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Cognitive Behavioral Techniques in Pediatric Pain Management

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Introduction

Pain is a common experience in childhood. One in 4 children experiences chronic pain.\(^1\) Nonspecific abdominal pain occurs in 10 – 15% of children, of whom only 5 – 10% are found to have a specific organic cause.\(^2\) Seventy-eight percent of children receiving treatment in the emergency department report having pain, and the assessment and treatment of this pain is often inconsistent and not well controlled.\(^3\) A 2017 survey done at Minnesota Children’s Hospital found that pain from needles was the least well-controlled.\(^4\) Most people are familiar with the use of needles in health care through vaccines; there are disorders that require regular, ongoing use of needles for testing and treatment. One example is hemophilia, a type of bleeding disorder that is treated with prophylactic infusions of missing blood factors. These can be required several times per week, so children must learn to tolerate needles on a regular basis.\(^5\) The treatment of pain, especially in pediatrics, can be complicated; having multiple options available for pain relief can be very helpful to providers.

The use of pain medication has been under scrutiny recently. The rise in opioid addiction and opioid-related deaths have resulted in increased health care provider vigilance related to the prescription of pain medication. This is especially true in the field of pediatrics. Children do not respond to medication in the same way as adults; extra care must be taken to treat pain appropriately and avoid prescribing substances that could ultimately do harm.

Cognitive behavioral therapy (CBT) is a familiar treatment for use in mood disorders, such as depression and anxiety. It encompasses a range of techniques that use educational, social learning theory, relaxation, and visualization methods to change physical and emotional reactions to stressful events. These treatments have been documented to promote attitudinal changes in patients thinking and behavior from a psychological point of view. CBT is now being
studied as an adjunctive pain treatment. It is of special interest in pediatrics, as it potentially can provide a means of reducing pain and anxiety without the risk associated with medications. This paper focuses on the use of CBT for the decrease of pain perception in children with bleeding disorders who must learn to self-administer peripheral infusions.
Background

The use of cognitive behavioral therapy (CBT) techniques can be a powerful adjunct to treatment of pain in children. By decreasing anxiety and increasing coping skills, these techniques help children to feel less discomfort from illness, injury, or procedures. When children have coping skills to deal with difficult situations, they feel less scared. Decreased anxiety leads to better outcomes, including less analgesic use, less emergence delirium post-procedure, and faster discharge from care.3

Pediatric pain management is an important aspect of care that has not always been emphasized. Early experience of pain has been found to lead to increased pain sensitivity later in life.3 Healthcare providers have become more aware that even very young infants can feel pain and there is a growing need to identify methods that can control pain without causing harm to patients. Techniques such as relaxation, distraction, imagery, comfort objects, and honest explanation of procedures, geared to the proper developmental stage, can impact the child’s perception of pain.3,6

Assisting parents with the use of CBT techniques can also decrease children’s experience of pain. Children sense anxiety in their parents, and this can increase physical discomfort. Parents are disturbed by seeing their child in pain, and so this becomes a vicious cycle. By giving the parents techniques to help their child, the parents become less distressed, and therefore the children become less distressed. Having the parent lead the child in deep breathing, providing distractions, using humor, or just talking can help to calm the child. Empathy from the parent has been found to increase children’s anxieties in these situations.3

The use of psychological techniques as pain management has been increasing. Behavioral techniques, based in classical and operant conditioning models, aim to produce specific
behavioral changes that are incompatible with pain. Classical conditioning is a reductionist model that describes learning in terms of the pairing of stimuli with responses. A stimulus that results in a naturally occurring response in the individual are both termed “unconditioned”. When a neutral stimulus is paired in time with the unconditioned stimulus, eventually it will be able to produce a similar response independent of the original stimulus, at which point they are referred to as the conditioned stimulus and response.\textsuperscript{7} This can have a negative effect, as in producing a phobia of needles (the needle being a neutral stimulus until it is associated with pain); it can also be used to produce a positive effect (a comfort object, such as a teddy bear, that is associated with feelings of relaxation and safety). In operant conditioning, as developed by B.F. Skinner, an operant is an intentional action. The application and/or removal of consequences in the environment influences the individual’s behavior. Consequences that increase the behavior are termed reinforcers, and ones that decrease the behavior are termed punishment or extinction.\textsuperscript{8} As an example, increasing school attendance via reinforcement, reward, or token economies such as gold stars on a calendar are techniques based in operant conditioning principles.\textsuperscript{8,9} Behavioral theories characterize learning and outcomes in terms of outwardly observable phenomena, with little regard to the internal mental or emotional workings of the individual.\textsuperscript{7}

Social learning theory, as developed by Albert Bandura, has been described as a bridge between behavioral and cognitive theories. In the social learning theory paradigm, the individual learns behavior by observation and imitation. The learner is actively processing the information between stimulus and response, although the occurrence of reinforcers and punishers are still assumed to influence the frequency of behaviors.\textsuperscript{10} This approach can be utilized with role models, imitation, and guided rehearsal in the development of new skills. Finally, cognitive
theories are rooted in the idea that all behavior can be attributed to cognitive processes, such as memory, perception, language, and attention. These are considered mediational behaviors between the input of stimulus and the output of a response.11

Cognitive behavioral therapy (CBT) has grown from these early models and encompasses a variety of techniques, including relaxation, biofeedback, imagery, and distraction. Hypnosis, which combines deep relaxation with imagery under the direction of a trained therapist, is sometimes broken out as a separate technique, though it shares many similarities with the relaxation and imagery of CBT. These techniques all help to decrease the sympathetic activity associated with anxiety and pain, which reduces the intensity of the experience.6 CBT can be delivered through a traditional face-to-face model; through group modalities, which has shown success with treating pain associated with irritable bowel syndrome, headache, and pain-related school absence in children; and through the internet, as a time and cost-effective treatment model.1 Internet-based CBT has shown efficacy in improving physical functioning in children with idiopathic chronic pain. Adolescents aged 11-17 participated in an online weekly module that covered chronic pain education, stress, relaxation techniques, sleep hygiene, cognitive skills, physical activity, and pain relapse prevention. Post-test and 3-month follow up indicated improvements in reported pain intensity, activity limitations and depression compared to a wait-list control group.12

Specific techniques have been found efficacious with differing situations. The use of affirmations, thought-stopping and cognitive restructuring has been reported to lower pain reports with sickle cell disease patients. Distraction was found to reduce anxiety (though not the feeling of pain) when used with children during laceration repair; parents of young children reported that their children seemed to be in less pain using this technique.3 Imagery, modeling,
behavioral rehearsal, and reinforcement has been shown to decrease pain and distress for children undergoing painful procedures such as lumbar puncture, venipuncture, burn treatment, and injection. Hypnosis combines deep relaxation with focused attention on imagery. This technique has been used with the treatment of headache, sickle cell anemia, chronic abdominal pain, and acute procedural pain. The use of deep breathing with autogenic or progressive muscle relaxation reduces anxiety. Guided imagery may help to decrease descending signals from the brain and block pain signals.

Systematic reviews of CBT have shown significant reduction of pain and disability in headache and mixed or non-headache pain. These findings hold true in both traditional and remote delivery of treatment, though the strength of the studies have varied. Pain and disability were both decreased for headache when using traditional relaxation and other cognitive therapy techniques. The multimodal use of self-hypnosis, guided imagery, distraction, and relaxation techniques fared better than placebo medication, meditation, or both together. The authors also saw promising evidence for this remote delivery of CBT, although many studies suffered from small sample sizes and unclear performance bias.

Sickle cell anemia patients were found to benefit from CBT in a Cochrane systematic review. Measures of quality of life (higher daily functioning, increased confidence); health beliefs (decreased influence of external factors, increased internal locus of control); and the affective components of pain all saw improvement. Patients also reported that patient education helped to improve their attitude toward medication and toward medical personnel. This study did not find a decrease in the sensory component of pain.

A randomized controlled trial (RCT) of the use of CBT in children with nonspecific recurrent abdominal pain (RAP) showed promising results. The researchers worked with children
ages 6 to 12 years old who had recurrent bouts of paroxysmal abdominal pain over a period of at least 3 months. The kids in the experimental group were given 8 sessions of treatment covering CBT techniques including distraction, competing activities, self-efficacy, relaxation, imagery, and self-administration of rewards. At follow up, 87.5% of the experimental group reported being free of pain, versus 37.5% in the control group. Improvements in the experimental group were reported by teachers and tended to generalize across settings.2

The use of CBT and self-hypnosis as separate techniques were put to the test against standard lidocaine injection treatment in helping children to deal with bone marrow aspiration, a painful procedure which often left children irritable, depressed, withdrawn, and with trouble sleeping due to the experience. Cancer patients between the ages of 5 to 15 years old were randomly assigned to groups using hypnosis (relaxation with visual imagery) plus lidocaine, CBT (progressive muscle or autogenic relaxation, breathing exercises and redirection of thoughts without use of visual imagery) plus lidocaine, or a standard care lidocaine injection control group. The results showed no difference in pain, anxiety, or observer reports of pain at baseline, but there were significant reductions on all three measurements for both the hypnosis and CBT groups, with hypnosis providing the strongest effects.15

Cognitive techniques have also been used to help children deal with chronic illness. A qualitative study done in the United Kingdom looked at coping skills used by boys diagnosed with hemophilia A or B. The boys in the study were ages 4 to 16 years old. They all received care through a pediatric hemophilia clinic, and they represented the first generation of hemophilia patients who received intensive levels of primarily preventative care.16 Hemophilia, and other bleeding disorders, are often treated with prophylactic infusions of clotting factors that are not produced by the patient in sufficient quantity. The severity of the disorder varies between
individuals. Those with a severe deficiency of a factor, generally producing less than 1% of the normal amount, must be given infusions of the factor prophylactically to prevent bleeding that can occur due to normal activities. Those with less severe disease can infuse less often, or on an as-needed basis if there is trauma due to an accident or vigorous physical activity. Bleeding within the joint can lead to damage and arthritis early in life if not controlled. Therefore, the ability to self-infuse factors provides patients with increased independence and decreased disability later in life, notes Skye Peltier, MPH, PA-C with Children’s Minnesota Cancer and Blood Disorders Clinic and University of Minnesota Center for Bleeding and Clotting Disorders (conversations, July 9 – 14, 2017). By helping children to deal with the pain and associated anxiety of frequent procedures, providers can increase patient adherence to treatment and facilitate improved health outcomes.

In the past, treatment focused on symptomatic relief after bleeding had occurred. The availability of prophylactic clotting factors produced a shift in treatment and lifestyle for this group of children. They reported higher quality of life levels, and participated in many of the same activities as their peers, but they also needed to increase their management skills of their disease. To maintain their active lifestyle, they needed to reliably follow their medical routines, learn to self-infuse, recognize when they were having a bleed, and appropriately judge risk of their activities.

Many of the patients had older family members who also had hemophilia. These older patients were not treated prophylactically, and would experience painful bleeds that led to decreased activities and more social isolation. Advances in treatment created more opportunities and freedoms for these young people, but they did not have the role models to demonstrate the necessary self-care skills. A 4-stage model of community; independence and confidence;
knowledge and skills; and engagement in self-care was used by the treatment facility. Self-infusion can be clumsy and difficult for children to learn, since they often need to perform venipuncture one-handed, and often learn it ambidextrously so that more sites will be available. The boys reported anxiety about performing it wrong and causing an injury and a bleed. But self-infusion allows more freedom and independence. Strict attention to a medical routine also decreases the chance of a bleed that would disrupt their normal activities. The adolescents found that putting an increased focus on their routine medical care meant that they could spend less time overall dealing with their medical problems. The authors noted that, as an early group to be living with hemophilia as a controllable condition, the patients have become experts in dealing with their illness. The cognitive skills of self-management, recognition of physical cues, coping with anxiety, health education, planning, risk-management, and increased use of social skills all factor into the boys’ ability to deal with their condition.¹⁶

Treatment of pain is an important factor in providing health care for young people. Untreated pain can produce poorer physical outcomes and increase anxiety in children and their families. While the use of medication is an option in reducing discomfort, there are adverse effects with the use of pharmaceuticals, and they do not always produce complete pain relief. The use of CBT can be an important adjunct in providing comfort and increasing a sense of self-efficacy in our young patients.
Methods

The keywords “pain”, “chronic pain”, “cognitive behavioral therapy”, “cognitive behavioral techniques”, “pain management”, “hemophilia”, “chronic illness” “nonpharmacological” were searched in PubMed. The Cochrane Database of Systematic Reviews website was searched for “cognitive behavioral therapy”, and “chronic pain”. 222 articles were elicited from PubMed and 4964 from the Cochrane Database of Systematic Reviews search. Criteria for inclusion were articles and studies that covered the use of cognitive behavioral techniques in the treatment or prevention of pain in patients under 18 years of age. Exclusionary criteria included a primary focus on adult subjects, and a lack of a cognitive behavioral component in pain management. Eleven articles and studies were included that met the stated criteria. Five articles and 1 oral presentation that provided factual background on psychological theories and hemophilia were also included.

Observation of the Hemophilia Foundation of Minnesota/Dakotas summer camp at True Friends Camp Courage North occurred July 9 – 14, 2017. This included observation (with participation as medically and legally appropriate) in set up of the health center; daily camper activities; prophylactic infusions; venipuncture education; bleeding disorders education; dispensing of medication; physical examination and management of pediatric illness, injury, and bleeding disorders; charting and record keeping. Staff, including hematologist/oncologists, pharmacists, physician assistants, nurses, social workers, genetic counselors, and physical therapists were observed and informal discussions regarding the nature of their work occurred during observation. Children at the camp were observed during prophylactic infusions, visits to the health center, and during camper activities. Informal discussions occurred with campers
regarding their experiences with hemophilia and the camp. Interviews were conducted with health care provider staff and volunteers via face-to-face interview and email.
Discussion

Many studies of cognitive behavioral therapy techniques have shown encouraging results when used to mitigate pain in children and adolescents. There are numerous advantages to employing these methods. CBT avoids the dangers of adverse effects that are often associated with analgesics and opioids. The techniques can easily accommodate individual needs and situations. They can be customized to the appropriate developmental level of children at varying ages. Delivery of the services can be done in-person or remotely via the telephone, internet, computer program, or as bibliotherapy. This allows the techniques to be used by patients who are isolated or have limited mobility. Studies have shown these treatments to have positive effects on pain. The techniques can also be used to decrease anxiety and facilitate adherence to treatment. Different techniques can be used as needed to develop personalized programs for treatment.

One case in point is the summer camp at Courage North, sponsored by the Hemophilia Foundation of Minnesota/Dakotas. This camp utilizes a multi-disciplinary approach. Staffed by hematologists, physician assistants, nurses, pharmacists, physical therapists, social workers, genetic counselors, and camp counselors, this facility enables children with bleeding disorders to have a typical summer camp experience while learning about the management of their condition. CBT is incorporated within the program to facilitate the learning or infusions and other self-care skills.

“Infusions are the biggest thing for most of the families. Unless you can master that skill it really limits everything,” notes Susan Purdie, RN in an interview on July 13, 2017. As a staff member of the Children’s Minnesota Cancer and Blood Disorders Clinic, Purdie teaches venipuncture to families and patients so they can do infusions themselves. The ability to do
infusions at home means that families are less reliant on clinic visits and home health care to provide this service; it also lessens reliance on a port, a device that allows quick access for infusions, but carries a much higher risk of infection and can limit children’s activities due to that risk. Play therapy can decrease needle phobia and anxiety about the infusion process, and can be started at an early age. Purdie recommends letting kids play with syringes in the bathtub and practice “infusing” teddy bears and dolls to increase their familiarity with the medical procedures. “Involving your child in every part of the process… just make it all part of their language, part of their world, so all of those things are less scary.” Hemophilia camp is an opportunity for the children to learn to do venipuncture independently, so that as they mature they are not reliant on family members. This minimizes the impact of the bleeding disorder on their social and emotional development. “We know if we start prophylaxis before the age of 4…the less joint damage you are going to have, the less arthritis issues as they age, so it’s important to start it and then figure out how they can incorporate that into their lives and make it normal,” says Purdie.

Cognitive behavioral techniques are woven into the camp experience and help kids to overcome their anxieties around treatment of their disorders. “There is a pervasive fear of needles in the human population,” says Purdie. Camp helps to deal with that by normalizing the experience. Infusions are done as a matter of routine, which helps to decrease anxiety by providing consistency. Children are encouraged to do as much of the infusion process independently as they can. Kids are taught to identify their needed factor and dosage, gather needed supplies, clean the supplies and hands for sterile technique, apply a tourniquet, identify an adequate vein, and ultimately perform their own venipuncture and infusion. Younger and less experienced campers learn side-by-side with older campers who can model self-infusion and
provide support and understanding to their younger peers (observation of prophylactic infusions, Camp Courage North, July 9 – 14, 2017).

Health care staff teach venipuncture using demonstration, guided practice, and imagery, techniques rooted in cognitive and behavioral theories. Relaxation, deep breathing, and imagery help to decrease autonomic arousal which is associated with increased perception of pain.\(^6\)

Children are taught to breathe deeply using toys and visualization, in order to decrease anxiety and pain (interview, Susan Purdie, RN, July 13, 2017). The use of a “buzzy bee”, a vibrating toy that is placed on the upper arm, provides distraction. Alterations in attention away from pain has its basis in cognitive theory.\(^6,11\) Visualization techniques are implemented to assist children in successfully entering a vein. Jay Charles, a nurse with the Hemophilia Outreach Center in Green Bay, WI, finds that both children and parents have the greatest struggles with the psychological aspect of infusions. The steps in venipuncture are not complicated, but when patients lack confidence in their own ability to perform the procedure, this in and of itself becomes a barrier to success. Visualization techniques are helpful in overcoming this hurdle (email communication, Jay Charles, RN, July 26, 2017). Cognitive restructuring around pain and needle phobia is also helpful. Many of the campers noted that they were scared to try infusing themselves, and that they were afraid of the pain, even if they were used to being infused by their families or health care workers. Several campers stated that they “powered through it” and decided to try self-infusion despite their fear; and that once they tried they realized that the actual pain was not as bad as their fear of the pain (oral communications with campers during infusion periods, July 10 – 14, 2017). This experience can help children to reset the way that they think about the pain from a needle poke. Purposeful, directed changes in language, perception, and attention to promote desired changes have a basis in cognitive theories of learning.\(^11\)
Role modeling and peer support is a large component of the camping program. Social learning theory is utilized through the pairing of young campers with older campers who can provide a role model for self-care.\textsuperscript{10} Campers come to the health center in groups for prophylaxis, increasing the opportunity for observational learning. During infusion periods, younger campers observe the older teens doing their own infusions. The teens describe what they are doing, and discuss their earlier experiences, challenges, and successes, with the younger children. “As a camper, the connection to others with hemophilia, same strives and struggles, pains and frustrations, was a very new and exciting aspect,” said former camper and current volunteer Cody Morrow in an email communication dated 8/1/2107. Kids who are learning to infuse are given a lot of social support and encouragement by staff and other campers. The peer mentors give suggestions as to how they dealt with pain, fear, and difficulties as they learned to infuse. They also model an example of a child who can do their own infusions, making it a more approachable goal in the minds of the younger campers. Morrow states:

Self-infusion. I can't stress it enough… it is an absolute necessity in my opinion and the longer it takes to learn, the more risk to that individual…Generally, the longer the person waits, the worse their anxiety and stress will be and the harder the hurdle will be to overcome… A 5 year doesn't seem like they are big enough to go to Kindergarten on the first day, but you're amazed at how normal it seems after a few weeks. The independence of self-infusion is enormous, but it’s also responsibility and ownership - they are in charge, it’s their diagnosis, their arm, and their hand on the needle. In some talks at family retreats or annual meetings I've related infusion to brushing teeth and a mother of a college-bound boy was astonished, but that's how rudimentary it becomes and how simple I think it should be seen… In fact, I could probably infuse faster than the 2 minutes that most dentists recommend for brushing.

Bleeding disorders patients can become expert at managing their illness,\textsuperscript{16} and sharing the use of coping and planning skills with other patients can provide a perspective beyond that which health care providers can give. Cheryl Hansen, physical therapist with Children’s Minnesota Cancer and Blood Disorders Clinic, notes that one of the benefits of attending hemophilia camp
is “…realizing that they’re not the only ones having day-to-day issues with their disease…They can be around other kids and it helps them feel more normal” (interview, July 14, 2017).

Peer mentoring and camp rituals have become an increasingly formalized part of the program. The *Amazing Race*-style activity paired older campers with younger ones for a series of challenges that incorporated learning about bleeding disorders in a fun, interactive way. This allows campers to gain skills and information that are necessary for them to manage their condition, without detracting from the fun experience of camp. Incorporating activities and mentorship into the structure of the camp also normalizes bleeding disorders as part of the shared experience of campers (Skye Peltier, MPH, PA-C, conversations, July 9 – 14, 2017). When campers attempt their first infusion independently, they can put their name on the “Big Stick”, which has become an informal rite of passage at the camp. There is no pressure or requirement for the campers to learn to poke themselves with a needle, but getting on the Big Stick serves as an enticement for many kids to try it, and once they have tried they often feel less fear, less anxiety, and less pain with future needle pokes. The Big Stick represents the use of operant conditioning techniques to facilitate learning and behavioral changes. It is an environmental consequence that is tied to a voluntary behavior of the child. Managing chronic medical conditions, especially ones that involve painful procedures, necessitates a multifaceted approach. Incorporating cognitive behavioral techniques allows the Hemophilia Foundation of Minnesota/Dakotas summer camp to address both the physical and psychological needs of the children attending the camp.

While CBT is often successfully used in clinical practice, research of the techniques can be limited due to weaknesses within the structure of the studies. The Cochrane systematic review articles found problems with the small sample sizes and limited number of studies. The studies
are often inadequately powered to draw conclusive results. Many of the studies within the reviews were unclear in reporting of their methodology and outcome data, as in the use of intent-to-treat analysis and handling of subject drop-outs. This lack of clarity meant that promising results were downgraded to low or very low-quality evidence. \(^1,^9,^{13}\)

The nature of psychological treatments can also create problems in empirical scientific studies. CBT techniques can be more amorphous than the taking of a measured dose of medication, which can be compared to a similar placebo dose. Small sample sizes, heterogeneity at baseline, extreme outliers and multiple testing that may have resulted in a regression toward the mean for the control group were all cited by researchers as possibly affecting results.\(^2\) In one study, waitlisted subjects had to complete assessments which included self-monitoring of their pain symptoms on a regular basis. It is possible that the self-monitoring activity had a change on their behavior.\(^2\) Additionally, all the subjects had been under medical care without finding relief from their pain. Knowing that they had been waitlisted for a treatment may have given them hope for change that manifested as an actual change in their behavior.

CBT techniques also have a considerable amount of overlap. Even if a study explicitly describes the terminology, there can still be questions about the use of the techniques. The use of hypnosis versus the use of relaxation and affirmations was investigated in the study of children undergoing bone marrow aspirations.\(^15\) While the researchers were careful to clearly describe their methods, it is impossible to tell if overlap between the two treatments occurred because the experience was within the minds of the subjects. There is no way to know that a CBT subject was not using any imagery, or that a hypnosis subject was. Ultimately, that may not be important to a child who is facing a necessary but very painful procedure. As a means of quantifying and identifying the most efficacious treatments, however, these differences become more than just
splitting hairs. Cognitive behavioral techniques show a promising role in the treatment of many illnesses, but more scrupulous standards are necessary in the development and reporting of the research. While rigorous research is needed to identify the most effective treatment approaches, cognitive behavioral techniques are widely accepted as adjunctive therapy to medical treatment in a variety of settings.
Conclusion

Pain management has increasingly become a focus of concern in patient care. The rise of opioid-related deaths and addiction have caused the health care community to re-evaluate the treatment of pain. As children react differently to medication than adults, we must be additionally cautious in their care. At the same time, we do not want to ignore or undertreat pain in our young patients. Pain can affect neural development and function, can cause emotional distress, and can undermine healing of physical ailments. The use of nonpharmacological treatments, such as cognitive behavioral therapy, can provide a valuable adjunct to treatment. Children who experience chronic medical problems, and the need for ongoing and frequent procedures, often suffer from increased anxiety and pain. For these children, it is especially important to find methods to ameliorate their pain without causing further damage. CBT can be woven into current pediatric care to address these issues. Studies in pediatric populations have shown promising results without the dangers of adverse effects. Further study, utilizing larger samples and rigorous reporting, can strengthen the evidence for this as an adjunctive treatment of pain. Meta-analysis and systematic reviews can be used to increase the power of studies into the use of CBT in smaller treatment settings.
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Appendix A

Interview questions - staff

1) What are the biggest challenges you see facing children with bleeding disorders?

2) What are the most helpful aspects of hemophilia camp?

3) What techniques do you find helpful in working with children and families with bleeding disorders?

Appendix B

Interview questions – volunteer/past camper

1) What was the most helpful aspect of hemophilia camp?

2) What have been your biggest challenges and successes regarding hemophilia?

3) What would you like to see happen in the treatment of chronic conditions in children, and is there anything that you would change?
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