Perspective

The Pain of Invisibility: A Perspective on the Treatment of Pediatric Chronic Pain

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Abstract

Although chronic pain can be debilitating and severely impacting, it can also be an affliction many take on privately. For many chronic pain patients and their families, the toll of symptom invisibility is often a prominent concern. The article expounds upon the theme of “symptom invisibility” and the need for and practice of developing a validating provider–family relationship in the treatment of children and adolescents with chronic pain. Suggestions for therapeutic pathways to building adaptive validation are provided.

Keywords
patient/relationship-centered skills, patient satisfaction, clinician–patient relationship, behavioral health, pain management

A Desire to Be Seen and Heard

They arrive to the office often defeated, sometimes defensive; for some, perhaps yearning simply to be seen or heard.

Although chronic pain can be debilitating and severely impacting, it can also be an affliction many take on privately. For many chronic pain patients and their families, the toll of symptom invisibility is often a prominent concern. As a pediatric pain psychologist working predominantly with chronic pain patients, I have the daily opportunity of hearing and sharing in families’ experiences with chronic pain. Responses to chronic pain range from efforts to deny or avoid acknowledging pain to fully identifying with (and at times conceding unwittingly to) a debilitated lifestyle due to pain.

Whether functioning despite pain or suffering from its impact, many patients and families describe validation of pain and its difficulties as one therapeutic component of treatment. One mother of an adolescent patient diagnosed with juvenile fibromyalgia confided how much she identified with the description of pain being a “silent symptom.” She described how difficult it was for others unable to see physical brokenness (eg, a cast, a bandage, a wheelchair) to acknowledge her daughter’s daily struggles. Tearfully, she recounted pleas for understanding and for others to stop implying her daughter is “making it up.” From the countless ways this sentiment has been expressed by parents and patients alike over my years of clinical practice, it seems this mother is by no means alone in her perspective.

I have often wondered if an initial act of validation—to acknowledge pain as real and problematic—is a first significant step to treatment that clinicians may overlook in the rush toward “fixing.” After all, it is natural for one in the role of healer to help generate solutions; however, comprehensive study has suggested that the nature of chronic pain is multifaceted, requiring multiple perspectives and multilayered understanding (of biology, culture, context, emotional state, prior experiences, expectations, etc) for optimal intervention (1). As chronic pain clinicians, does focus on steering a patient too quickly toward activity (despite pain) somehow invalidate families’ cries for help, especially when many feel they must make great efforts to be heard?

An Interdisciplinary Investment in Treating Pain and Offering Validation

As families rotate in and out of our interdisciplinary clinic, a primary goal is to communicate to them that our clinical perspective always begins with an acknowledgment of the difficulty of pain. By investment of substantial resources (ie, multiple clinicians and hours-long appointments), we hope

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to convey recognition of the heavy burden of their pain and commitment to understanding their individual experiences. Our patient experience surveys, taken at the end of each patient encounter, reveal high satisfaction with the amount of time spent by clinicians simply gathering and closely assessing patient stories.

Pain, especially chronic pain, is mysterious in that symptom instigating, sensitizing, exacerbating, maintaining, and contributing factors are many and varied. For families eager to pinpoint and convey a cause for suffering, the response of “multifactorial causes requiring multimodal therapy” often seems unsatisfactory in its assumed simplicity, and providers must take care and effort to obtain “buy-in.” In this way, perhaps more so than other specialty areas, developing a positive patient experience and validating provider–family relationship are key steps in achieving best outcomes. In practice then, how can a validating relationship be established between family and treatment team?

**Team Cohesiveness, Language Use, and a Graduated Approach to Restoring Function**

Perhaps one supportive practice may be for an entire treatment team to remain available throughout the course of intervention and when possible, jointly see a patient and family. Although follow-up appointments or contact frequency with various disciplines (ie, pain medicine, physical therapy, pain psychology) may differ, an assurance that multiple disciplines will remain accessible, as warranted, can help underscore the message that providers are continuing to work together. Our patients have reflected that when they perceive team members are collaborating to develop needed solutions rather than handing off the case between clinicians, more support is communicated.

Another aspect of validation rests on language selection and use. One of the most common and frustrating sentiments families have shared has been the impression that clinicians believe pain is “all in their heads.” They often describe equating this with an assumption that they are “crazy” or “faking it.” It takes time and experience to provide patients and families adequate and comprehensive information regarding the mechanism and intervention strategies for chronic pain. Often, metaphors and analogies (eg, likening chronic pain to a broken alarm system or software vs hardware problem) can be useful tools for describing the mechanism of chronic pain and helping families understand that even though the issue may be one having to do with faulty signaling or physiological connections rather than anatomical structures, the clinical team firmly acknowledges the existence of a biological difficulty that warrants support.

Additionally, it can often be difficult for families struggling with chronic pain to envision the pathway to resuming activity. Utilizing a paced and graduated approach to restorative function acknowledges this difficulty, both physically and psychologically, and thus, the need for a scaffolded approach. Involvement of disciplines of pain psychology and physical therapy are especially important toward this end. Pain psychology interventions provide teaching of cognitive and behavioral tools that support more adaptive frameworks for responding to and finding hope in the midst of pain, while pain-specific physical therapy provides the vehicle and guided pathway for functional restoration and reinforcing pain neuroscience education.

For practitioners providing care outside of an interdisciplinary or multidisciplinary care setup, beginning a validating conversation around pain is key for laying secure groundwork for a family’s relationship with medical providers and the health care system at large. In summary, even in a nonspecialty care format, (a) remaining available for questions, concerns, and resources; (b) taking care to utilize language and phrasing that acknowledges patient-reported challenges and providing mechanistic explanations for chronic pain; and (c) introducing the importance of a potential scaffolded, multidisciplinary approach to pain treatment often makes a significant difference in the trajectory of a family’s rehabilitative course.

**Building Validation and Trust in Patient–Provider Relationships**

Providers may take strides toward the approaches mentioned above in multiple ways. First, simply adjusting expectations for care of a patient with chronic pain may allow providers to plan for time spent on explanation and coordination of referral(s) to specialty care services, as needed. If the service of crafting a comprehensive explanation is seen in and of itself as therapeutic, the additional time spent may be deemed more important and validating for the provider as well, especially given that many clinicians experience work with chronic pain patients as a major source of frustration. Secondly and toward this end, review and rehearsal of mechanistic explanations for chronic pain occurrence, along with relevant analogies and metaphor use, would be a valuable investment. Thirdly, developing some familiarity with the purpose and content of physical therapy and psychology approaches for chronic pain treatment can aid a provider in facilitating a more reassuring discussion of potential next steps with families.

The burden of chronic pain can be heavy and debilitating. Minimizing the pain of symptom invisibility may be one way of extending a bridge of validation and trust between patients and clinicians. After all, for all of us, perhaps a significant start to healing is simply for one’s pain to be acknowledged, seen, and heard.

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