Brief Clinical Report: Procedural Pain and Anxiety Management With Mother and Sibling as Co-therapists

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Objective: To describe a multidimensional family-focused intervention for pain and anxiety management during port-access with a Spanish-speaking preschool child being treated for acute lymphoblastic leukemia, using the patient’s mother and one sibling as co-therapists.

Methods: Assessment procedures included interviews with mother, sibling, and primary nurse and behavioral observations during port-access, and during a medical examination. Intervention consisted of two training and two “in-vivo” sessions, using behavioral and cognitive behavioral techniques.

Results: Physical resistance was eliminated and anxiety responses reduced during port-access sessions. Maternal anxiety and sibling distress were also reduced.

Conclusions: This case study illustrates an empirically supported child and family focused in the clinical care context and highlights cultural factors that may influence the success of such interventions.

Key words: procedural pain; anxiety; psychological intervention; pediatric cancer.

Over the last 20 years, significant advances in the treatment of pediatric acute lymphoblastic leukemia (ALL) have resulted in a dramatic improvement in long-term survival. However, children diagnosed with ALL must undergo lengthy treatment involving many invasive procedures, some painful or anxiety provoking. This article describes a multidimensional, empirically supported psychological intervention for a Spanish-speaking preschool child undergoing port-access for ALL treatment. Port-access is a procedure commonly used in current pediatric cancer treatment to facilitate intravenous access and to minimize pain. However, its psychological impact has not been previously reported. This study exemplifies the unique role of a sibling and the mother in the use of empirically supported behavioral and cognitive behavior techniques within a clinical setting, and it identifies cultural and linguistic factors relevant to the intervention.

Psychological interventions have been proven to be effective in reducing pain responses and anxiety in children who require intravenous access for cancer treatment (e.g., Kuttner, Bowman, & Teasdale, 1988; Powers, Blount, Bachanas, Cotter, & Swan, 1993), but they have not been implemented during port-access. The majority of children undergoing painful procedures, however, do not engage in effective coping strategies unless prompted to do so by an adult (Blount, Landolf-Fritsche, Powers, & Sturges, 1991). The use of a parent as co-therapist for pain and distress reduction during painful procedures has been suggested (e.g., Blount, et al.,

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1991), but results are mixed (Powers et al., 1993). Parental anxiety may contribute to the child’s anxiety and may interfere with the child’s ability to cope (Dahlquist, Powers, Cox, & Fernbach, 1994). In addition, a reduction in parental anxiety alone may not result in a corresponding reduction of children’s distress during painful procedures (Jay, Elliot, Katz, & Siegel, 1987).

Cultural factors, such as traditions and language, may be important in the success of psychological interventions in medical settings. Immigrants display a sense of community toward groups or individuals that are “proximate” (work in the same place, speak the same language), resulting in feelings of “psychological closeness” (Regis, 1988). Hispanic families seek and accept psychological help from individuals they perceive to be connected with them such as relatives, friends, and key community members, such as priests, rather than from health professionals (Padilla, Cervantes, Maldonado, & Garcia, 1988). In the case described here, Spanish was used throughout the intervention for two reasons: (1) it was assumed that its use would enhance the sense of closeness between the therapist and the family, and (2) Spanish was the language spoken at home and the mother expressed preference for its use.

Case Report

Assessment

History of the Problem
JC was referred for psychological intervention near the end of a 3-year chemotherapy protocol for ALL, at age 4 years, because of severely disruptive behavior during port-access. Port-access required physical restraint by two nurses and his mother. His behavior had become progressively worse and unmanageable in the 3 months prior to the referral. Lumbar punctures and bone marrow aspirations were done under deep sedation or general anesthesia and thus did not present problems for JC. During the induction phase of treatment, JC was hospitalized for approximately 4 weeks and required many blood products and several periods of isolation because of infections. Reportedly, JC became clingy with his mother, fearful and difficult to console, and stopped walking and talking. When JC went home, his parents did not allow him to play with other children, even his own siblings, for fear of infections. Most of JC’s subsequent treatment was as an outpatient. Medically speaking, JC’s health became stable during the maintenance phase of his treatment. He is described in his medical chart as “growing by leaps and bounds.”

Observations During Port-Access
During the port-access observation, JC sat on his mother’s lap while two nurses restrained him. JC’s behavior throughout the procedure included kicking, fighting, scratching, biting, and spitting. JC’s mother tried to reassure him and she appeared to be distressed herself. The staff seemed to be tense and guarded and expressed fear of being hit by him. The procedure lasted approximately 20 minutes, about double the usual time required for a calmer child. According to the staff, JC’s behavior during this observation was typical of how he had behaved in previous access-to-port sessions for the last three months. Using a visual analog scale with ratings from 1 to 10 (10 being the worst pain), both Mrs. C and the primary nurse rated JC’s pain response as 10 during the access-to-port procedure.

Observations During the Physical Examination and in the Playroom
During outpatient clinic visits, JC became highly anxious and fearful. He appeared tense and agitated, he shifted his eyes repeatedly, and he was unable to focus on any play activity. After a while, JC played quietly on his own but in close proximity to his mother. He continued to be apprehensive. During the physical examination, JC resisted initially but the physician managed to partially engage him. While JC’s mother spoke with the physician, the therapist began to establish social contact with JC. He approached the toy offered after some hesitation. JC established eye contact momentarily but allowed the therapist to sit close to him. Because he appeared to be very tense, the therapist began to rub his back gently. JC responded by moving closer to the therapist and leaning toward her as he drew and scribbled on a magnetic board. He did not speak to anyone during the observation.

Cultural and Family Background

JC comes from a traditional Hispanic family from Central America who arrived in Canada 4 years prior to his diagnosis. JC is the youngest of 4 children: three boys (4, 9, and 12 years old) and a girl (14 years old). Mrs. C has a postsecondary educa-
discussed her personal issues with the staff before because she felt more comfortable addressing such issues in Spanish. JC’s mother was described in the medical chart as “very anxious” on several occasions. In addition, the family was described as being “resistant to assistance.” Mrs. C indicated that her husband was not willing to be part of this intervention. The decision to actively involve Mrs. C in the intervention was based on previous suggestions that reduction of maternal anxiety during the child’s painful procedure may be beneficial to both the child and the parent (Kazak, Penati, Waibel, and Blackall, 1996).

In summary, during the assessment, JC presented a high level of anxiety associated with clinic visits and learned disruptive behaviors associated with port-access procedures for his chemotherapy treatment. Mrs. C was experiencing a high level of anxiety, and LC was showing signs of emotional maladjustment.

**Intervention**

The behavioral and cognitive-behavior techniques used in this case were similar to those used in previous studies with young children undergoing treatment procedures (e.g., Jay et al., 1987; Kutter et al., 1988). Three main goals were set for the intervention: (1) to reduce JC’s anxiety and disruptive behavior associated with access-to-port procedures; (2) to reduce Mrs. C’s anxiety while enhancing confidence in her parenting skills; and (3) to reduce LC’s distress. Relaxation, induced by rubbing JC’s back and encouraging play, was used to reduce JC’s anxiety during clinic visits. During port-access, “bubble making” was selected to redirect his attention because it was JC’s favorite activity. The intervention consisted of two training sessions: in session one, JC’s mother and JC were present; in session two, LC was seen alone first, and the mother and JC joined in later. These sessions were scheduled prior to the next required port-access. Praise and verbal encouragement were used throughout training to help build self-confidence in Mrs. C and LC. During the first session, maternal training included learning to identify specific behaviors such as listening and following directions, learning to use reinforcement for appropriate behavior, learning to induce JC’s relaxation, using distraction techniques with JC (active breathing by blowing bubbles), and learning how to coach him. To reduce maternal anxiety, deep breathing paired with muscle relaxation, self-
direction, and reframing of stressful events were used. The second session focused on the training of the sibling. The steps that were used to train Mrs. C were repeated to train LC. In addition, LC was provided with information about ALL treatment. For example, the treatment protocol and its side effects were explained to him.

For the first “in vivo” port-access session, the therapist, Mrs. C, and JC met 20 minutes prior to its onset to induce relaxation and to role-play the procedure. Mrs. C was asked to hold JC on her lap as before and to follow the strategies learned during the training sessions. The therapist held the bottle of “bubble” soap while JC held the bubble stick and blew bubbles. When it was time to go to the treatment room, JC became somewhat apprehensive but his mother remained reassuring, relaxed, and confident. She explained to JC that they will make bubbles in the treatment room as the nurse “got the chemo done.” The nurse, noticing the difference in Mrs. C’s and JC’s attitude, made a positive remark and remained reassuring throughout the session. JC did not kick, scratch, or scream during the procedure. Except for two instances during which JC looked at his mother for reassurance, JC kept his attention on the bubble making. The entire procedure lasted 6 minutes. The response of the other nurses in the clinic was very positive toward JC and his mother. Both mother and son left the clinic smiling.

For the second port-access session, the therapist met JC, Mrs. C, and LC 30 minutes prior to the procedure for preparation. During the procedure, the mother held JC on her lap while the sibling held the soap bottle and talked to JC “coaching him” to make bubbles, and the therapist observed. The procedure went as smoothly as it did during the previous session. JC responded with a smile to the comments of approval from the staff. He seemed calm and happy. Both Mrs. C and LC appeared to be very proud of themselves and of JC.

Follow-up contacts, 1 and 2 months after termination of the intervention, were made by phone with Mrs. C to find out how all three family members were doing. Mrs. C reported that she and LC were talking more with one another. Moreover, Mrs. C said that LC was “more cooperative” at home and less irritable. She expressed that she felt more in control of her parenting skills at home and at the clinic. She reported feeling particularly pleased during her visits to the clinic because JC was no longer a “behavior problem” during port-access.

LC assisted during port-access twice, after which Mrs. C brought JC alone. JC continued to blow bubbles through the procedure with his mother’s assistance and reportedly did not have any more difficulties with port-access through to the termination of his treatment (3 months after the psychological intervention). A report from JC’s primary nurse confirmed maternal reports of his behavior.

Discussion

This article describes a multidimensional intervention that included the elimination of disruptive behavior and a reduction of anxiety during port-access with a Spanish-speaking 4-year-old boy undergoing treatment for ALL. Previous studies have suggested that distress during invasive procedures does not typically decrease over time (e.g., Katz, Kelberman, & Siegel, 1980), and may actually increase. In this study, JC’s distress had increased over time to a level difficult to manage by staff and the mother without psychological intervention.

This case intervention was unique in several ways. First, although psychological techniques have been previously reported to be effective in reducing pain response during venipunctures, lumbar punctures, and bone marrow aspirations, these techniques, however, have not been used before during port-access. This omission might be due to an assumption that this procedure is neither distressing or painful for young children. As this report illustrates, this may not be the case. Second, the mother and one of the siblings became co-therapists for JC, and their involvement may have had additional therapeutic benefits for them, such as increasing their repertoire of skills to help JC cope with the cancer treatment, reducing their own anxiety, increasing their self-confidence, and improving communication in the family. The suggestion that pediatric cancer affects the family as a unit as well as each of its members (e.g., Kazak et al., 1996) is supported in this report, as is the effectiveness of family-centered intervention. Finally, this case illustrates how cultural factors may contribute to the success of these interventions.

The use of the family’s native language throughout the intervention may have facilitated the development of psychological closeness (Regis, 1988) and trust in the therapist, which in turn may have increased the likelihood of success. The development of trust in health professionals may require a
Meeting the special needs of healthy siblings. Cancer Nursing, 6, 213–217.

In conclusion, this article describes a unique multidimensional family-focused intervention for procedural pain and anxiety management during port-access for a child being treated for ALL. The intervention illustrates the extent of the impact of the disease and its treatment on the family as a unit and supports the importance of family-centered care. The successful use of the mother and a sibling as co-therapists, after their own anxiety and needs for information were addressed, supports the notion that greater utilization of family personal resources is possible in psychological interventions planned for the ill child. Finally, this case highlights the need to develop culturally sensitive interventions and illustrates the role of sociocultural factors, such as language and cultural beliefs, in the success of psychological intervention.

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Kramer, R. E., & Moore, I. M. (1983). Childhood cancer: culturally sensitive approach tailored to the unique needs of the child and his or her family. The limited openness that this family demonstrated with the health care team before the psychological intervention may have served to preserve normalcy, dignity, and identity within the cultural group (Thorne, 1985). However, communication was limited even within their own family, as demonstrated by the sibling’s lack of knowledge of ALL and its treatment. “Protecting” the sibling from factual information about ALL and its treatment led to symptoms of anxiety similar to those of children who were uninformed of their parents’ terminal illness. Uninformed children were found to be more anxious than children who were kept informed (Rosenheim & Reicher, 1985).

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References
Society of Pediatric Psychology, Executive Committee, February 1986
Left to Right: Gerry Koocher, Ken Whitt, Elizabeth Robinson, Gene Walker, Debra Bendell Estroff, Brian Stabler, Don Routh, Dennis Harper, Michael Roberts, Annette La Greca, Sue White

Society of Pediatric Psychology, Executive Committee, August 1999
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