
Preparation, Education, and Procedural Support in Pediatric Cancer

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Introduction

Considering the rigorous treatment involved with a cancer diagnosis and the stress it inflicts on pediatric patients, defining best practices to enhance emotional and psychosocial well-being has become vital. One area where best practices are needed is procedural support. Built on the premise of providing honest, accurate, and developmentally appropriate information to children with cancer, procedural support includes education about the diagnosis, preparation for tests and procedures, and supportive interventions to enhance coping of the patient and family throughout the course of oncology treatment.

Childhood cancer treatment often includes repetitive, invasive, painful, and anxiety-producing procedures. As research has revealed, with increased anxiety comes the increased

perception of pain and the occurrence of chemotherapy side effects (DuHamel et al. 1999). Inadequately addressed pediatric pain can lead to “conditioned anxiety” (Slifer et al. 2011), pain intolerance, and increased distress and anxiety during subsequent procedures leading to long-term negative neurological, emotional, and health outcomes (Cramton and Gruchala 2012; Taddio et al. 2010). Pain memories of children receiving cancer therapy (Kennedy et al. 2008) can lead to fear of future procedures (Corwin et al. 2012). Therefore, creating the best possible first experience for children by minimizing procedure-related anxiety and pain through the use of procedural support techniques is crucial for children who will face a long road of treatment and repeated procedures.

Education and Preparation

The first step to providing procedural support for children and their families is the implementation of developmentally appropriate education about the diagnosis and procedural preparation. Uncertainty, fear, anxiety, and pain are closely intertwined for many patients with medical conditions. In a 2010 study examining fear of the hospital, Salmela et al. found that 91 % of preschoolers ages four to six expressed fear of at least one element of the hospital or medical treatment with 48 % reporting over seven fears.

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Based on their cognitive development, young children may struggle to cope with medical experiences that are perceived as threatening (Salmela et al. 2010). However providing applicable interventions can reduce medically related anxiety and distress not only for preschoolers but also for children of all ages. Increased general anxiety, eating problems (Salmela et al. 2010), aggression, separation anxiety, sleep disturbances, and behavioral changes (Gaynard et al. 1990) are potential short- and long-term detrimental effects of hospitalization for which practical supportive interventions have become a critical element of caring for children with cancer. In addition to age and cognitive development, it is important to consider the child's premorbid temperament and coping style, previous healthcare experiences, diagnosis, and family dynamics (Koller 2007).

Diagnosis Education: Interventions and Tools

Providing children with information about their illness and medical care at the beginning of their cancer treatment can help to frame the purpose of subsequent procedures, increase understanding, address misconceptions, and open the door for continued communication. Information should be culturally sensitive, accurate, honest, and developmentally appropriate and provided in a child- and family-focused, nonthreatening environment (Mahan 2005; Sobo and Kurtin 2007). Education generally begins by describing how a healthy body functions and then transitions into explaining what is happening in the body when a child has cancer. Various teaching tools, including dolls, books, visuals, and interactive activities, can assist the psychosocial clinician and provide learning opportunities that are tailored to the specific diagnosis of the patient.

Teaching Dolls

Common diagnosis education materials include dolls such as MediKin™ teaching aids. These dolls offer a wide variety of accessories that can be adapted for multiple oncology diagnoses including leukemia, brain, and bone tumors. Since children typically receive a PORT-A-

CATH® (port) or central line soon after their diagnosis, the MediKins™ can also be a helpful tool to illustrate where the lines will be placed and how they feel through the “skin” of the doll. For many children, having the opportunity to ask questions about the doll and being able to touch and feel the port, for example, before it is surgically placed, is very empowering. Dolls can serve as a meaningful tool to increase understanding and familiarity not only during diagnosis education but also for procedural preparation.

Diagnosis and Emotion-Themed Reading and Visual Materials

Child friendly books can provide an overview of what children and families can expect while demystifying potentially threatening terms such as “cancer” or “oncology.” Helpful explanations of treatment and coping tools can be found in books such as *Chemo, Crazyness & Comfort: My book about childhood cancer* and *Healing Images for Children: Teaching Relaxation and Guided Imagery to Children Facing Cancer and Other Serious Illnesses* which serve as useful guides for parents and children. At this early stage in forming a relationship of trust and in an effort to encourage self-expression, books with general themes of identifying and sharing feelings can also be helpful. Some examples include: *How Are You Peeling? Foods with Moods, It's Okay to Be Different*, and *Moody Cow Meditates*. For additional suggestions see Chap. 6 regarding bibliotherapy and Chap. 25 for resources. Visual materials such as diagrams or interactive iPad applications (“My Incredible Body” for 9–11-year-olds or “3D Anatomy Lite” for 12–18-year-olds) can assist older school-age patients and adolescents learn about how the body works and launch further discussion regarding diagnosis and treatment.

Interactive Educational Activities

Interactive, hands-on activities can also help children explore the fundamentals of how the body works in relation to their diagnosis. The opportunities for creativity are endless and interventions will vary depending on the child's specific diagnosis and development. One example is a “blood workshop” to help patients diagnosed

Table 7.1 Blood workshop

Ingredients and descriptions
<i>Plasma (corn syrup):</i> makes our body's blood, like a workshop
<i>Red blood cells (dry kidney beans or red hot candies):</i> give our bodies energy
<i>White blood cells (dry navy beans or white jellybeans):</i> keep us healthy
<i>Platelets (rice or white sprinkles):</i> help our bodies heal
<i>Leukemia cells "blasts" (mini marshmallows or white hard candies):</i> fill up the blood workshop of children who have leukemia
Instructions
1. Fill 2 specimen cups with plasma and explain that these are like the body's blood workshops
2. In one of the cups, make "healthy blood" by inviting the patient to add the red and white blood cells and platelets while you explain the role of each
3. In the second cup, make "unhealthy blood" by inviting the patient to fill this cup nearly all the way with the leukemia cells while explaining that when someone has leukemia, the body's blood workshop makes too many of these cells so that there is no room for the healthy parts of the blood to be made. The child can then add 2 or 3 of the red and white cells and platelets
4. Compare the two cups and explain that the job of the medicine "chemotherapy" is to take the leukemia cells out of the body's blood workshop to make room for healthy blood to be made

with leukemia understand what is happening in their body (Table 7.1). This activity makes the abstract and confusing medical terminology more tangible and easier to visualize. It also gives clinicians the opportunity to explain the purpose of treatment. Other options include beading programs, such as "My Story in Beads" and "Legacy Beads", which offer children an opportunity to document and honor their cancer journey by stringing together beads specific for each aspect of their treatment. Journaling is oftentimes a component of beading journey programs and allows the patients or parents to record treatment facts and/or their feelings about the process.

Role of Child Life Specialists

As described throughout this chapter, children benefit from diagnosis education and procedural preparation and support, which can be provided by various members of the pediatric oncology team. Child life specialists are specifically trained and certified to assist children by optimizing their growth and development, decreasing their anxiety, and fostering positive coping skills through the use of play, education, and art. Child life specialists strive to positively impact how children with cancer manage their medical journey by helping them process potentially traumatic healthcare experiences. Through consultations and interventions,

child life specialists address the impact of a cancer diagnosis on children and families and utilize the tools discussed in this chapter to support self-expression, learning, and optimal coping.

Procedural Preparation: Interventions and Tools

The American Pain Society and American Academy of Pediatrics state that one of the keys to managing pain and distress is preparation (Cramton and Gruchala 2012). In turn, preparation can reduce the perception of pain particularly in perioperative settings (Fincher et al. 2012). Therefore, once clinicians have established a relationship of trust and an understanding of treatment goals, procedural preparation becomes the next integral piece to providing continued support. Detailed procedural preparation sessions are most effective for children over 2 years of age (Schechter et al. 2007) and include education about procedure duration, sequence of events, role of the child and caregiver, and sensory information (what the child will see, hear, smell, taste, and feel) (DeMaso and Snell 2013; Mahan 2005). Common procedures that patients may face include surgery, bone marrow aspirations (BMA), lumbar punctures (LP), port accesses, dressing changes, MRIs, CT scans, IVs, and IM injections. The

tools psychosocial clinicians implement should be tailored to the developmental needs of the child and may vary in detail depending on the child's learning and coping style, purpose of the procedure, and time frame of the intervention.

Considering the timing for procedural preparation, it is important to allow enough time for information processing while not causing increased anxiety to build (Cramton and Gruchala 2012; Schechter et al. 2007). Generally speaking, procedural preparation should take place earlier for adolescents and closer to the time of the procedure for younger children and always in collaboration with parents to tailor the timing of preparation to the individual needs of the child.

Preparation Books

Preparation books, including those 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. Younger children may feel less threatened by illustrated images or photos of a stuffed animal undergoing the procedure, while older children may respond better to photos of a child their own age. To ensure comprehension and to minimize potential misconceptions, it is helpful to ask patients to share their questions, to repeat the steps of the procedure, and to identify their role in the process, for example, to hold their arm as still as a statue. In addition to understanding a child's learning style, coping strategies must also be assessed and understood as a continuum as a child may respond differently to various stressors over time (Kuttner 1996). See Chap. 5 on coping for details. Children who utilize a problem-oriented coping strategy would be more likely to participate in preparations where they generate their own questions; whereas, children with an emotion-oriented coping style may call upon denial tactics or silence (Salmela et al. 2010; Li et al. 2011a). While research suggests that problem-focused coping tends to be more effective for patients, it is important to utilize interventions that reflect each child's needs, comfort level, and ability to engage in the intervention.

Medical Play

In addition to creating pleasure and joy, play can assist children as they prepare for and reenact stressful or threatening medical experiences. Children who engaged in a therapeutic play intervention prior to day surgery demonstrated decreased anxiety scores and emotional behaviors both pre- and postoperatively (Li et al. 2011b). Medical play is a powerful tool that can help children process their treatment journey prior to and following procedures. The goal of medical play is to increase communication, self-expression, preparation, familiarization, and reflection in a developmentally appropriate manner. Medical play provides opportunities for children to practice the steps of a procedure on a doll (role rehearsal/role reversal); engage with symbolic, real, or play medical equipment (medical fantasy play); use medically themed games or puzzles (indirect medical play); or manipulate medical supplies through expressive painting, sculpting, or collage (medical art) (Goldberger 1984). By facilitating educational opportunities in a supervised, nonthreatening environment, psychosocial clinicians can help to reduce the child's fears surrounding their treatment.

Examples of medical play dolls include blank muslin dolls that children can personalize or teaching dolls that are specifically designed for children with cancer. These include Gabe's Chemo Duck Program™ and Shadow Buddies™ which teach children about ports or central lines. With guided supervision, children can practice port accesses or lab draws on their dolls using play or real medical equipment to increase familiarity and empowerment.

Case Vignette

Chris, a 4-year-old boy with ALL, always arrived to the outpatient hematology and oncology unit with his doll named Annie. At the onset of his diagnosis, the child life specialist had inserted some tubing into Annie that replicated Chris' port. While initially observing the child life specialist with some trepidation, Chris began to actively participate in the steps of "accessing" Annie's port in subsequent sessions.

As he gained mastery over this procedure, these medical play opportunities translated into Chris becoming more comfortable when his own port was accessed.

In addition to these medical play materials, Cuzzocrea et al. (2013) found that significant reductions in anxiety can occur following preparation using puppets and storytelling, involving exploratory opportunities with relevant medical equipment, and having a supportive adult present during procedures to remind children of their practiced coping techniques. Preparation, in addition to the use of distraction tools, was most effective in increasing adherence and reducing anxiety compared to distraction alone (Cuzzocrea et al. 2013). 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 (Hatava et al. 2000).

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 (Fein et al. 2012). Such interventions can also foster trust, reduce uncertainty, correct misconceptions, enhance self-efficacy, and decrease distress (DeMaso and Snell 2013) while increasing coping, understanding, medical adherence, and a sense of control for the child and parent (Schechter et al. 2007; Pattillo and Itano 2001). Diagnosis education and procedural preparation tools help psychosocial clinicians collaborate with children and families to develop a coping plan for the procedure and may involve some of the techniques reviewed in the following section.

Procedural Support: Non-Pharmacological Interventions and Tools

Procedural support works best when both pharmacological and non-pharmacological interventions are utilized when appropriate (Cuzzocrea

et al. 2013). 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 (Wente 2013). Non-pharmacological strategies may even reduce the overall need for opioid use when effective pain management is achieved (Ahmed et al. 2014). Establishing optimal procedural support includes listening to the child and parents about what has been helpful in the past and introducing supplementary coping tools that build upon what is familiar. More on pain management can be found in Chap. 3.

Environmental Considerations

Creating a calm, child-friendly, engaging environment is essential for anxiety reduction (Fein et al. 2012). Hospital design and its impact on patients exceed the scope of this chapter; however, environmental adjustments can make a tremendous difference. For example, the child's inpatient hospital room should be maintained as a safe haven as much as possible and treatment rooms should be used for invasive procedures (DeMaso and Snell 2013). 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 (Baxter 2013), playing music of the patient's choice, speaking softly, and limiting speakers (Pasero and Smith 1997) establish a setting of comfort. 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 (Baxter 2013), thus avoiding an otherwise chaotic scene. 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 (Cramton and Gruchala 2012).

Table 7.2 Procedural communication and language considerations

Helpful	Not helpful
<ul style="list-style-type: none"> • Simple, honest, concrete explanations of procedures • Talk with a child before touching him and speak with firm but warm confidence • 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” • 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” • Implement a practiced coping plan • Redirect with humor or nonprocedural talk • Recognize a child’s specific behavior during procedure, for example, “You held your arm very still” 	<ul style="list-style-type: none"> • Confusing medical jargon: “CAT scan” (cats), IV (ivy plants), shot (guns, punishment), or dressing change (removing clothing) • Apologizing and allowing children to delay procedures. Examples include: “I’m sorry” or “You’ll be OK” • Threatening language like “burn,” “cut,” or “hurt.” Examples include: “we are giving you a shot and this may hurt” • 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!” • Lack of a discussed coping plan or strategy • Excess clinician and/or caregiver side conversations during procedure or talking as if child is not present • Generalizing comments about the child such as “You’re such a brave patient” that can lead to shame or a seemingly unattainable expectation

Communication and Language

Honesty before and during interventions will help build trust between the clinician and patient (DeMaso and Snell 2013). Telling children “it won’t hurt” does not decrease pain perception and erodes the trust between the patient and clinician if discomfort is felt. Table 7.2 provides communication and language considerations that have been found to both increase and decrease children’s ability to cope with procedures. In general, terms of reassurance, apologies, and criticisms (Cramton and Gruchala 2012) have been shown to increase distress during procedures, while positive encouragement and validation (Leahy et al. 2008) can help to decrease stress. Additionally, humor can facilitate coping as well as physical, emotional, and spiritual healing by reducing tension and stress while supporting the immune system and increasing control, relaxation, and the release of endorphins (Pattillo and Itano 2001).

Positioning

During a procedure, the experience of fear, lack of control, or a sense of helplessness can be impacted by the child’s physical position. Research supports that the supine position causes

greater distress to children and parents. Coached and practiced comfort holding techniques can therefore offer more choice, control, and security for the child (Taddio et al. 2010). “Lying supine is the most vulnerable position for humans, particularly when physically restrained with a papoose board or by adults” (Baxter 2013); whereas, sitting upright, having the opportunity to watch the procedure, and being held by a parent can increase a sense of empowerment and safety. The Comfort Measures model developed by Stephens et al. (1999) starts by welcoming parents to be present during the procedure but not forcing parents to do so if they are not comfortable. To enhance coping, the team involved in a procedure should review procedural positioning choices and each person’s role so that the child and parent have comfortable physical contact, and the clinician has necessary access and room to perform the medical intervention. A study by Sparks et al. (2007) found that seated parental holding decreased anticipatory stress, recovery time, and distress pre-, during, and post-IV placement and increased comfort and parental satisfaction. Additional benefits of this positioning included fewer staff required to safely hold a child still and a reduction in the time it took for IV placement (Sparks et al. 2007). Certainly, considerations of safety for the patient, parent, and clinician must always be taken into account.

Table 7.3 Cognitive-behavioral procedural distraction and relaxation interventions

Infant: birth–1 year	<ul style="list-style-type: none"> • Maternal nursing or sweetened solutions on a pacifier • Gently stroking a baby’s face or rubbing their back • Singing softly or playing soothing music • Having comfort item (blanket or stuffed animal)
Toddler: 1–3 years	<ul style="list-style-type: none"> • Blowing bubbles or pinwheels • Shaking rattles, watching light up toys • Reading books that make noise or pop up • Playing peek-a-boo
Preschool: 3–5 years	<ul style="list-style-type: none"> • Playing with interactive toys (matchbox cars, trains, dolls, or puppets) • Storytelling and singing • Blowing bubbles or pinwheels • Reading books
School-age: 6–12 years	<ul style="list-style-type: none"> • Holding a parent or clinician’s hand • Reading books, toys, counting games, or I Spy games • Breathing exercises: bubble blowing, party blowers, or controlled/conscious breathing such as imagining blowing up a balloon or blowing out birthday candles • Using your imagination to “travel” to a favorite or calming place
Adolescent: 13–18 years	<ul style="list-style-type: none"> • Practicing coping techniques in advance • Utilizing relaxation, breathing, guided imagery, or progressive muscle relaxation • Squeezing a stress ball or parent’s hand • Listening to calming or favorite music

Distraction

Children who have experienced extreme distress in previous procedures typically respond similarly in later procedures. With the intention of alleviating distress and increasing children’s ability to cope (Heden et al. 2009), distraction redirects attention away from the pain-inflicting stressor and positively influences their reactions to future procedures (McCarthy et al. 2010). Benefits of distraction for children with chronic conditions include improving cooperation and reducing self-reported pain (Slifer et al. 2011). Distraction is commonly utilized during needlesticks (Sadeghi et al. 2013) and may also be extremely helpful during other repeated procedures such as dressing changes in pediatric oncology treatment.

Distraction interventions can be considered *active* when patients are fully engaged during the procedure and are using multiple senses such as breathing exercises, interactive toys, and guided imagery or *passive* when the child remains focused on a stimulus such as reading, watching a movie, or listening to music (Sadeghi et al. 2013; Koller and Goldman 2012). For example, children distracted by interactive electronic tablets during IM injections and port accesses

reported significantly less distress the second time the procedure took place compared to those who did not have the intervention (Dahlquist et al. 2002). Distraction can also influence perceived pain perception. In a prospective, randomized controlled study of 123 children, 96 % of the children in the experimental group using Flippits® cards as distraction during venipuncture reported less pain than their previous experience without the cards (Inal and Kelleci 2012).

For some children active distraction can be more effective as it is multisensory; however, passive distraction can benefit children who may have difficulty engaging in a complex activity while undergoing a procedure. Similar to the other interventions described in the chapter, distraction techniques should be tailored to the individual child and the procedure involved (Koller and Goldman 2012; Sadeghi et al. 2013). Table 7.3 reviews cognitive-behavioral procedural distraction and relaxation interventions that empower children by giving them a defined role and the tools to help themselves during a procedure.

Children with cancer can gain a greater sense of control when given a choice of specific distraction interventions to help them through a procedure. Lazarus and Folkman’s (1984) theory on cognitive appraisal, stress, and coping links one’s

sense of control over a threatening source to one's assessment of that threat. Accordingly, children who have more control over their procedures and environment experience decreased perceived threat appraisal and distress (Li et al. 2011b). For children who like to be actively involved, they might cope best by participating in removing their dressing, counting, or watching the port access (Pasero and Smith 1997); whereas, for information-avoiders, watching the procedure may increase their level of distress and looking away would be more applicable (Walworth 2005). While research indicates that children who like to be actively involved experience better patient outcomes (DeMaso and Snell 2013), careful assessment of each child's unique coping abilities during the time of the intervention is necessary in order to develop a personalized coping plan.

Relaxation

Teaching and implementing relaxation techniques provide another option for procedural support. An essential element of "relaxation training" includes deep breathing exercises which bring awareness to the breath (DeMaso and Snell 2013). Breathing exercises can be a powerful tool to help children practice for repeated port accesses and dressing changes. Children's yoga taught by certified practitioners can also assist children in gaining a sense of empowerment, control, relaxation, mindfulness, confidence, and self-esteem.

Case Vignette

Amy, a 7-year-old girl with rhabdomyosarcoma, participated in a weekly yoga class for children with cancer taught by the child life specialist. She learned a number of breathing techniques and chose the "snake breath," breathing in deeply and steadily releasing the breath with a hissing sound, to help her relax prior to and during her weekly port accessing. Throughout the course of her year-long treatment, she used the "snake breath" as her primary coping tool during her many procedures.

In addition to controlled breathing, progressive muscle relaxation is another empowering intervention that can promote a sense of calm and tension release. This requires complete concentration and involves the flexing and relaxation of isolated muscle groups (DeMaso and Snell 2013). Engaging the natural creativity of children through relaxation and imagery techniques may also be very beneficial. Guided imagery and visualization actively engage children in vividly reconstructing a place that brings a sense of comfort and happiness or even alters the pain perception and sensation (Kuttner 1996), for example, shrinking a "boulder" of pain down to a "pebble."

Visualization is an important tool that encourages relaxation and sleep and even decreases the need for medications and restraining measures by increasing endorphins and lowering blood pressure (Hoffart and Keene 1998). For pediatric patients in particular, visualization harnesses their imaginations, helps them to develop a sense of inner strength and confidence, and reduces anxiety, thus making this a helpful support for children with cancer (Hoffart and Keene 1998). For example, during a guided imagery session, a clinician can work with the patient to determine a setting to which he would like to travel, such as the beach. This "visit" to the beach should include all of the sensory experiences in order to fully engage the child's imagination and shift the focus from the stress of the procedure to a relaxed and calm state.

"The Magic Glove" is an example of a hypnotic pain management technique used to control anticipatory anxiety. It involves having the child concentrate and imagine the magic glove protecting the child's hand and creating an analgesic response to pain stimuli. This technique is generally most successful among 3–12-year-olds (Kuttner 2013). Procedural support techniques can offer children the opportunity to gain self-confidence and feel empowered as they learn coping strategies which may also be utilized for stressors beyond their medical treatment. The more often a tool such as progressive muscle relaxation or visual imagery is used, the more quickly the child is likely to experience benefits

(Kuttner 1996). Therefore it is important to introduce such resources early on and repeatedly in a child's treatment.

Family-Centered Procedural Preparation and Support

The family plays an integral role during procedural support interventions as the core source of comfort for the child. Parental presence has been found to be the most common benefiting factor for preschoolers while they are in the hospital (Salmela et al. 2010). According to Ross and Ross (1984), 99 % of children ages five to twelve ($n=994$) stated that having their parents present would have helped them the most during their procedure regardless of the level of reported pain involved.

When parents are empowered and well informed of the procedure, coping tools, and their role, their own anxiety decreases and they are better able to support and reduce the anxiety felt by their child (Fein et al. 2012; Fincher et al. 2012). Parental presence and involvement during behavioral interventions have been found to decrease procedural-related distress and impact how the child reacts to painful procedures (McCarthy et al. 2010). Since calm parental presence is most beneficial to children (DeMaso and Snell 2013; Yip et al. 2009), it is important to increase parental understanding and decrease their procedure-related stress as well. However, parents who do not feel comfortable being present should be respected for their decision and not forced to participate (Fincher et al. 2012) as they can still provide comfort and support to their child in many other meaningful ways both prior to and following medical procedures.

Procedure Processing and Reflection

Following each stage of intervention, be it diagnosis education, procedural preparation, or procedural support, the clinician should engage the child to make sure that there are no misunder-

standings and correct misconceptions. Regardless of the tool(s) used, post-procedural review with the child to determine the accuracy of the preparation and to make any notable changes for future treatment is important (DeMaso and Snell 2013). It is useful to ask the child what the experience was like. For example, questions such as "Was it what you expected?," "Were there any surprises?," and "Was the distraction you chose helpful?" can empower children to reflect on the procedure and their coping strategy. These conversations bring the process of preparation and support full circle and ensure that the interventions were beneficial in reducing distress. By obtaining feedback, clinicians are able to validate children's feelings and assure them that their needs were heard and that they will remain involved in their care. As children may receive active treatment for 2–3 years, and follow-up well beyond, revisiting coping strategies as they progress through treatment is important to make sure that with growth and development, any questions or adaptations to coping techniques are addressed.

Conclusion

Throughout the cancer trajectory, children will face multiple invasive procedures. By involving children in a procedural plan, psychosocial clinicians empower patients in their care and decrease their stress. Diagnosis education, procedural preparation, and procedural support are crucial elements in caring for children with cancer. While the American Academy of Pediatrics recommends the incorporation of child life specialists or other psychosocial team members trained in non-pharmacological strategies for reducing anxiety and perceived pain in children (Fein et al. 2012), supportive interventions can also be implemented by other members of the multidisciplinary team. As each child is unique, psychosocial clinicians, parents, and children should collaborate to create an individual care plan that enhances development, optimal coping skills, and ultimately mastery of procedures throughout cancer treatment.

Clinical Pearls

- Diagnosis education, preparation, and supportive interventions are key elements of procedural support.
- Children, parents, and psychosocial clinicians should work together to create a procedural support plan that reflects each child's unique needs to maximize optimal coping and mastery.
- Providing children with information about their illness and medical care at the beginning of their cancer treatment can help to frame the purpose of subsequent procedures, increase understanding, address misconceptions, and open the door for continued communication.
- Education and preparation should include accurate, honest, and developmentally appropriate information given within a culturally sensitive, child- and family-focused nonthreatening environment.

Considerations for non-pharmacological procedural interventions should include distraction, relaxation, environment, positioning, and communication/language to help children cope throughout their cancer treatment.

Additional Resources

Suggested Book Resources

3 months to 3 years:

This Is my Hair. Parr, T (2011). Little, Brown Books for Young Readers, New York, NY.

3 to 7 years:

It's Okay to Be Different. Parr, T (2001). Little, Brown Books for Young Readers, New York, NY.

Feelings. Parr, T (2009). Little, Brown Books for Young Readers, New York, NY.

4 to 8 years:

How Are You Peeling? Foods with Moods. Play with Your Food. Freymann, S., and Elffers, J. (2004). LLC. Scholastic, New York, NY.

Visiting Feelings. Rubenstein, L (2002). Magination Press. American Psychological Association, Washington, DC.

Moody Cow Meditates. MacLean, K.L (2009). Wisdom Publications MA. Somerville, MA.

Websites

Medkin Teaching Aids: <https://legacyproductsinc.com/>

Cloth Dolls: <http://www.mefinefoundation.org/what-we-do/striving-for-more/cancer-support-programs/medical-play-dolls/>

Shadow Buddies Foundation: <http://www.shadowbuddies.org/product/port-a-cath-buddy/>

Gabe's Chemo Duck: <http://chemoduck.org/for-kids/meet-chemo-duck/>

ONE VOICE: <http://www.onevoice4kids.com/>

Legacy Beads: <http://www.stjude.org/legacy-beads>

Educational Apps

My Incredible Body-Guide to learn about the human body for children (age 4+ but designed for 9–11)

The Human Body by Tinybop (ages 6–8)

Visual Anatomy Lite (12+)

3D Anatomy Lite (12+)

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