increase coping ability (Abrams, Muriel, & Wiener, 2016). In addition, the use of visual media and the adoption of a narrative style enhances information understanding and retention (Chilman-Blair, 2010). Research also shows that the younger age group responds well to a narrative approach as opposed to an

information brochure or leaflet (Chilman-Blair, 2010). Preparation books (that can be printed, electronic, or on an iPad) can also help to describe the steps of upcoming procedures and encourage dialogue about any concerns or questions that a child may have (Abrams, Muriel, & Wiener, 2016). The narrative approach holds their attention longer and enables them to identify with characters and situations more readily (Chilman-Blair, 2010). Additionally, since children respond well to visual material, the research has shown that the use of illustrations in educational resources for children has a profoundly beneficial effect that increases both comprehension and retention of key facts (Chilman-Blair, 2010). For example, children with no prior experience of dental treatment have been found to respond to a short video demonstration of the procedure with heightened distress, unless the demonstration used a peer model (Jaaniste, Hayes, & von Baeyer, 2007). Given this research, it is important to include case vignettes in information specifically for children and providing a child or person with a disease that the child can relate to, and it will make the information relevant to the patient (Chilman-Blair, 2010). Additionally, modeling by more competent peers may also provide the necessary scaffolding to cope with situations that would otherwise exceed the child's coping abilities (Jaaniste, Hayes, & von Baeyer, 2007). It would be expected that less scaffolding would be needed with older children, those with greater coping skills, and those facing mild rather than severely painful or stressful stimuli (Jaaniste, Hayes, & von Baeyer, 2007).

Consideration of timing for procedural preparation is important to allow enough time for information processing while not causing increased anxiety to build (Abrams, Muriel, & Wiener, 2016). Procedural preparation can reduce the perception of pain and especially in perioperative settings (Abrams, Muriel, & Wiener, 2016). There is consensus that children who are better informed about a forthcoming procedure generally have better outcomes such as lower distress

and better adjustment during and after the procedure (Jaaniste, Hayes, & von Baeyer, 2007). Detailed procedural preparation sessions are most effective for children over 2 years of age and include education about procedure duration, sequence of events, role of the child and caregiver, and sensory information (such as what the child will see, hear, smell, taste, and feel) (Abrams, Muriel, & Wiener, 2016).

Procedural preparation should take place earlier for adolescents and closer to time of the procedure for younger children. Two studies found that children receiving more information had elevated stress responses before surgery but demonstrated better preoperative adjustment with fewer postoperative complications (Jaaniste, Hayes, & von Baeyer, 2007). In addition, procedural preparation should be provided always in collaboration with parents to tailor the timing of preparation for the individual needs of the child (Abrams, Muriel, & Wiener, 2016). For instance, if children respond to information about certain aspects of a forthcoming medical procedure with very high levels of fear, then systematic desensitization techniques exposing them in a gradual way to feared stimuli may be beneficial (Janniste, Hayes, & von Baeyer, 2007). Further, levels of distress and feelings of helplessness may be minimized if the information about the impending experience is presented in conjunction with advice on strategies to cope with the experience (Janniste, Hayes, & von Baeyer, 2007).

Parental Anxiety and Procedural preparation

The behavior of parents or adults caring for children has an impact on their reactions to medical procedures. Parent anxiety is another influential predictor of child medical procedural distress (Bearden, Feinstein, & Cohen, 2012). According to Craig's (2009) social communication model of pain, the person in pain and the observer contributes intrapersonal factors that influence the person's experience and expression of pain, pain assessment, and pain management. The

model posits that there is an interaction of factors that include social, biological, and psychological factors (as cited in McMurtry, 2012). A common parent behavior during painful medical procedures for children is for the parent to engage in reassurance such as saying, “don’t worry, you are okay.” Research has revealed that reassurance acts as a signal of parental fear and that reassurance generally seems to be an ineffective comforting strategy during acute pain and can actually increase child pain and upset (McMurtry, 2013). Results of another study demonstrated that children perceive parents as worried when they reassure (McMurtry, 2013). Research findings suggest that parent behaviors such as excessive reassurance, giving too much control to the child, apologizing, and criticizing; are associated with high child distress (Bearden, Feinstein, & Cohen, 2012). Finding suggest that parent behaviors such as distracting, coaching to cope; predicted low child distress which has led to parent training interventions aimed to reduce children medical anxiety and pain (Bearden, Feinstein, & Cohen, 2012).

A number of studies have shown that parent anxiety predicts child anxiety and pain across a range of medical and nonmedical events (Bearden, Feinstein, & Cohen, 2012). There is a plethora of data that links parent’s state anxiety and children’ procedural anxiety and pain (Bearden, Feinstein, & Cohen, 2012). In another study, the results indicated a significant relationship between parent anxiety, and children’s distress during medical procedures with a correlation between parent’s trait anxiety scores and children’s total distress scores (Jay et al., 1983). Further, the results suggest that parents who have more anxious personality styles tend to have children who exhibit higher levels of distress during bone marrow aspiration (Jay et al., 1983). In treatment outcome studies that are aimed at reducing children’s distress, the parents have been used effectively as “coaches” during medical procedures (Jay et al., 1983). Parental involvement when they are trained as “coaches” seems to lower the anxiety-distress levels of

both parents and children and minimize the interactive or contagious aspect of the anxiety-distress (Jay et al., 1983). The results of this study suggest that effective intervention include parents since the relationship between parental anxiety and children's distress is so clearly demonstrated (Jay et al., 1983). Bernard and Cohen (2006) conducted a study in rural health department and two nurses administered all of the injections. The purpose of the study was to thoroughly examine parent anxiety and its effects on infant procedural pain for 37 parent-infant dyads (Bernard, & Cohen, 2006). The participants in the study included 37 infants, 18 boys, and 19 girls whose ages ranged from seven weeks to one year and eleven months. The study found a positive association between parent's anxiety and their infant's procedural pain. The study provided evidence to suggest a positive relation between parent and infant pain during pediatric procedures, which also parallels the literature with preschoolers (Bernard & Cohen, 2006).

Medical Play

Medical play is a powerful tool that can help children process their treatment journey prior to and following procedures. Play stimulates and facilitates communication and autonomy (Diaz-Rodriguez et al., 2021). Play also encourages children to express and understand the situation they are experiencing with an active participation role in their recovery process (Diaz-Rodriguez et al., 2021). The goal of medical play is to increase communication, self-expression, preparation, familiarization, and reflection in a developmentally appropriate manner (Abrams, Muriel, & Wiener, 2016). Medical play also provides opportunities for children to practice the steps of a procedure on a doll through role rehearsal and role reversal (Abrams, Muriel, & Wiener, 2016). For instance, children can engage in medical fantasy play or play medical equipment or indirect medical play with medically themed games or puzzles. The use of games and toys is also relevant for reducing children's fear and embarrassment since it creates an

environment for children to express their feelings and participate in their care (Diaz-Rodriguez et al., 2021). Children can also manipulate medical supplies through expressive painting, sculpting, or collage (medical art). Some examples of medical play dolls are muslin dolls that children can personalize or teaching dolls such as Shadow Buddies (Abrams, Muriel, & Wiener, 2016).

The use of therapeutic play in hospitals is considered to be positive because hospitals become more pleasant and similar to aspects of children's daily lives. This can provide children with peace of mind, courage, and calmness to facilitate their communication and participation in procedures (Diaz-Rodriguez et al., 2021). Research study results show that children who engaged in therapeutic play intervention prior to day surgery demonstrated decreased anxiety scores and emotional behaviors both pre-and postoperatively (Abrams, Muriel, & Wiener, 2016). Falke et al (2018) conducted a qualitative study to gather data on the nursing team's perception of using a playful approach in the care of hospitalized children (as cited in Diaz-Rodriguez et al., 2021). It was observed that the nursing staff do no possess the technical and scientific training to implement a playful approach in the provision of nursing (Diaz-Rodriguez et al., 2021). This study established a need to not only introduce this type of training in undergraduate nursing curriculum but also established a need for hospital to promote playful care to improve the comprehensive care of hospitalized children (Diaz-Rodriguez, 2021).

Section III: Training Protocol and Utilization of Resource Kit

General Description

The goal of this proposed protocol it to provide an educational protocol to nursing staff in an infusion center about procedural anxiety in pediatric patients with Crohn's disease and Ulcerative Colitis. This training protocol provides educational materials on procedural anxiety and procedural support (refer to Appendix B for training resource kit). Also, this author developed a social narrative about getting in IV in an infusion center (refer to Appendix B). In addition, this author has developed distraction card prototypes that will be developed in distraction easels that can be utilized as a distraction technique during IV placements and infusion treatments (see prototypes in Appendix A).

Nurses need to be aware of procedural anxiety and pain during needle procedures and interventions need to be implemented to decrease anxiety and pain in children (Inal & Kelleci, 2012b). Distraction techniques can be integrated into nursing care and have been shown to be effective in managing procedural pain and distress in children and adolescence (Addab et al., 2021). Often due to the time constraints of doctors, the task of explaining disease diagnosis and treatment to children often falls to the practice nurse (Chilman-Blair, 2010). In fact, the nurse is often the primary source of information and care in children with chronic medical conditions (Chilman-Blair, 2010). Pediatric nurses have a vital role in providing psycho-emotional support to children. Children need to have coping methods and techniques in which they have an active role that allows them to have a sense of control over the hospital environment and medical procedures (Diaz-Rodriguez et al., 2021). For this reason, it is crucial for nurses to learn

effective ways to communicate with children and use information resources and interventions to have a good outcome.

Research supports that the supine position causes greater distress to children and parents (Abram, Muriel, & Wiener, 2016). Sparks, Setlik, & Luhman (2007) found that nurses using the upright positioning indicated needing to change their technique in 25% of the cases, whereas nurses using the supine position indicated needing to change their technique in 10% of cases (Sparks, Setlik, & Luhman, 2007). In addition, the nurses reported greater satisfaction with supine positioning with 86% of nurses reported satisfaction with the supine position (Sparks, Setlik, & Luhman, 2007); whereas 54% of nurses reported satisfaction with the upright position (Sparks, Setlik, & Luhman, 2007). This suggests that methods to help nurses make these changes in practice need to be identified and provided. Brown (2002) suggested that the nurse's perception that upright positioning makes starting an IV more difficult may account for the reported lack of satisfaction by nurses. Identifying barriers to changes in IV technique to determine ways to provide support and encourage nurses to make these changes (as cited in Sparks, Setlik, & Luhman, 2007). This training resource kit and in person training protocol for nurses in infusions centers serves to help bridge that transition to utilizing comfort positioning with pediatric patients. Sparks, Setlik, and Luhman (2007) results have suggested that nurses need to be willing to try new methods that have been found to be beneficial and this requires stepping out of "comfort zones" for the benefit of the patient (Sparks, Setlik, & Luhman, 2007). Coached and practiced comfort holding techniques can offer more choice, control, and security for children (Abrams, Muriel, & Weiner, 2016).

The training can serve to help nurses to provide a more family-centered care during technical procedures. Training pediatric medical staff in behavioral pain management strategies,

including distraction has also been emphasized in recent research (Abram, Muriel, & Wiener, 2016). There are interventions that can be used to help prepare children for medical procedures that include the following: providing information ahead of time about a procedure, altering the enviornment surrounding the procedure, and teaching children coping strategies to enhance coping before, during, and after a painful procedure (Slifer et al., 2011). These interventions also involve the child's caregiver or parent. Therefore, parent anxiety is important to consider not only for the benefit of the parent, but also because of its impact on the child (Bernard & Cohen, 2006). Bernard and Cohen (2006) study results suggest that nurses may need to be trained as to which behaviors are indicative of parent anxiety and query parents about their anxiety level (Bernard & Cohen, 2006). Therefore, this training resource kit also includes a resource handout for parents that provides information on how they can coach their child during medical procedures and helpful and unhelpful communication with their child during medical procedures. In a study conducted by Salmela, Aronen, and Salentera (2011), they found that among the worst things that children describe during hospitalization are fears related to nursing procedures and pain (Salmela, Aronen, & Salentera, 2011). Further the results indicated that essential fears to nursing interventions and pain, separation from parents and being left alone, to the lack of information, and to the instruments and equipment. Children expressed these fears verbally and through their actions (Salmela, Aronen, & Salantera, 2011). When the quality of pediatric nursing care in hospitals is improved then this can alleviate and prevent children's fear and procedural anxiety (Salmela, Aronen, & Salantera, 2011).

Collaboration with Treatment Team

Pediatric patients with inflammatory bowel disease often will have a treatment team across different specialties. For instance, there is a pediatric gastroenterologist, pediatric

psychologist, child-life specialist, and infusion center nursing staff that may comprise a healthcare team for an individual case. Pediatric psychologists are consulted on a wide array of medical procedures and conditions (Roberts, Aylward, & Wu, 2014). For that reason, it may be necessary for pediatric psychologists to extrapolate evidence-based psychological techniques from the existing literature to apply it to less traditionally studied procedures that cause distress for some children (Roberts, Aylward, & Wu, 2014). Additionally, pediatric psychologists may need to draw from the broader psychological literature to guide their interventions (Roberts, Aylward, & Wu, 2014).

Section IV: Protocol Utility and Future Directions

Case Study

This case is de-identified and certain details included in this case study have been omitted or altered in order to protect the confidentiality of the individual and family described, To illustrate the utility of this protocol, a case study is presented.

Referral: Ava was referred by her pediatric gastroenterologist due to concerns with procedural anxiety related to infusions.

Ava is a 9-year-old Caucasian female diagnosed with perianal Crohn's disease at age 9. Ava is in 3rd grade and has been homeschooled since she started school. The onset of her symptoms was two months before her diagnosis. At onset of symptoms, she experienced pain with stooling and would cry. She was taken to urgent care where she was prescribed Miralax for several weeks; however, her stooling issues continued, and her pain increased. She was taken to urgent care twice, and the emergency department twice. Her PCP had her on different laxatives that did not appear to provide relief of symptoms. She was unable to sit upright due to her pain and wouldn't play or do anything. In addition, she had lost 20 pounds unintentionally. Ava would hold her stool due to the pain she experienced with elimination. During one of her emergency department visits, they inserted an IV and she was screaming, and began flailing when they put the tourniquet on. She would scream, "get off of me, don't touch me," and had to be held down. It took an hour to start the infusion during her hospitalization because she felt the flush and Benadryl in her wrist (cool sensation) and this made her scared.

After completing an EGD and colonoscopy it was found that she had perianal tear, two fissures, and an ulcer. Ava was hospitalized and given antibiotics and Remicade. She had her

first infusion during a three-day hospitalization. Notably, her IV had been placed while she was under sedation. In addition, her blood draw was also done when she was under sedation. Ava has not had vaccinations since she was a one-year-old due to the family electing not to vaccinate her. Prior to the onset of her symptoms, Ava had always been healthy. When Ava went to her first infusion at the Infusion center a few weeks after her hospitalization, she was "pouty" and the night before the infusion she began crying and was getting upset. She made statements to her mother that she did not want to go. At the infusion center, she would not answer questions and put her head down. Ava began yelling when the nurses touched her to feel for a vein with the tourniquet on. She screamed, "Get off me, I want to go home." Ava was screaming and holding her breath and her mother would blow in her face to try to comfort her. It took them four sticks to get an IV placed and it was an hour and a half before they were able to start the infusion. Ava spent the first hour fighting the administration of the IV. She also freaked out when they went to flush the IV. She began mistrusting her mother because while she was in the hospital, her mother would say "it is in," however, it would not work, and they would have to try again. Among Ava's triggers are IV placement, tourniquets, IV flush, and IV removal.

Consultation with the referring team and treatment planning:

Collaborating with her pediatric gastroenterologist, nursing team at the infusion center, child-life specialist (for a short time), and her pediatric psychologist was essential to her care. Buzzy bee was initially used by the child-life specialist with Ava in her first infusion procedure, however, Ava reportedly did not like distraction. The RN at the infusion center offered modification of the comfort hold during one of her infusions due to Ava pushing against the bottom of the bed. As a result, Ava had shown significant improvement in her response and tolerance of her infusions, however, during one appointment when the nurse, whom she was

familiar with was no longer there, she had a difficult time emotionally and the protocol she was used to, was not followed as she had a new nurse. Thereafter, the pediatric psychologist collaborated with the nursing staff at the infusion center to discuss a protocol and plan for Ava. Furthermore, the pediatric psychologist collaborated with the infusion center to set up an exposure therapy session for Ava such as meeting the nurses who would be working with her at her next infusion visit two days prior to her infusion appointment. During the exposure with meeting the nurses in advance, the pediatric psychologist, Ava, her father, and the nursing staff were able to discuss together what her needs would be for her infusions which served to be highly beneficial. Ava did well at her infusion where she got into the bed calmly upon arrival to the infusion center and her IV was started within 10 minutes of her arrival. She was talkative with the nurses. Ava did yell and scream when the IV was getting started but she met her goals of getting into the hospital bed calmly and remaining still during the IV start.

Initial meeting with Ava and her parents:

During the initial meeting, Ava was engaged at the start of the session when discussing benign topics. However, upon gathering history related to her new diagnosis and procedures, she became guarded, tearful, irritable, and refused to talk/answer questions. Her mother made frequent efforts to calm her and was over attending to Ava's negative refusal behaviors. Her mother engaged in excessive re-assurance and made negative comments about procedures and her own inability to tolerate similar procedures. Ava's family history is significant for her mother being diagnosed with Crohn's disease at age 10 with her symptoms beginning at age 9. Her mother has been in remission for 19 years and is not on any medications. She was never put on infusions. Since Ava's mother was pregnant and her due date was near, it was discussed that

Ava's father would be her support person that would go with her to the infusion center appointments. Her parents stated, "Ava is very stubborn."

Intervention:

The interventions included providing psychoeducation about the role of pediatric psychology in management of procedural anxiety and pain was provided as well as adjustment to diagnosis. As her infusion appointment approached, a plan was introduced, creating a system for earning rewards upon completion of infusions was developed and implemented. Ava wanted to earn Legos, Roblox time, YouTube Minecraft videos, and a Sonic slushy. Psychoeducation was also provided to Ava's parents about system level and parent level interventions. Comfort positioning and ways to alter their current positioning techniques to meet the needs of Ava and not allow for escape behaviors during her infusion were discussed. Psychoeducation was provided to her mother in another session regarding helpful and unhelpful ways to communicate about procedures and what should and should not be reinforced. This same information was discussed in another session with Ava's father. It was recommended that both parents have daily practice of comfort position holding at home with Ava.

During sessions, Ava would become guarded, tearful, irritable, and would refuse to talk or answer questions once the discussion turned to talk about her infusion procedure or her diagnosis. For instance, in one session, she refused to watch the video on comfort holds and refused to participate in the discussion. She would look down and cry. In another session, while discussing comfort positioning, she burst into tears. Her parents indicated that they practiced comfort positioning twice during that week with Ava and each time she grumbled, got into the position, and then went limp. Among other sessions, parents were provided with psychoeducation about the role of parents in helping children overcome procedural pain and

anxiety as well as helpful and unhelpful things to say and messages to communicate. The importance of decreasing excessive reassurance and increasing focus on bravery and safe procedural behaviors (such as sitting still during IV placement) was emphasized throughout sessions. Also, discussion focused on the reinforcement system to be used to help increase Ava's cooperation in getting into the bed in the treatment room; it was emphasized that she could earn one reward for cooperation as well as another reward for remaining still for staff.

During one infusion center appointment, Ava ran and hid behind a chair for a few minutes. Her father had to move the chair and guide her over to the bed by her hand/arm. Her father did a comfort hold and Ava was screaming and using the bottom of the bed to push back. The first stick failed because EMLA seemed to hide the vein on her hand. However, they switched to her arm and got it immediately. They continued the comfort hold because it was keeping her arm still. Ava's anxiety started the night before the infusion, with her crying and stating she did not want to go to the infusion center. Her parents continued to practice comfort holds every night and although she was comfortable with it, she would verbalize that she "hated it." On the way to the infusion center, she shut down and was making statements that she wanted to go home. Her parents tried to respond to her with encouraging statements. Pointing out that she would get a reward seemed to help. It served to encourage her cooperation with sitting on the bed in preparation. Her mother was (she elected her mother although child life specialist can help with that) within her view, holding the tablet, talking to her, and getting her to do deep breathing. She was also told that her next reward would come if she remained still for the poke(s).

The comfort position was implemented by having her father sit next to her in the bed, immobilizing one arm behind him with her head placed on his chest and the other arm out and available to healthcare staff. The nurse decided that her vital signs would be taken after the IV

insertion, to reduce the amount of time between arrival and IV placement and to reduce her anticipatory anxiety. In one session, the "What to do when fear interferes" treatment book was read, however, Ava would not engage or follow along. In order to not reinforce her escape avoidance, the first chapter was continued. Other sessions focused on rapport building and increasing cooperation around simply interacting in a session and the likely need for an initial exposure to simply be participating in talking about her Crohn's disease. In other sessions, the "This is My World," workbook was completed as a way for Ava to make a book about herself and become more desensitized to conversing about her illness. The workbook is published by the NIMH, to help children that are diagnosed with a medical illness. At times Ava would become oppositional in answering certain questions that required her to have an immediate answer, such as "one thing that is different about me from other people is…." and "Some words that describe me are." In another session, she did not want to complete the thoughts/feelings page nor a page asking her about her family and another page asking her about her illness. In response to these she replied, "I don't think that way and "I'm not going to start."

Games were played during sessions to reinforce compliance with therapy materials. For example, Ava played Jenga while completing the page about "My illness," with Ava completing one sentence prompt, followed by her taking a turn in the Jenga game. Ava wrote "nothing" next to the following prompt, "The things I want to know about my illness are…" She did acknowledge feeling sad, mad, and scared when she found out that she had Crohns and stated, "The thing that scares me most is… "IV." She also responded to one prompt noting, "The treatment for my illness makes me feel… scared." Other interventions focused on exposures such as watching a video about Crohn's disease. Ava was not pleased about watching the video, but she was agreeable to making a Crohn's match game which brightened her mood. This involved

watching the video again to identify terms for the game. Ava was initially resistant to watching the video again but as she watched and found terms to use for her matching game then she was more amendable. In other sessions, the match game was played with words related to her diagnosis and infusion, which served as an exposure exercise. This was significant improvement, given that Ava would not talk about her illness in previous sessions. The match game was a type of exposure to her Crohn's disease and the board game had additional exposures to details related to her illness and infusions. Ava was happy and laughing during the game. The complexity of the game was increased by having her answer questions related to what the words meant. She initially did not know that Avsola was the name of her medication. She learned more about what having Crohn's disease meant as well as where the small and large intestines are in the body.

Ava was agreeable to making a board game for her Crohn's disease (refer to Appendix C for images of the game and handouts) and began generating ideas. Ava was excited about making a board game. Ava requested to continue to come up with ideas for her Crohn's board game. She did not like the idea of "challenge cards," which would involve further exposures, however, in later sessions, she was able to generate some challenge cards. In other sessions, Ava came to session with drawings for the cards and game board that she was creating in sessions about her Crohn's disease. Ava created cards including deep breathing during infusion, holding still for the IV, taking medicine, and being brave; all for the purpose of moving forward in her game. These included cards of someone not taking medicine and not getting the infusion and these cards required one to move back spaces in the game. She also created illustrations for different destinations on the board. She was praised for her creativity and work, both within and outside of session. She was agreeable to add additional components that would emphasize

learning additional coping tools, information about Crohn's disease, and eventually further exposures. After a few sessions, Ava showed a vast improvement from her initial infusions. With the reward system in place, she was able to get out of bed without fussing and once she was at the infusion center she did not scream, and got into the bed. She was tearful and wanted to go home, however, she did not scream and only had to have one stick to get the IV in, which she was pleased with. She was also given two Lego sets from the nursing staff after doing so well. In her next session, she showed a significantly decreased resistance to talking about her illness and infusions. At a later infusion appointment, she woke up that morning in a good mood and got ready easily and without procrastination or refusal. However, when she arrived at the infusion center and found out that her usual nurse was not there, she started to struggle emotionally. In addition, there was 1.5 hour wait until her IV was inserted which led to significant anticipatory anxiety. They were unable to find a vein initially and instead of continuing with the other arm, and having her use the comfort positioning she had become accustomed to, they asked her to get up and move to the other side of her father. This led her to bury her head in her arms and it took several minutes for her to get calm and give them her arm. She was yelling and screaming throughout the procedure. This led to further collaboration with the infusion center staff on her protocol and process. In another session, Ava played the Crohn's game in session with her father, and she enjoyed seeing her father participate in the learning exercises, challenges, and exposures that were part of the board game. She was able to demonstrate her knowledge as well as her tolerance of exposures. During sessions, she had exposures that included watching a video of an IV start, watching two videos of children being taught about infusions and IV cannulas, and a video of a needle going into skin (this video also served as peer modeling of calm/still behavior during IV insertion). In another session, she was exposed to the psychologist holding the IV

catheter and found that to be of medium difficulty to watch. The game challenge cards were added for further exposures and learning opportunities for both knowledge of Crohn's as well as peer modeling. To date, Ava has continued with the Crohn's board game and created new cards for the game that represented positive coping strategies for infusions. Additionally, she has added ones that represent future goals for infusions, such as staying calm and quiet during infusion and sitting by herself.

Case Study Summary:

Ava presented with procedural anxiety, needle phobia, and resistance to talking about her Crohn's diagnosis and infusion treatments. Ava would refuse in sessions initially to discuss anything related to her illness. Treatment focused on building rapport, collaboration with the treatment team, and a hierarchy of exposure therapy. The "IBD and Me," activity book (refer to appendix C for the link of the book), along with the Crohn's board game she created; served as therapeutic exposure to both learning about her Crohn's diagnosis and talking about it. The Crohn's board game, matching game, and activity book led to an exposure-based challenge. She was highly engaged and responsive to "games" and showed tolerance to more discussion around her Crohn's diagnosis as a result of the game. The Crohn's board game continues to provide an avenue for exposures related to fears around her infusions.

Future Direction for this training protocol

The proposed training protocol will be administered to nursing staff in an infusion center in a Midwestern hospital. This will provide opportunity for program evaluation to be completed by the nurses. Moving forward it would be ideal to utilize a standardized way to provide the training. In addition, the distraction card prototypes that were developed by this author will

utilize member checking to assess the impact of the distraction task and illustration on children. Each distraction prototype has developed prompts by this author that can be used by healthcare staff or guardians, or caregivers that accompany a child during medical procedures. There will be adaptations of this such as allowing the child to circle items as they find them or telling a caregiver where to circle the items to just pointing to items. In the future, a pilot study will be conducted on the distraction card easel prototypes.

An Important Note: Adapting to Individual Differences

Procedural anxiety and medical fears do not affect all children the same way. A number of factors influence how a child will respond to and be affected by a medical situation (Diener et al, 2019). Several factors influence how an individual will cope with a medical procedure, including age, developmental level, temperament, culture, previous medical history, traumatic memories associated with medical events, and parental anxiety and behavior (Roberts, Aylward, & Wu, 2014). A child's behavioral style (temperament), especially a behavioral style high in emotionality, may influence the degree of attention devoted to painful stimuli and therefore, a child's memory for pain (Rocha, Marche, & Von Baeyer, 2009). Temperament is believed to influence sensitivity and reactivity to stressful situations and more specifically painful situations (Rocha, Marche, & Von Baeyer, 2009). It is important to develop a personalized coping plan for a child by assessing the child's coping abilities during the time of intervention (Abrams, Muriel, & Wiener, 2016). Other factors such a child's cognitive development need to be considered as young children may struggle to cope with medical experiences that are perceived as threatening. In addition to age and cognitive development, it is also important to consider the child's premorbid temperament and coping style, previous healthcare experiences, diagnosis, and family dynamics (Abrams, Muriel, & Wiener, 2016). Distraction techniques should be tailored to the

individual child and the procedure involved. For some children active distraction can be more effective since it is multisensory; whereas passive distraction can benefit children who may have difficulty engaging in a complex activity while undergoing a procedure (Abrams, Muriel, & Wiener, 2016). The techniques and tools that psychosocial clinicians implement should be tailored to the developmental needs of the child and take into consideration the child's learning and coping style, purpose of the procedure, and the time frame of the intervention (Abrams, Muriel, & Wiener, 2016). Healthcare staff need to be aware of vulnerable populations who are susceptible to side effects such as patients with vestibular abnormalities, seizure disorders, and those who experience migraines and headaches (Smith et al., 2020). These vulnerable populations may not be good candidates for the use of VR as a distraction technique during medical procedures. It is imperative to utilize the literature in developing an individualized assessment and treatment plan.

Conclusions

This project has conducted a thorough review of the research investigating medical procedural anxiety in children, as well as interventions designed to provide procedural support. In brief summary, research has suggested that the experience of intense anxiety heightens pain perception and responses as well as associated distress and disruptive behaviors in reaction to medical procedures. The use of comfort positioning has been found to significantly improve the experience of patients and the ease with which staff can provide the medical intervention. In addition, other interventions such as the use of Buzzy and distraction techniques have also been empirically supported in improving patient and medical staff experience, safety, and in facilitating completion of the necessary medical interventions.

In addition to this literature review, this project has developed a research-grounded training protocol to provide educational materials and resources for nursing staff who will be directly providing procedures, in this case, infusion treatments for IBD. Materials included in this comprehensive protocol are an instructive social narrative (written by this author) to read to and with children in preparation of their infusion center visit, comfort position guides, current author-designed resource handouts for nurses, a resource handout for parents/caregivers, nine developmental age-focused distraction images and tasks commissioned and designed by this author, and finally an illustrative case study. This research-based protocol is a first step in providing easy-to-use and comprehensive resources to significantly improve the experience of medical staff and children and their families as they navigate their illness and the repeated temporary discomforts necessary to improve health and quality of life.

Appendix A

Distraction Easel Card Prototypes

Developed by Mera El Ramahi, Psy.D.

Beach Adventures

18 months – 3-year-old age group

Illustrated by Akiko White

Prompts:

Tell me where you see the sandcastles?

Where are the rainbows?

Find all the stars.

Find all the different colored fish.

Beach Adventures: 18months- 3-year-old age group

Illustrated by Akiko White

Prompts:

Find all the sandcastles. How many can you find?

Which one is your favorite sandcastle?

What do you like to build in the sand?

Can you find all the rainbows?

Find all the stars

Find all the turtles

Find all the beach balls

Find all the hearts

Beach Adventures: 4–10-year-old age group

Illustrated by Akiko White

Prompts:

Find all the sandcastles.

Find all the beachballs.

How many stars can you find?

How many birds can you find?

Share a time you had fun. What were you doing?

Find all the turtles. How many turtles do you see?

Find all the rainbows. What is your favorite color?

Beach Adventures: 11–17-year-old age group

Illustrated by Akiko White

Prompts:

Find all the sandcastles. Which one is your favorite sandcastle?

What would you enjoy doing at the beach? Can you share a happy memory?

Find all the stars. How many stars can you find?

Find all the hearts. How many hearts can you find?

Find all the crabs? How many crabs did you find?

How many birds can you find?

Find all the turtles. How many turtles can you find?

Find all the fish. How many fish can you find?

Can you find all the seashells?

Toy Treasures – 18mos- 3year old age group

Illustrated by Leslie Nelson

Prompts:

What is your favorite toy?

Can you find all the bears?

What colors do you see in the picture?

What is your favorite color?

How many ducks do you see in the picture?

Where is the gum ball machine?

Where is the monkey?

Can you find the airplane?

Toy Treasures: 4-10 years old age group

Illustrated by Leslie Nelson

Prompts:

Can you find all the Legos?

Count how many Legos you see?

What do you like to build with Legos?

Where is the teddy bear?

Find the rainbows

Where is the giraffe?

Find the play dough?

What toys do you enjoy playing with? If you were in this playroom, what would you play with?

Toy Treasures: 11–17-year-old age group

Illustrated by Leslie Nelson

Prompts:

Count how many bubbles you see?

Can you find the scooters?

Can you find the Nintendo Switch? How many can you find?

How many balls do you see?

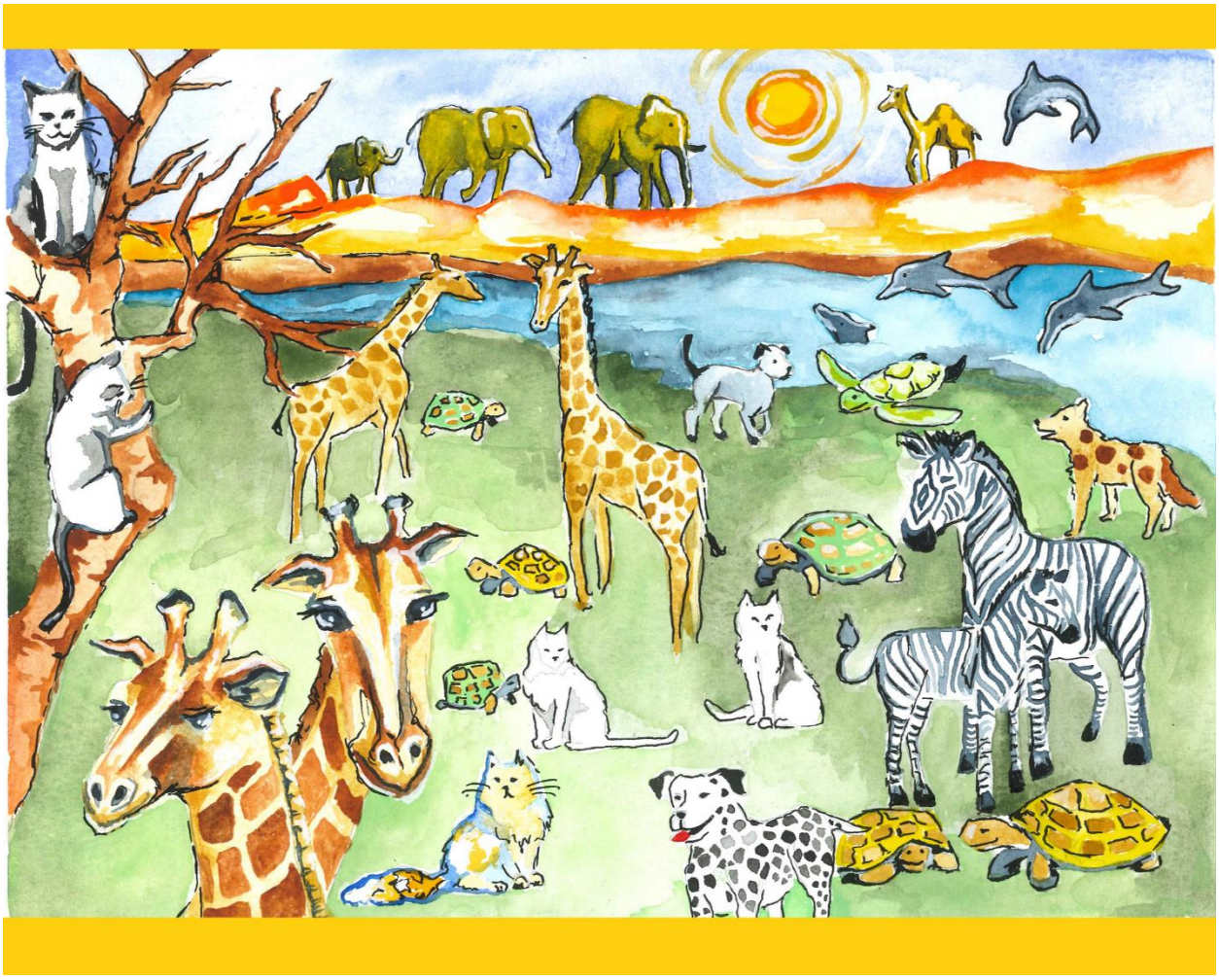
Looking at this picture, what would you enjoy playing with?

Tell a story about this picture.

Can you tell me about a happy memory?

Animal Adventures

18months- 3-year-old age group



Illustrated by Leslie Nelson

Prompts:

What is your favorite animal?

What animals do you see in the picture?

Can you find the dog in the picture?

How many cats do you see in the picture?

How many turtles do you see in the picture?

Where are the dolphins in the picture?

How many elephants do you see?

Fantasy Land

18months- 3-year-old age group

Illustrated by Leslie Nelson

Prompts:

Can you find the butterflies?

How many rainbows do you see?

Can you find all the unicorns?

What colors do you see?

What is your favorite color?

How many butterflies are in the picture?

Tell me a story about a Unicorn.

Beach Day

18months- 3-year-old age group

Illustrated by Leslie Nelson

Prompts:

Can you find the sandcastle?

What is your favorite thing to do at the beach?

How many trees do you see in the picture?

What color is the umbrella?

Can you find the sunglasses? Can you find the grapes?

What are the colors of the beach ball?

Appendix B

Training Resource Kit

My trip to the Infusion Center

Social Narrative

By Mera El Ramahi, Psy.D.

*A note to parents and caregivers:

This social narrative is written and intended for children of different ages who are getting an infusion in an infusion center. There are different reasons that children may need an IV placement. Therefore, not all steps in this narrative may apply to your child. This social narrative can be modified for other hospital settings.

Read this story before sharing it with your child and choose the information that you think will help your child. Please be mindful that some children can cope with a lot of information and want to know many details, while other children prefer only to see pictures without being given a lot of information.

We encourage you to be a part of your child's procedure and to help coach them to make the experience go as well as possible. You can be with your child in most cases when they are getting an IV. If you have more questions or are concerned with how your child may cope and would like to schedule a consultation with a pediatric psychologist, please discuss your concerns with your medical provider who is able to provide a referral if needed.

Social Narrative

By Mera El Ramahi, Psy.D.

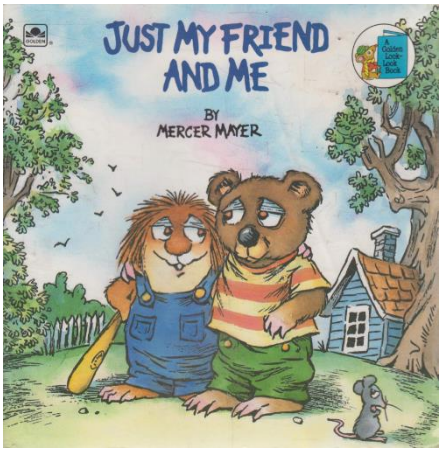
Today I am going to see my doctor or nurse at the infusion center to get my medicine. I will need to get an IV. An IV is small, bendy straw that my nurse will use to give me medicine. This medicine will make me feel better and help my body so I can do the things I love to do.

I am brave

An adult in my family or another adult that takes care of me will go with me.

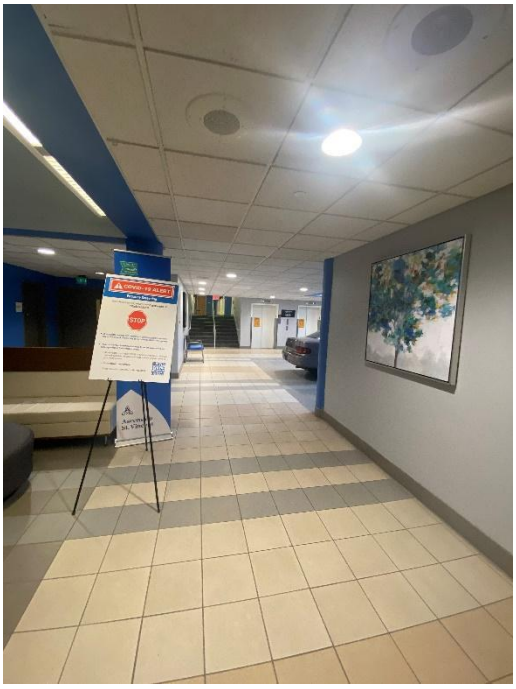
I am safe

Some children like to bring a favorite stuffed animal, toy, book, or blanket from home. What could you bring with you?



Once we arrive, we will walk from the parking lot to the building.

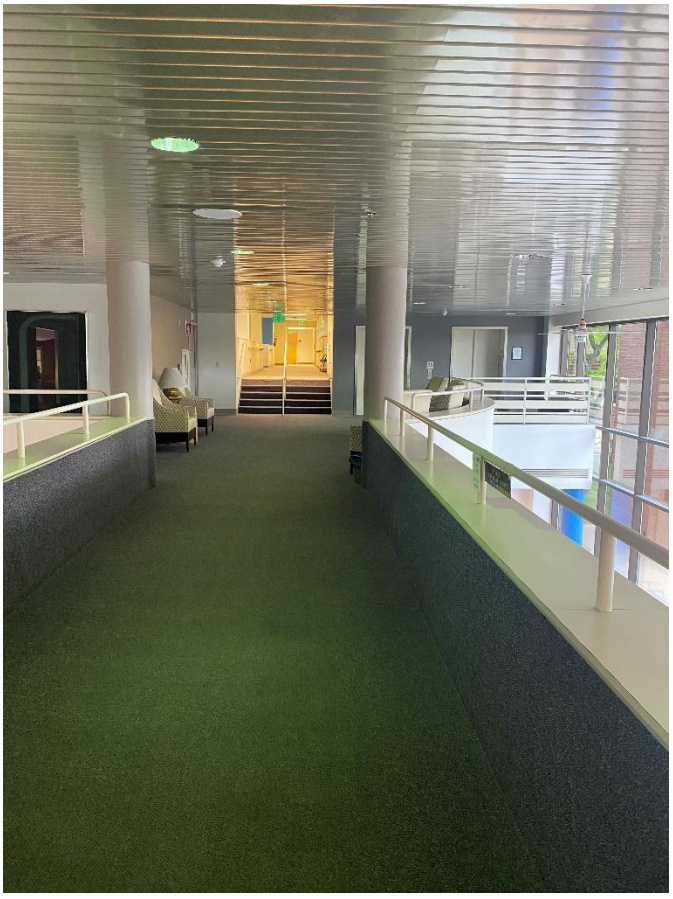
In the building we will walk to the elevator and press the elevator button to go up.

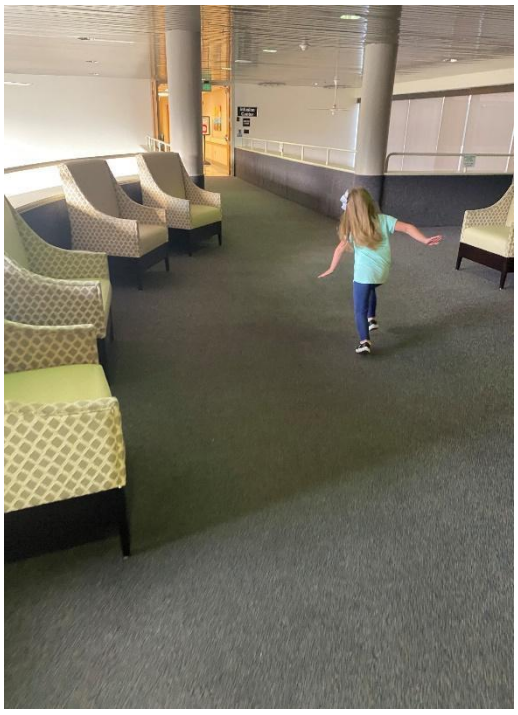


In the elevator, we will press the 2F button.

If I feel nervous or scared, I can take deep breaths. I can pretend I am blowing bubbles, a pinwheel, or birthday candles.

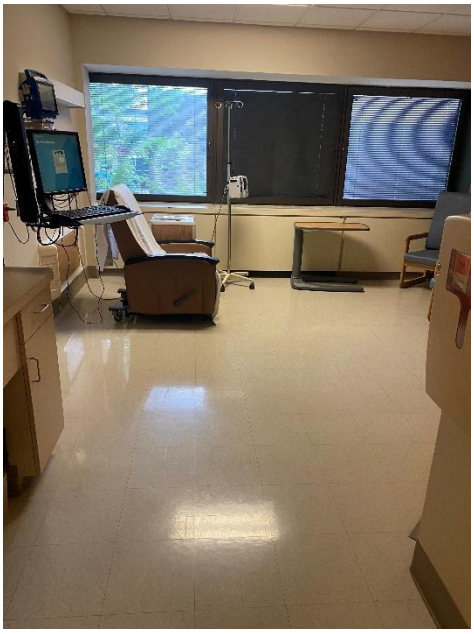
When the elevator stops, we will walk to the Infusion Center. I can see the parking lot from the two big windows.





In the Infusion Center, we will talk to a person at the front desk and answer some questions. I can say hello or stand quietly next to the adult I'm with. Next, they will let my nurse know I am here.

The nurse will take me to my treatment room where there will be a bed and a TV. My family (1 or 2 adults) can come with me. I can continue doing deep breathing if I feel nervous or scared. Or I can talk to my family or play with my favorite toy or game that I brought from home.



Next, the nurse will ask me to stand on a scale to measure how much I weigh and how tall I am.

After that, the nurse will take my temperature with a thermometer that she might put on my head, side of my face, near my ear, or under my tongue. This will not bother me. Some kids say it tickles! I will hold still.

Then the nurse will put a blood pressure cuff on my arm. This will hug my arm. It may feel tight for a short time. I will hold still and can sing a song that I like in my head.

While the nurse asks my parents questions, I can watch TV, play a game sitting down, or ask my family to read my favorite book that I brought from home. I can do deep breathing while I wait for the nurse to get everything ready.

Next, my nurse will ask me if I want to have the bed sitting up or laying down. I can pick what makes me feel comfortable. My adult might hold me so I can feel calm and brave. I will remember to sit still. I can look for a show to watch on the tv in my room.

My nurse will wrap a soft stretchy band around my arm. This is called a tourniquet. It might feel tight around my arm for a short time. It is tight to help my nurse see my veins. My family can help me count to 10 or 20. I can tell myself "I am safe." I can watch the tv. I will keep my body very still.

Next, the nurse will feel on my arm or hand to find the right spot for my medicine to go. The IV is placed into a vein inside a part of my body like my arm, hand, or foot. My nurse will tell me that I am going to feel a poke in that spot. If I stay still the poke will be short. I will stay still and be brave. I am safe when I am still and brave. I can choose to watch what my nurse does, or I can choose to look away.

If I feel scared, I can take deep breaths and think of the fun things I like to do. I can ask my family to hold my hand. I can choose to watch what the nurse is doing or to look at something else instead. I can look at pictures or the tv. Doing these things will help me stay calm and brave and help my poke be short. It will be important to keep my body still.

Next, the nurse will take out the needle that poked me and a tiny bendable straw will be left to give me my medicine. I may not even feel when my nurse takes the needle out. The bendy straw does not hurt.

The nurse will put tape over the bendy straw to keep it in place. This will not bother me. I can still play my game or watch tv.

My doctor may need labs so they will hook a special tube up to my IV. This is called a blood sample. Only a small amount of blood is taken from my body. My body makes new blood all the time. I will not need another poke. I will not feel this. This will not bother me.

The bendy straw helps me get my medicine. A bag with my medicine will be connected to the tiny bendable straw and my medicine will go through the tube from a machine like this. This is called an IV. My medicine makes me feel better and I want to feel better so I can be healthy and do fun things.

While I wait for my medicine to go in my body, I can do things like watch a movie, talk to my family, or use coping skills I have practiced. I can ask my nurse or adult if I need help.

When the medicine is done, my nurse will let me know when she takes out the bendable straw in my arm or hand. The nurse will connect water to my IV through a tube and I might feel something cold in my hand or arm, but it will not last long and it will not bother me. This helps me to get all my medicine. This is the last thing my nurse will do before taking my IV out.

The nurse will press down on my spot and take the bendy straw out. I am finished!

I will get a reward for sitting still and listening.

I was so brave! I got my medicine that will help my body.

Now I get to leave. Everyone will be so proud of me for staying still with my IV.

Resource Handout for Nurses

Procedural support includes education about the diagnosis, preparation for tests and procedures, and supportive interventions to enhance coping of the patient and family throughout treatment (Abrams, Muriel, & Abrams, 2016). Diagnosis education and procedural preparation tools help psychosocial clinicians collaborate with children and families to develop a coping plan for the procedure (Abrams, Muriel, & Wiener, 2016). Removing excess stimuli can help to create a relaxing environment regardless of the procedure taking place in a treatment exam, or infusion room. When possible, dimming bright lights, playing music of the patient's choice, speaking softly, and limiting speakers establish a setting of comfort (Abrams, Muriel, & Wiener, 2016).

Reducing the number of healthcare providers in the room by implementing the ONE VOICE approach includes assigning one person to provide verbal instruction to the child during the procedure thus avoiding an otherwise chaotic scene (Abrams, Muriel, & Wiener, 2016). While limiting the number of clinicians is important, encouraging parental presence once parents have been coached on coping techniques and their role can provide increased security for the child in addition to a comfort item such as a stuffed animal from home (Abrams, Muriel, & Wiener, 2016).

A Guide to Medical Play

https://www.acco.org/wp-content/uploads/2021/06/MedicalPlayKitBooklet_web.pdf

Benefits of Medical Play:

https://www.stjude.org/treatment/patient-resources/caregiver-resources/patient-family-education-sheets/child-life/benefits-of-medical-play.html

Medical Play dolls

http://bourbon.ca.uky.edu/files/medical_play_dolls.pdf

Shadow Buddies Foundation:

https://www.shadowbuddies.org/buddies/buddies

Medkin Teaching Aids:

https://legacyproductsinc.com/

Cloth Dolls:

http://www.mefinefoundation.org/

Comfort positioning for medical procedure:

https://onevoice4kids.com/research/

Resource Handout for Parents/Caregivers

Clinical recommendations for information to children based on the available evidence:

Content
- Include sensory as well as procedural information - Use specific and detailed, rather than general information. - Children with previous stressful medical experiences will benefit from receiving advice on coping strategies in addition to receiving information about the procedure. - Children should be told if a forthcoming procedure is likely to be painful. - Information about a forthcoming should be provided using nonemotive language. - Explanations regarding the relative merits of alternative treatment approaches may be of value for adolescents but are likely to be difficult for younger children to comprehend. - Developmentally appropriate language should be used. - Children should be provided opportunities to ask questions about the information provided. - Clinicians should try to establish when carrying out an assessment whether a child is using inaccurate or distorted health-related schemas to interpret medical information.
Jaaniste, T., Hayes, B., & von Baeyer, C. L. (2007). Providing children with information about forthcoming medical procedures: A review and synthesis. *Clinical Psychology: Science and Practice, 14*(2), 124–143. https://doi-org.libproxy.eku.edu/10.1111/j.1468-2850.2007.00072.x

Format
- Peer modeling (via video for example) is a useful method of conveying preparatory information to children. - Medical play using dolls or toys is not a sufficient medium for communicating preparatory medical information to preschoolers. - Written information should be accompanied by illustrations, particularly for less competent readers.
Jaaniste, T., Hayes, B., & von Baeyer, C. L. (2007). Providing children with information about forthcoming medical procedures: A review and synthesis. *Clinical Psychology: Science and Practice, 14*(2), 124–143. https://doi-org.libproxy.eku.edu/10.1111/j.1468-2850.2007.00072.x

Timing of Information
- New procedure-related information should be kept to a minimum immediately prior to or during a medical procedure. - For major medical procedures, children older than 6 years should receive at least a 5-day notice. - Children younger than about 6 years of age are likely to be better off with less than a 5-day notice. - Children require less notice for more minor and less distressing procedures as compared to major procedures.
Jaaniste, T., Hayes, B., & von Baeyer, C. L. (2007). Providing children with information about forthcoming medical procedures: A review and synthesis. *Clinical Psychology: Science and Practice, 14*(2), 124–143. https://doi-org.libproxy.eku.edu/10.1111/j.1468-2850.2007.00072.x

Procedural Communication and Language Considerations:

Telling children "It won't hurt" does not decrease pain perception and erodes the trust between the patient and clinician if discomfort is felt (Abrams, Muriel, & Weiner, 2016)

Generally, terms of reassurance, apologies, and criticisms have been shown to increase distress during procedures, while positive encouragement and validation can help to decrease stress. (Abrams, Muriel, & Weiner, 2016)

Helpful	**Not Helpful**
Simple, honest, concrete explanations of procedures.	Confusing medical jargon: "CAT scan (cats), IV (ivy plants), shot (guns, punishment), or dressing change (remove clothing).
Talk with a child before touching them and speak with firm but warm confidence	Apologizing and allowing children to delay procedures. Examples include: "I'm sorry" or "You'll be OK."

Use soft language such as “pressure,” tight squeeze,” or “uncomfortable.” For example, “Some children say that they can feel pressure, you can tell me how it feels for you.” Implement a practiced coping plan. Redirect with humor or nonprocedural talk.	Threatening language like “burn,” “cut,” or “hurt.” Examples include: “we are giving you a shot, and this may hurt.”
Offer choices only when possible and give directions in the positive: “you will need to keep your body very still, but you can choose something to hold.”	Unrealistic choices, criticism, threatening punishment, and negative instructions. For example, “you’re such a big boy, you didn’t cry last time” or don’t move!”
Implement a practiced coping plan	Lack of a discussed coping plan or strategy
Redirect with humor or nonprocedural talk	Excess clinician and/or caregiver side conversations during procedure or talking as if the child is not present.
Recognize a child’s specific behavior during a procedure, for example, “you held your arm very still.”	Generalizing comments about the child such as “You’re such a brave patient” that can lead to shame or a seeming unattainable expectation.
Abrams, A. N., Muriel, A. C., & Wiener, L. (2016). *Pediatric psychosocial oncology: Textbook for multidisciplinary care*. Springer.	Abrams, A. N., Muriel, A. C., & Wiener, L. (2016). *Pediatric psychosocial oncology: Textbook for multidisciplinary care*. Springer.

Program Evaluation Form

Training Program Title: _____

Location: _____ Date: _____

1. Circle the number that best represents your reaction about the training program.

a. The training program prepared me to be successful on the job.

(strongly disagree) 1 2 3 4 5 (strongly agree)

b. The skills that I have gained from the training program were relevant.

(strongly disagree) 1 2 3 4 5 (strongly agree)

c. I feel motivated to use what I have learned on the job.

(strongly disagree) 1 2 3 4 5 (strongly agree)

d. The training program achieved the outlined learning goals.

(strongly disagree) 1 2 3 4 5 (strongly agree)

e. The training program achieved the outlined objectives.

(strongly disagree) 1 2 3 4 5 (strongly agree)

f. The facilitator encouraged participation and questions.

(strongly disagree) 1 2 3 4 5 (strongly agree)

2. What did you like most about the training program?

3. What did you like least about the training program?

4. What suggestions/recommendations do you have to help improve this training program?

5. Would it be okay to follow up with you in 3 months regarding your progress? (If so, please provide an email address.)

Email address (optional) _____

Comfort positions- Family Education Sheet

This handout discusses and describes how comfort positions can be used during procedures with children. It also outlines the different comfort positons and how each one can be helpful for different procedures.

The chest to chest comfort position can be used with IVs, blood draws, vaccines, NG tube placement, and dressing changes. This position entails holding the child's chest against your chest. The back to chest position can be used for IVs, blood draws, NG tube placement, drain removal, dressing changes, and catheter insertion. The back to chest position entails holding the child's back against the caregivers (or nursing staff) chest.

The side sitting position can be used with IVs, blood draws, lumbar punctures, NG tube placement, taking out a drain, and abscess drainages. This position is described as sitting side by side with the child. The cradle hold is used to cradle the child in a feeding or nusring positon. It can ve used for a heel stick, IVs, blood draw, immunization, and catheter insertion.

The Family Education Sheet can be found at this link and is avialable in Arabic and Spanish.

https://extapps.childrenshospital.org/EFPEC/Home/Sheet/6246

Comfort Position Guide

This comfort position guidebook is developed by the Hospital and Clinics of Minnesota. It provides descriptions and images of comfort positions for the following age groups: 0-6 months, 0-12 months, 6-12 months, 1-5 years. 6-12 years, 13-18 years.

Access to the full guide is available at this link:

https://www.childrensmn.org/departments/pdf/positioning-book.pdf

Comfort positioning for Procedures for Pediatric ED Patients

This comfort positioning guide describes the process of a comfort hold, techniques for swaddle and snuggle comfort positions, Bear hug techniques for comfort positioning, Kangaroo hug techniques for comfort positions, and techniques for comfort touch. This guide contains images demonstrating each technique and can be accessed at the following link:

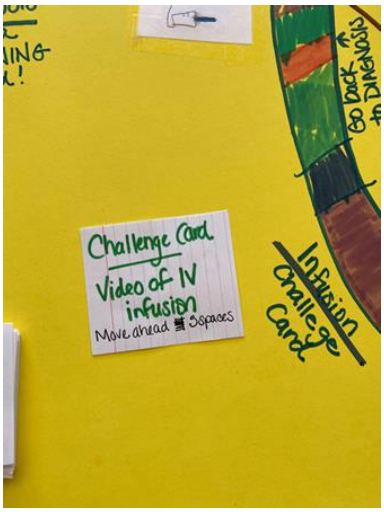
https://www.uwhealth.org/files/uwhealth/docs/ems/2015symposium/child_life_handout_2.pdf

Appendix C

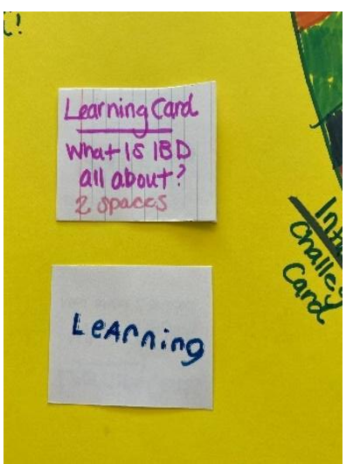
Buzzy Device

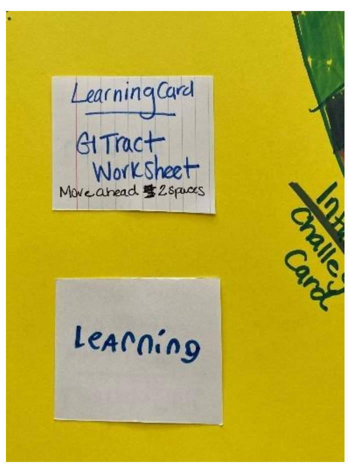
Photo courtesy of MMJ Labs LLC

Crohn's Game

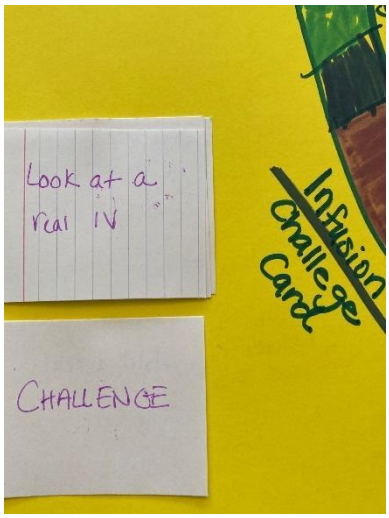


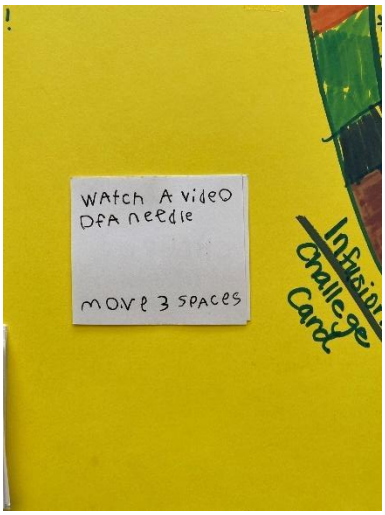

Art
Draw a card
Video Games
Draw a card
Infusion Challenge Card
draw a card
go back to IV
Go back to Diagnosis
Pick Learning Card!
Doctor Visit
Diagnosis
Pick a LEARNING Card!
Scope
Draw a card
EGD
Draw a card
Dr Vist
Draw a card
Pick Infusion Challenge Card!
Hospital
friend comes over
Draw a card
School
Learn card
go back to hospital
End

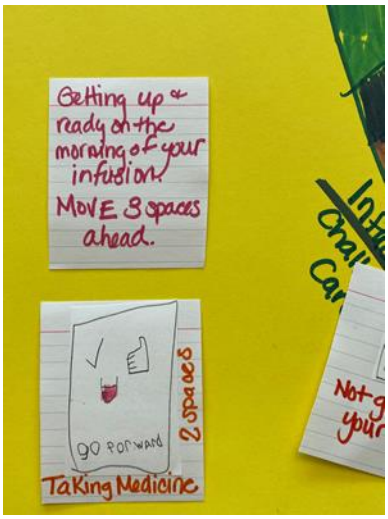

Learning Card
What is IBD all about?
2 spaces
Learning


Learning Card
GI Tract Worksheet
Move ahead 2 spaces
Learning


Diagnosis
Pick a LEARNING Card!
5 spaces
Not getting your infusion
Drinking water the day before
1 space
1 space
Being BRAVE!
Go to IV destination
Hold still for IV
Not taking medicine







The Crohn's and Colitis Foundation of America has an activity book titled, "IBD & Me," activity book. The education handouts used in the case study were utilized from this activity book and can be accessed at the following link:

https://www.crohnscolitisfoundation.org/sites/default/files/legacy/assets/pdfs/ibd-me-ac.pdf

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