

## Commentary

### **“It all seems so unfair”: Pain-related injustice appraisals in youth with chronic pain and their caregivers**

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Appraisals of injustice can arise from a variety of circumstances including violations of basic human rights, challenges to equity norms and just world beliefs (Mohiyeddini & Schmitt, 1997; Fetchenhauer & Huang, 2004; Hafer & Begue, 2005), or experiences of suffering or irreparable loss (Miller, 2001). Of particular relevance to the lattermost, chronic pain is often appraised as unfair or unjust. As defined by the Injustice Experiences Questionnaire (IEQ; Sullivan et al., 2008), pain-related injustice is a cognitive-emotional factor comprised of appraisals of blame (e.g. “I feel as if I have been robbed of something very precious”), unfairness (e.g. “It all seems so unfair”), severity (e.g. “No one should have to live this way”), and irreparable loss (e.g. “My life will never be the same”). Although the IEQ was initially developed for accidental injury-related pain, injustice appraisals have been linked to poor functional and psychological outcomes in adults with a variety of chronic pain conditions including fibromyalgia (Rodero et al., 2012; Ferrari & Russell, 2014), arthritis (Yakobov et al., 2014a; Ferrari & Russell, 2014; Ferrari, 2015), post-surgical pain (Yakobov et al., 2014b; Yakobov et al., 2018), genito-pelvic pain (Pâquet et al., 2016), HIV-related pain (Penn et al., 2019), traumatic brain injury (Iverson et al., 2018), and mixed chronic pain conditions (Carriere et al., 2017; Carriere et al., 2018; Sturgeon et al., 2017).

Initial findings also suggest that pain-related injustice is an important and distinct cognitive-emotional factor in the chronic pain experience for

youth. Cross-sectionally, higher levels of pain-related injustice are associated with higher levels of pain intensity, pain catastrophizing, and functional disability, and with poorer emotional, social, and school functioning (Miller et al., 2016a). Importantly, pain-related injustice accounted for significant variance in pain intensity, functional disability, and emotional, social, and school functioning even after accounting for pain catastrophizing (Miller et al., 2016a). These findings also highlight that pain-related injustice is distinct from other well-established constructs such as catastrophizing. Initial longitudinal findings are especially compelling, suggesting that baseline pain-related injustice appraisals predict future levels of emotional (3- and 12-month), social (3- and 12-month), and school (3-month) functioning, above and beyond that of baseline pain intensity and catastrophizing (Miller et al., 2016b; Miller et al., 2018a). It is important to note that perceptions of pain-related injustice are not necessarily cognitive distortions; rather they often develop in response to very real differential or otherwise unfair treatment that individuals experience related to their chronic pain.

The social aspect of pain is especially important for youth, as caregivers play a salient role in youth’s pain experience. To date, two studies have examined injustice appraisals among caregivers of youth with chronic pain. Higher levels of caregiver injustice appraisals about their child’s pain are associated with worse child-reported

physical, emotional, social, and academic functioning (Baert et al., 2020). Interestingly, caregivers have been found to endorse higher levels of injustice about their child's pain than does their child (Miller et al., 2018b), which inspired an examination of the interaction between caregiver and child appraisals of injustice. In a sample of 253 child-caregiver dyads from a university-affiliated pain clinic, the majority of dyads (78%) endorsed concordant (i.e. child and caregiver reported similar levels) appraisals. Dyads where the child endorsed significantly higher injustice appraisals than the caregiver reported the most severe pain and functional disability and the worst quality of life compared to dyads with concordant appraisals and to dyads where the child endorsed significantly lower appraisals than the caregiver (Miller et al., 2018b). Taken together, these findings suggest that child and caregiver pain-related injustice appraisals play a unique and interactive role in the child's pain experience. Although much remains to be known, at this point we contend that routine assessment of pain-related injustice appraisals should be integrated into pediatric clinical practice.

As a distinct construct, pain-related injustice should be assessed separately from other constructs relevant to the pediatric pain experience. The child and parent forms of the IEQ (12 items that are summed for a total score) provide a brief but thorough assessment of pain-related injustice. In adults with chronic pain a score of 19 or above is considered clinically significant (Scott et al., 2013a), however a parallel score has yet to be established for youth with chronic pain. We recommend clinicians assess from all aspects of the construct including blame (e.g. "I feel as if I have been robbed of something very precious"), unfairness (e.g. "It all seems so unfair"), severity (e.g. "Most people don't understand how severe my condition is"), and irreparable loss (e.g. "My life will never be the same") appraisals. Clinicians could further leverage these measures by querying about highly endorsed items during the assessment interview and periodically throughout treatment. Alternatively, clinicians might include select questions that seem particularly relevant to a given patient and/or family with chronic pain. This may include ascertaining if the patient feels others (i.e. family, friends, and

medical professionals) believe and understand the severity of their pain. Identifying the source of the perceived injustice is important, as it may impair the child's medical care or social interactions (Mohammadi et al., 2017; Monden et al., 2020). Additionally, caregivers may believe that their child has lost the ability to achieve their goals or live a normal life (i.e. irreparability of loss), which may inadvertently hinder child development. Finally, some patients and families may express thoughts of blame toward someone or something that is seen as having caused or perpetuated their chronic pain. Given the connections between pain-related injustice and negative emotions for the patient (Scott et al., 2013b), as well as those between caregiver behaviors and the child's pain experience (Mohammadi et al., 2017; Palermo & Chambers, 2005; Palermo et al., 2014), injustice appraisals may be a novel intervention target to enhance patient and family functioning.

While specific interventions for pain-related injustice have yet to be identified, treatment techniques from Acceptance and Commitment Therapy (ACT) and Cognitive Behavioral Therapy (CBT) may be tailored for this purpose. Given the importance of parental injustice appraisals in this context, the techniques discussed below may also be adjusted for work with caregivers of youth with chronic pain. Prior to beginning any of this work, it is vital to validate the patient and family in their pain journey, as many have likely experienced negative or unfair pain-related situations (e.g. pain-related dismissal/invalidation by providers/family/peers, misdiagnoses, lack of financial support for treatments) prior to arriving in your office. Dismissal or invalidation of one's pain by healthcare providers is a common experience for youth with chronic pain (Iglar et al., 2017; Defenderfer et al., 2018) particularly for those with diagnostic uncertainty (Neville et al., 2019). Validation of these experiences can allay patient/family concerns that you are telling them to "get over it". Research has indicated that individuals high in pain-related injustice often display cognitive inflexibility (i.e. strongly connected to/fused with their thoughts of blame and unfairness; Scott et al., 2014). In turn, this limits their use of active coping strategies and engagement in activities they deem

important or valuable. This suggests that using ACT principles to identify value-based activities while supporting a growth mindset and flexible thinking may reduce the functional repercussions of injustice appraisals. Cognitive coping strategies that facilitate acceptance of one's current experience, such as cognitive diffusion or cognitive reframing, may further reduce pain-related injustice appraisals and improve functioning (Rodero et al., 2012). When active coping strategies and pain acceptance are used, treatment suggestions such as physical activity, adherence to medications, and use of relaxation and distraction can be incorporated as enjoyment and values based living.

As noted above, negative emotions often accompany injustice appraisals. In particular, appraisals of blame/unfairness are associated with increased anger (Scott et al., 2013b). Forgiveness based techniques have been suggested to build empathy and compassion for those believed to have wronged them or caused their pain (Monden et al., 2016). Additionally, appraisals of irreparable loss and pain severity have been associated with increased depressive symptoms (Scott et al., 2013b). Standard techniques from CBT for chronic pain, including behavioral activation and cognitive reframing (Palermo, 2012), may be particularly useful in managing these symptoms. Strategies to improve emotion regulation, while not directly targeting pain-related injustice, may serve to generally decrease the internalization of or fusion with the injustice appraisals (Williams, 2016).

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Social connection and engagement, a common challenge among youth with chronic pain, may be a mechanism by which pain-related injustice impacts outcomes and, thus, a possible area for intervention. Preliminary findings suggest that the deterioration of social connections mediates the relationship between pain-related injustice and poor outcomes in adults (Sturgeon et al., 2016). Fostering peer relationships and community engagement in youth would likely enhance their social support and increase their positive interactions, both in general and in relation to pain.

In addition to intervening at the patient/family level, efforts to address common situations that may drive appraisals of injustice are necessary. Developing educational modules surrounding common situations or patient-provider interactions that result in patient appraisals of injustice would enable healthcare trainees and providers to gain insight into how their actions may drive injustice appraisals and give them guidance on how to appropriately validate a patient's pain.

While no single strategy will fit for all patients or caregivers with high pain-related injustice, identifying the specific underlying thoughts, as well as their emotional and social correlates, will provide specific targets for treatment. We recommend that clinicians (1) strongly consider evaluating and addressing pain-related injustice when working with youth with chronic pain and their families and (2) actively work to improve awareness and training for healthcare providers regarding pain-related injustice.

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