

Commentary

A Parent Support Model for Intensive Pediatric Chronic Pain Rehabilitation

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The importance of supporting parents caring for a child with chronic pain is gaining greater recognition within pediatric treatment contexts given research identifying the impact of chronic pain on the entire family system (Guite et al., 2018; Kemani et al., 2018; Palermo & Eccleston, 2009). Parents of youth with chronic pain often experience greater distress and caregiver burden (Guite et al., 2018; Palermo & Eccleston, 2009; Pielech et al., 2018), which poses risks to parents' emotional wellbeing. We also know that patient pain experience and ability to cope are influenced by those around them (Christofferson et al., 2024; Cordts et al., 2019; Guite et al., 2018; Kemani et al., 2018; Vowels et al., 2010), highlighting the importance of parent-focused interventions alongside child-focused interventions. It is important that parents learn to address their own distress around their child's pain to be able to assist their child to self-manage their pain (Guite et al., 2018). There is a growing body of literature outlining parent-support models at the outpatient (Guite et al., 2018; Lee et al., 2023) and inpatient levels (Pielech et al., 2018; Sieberg et al., 2017); however, much of the literature on chronic pain still centers on clinical practice as it relates to the patient, with far less focus on intervention for parents and caregivers. The purpose of this discussion is to present, through the social work lens, one intensive interdisciplinary pain treatment (IIPT) program's parent treatment model to provide further support for the role of parent-specific programming within IIPT.

Treatment Setting

This IIPT is a standardized 4-week rehabilitation program, consisting of a 2-week inpatient followed by a 2-week day patient program for children with persistent pain in Canada. It is aimed at helping youth (ages 12-19) work on functional goals and return to desired activities. During a four-week admission, parents participate in individual and group interventions, with the overall goal of addressing parental factors in relation to their child's pain by increasing psychological flexibility and adaptive responses to pain. Social workers function as a part of the multidisciplinary team which provides a rich opportunity for patient support from a variety of perspectives.

Social Work Role

One focus of social work within pediatric IIPT is to work with parents to provide education, counselling, group facilitation, case planning, and reviewing follow-up care. We are not the only profession interacting with parents. As part of the interventions provided, parents partake in weekly sessions of family therapy. Family therapy (parents and child only) is a time to come together with a mental health professional, typically our child and adolescent psychiatrist, to work towards building stronger relationships with each other and uncover where the family unit is stuck. These sessions often support and inform our work as social workers in individual and group parent sessions.

Individual Parent Sessions

Parents receive, at a minimum, weekly individual counselling with social work. The sessions allow parents to reflect on the impact of their child's journey with chronic pain. We approach these sessions using an Acceptance and Commitment Therapy (ACT) framework with special emphasis on meeting the parent where they are at, understanding how they feel stuck, and determining how they feel they can be best supported. ACT has been shown to be effective when there is excess suffering due to perceived problems that are not (readily) solvable. For chronic pain, ACT does not require the pain to be eliminated or even reduced for suffering to lessen (Hayes et al., 1999; Vowles et al., 2014). Suffering diminishes when responses to pain change (Harris, 2006). For parents, this often looks like working towards pain acceptance, which can be defined as experiencing pain without constant monitoring, judging, or attempting to reduce or avoid it, while simultaneously working towards living a full and meaningful life (Hayes et al., 1999; Wicksell, 2007). This can be achieved in many ways including having parents work on noticing thoughts, feelings, memories, and body sensations without judging, avoiding, or pushing them away (Harris, 2006). ACT is a framework that is guided by values (Harris, 2006; Wicksell, 2007); therefore, we spend time supporting parents in identifying their own parenting values and aligning them with committed action. Other in-session activities include: mindfulness, defusion strategies, grounding skills, and discussing intentional self-care as a coping tool. Given that ACT is a very active and playful form of therapy, we often illustrate ideas using ACT's experiential activities such as 'Pushing Away the Paper' and 'Hands as Thoughts and Feelings' (Harris, 2019). Parents are encouraged to practice applying concepts discussed in session to their own routines throughout the week and bring specific examples to their next session for discussion.

Upon reflection, one parent likened the experience to taking off a backpack, "it was there, and it was loaded, but you are helped to not carry it on your back". Another parent reflected that she expected "the worst" based on previous interactions with the healthcare system. Instead, she reported that she felt - in the individual sessions with the social

worker - that she was met with respect and compassion and felt relief in being able to "take my first breath." For the first time she stated that she felt that she was validated. Another parent reflected on her surprise that the individual sessions "felt so personal" and facilitated a shift in her thinking about the impact that her child's situation had on her.

Parent Education Groups

Parents participate in seven 1-hour group sessions occurring over the span of the 4-week admission. These groups are composed of parents and typically consist of 4-6 participants with both in-person and virtual options available. The curriculum is aligned with that of the client, covering topics of: sleep hygiene, advocacy, parenting strategies, mindfulness, values and committed action, pain science, and maintenance planning. In each group, parents can come together to discuss common scenarios formulated by facilitators and through examples brought to the group by participants. Feedback and support are provided by facilitators and group members based on their lived experience. Like in the individual sessions, parents are encouraged to apply group content throughout the week.

While providing psychoeducational content is important, it is the opportunity for parents to connect and share their experiences with each other that makes the groups special. One mother shared that she appreciated the role-playing and that she learned a lot about her use of language as a parent. One parent expressed that despite participants coming from different backgrounds, the environment in the group was described as one of mutual support and safety and the connections went beyond the group. "We felt comforted. It was not about me being a black mom and him being a white dad, we felt aligned in our experiences as parents." Another mother shared that she enjoyed learning the perspectives of others and "how they handled things." She described it as helping her feel less alone.

Parent Reflections

By virtue of its intensity, this program offers parents a unique opportunity to immerse themselves in the parent program component. Parents are not only dropping in for an outpatient appointment. They are provided with the space and time to pause and

consider the ideas and support they are being offered; and access to a team of different practitioners using a variety of therapeutic modalities. Organically, the program offers parents opportunities for greater self-care, peer support, and real-time assistance as issues arise. A parent reflected, “This was the first time where it changed the trajectory in terms of how I perceived care. Not from a place of frustration.”

Parents arrive at the program having worked hard over a long period of time to find a ‘solution’ to their child’s pain. The parent program is focused on getting parents to acknowledge their feelings around this struggle, often comparing it to dropping a rope in tug of war. Parents who work with our team are given the opportunity to re-imagine returning to life despite the pain, and modeling this for their children. Referring to their time in family therapy, a parent shared that these sessions were the first time they

could connect as a family, in a safe setting, having a “helpful, other voice.”

Parents who participate in the program often reflect the challenge of applying what they have learned once discharged from the program where this level of support is no longer available. Social work considers with parents what the transition home may look like, not just for their child. We encourage parents to build a network of personal, community, and professional supports to meet their needs and to ensure that the valued direction that they have identified remains aligned upon their return home. It is the hope that this discussion further highlights the importance of parent programming in IIPT due to its impact on the entire family system. Further review of other IIPT programs would be helpful to better understand how we can support parents transitioning from intensive programming to their home communities.

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