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Commentary

Changing parental responses to pediatric hematology/oncology pain with a single session, operant-based group intervention

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The operant model of pain highlights learning as essential to the development and maintenance of chronic pain; it postulates that pain behaviors (e.g. grimacing, guarding, moaning, rubbing, verbalizing pain) are integral to the problem of pain, and that these behaviors are impacted by environmental contingencies (Gatzounis et al., 2012). Indeed, a parent's solicitous, or concerned and inquiring, behavior to a child's demonstration of pain is associated with increased sick role behavior in children with chronic or recurrent pain (Walker & Zeman, 1992); and, protective or critical parental responses to pain can result in increased child impairment or somatic symptoms (Claar et al., 2008). The relationship of family factors and the child's pain experience is transactional. Families that have a child who experiences chronic pain report more disruptions in their life (i.e. less cohesion, greater conflict) than families who do not; Palermo & Eccleston, 2009; Lewandowski et al., 2010). Similarly, during hospitalization, pain is often described as extremely stressful for parents (Forgeron et al., 2006); and, parental responding and parental experience of their child's somatic symptoms can impact a child's pain experience (Flor et al., 1987; Flor et al., 2002; Hechler et al., 2011; Levy et al., 2010; Levy et al., 2013; van Tilburg et al., 2015). These findings highlight the importance of including parents in interventions targeting pain.

Research has demonstrated that inclusion of parents in pain interventions is not only beneficial but also feasible and acceptable. A one-day workshop focusing on educating adolescents with chronic pain and their parents resulted in significant gains in parenting practices, parental beliefs about adolescents' ability to manage pain, and knowledge; these findings were maintained at the 3-month posttreatment follow-up (Coakley et al., 2018). Similarly, a randomized controlled trial evaluated the effectiveness of teaching children and parents cognitive behavioral strategies to manage functional abdominal pain, and taught parents social learning strategies to reduce solicitous responses to illness behavior (Levy et al., 2010; Levy et al., 2013). At six (Levy et al., 2010) and 12-month (Levy et al., 2013) follow-ups, parents who received those interventions reported reductions in their children's pain, parental solicitous responses, and perceived threat of their children's pain.

Intervening with parents to improve the child's pain experience: a pilot clinical program

Given the impact that parents can have on their children's pain experiences, single-session, one-hour parent groups (n = 5) based on the operant model of pain were offered as a clinical adjuvant to individual therapy for pediatric hematology/ oncology patients with pain. Group content was created based upon clinical experiences and previous literature (e.g. Walker & Zeman, 1992; Flor et al., 2002; Claar et al., 2008; Gatzounis et al., 2012). Goals of the group were to provide psychoeducation regarding pain, to strengthen parenting strategies to manage their children's pain, and to offer a supportive environment that afforded parents an opportunity to learn from each other.

The group intervention provided education related to the role of learning in the maintenance of persistent/chronic pain. Discussion and handouts helped to convey important constructs; for example, parents received a handout that defined pain, pain behaviors, and well behaviors, explained how pain behaviors may be inadvertently reinforced, and provided tips for decreasing pain behaviors and increasing well behaviors. (See Appendix for excerpts. On request, handouts available from the author.)

Group discussions focused on the application of planned ignoring of pain behaviors and reinforcement of well behaviors. Parents learned the importance of privately noticing a child's pain without inadvertently reinforcing pain behaviors; empathic support was provided to acknowledge that this may be difficult for parents of hematology/oncology patients given that pain historically served as an indicator that something was wrong. Anecdotally speaking, the operant model of pain appeared more readily accepted by group members on occasions where at least one parent in the group described a time when their child demonstrated pain behaviors prior to engaging in an unwanted activity (e.g. attending school, going to an ancillary appointment the patient did not particularly enjoy). This allowed parents to identify real-life connections between pain and avoidance behaviors which contributed to more rich discussion of how parents can respond to their child during these times.

Evidence of group effectiveness

Following approval from the Institutional Review Board, demographic and questionnaire data were abstracted from medical records. Given the small sample size the Wilcoxon Signed-rank test was used to compare median scores on standardized measures.

Parents (N =10) had children (ages 9 to 17; M = 13.7 ± 2.5 years) who previously attended individual psychotherapy. Sixty percent of patients were female. The majority of patients experienced pain related to a malignant solid tumor (n = 6, 60%). Other primary medical diagnoses included acute lymphoblastic leukemia (n = 2, 20%), sickle cell anemia (n = 1, 10%), and factor VIII deficiency (n = 1, 10%). All patients experienced disease and/or treatment related pain. Unfortunately, data regarding how actively parents participated in other pain interventions previously or concurrently were not collected. Groups (n = 3) varied in size, with two to four mothers per group.

Mothers completed a measure of their responses to their child's pain (adapted from Adult Responses to Children's Symptoms; ARCS, Van Slyke & Walker, 2006) prior to group attendance. On this measure, higher scores are indicative of more solicitous responses to pain behaviors. Mothers also completed a measure of treatment acceptability adapted from the Treatment Evaluation Inventory, Short Form; (TEI-SF; Kelley et al., 1989) after participation. These mothers were then contacted by phone 6-18 months (M = 14.9 ± 4.9 months) subsequent to group participation. At that time, mothers who attended a group completed another ARCS via telephone. The median ARCS response to a child's pain prior to group participation significantly decreased, as was desired (W = 1, $Z = -2.55$, $p = .011$, $r = 0.81$)

Treatment acceptability

All mothers found the group acceptable (n = 10, 100%) and enjoyable (n = 10, 100%); and, most mothers (n = 9, 90%) believed operant strategies were likely to be effective in decreasing their child's pain. Mothers commented that they liked "the open format," "learning strategies that work," "being able to discuss with other parents who understand," and "discussion to pinpoint (application to) personal circumstances."

Conclusion

Mothers who attended a one-hour, single-session psychoeducational group based on the operant model of pain found the group acceptable and enjoyable. As a group, mothers reported significant improvements in appropriate responses to pain behaviors that were maintained following group participation. Yet, information regarding prior parental involvement in pain intervention(s) remains unknown. The impact of participation in this group may have been moderated by parents' prior involvement in other intervention(s), particularly if parents previously received similar information. These are important factors for future research to explore. Nonetheless, these results and results of previous research suggest that parent groups are likely a beneficial adjuvant to pain interventions for pediatric hematology/oncology patients. Future research should consider a more rigorous, intentional research design and inclusion of child self-report of pain.

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Appendix. What is a pain behavior?

Pain Behaviors

Behaviors that tell us or another person that we are in pain

- Tense face, grimace
- Eyes squeezed
- Clenched fist(s)
- Trembling chin
- Moaning and/or groaning
- Looks/turns red
- Tears/crying/whimpering
- Stating pain is present
- Avoiding activity/movement
- Clenched teeth
- Tense body

Well Behaviors

Behaviors that are incompatible with the expression of pain

- Exercising
- Engaging in physical activity
- Talking about topics other than pain
- Avoiding talk about pain medication
- Smiling
- Laughing

Appendix: Parental responses to pain behaviors

Positive reinforcement is providing a response to your child's behavior that will increase the likelihood of the behavior occurring again. Attention for pain behavior is a very powerful reinforcer for children.

Important: We are not saying to be cruel or inattentive to your child. We suggest you consider how you respond to behaviors that let you know your child is in pain. Responding in a different way may lead to decreased pain and increased ability in your child!

Emphasize that you are unable to take your child's pain away, but say that she/he will receive lots of love and attention (not about pain or pain behavior) and given rewards and attention for coping.

- Ignore any pain behaviors exhibited by your child (verbal groaning, crying, guarding)
- Give special attention and praise for coping behaviors
- Do not enter into a discussion with your child regarding their pain and function (e.g. walk away)

Do . . .
- Give attention during symptom-free periods (e.g. you are working well, and you are doing well)
- Be aware of demands for positioning; they are probably requests for attention
- Expect your child to function in spite of physical distress (this is not cruel but actually therapeutic as your child will be convinced of their ability to manage by the experience of success)
- Be firm – this communicates the conviction that your child is strong enough and competent enough to overcome this distress
- Believe that your child can increase his/her functioning
- Treat your child as an active agent in his/her treatment
- Help your child to problem solve about how to actively change things
- Follow through with expectations put into place

Do not. . .
- Assume responsibility for anything your child can do for him/herself
- Use punishment or assess your child's progress negatively in front of your child
- Focus on the illness behaviors or give attention for pain behavior
- Ask how she/he is feeling or how much pain she/he has
- Give excessive reassurance
- Focus attention on the symptoms or show concern (even though you may feel it!)
- Provide excessive attention to your child when she/he is in pain or in discomfort
- Believe your child is vulnerable and unable to cope

(Adapted from information by Sophia Franks, www.painmanagement.org.au)