

Commentary

Tools to enhance education about pain and emotional distress for pediatric patients with chronic pain

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Best practices in chronic pain management include providing psychoeducation to patients regarding pain processes and the neurobiological underpinnings of pain (US Department of Health and Human Services, 2019). Accurate pain-related knowledge is associated with significantly better treatment outcomes for adult patients (e.g. decreased pain severity, disability, pain catastrophizing, increased physical activity; Watson et al., 2019) and fewer physician visits for pediatric patients (Abram et al., 2007). In pediatric chronic pain treatment, it is important to provide evidence-based psychoeducation in a developmentally appropriate manner (Robins et al., 2016). Metaphors that provide accurate information, challenge misconceptions about pain, and break down complex constructs into concrete, relatable terms, are helpful tools to facilitate pain education (Coakley & Schechter, 2013). Melzack and Wall's (1965) gate-control theory of pain is one example of how the complex neurobiological nature of pain can be explained in relatable terms, and accounts for both physiological and psychosocial processes that impact pain perception.

Despite the large body of research documenting the neurological connection of physical pain and emotional distress, as well as thinking and activity patterns (e.g. Rainville et al., 2005; Borsook et al., 2007; Simons et al., 2014; Koechlin et al., 2018), there are no developmentally appropriate resources to explain this relationship to pediatric patients with chronic pain. Due to the high

comorbidity of depressive and anxiety symptoms in this population (Fearon & Hotopf, 2001; Eccleston et al., 2004) and the tendency for many patients to downplay or deny the impact that stress or emotional distress has on pain (Edwards et al., 2016), it is critical to prioritize intervention around the relationship between pain and emotion to successfully restore functioning (Simons et al., 2014).

To our knowledge, no developmentally appropriate pediatric educational materials that explain the relationship between pain and emotion exist. To bridge this gap, we built on Fordyce's (1976) operant behavioral conditioning approach to pain treatment. This model emphasizes the importance of minimizing attention to pain behaviors (e.g. pain verbalizations, facial expressions, guarding behaviors) that increase dysfunction and maximizing attention to well behaviors (e.g. engaging in regular activities, use of coping strategies) in an effort to improve functioning. While a helpful starting point, this approach lacks specific direction on how to explain the goal of reducing pain talk in developmentally appropriate terms. In our clinical experience, this approach can result in patients' and caregivers' misunderstanding that all distress (physical and emotional) should be minimized, and therefore can be hard for families to adopt. As a result, we saw an opportunity to create two psychoeducational tools (see: ppl.childpain.org). The first tool provides an overview of the main tenants of chronic pain that

set the stage for the role of function and reducing attention to pain as part of treatment. The second tool explains the relationship between pain and emotion in a developmentally appropriate manner and provides thinking and action strategies for rebalancing the brain's focus on both pain and emotion.

Clinical/Family Tool: Overview of Chronic Pain ([link](#))

The first tool includes an overview of the biopsychosocial model of pain, the difference between acute and chronic pain, and how pain works in the brain and body. It was designed to be a didactic tool used by the clinician to provide psychoeducation about pain to a patient and their family at the beginning of pain treatment to increase buy-in to the functional approach. It may also be used as a handout for family members who are unable to be present in treatment and/or mental health clinicians who may also be working with patients with chronic pain but are unfamiliar with the nuances of chronic pain treatment. In this way, it is a flexible educational tool that can aid in patient and family education during a session or enhance the family's or collaborating provider's understanding of pain outside of a session.

The Clinician/Family Tool uses the analogy of a faulty alarm system, which we have found is a relatable, concrete way to explain the differences between acute and chronic pain and why they are treated differently. Our goal in laying this educational foundation is to help patients, families, and clinicians understand that because attention to pain increases pain perception, which in turn worsens pain, we discourage patients from talking about the physical aspect of their chronic pain (i.e. pain talk; "My knee hurts," "Ouch") or engaging in behaviors that communicate chronic pain to others (i.e. pain behaviors; limping, leaning on things, holding a body part). The goal of shifting attention and communication about pain is to help patients place the emphasis on function first versus focusing on getting rid of or controlling the pain before functioning. This is consistent with research demonstrating that function improves before chronic pain (Lynch-Jordan et al., 2014).

The last part of the Clinician/Family Tool sets the stage for how to help patients replace pain talk and behaviors with expression of emotion, while providing the underlying neurobiological rationale for doing so. For example, if patients are distressed, they are encouraged to talk about their feelings (e.g. "I'm scared," "I am frustrated") instead of focusing on physical/body responses (e.g. "My leg hurts," "I am tired"). Helping patients identify and express their emotions allows them to learn a new emotion-focused set of coping skills. This approach has the potential to enhance their coping efficacy as they manage challenges associated with improving function and may reduce amygdala activity and related emotional distress (e.g. Lieberman et al., 2007).

Patient Tool: Balancing the Pain/Emotion Seesaw ([link](#))

The second tool was created as a patient facing tool, presented as an illustrated handout using a seesaw metaphor to explain the imbalance that chronic pain creates between physical and emotional responses, and how rebalancing can occur through pain treatment. This tool utilizes the same verbiage as presented in the Clinician/Family Tool while introducing a visual metaphor to appeal to youth and accommodate different learning styles. First, an image illustrating an ideal/typical balance of physical and emotional responses is depicted. Then, a second image illustrates how an overfocus on physical responses, occurring as the result of chronic pain leads to an equal and opposite response of an underfocus on emotions. In this picture, the seesaw is tipped in favor of body response. As such, body (physical) response is on the higher end of the seesaw symbolizing the increase in focus on this aspect of pain and pain perception. A third image depicts that, with effort to increase awareness and expression of emotions instead of physical responses, through changing thoughts and actions, rebalance can be achieved as shown in the final image. In our clinical experience, the Patient Tool is well received after the Clinician/Family Tool has been introduced and validation has been provided that the patient's pain is real within a functional restoration treatment approach.

Methods and procedures

Both tools were developed and piloted within the Functional Independence Restoration (FIRST) program, an inpatient interdisciplinary intensive pain treatment (IIPT) program for pediatric chronic pain rehabilitation at Cincinnati Children's Hospital Medical Center. In accordance with the pain rehabilitation model (e.g. Stanos, 2012), the goal of the FIRST program is to provide a functional rehabilitative approach to pediatric patients who are severely impaired by chronic pain (see Williams et al., 2020 for detailed program description). The average length of admission is approximately three weeks; patients attend daily individual and family psychology sessions where the Clinician/Family Tool and Patient Tool are introduced. During the first week of the program, psychology sessions typically focus on psychoeducation including the presentation of the Clinician/Family Tool. In the second week, psychology sessions focus on developing coping strategies from both cognitive behavioral therapy and acceptance and commitment therapy frameworks (e.g. teaching and addressing positive self-talk, cognitive distortions and restructuring, defusion, emotion identification), including presentation of the Patient Tool. Material from both tools is frequently referred to and used across disciplines (e.g. physical therapy, occupational therapy) to provide a consistent framework and message to patients and families throughout treatment. In addition to weekly family psychology sessions, parents attend three parent-only educational groups where the concepts of pain education and parents' support of patients' decreasing pain talk and increasing emotional communication are further reinforced (e.g. modeling emotional expression, encouraging the use of emotion-focused coping strategies, ignoring pain talk/behavior etc.; see Guite et al., 2018; Russell et al., 2020 for more information).

Both tools were initially examined with a sample of patients ($N = 5$; $M_{age} = 15$ years old) and their parents during their admission to the FIRST program in the summer of 2020. After delivery of the tools, patients and parents completed a brief seven question evaluation. The first five questions used a five-point Likert scale ranging from 0

(*Strongly Disagree*) to 4 (*Strongly Agree*) to assess satisfaction with the tools as well as their relevance, utility, comprehension level, and acceptability. The remaining two questions asked patients and families to comment on anything that would be helpful to add/remove from the tools and for their general feedback about the delivery of the tools.

Summary and lessons learned

Changing communication about pain is challenging, but essential to help pediatric patients with chronic pain improve their function. To help with this, we created two educational tools for clinicians/families and patients to improve their understanding of chronic pain and hopefully increase their buy-in to treatment. In general, the feedback received from parent-child dyads was positive; patients and families surveyed all selected the highest ratings (strongly agree) for each of the assessed domains. In their open-ended feedback, they reported that both tools were easy to follow and found the illustrations to be informative. Specific comments included the following: "The education (Clinician/Family Tool) prior to the handout (Patient Tool) was helpful. It was a lightbulb moment," "I thought it was helpful to have an explanation (Clinician/Family Tool) along with the handout (Patient Tool)," and "I would not change any part of the handout (Patient Tool) or explanation (Clinician/Family Tool)." Overall, the goal to create educational tools to validate the reality of chronic pain and help patients and families learn how to decrease attention to physical pain while increasing opportunities for emotional support through thoughts and actions was achieved.

Improving health literacy while validating patients' pain-related thoughts and emotions can have positive effects on treatment outcomes (e.g. Louw et al., 2011; Edmond & Keefe, 2015). In our experience, patients and families undergoing chronic pain treatment benefited from learning to communicate about a different type of distress (emotional versus physical) and demonstrated improved emotional coping abilities, which further enhanced their achievement of measurable functional goals. On the rare occasion when patients' expression of emotional distress led to functional impairment (e.g. anxiety related to school

attendance), we also found this experience to be clinically valuable as it made evident the need for additional treatment from a mental health standpoint. It is our hope that these educational tools are used to

bring neurobiological research on pain and emotion into clinical care in a manner that is concrete, tangible, and developmentally appropriate for youth with chronic pain.

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