

Commentary

No Pain, All Gain: The creation of a non-pharmacological pain management group for children and their families

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Introduction

It is well documented that children have been historically undertreated for pain. Pediatric pain assessment and management is a complex interprofessional responsibility that requires knowledge and clinical judgment to ensure each child's need for prevention and relief of pain is met. The nature of the inpatient rehabilitation setting requires children to spend less time on the nursing units versus the acute setting, and more time off the units participating in therapy sessions and classrooms. The sources of pain within the rehabilitation setting include postoperative, procedural, acute, and chronic. Clinicians recognize that the approach to pain management can not solely be managed by medications. A plan to successfully manage pain requires the entire interprofessional team and must also incorporate non-pharmacological interventions, with special attention to age, and cognitive and physical ability. Upon discharge, much of the responsibility for pain management will fall on the client and their caregivers and therefore clinicians recognized that parents and caregivers need to be trained and prepared to help manage pain in their children.

It is now understood that a child's pain perception is more than a sensory event and is not simply a direct result of the level of tissue damage, but rather a combination of cognitive, emotional, social and behavioral factors (Tobias & Deshpande, 1996). A variety of practical strategies to reduce acute, chronic or recurrent pain can be taught to, and mastered by, children of all ages (McGrath,

1990). A Child Life Specialist (CLS) can work with children to reduce the pain they experience and work towards decreasing the traumatic effects often associated with an experience of pain (Rothenberg, 1982; Bandstra et al., 2008). The child's family and nursing team are integral in advocating and administering both pharmacological and non-pharmacological pain management techniques. Non-pharmacological pain management techniques are important adjuncts to medication in managing acute, recurrent or chronic pain in children. In fact, recommendations from the American Pain Society and the American Academy of Pediatrics advocate for the use of a multimodal approach (pharmacological, cognitive, behavioral, and physical) to pain management and the use of a multidisciplinary approach when possible. They also stress the importance of involving families and allowing opportunities to tailor interventions to an individual child (American Academy of Pediatrics, 2001). The Registered Nurses Association of Ontario also supports and encourages the use of non-pharmacological interventions in their best practice guidelines (Registered Nurses Association of Ontario, 2007).

A review of current practices was conducted by the Registered Nurse (RN) as part of an Advanced Clinical Practice Fellowship and it was recognized that there is a major emphasis on the use of pain medications, with little use of non-pharmacological interventions. A CLS and RN set out to eliminate the gap in practice with the creation of a non-pharmacological pain management group

for children and their parents/caregivers entitled *No Pain, All Gain*.

The purpose of *No Pain, All Gain* is to empower and equip children and families with practical ways to help manage their pain using non-pharmacological interventions that complement medical treatment.

One of the core guiding principles in *No Pain, All Gain* is that children and their parents attend the sessions together, allowing them to be presented with and leave with the same message.

No Pain, All Gain runs for one month cycles each Wednesday for 30 minutes from 4:00pm to 4:30pm to ensure that therapies and school are not interfered with. The authors chose 30 minutes to deliver quick impactful education with minimal impact to the child's and caregivers' schedule. Parents and other caregivers were encouraged to attend with the client with no rules around maximum attendees per child or required relationship, allowing parents, grandparents, family friends and other caregivers to attend if interested. There were no minimum or maximum attendance numbers set out and as long as at least one client/parent dyad is in attendance, the session is run. Attendance fluctuated from one caregiver/child to six child/caregiver pairings with the average being around four to five dyads per session.

Planning

Each session begins with the RN and CLS introducing the topic for the session. Topics of the four week sessions are shown in Table 1. They include tips for parents (how to advocate for your child or for yourself), creating a distraction box (Broome et al., 1992; Russell & Smart, 2007), use of humor (Smith, 1986; Matz & Brown, 1998; Goodenough & Ford, 2005), creating a Snoezelen and/or multisensory environment (Schofield, 2002), and setting up your environment for successful pain management. The groups were made up of children ranging in age from 5 to 18 years, from various units across the hospital from Orthopedics to Brain Injury, with a variety of abilities, mobility devices, developmental and cognitive delays and children who are verbal and non-verbal. The participants experienced a variety of types of pain such as postoperative, procedural, acute, and chronic pain

and the chosen topics and techniques were intended to address any of these types of pain. Three children and their parents completed all four sessions, and an additional 10 children attended individual sessions.

The facilitators recognized and stressed to parents and clients that pain is a very individual experience and therefore there is no perfect non-pharmacological pain management technique that is effective for every pain situation or for every client. The families were encouraged to explore a variety of pain management techniques to discover the best methods for pain control prior to the onset of pain rather than experiment with multiple techniques in the midst of a painful moment. It was also emphasized to clients and their caregivers that though they were taught many techniques, it is important that they tailor the choice of intervention to the client based on their abilities, the situation, tools available, client preferences and the type, location and severity of the pain.

Implementation

The aim of each session was to provide children and parents with tips, techniques, and information to manage pain using non-pharmacological interventions. Each session is a stand alone topic and it is open to any inpatient rehabilitation client with no exclusion and sessions are not geared towards a particular type of pain. At every session, children are provided with a hands-on tool to help apply the learning (e.g. joke book, distraction box). Parents and children are given a tip sheet to help facilitate implementation at the bedside, or at home. A small graduation is held after the four weeks to celebrate their success. The intention of the graduation session is not test their learning but as recognition of their participation in all or some of the sessions. The final session is also used as a review of prior topics and an opportunity to ask questions and obtain resources from previous weeks.

Evaluation

The sessions are evaluated by parents and children using separate forms. The evaluation by parents seeks to determine if the group has increased their knowledge and comfort of using non-pharmacological pain interventions with their

Table 1
Week by week session breakdown

	Education topics	Hands-on activity	Parental handout
Week 1 Introduction and distraction box	<p><i>Introduction to pain</i></p> <p>Clients- Importance of distraction, list of possible items to add to box and discussion about techniques (e.g. deep breathing and bubbles).</p> <p>Parents- Tips for parents, how to educate yourself about pain and how to advocate for your child.</p>	Creation of distraction box and/or I Spy bottle.	<i>Top 10 tips for parents and Distraction techniques and the pediatric pain experience</i>
Week 2 Humor and environment	<p><i>Introduction to humor as a technique</i></p> <p>Why humor works, importance of setting up environment for success and importance of diet and sleep.</p>	Creation of personal joke book. Watch Therapeutic Clown video titled "What is humor".	<i>Use of humor to reduce pediatric pain</i>
Week 3 Snoezelen and multisensory spaces	<p><i>Introduction to Snoezelen</i></p> <p>How to create a sensory space at home, how multisensory experiences can help in pain management and how to build a space on a budget.</p>	20 minutes experiencing equipment of portable Snoezelen cart and experimenting with various elements.	<i>Creating a sensory space in your bathroom and Sensory rooms at home</i>
Week 4 Graduation	Review of learning, questions, comments or concerns.	-	Graduation certificate

children. We also sought input into future groups, including how practical the interventions are to utilize within the hospital or at home. Due to different ages and cognitive abilities of the children it was difficult to standardize their evaluation. The children evaluated the sessions based on practicality, and whether they would recommend the group to their peers. Depending on the age and cognitive level of the children, assistance from parents was utilized to complete the evaluation. The feedback from both children and parents was extremely positive. One child commented “why can’t the whole hospital come”, while one parent commented the group was “very emotionally reassuring”. Using a scale ranging from 1 (*No Good*) to 5 (*Awesome*), 13 children who attended the sessions rated the

sessions as a 5 and if the child did not understand the 1 to 5 scale a simple *yes* or *no* was utilized to respond. Parents rated each session on the same 1 to 5 scale, and rated each session as a 5, parents noted that this was the first group on pain management they had attended with their child, and that they enjoyed the time together while in hospital. A positive and unexpected outcome of the group was that both children and parents commented on the networking as a valuable experience apart from the non-pharmacological education. As in any hospital setting, children are admitted and discharged at various points which accounts for creation of stand alone sessions and children not being able to participate in all four sessions.

Lessons learned

Though the group was well received, there were several lessons learned along the way and though they were minimal in nature they must be considered in all future planning. Scheduling sometimes was a barrier as finding a common time that both children and their parents could attend was difficult and, in addition, the rehabilitation team's time needed to be considered. Developing sessions that included both children who are verbal and non-verbal, with a wide range of ages and cognitive and physical abilities took a lot of creativity. With the help of nursing students we were able to provide more one-on-one attention and hand over hand facilitation to allow for more individualized participation of the children and to support parents. Extra time was allotted for activities if children who were non-verbal were present to promote full inclusion for all children. The pre-planning was important to ensure that material was both parent and child user friendly, including specific attention to readability.

The authors also learned very quickly about the importance of advertising in increasing attendance and enthusiasm. Despite posters being displayed and flyers being handed out, word of mouth was very valuable in the success of the group. Though the participants were not directly quizzed as to which method of advertising brought them to the sessions, it is the facilitators' belief that most clients attended due to interest in the topic from the advertisements in combination with the buzz created by clients speaking about the program. Reminders and encouragement from others who were attending as well as personal invitations on the day of by facilitators also played a part in promoting attendance. Clients attended for various reasons so in the future, it would be important to ensure that facilitators use as many advertising mediums as possible but also to encourage clients to speak about the program with others to capitalize on the strong influence of word of mouth.

After running the entire *No Pain, All Gain* group a total of three times we believe that an educational program designed for both children and parents can be an effective method to provide valuable information, allowing parents to connect

and network, and allowing children to support each other during their rehabilitation. The success of the group has highlighted the importance of interprofessional collaboration in helping to increase and improve the health care team's responsiveness to noted gaps especially in the area of pain. By combining the skills, knowledge, passion and ideas of the RN and CLS, clients and their families were provided with the supplies and information they need to learn, practice and master a variety of non-pharmacological pain management techniques. The result was an improvement in the effectiveness and efficiency of our teams' pain management practice as well as a move towards increased client control, ownership and choice over their pain experiences.

The *No Pain, All Gain* group has attracted a lot of attention, internally and externally. A formal research study would be beneficial to evaluate this model of educating children with disabilities and their parents on the use of non-pharmacological pain interventions. An area that requires special attention is in the education of the interprofessional team on these same strategies, to ensure implementation during therapy and by nurses at the bedside. Current chart reviews, have revealed that non-pharmacological intervention continues to be secondary to pharmacological. The sustainability of the group is a constant struggle related to the facilitators' schedules, but the non-salary budget is not a concern as this group can be run with little funds. Children with physical and cognitive disabilities who have communication challenges may be overlooked when programs are run surrounding the non-pharmacological management of pain due to the lack of the ability to provide self-report on the effectiveness of the interventions. The authors believe that including parents and caregivers in the group dynamic can be valuable in ensuring that all children receive access to non-pharmacological pain management strategies and both children and parents leave with the same understanding.

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