ORIGINAL ARTICLE

Child appraisals of injustice in the context of acute & chronic pain: An interpretative phenomenological analysis

(Running head): Phenomenology of child pain injustice appraisals

Keywords: pediatric pain, injustice, phenomenology, interpretative phenomenological analysis, focus group

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Disclosures & funding: No conflicts of interest to disclose. Funding for this research was provided through a grant awarded by Research Foundation Flanders to Tine Vervoort.

Significance: The current study offers the first exploration of the phenomenology of child pain-related injustice appraisals in both pain free children and pediatric chronic pain patients. Findings highlight the interpersonal nature of injustice appraisals that are specific to the experience of chronic rather than acute pain. These appraisals are not fully captured by current child pain-related injustice measures.

Author Contributions: Frederick Daenen: Writing of the manuscript, data collection, & data analysis. Fleur Baert: Data analysis, review & editing of the manuscript. Joanna McParland: Review & editing of the manuscript. Zina Trost: Review & editing of the manuscript. An Schillemans: Data collection & review of the manuscript. Ann Tanghe: Data collection & review of the manuscript. Tine Vervoort: Review & editing of the manuscript.

Abstract

Background: Recent research has found child pain-related injustice appraisals to be associated with adverse pain-related outcomes. However, this evidence is mainly based on research using a measure developed for adults in the context of accident-related injuries, which may not translate to pediatric pain populations. Research on the phenomenology of child pain-related injustice appraisals is lacking. This study aimed to examine the phenomenology of pain-related injustice appraisals among both pain free children as well as children living with chronic pain, to compare and contrast their experiences.

Methods: Two focus groups were held with pain free children (*n* = 16), and three focus groups were held with pediatric chronic pain patients attending a rehabilitation center (*n* = 15) in Belgium. Interpretative phenomenological analysis was applied.

Results: Two injustice-related themes were generated from the focus groups with pain free children: 1) ‘Someone else is at fault’, and 2) ‘I am in pain and he is not’. Two injustice-related themes were generated from the focus groups with pediatric chronic pain patients: 1) ‘People don’t see my pain’, and 2) ‘I am missing out because of my pain’.

Conclusions: This study offers the first exploration of the phenomenology of child pain-related injustice appraisals in both pain free children and pediatric pain patients. Findings highlight the interpersonal nature of lived injustice experiences caused by chronic pain, which is not fully captured by existing child pain-related injustice measures. Findings further suggest that pain-related injustice notions may not be extrapolated from a chronic to an acute pain context.

Introduction

A growing body of work in pain psychology centers around pain-related injustice appraisals, conceptualized as cognitions comprising attributions of blame/unfairness and severity/irreparability of loss due to pain (Sullivan et al., 2008). A large body of research has supported the association between injustice appraisals and adverse pain-related functioning among adults with pain (Carriere et al., 2020; Scott et al., 2013; Sullivan et al., 2012; Yakobov et al., 2018). Recent evidence has pointed to the salience and significant impact of injustice appraisals in the child pain population. Children with elevated pain-related injustice appraisals reported increased pain intensity and disability, and reduced daily, social and academic functioning (Daenen et al., 2021; Miller et al., 2016).

To date, the measurement of pain-related injustice in both adult and child studies has relied almost exclusively on the Injustice Experiences Questionnaire (IEQ) (Sullivan et al., 2008), which assesses a severity/irreparability of loss subscale (e.g., “My life will never be the same”) and a blame/unfairness subscale (e.g., “I am suffering because of someone else’s negligence”). Recent research has suggested some limitations of IEQ, particularly in its application to pediatric populations. Specifically, there is evidence that the IEQ may not capture all domains of injustice that may be relevant to the everyday experience of pain among different populations. In particular, phenomenological studies of pain-related injustice among adults with chronic pain (Karos, 2017; Karos et al., 2018; Kugelmann, 1999; McParland, Eccleston, et al., 2011; McParland, Hezseltine, et al., 2011; Wernicke et al., 2017) as well as parents of children with chronic pain (Baert et al., 2020; Jordan et al., 2007) have highlighted the importance of interpersonal injustice, i.e., the perceived unfair treatment by others due to pain, to which the IEQ makes only limited reference. Such interpersonal dimensions are noted to be particularly important in children, as children with chronic pain often experience victimization and isolation from peers (Forgeron et al., 2010; Jordan et al., 2017). Furthermore, children may be especially prone to so-called epistemic injustice in healthcare, i.e., they are assigned reduced credibility compared to adults, with children's (medical) testimony being more likely to be put into doubt (Carel & Györffy, 2014; Carel & Kidd, 2014; Fricker, 2007). Previous research has found chronically ill adults to be similarly prone to epistemic injustice (Blease et al., 2017), which suggests that children with chronic pain may be an even more vulnerable population. More fundamentally, despite the demonstrated relevance of injustice appraisals in the pediatric context, the phenomenology and accompanying conceptualization of child pain-related injustice appraisals has thus far remained unexamined. This is because the IEQ – the main instrument used in quantitative research regarding child pain-related injustice appraisals – was originally developed for adults, without an understanding of the aforementioned phenomenological child perspective.

To address this important gap in measurement and conceptualization, the present study aimed to examine the phenomenology of child pain-related injustice appraisals using an explicitly child-centered approach. The study utilized a focus group approach and included both pain free children as well as those living with chronic pain, to allow potential comparison of perspectives on pain-related injustice. Indeed, previous quantitative research suggests a potentially differential phenomenology of injustice appraisals across pain free and chronic pain groups, as findings did not always translate between groups (Daenen et al., 2022). Results of the proposed study are expected to contribute to our understanding of children's experience of pain-related injustice.

Method

Study design

Interpretative phenomenological analysis (IPA), an analysis method based on phenomenology, hermeneutics, and idiography (Pietkiewicz & Smith, 2014; Smith & Osborn, 2015), was selected as the qualitative approach. As the aims of this study comprise the exploration of the phenomenology of child injustice appraisals, it is appropriate to select an analysis method drawing from this particular approach. Specifically, IPA is a bottom-up oriented approach allowing the experiences of participants to speak for themselves, rather than fitting them into a predetermined categorical system (Pietkiewicz & Smith, 2014). IPA has been used successfully in the past to examine both lived chronic pain experiences (Osborn & Smith, 1998; Smith & Osborn, 2007), as well as the phenomenology of pain-related injustice appraisals in adults (Baert et al., 2020; McParland, Eccleston, et al., 2011).

Focus groups were applied as the chosen qualitative methodology to allow for the sharing of personal experiences, as the current research is of an explorative nature and both injustice and pain are experiences of a particularly personal nature; previous research has shown focus groups to facilitate personal, sensitive disclosures over individual interviews (Guest et al., 2017). To address the potentially differential phenomenology of pain-related injustice appraisals between pain free children and children with chronic pain, two sets of focus groups were conducted, with one set including pain free children, and another including children with chronic pain. Focus groups were conducted by means of a semi-structured schedule to both address the core research themes (i.e., pain and injustice) as well as provide sufficient freedom in the conversation by means of group discussion. The focus group schedule was developed based on similar focus groups on the phenomenology of pain-related injustice appraisals among parents of pediatric pain patients (Baert et al., 2020), with adaptations in language being made to ensure suitability for children, such as talking about unfairness rather than injustice as well as including examples to prompt discussion if required. The schedule started with an introduction round, followed by three major parts: 1) questions concerning the nature of pain and associated feelings or reactions; 2) questions concerning unfairness; 3) questions concerning whether pain can sometimes feel unfair, in what situations, and why. Probing questions were used to gain more insight into the responses of the participants to the open-ended questions. Focus group questions can be found in Table 1.

Participants

Pain free children

A total of 16 pain free children participated across two focus groups of eight children each, grouped by age: one group comprised children aged 9-12, a second group comprised children aged 13-16. Inclusion criteria were (1) being aged between 9-16 years old, (2) being Dutch-speaking, and (3) not having chronic pain (recurring pain lasting over 3 months). Children who had previously participated in research at the Department of Experimental-Clinical and Health Psychology and had indicated interest in participating in future research were recruited into the study. In line with IPA standards (Smith & Osborn, 2003), purposive sampling was used, in this case specifically to recruit children into two homogeneous groups in terms of age. Recruitment was stopped once an a priori determined limit of eight available children for each age category (i.e., 9-12 and 13-16) had been reached. We chose to include a maximum of eight children per group, as four to eight children are suggested as the group size for focus groups with children (Gibson, 2007), accounting for participants possibly not attending their focus group session. We chose to include a limited number of focus groups, as the analysis method, IPA, is better suited to a small amount of cases (Smith et al., 2009), with two groups the final result based on the feasibility of dividing groups and availability of the children in terms of picking a date and time.

Children with chronic pain

Fifteen children with chronic pain, aged 12-17, participated across three focus groups (n_1 = 4, n_2 = 4, n_3 = 7). Participants were recruited through purposive sampling via a rehabilitation center for children with chronic illness in Flanders. Inclusion criteria to attend the rehabilitation center included: (1) being aged between 7-18 years old, (2) having functional complaints that are insufficiently explained by a somatic disease, (3) having completed thorough somatic medical treatment, and (4) parents being actively involved in the treatment. Exclusion criteria to attend the rehabilitation center included: (1) the presence of comorbid symptoms which impede treatment (e.g., suicidality, psychosis), (2) and the physical inability to move. Inclusion criteria for this study were (1) being aged between 9-16 years old, (2) being Dutch-speaking, and (3) having chronic pain (recurring pain lasting over 3 months). Once an a priori determined minimum number of four participants per focus group had been reached to ensure sufficiently rich data (Gibson, 2007), a focus group was organized; one focus group was organized with seven participants, as multiple children reported interest at this time. As with the pain free children, we chose to include a limited number of focus groups, based on the choice for IPA as the analysis method (Smith et al., 2009). The final result was three focus groups, based on the availability of children at the rehabilitation center and the study timing.

Procedure

Pain free children

Ethical approval was obtained from the Ethics Committee of the Faculty of Psychology and Educational Sciences, Ghent University. The parents of the children were telephoned and informed about the study. If both parent and child indicated interest, they were sent further information about the study through e-mail. For both focus groups, children and their parents visited the faculty in October 2019. Upon arrival at the faculty, both children and parents signed consent forms for participation in the study and gave permission for the conversation to be audio-recorded and transcribed. After signing the consent forms, children were taken to the room where the focus group would take place, while parents either waited in the faculty lobby or returned once the focus group had been completed. Both focus groups were led by the primary author, with a faculty student attending to take notes and facilitate the audio-recording. Prior to starting the focus group, children completed a short demographic questionnaire, as well as questions regarding recent pain experiences to allow additional screening of pain symptoms among the participants. The focus groups took around 90 minutes each. All focus groups were conducted in Dutch. Audio-recordings of the focus groups were transcribed verbatim afterwards. Participants were reimbursed €35 for their participation in the study.

Children with chronic pain

Ethical approval was obtained from the Ethics Committee of the Faculty of Psychology and Educational Sciences, Ghent University, as well as the Ethics Committee of the Ghent University Hospital. Information sheets and informed consent forms were provided to a doctor acting as a contact person at the rehabilitation center, who reached out to children at the center living with chronic pain. If they indicated interest, they and their parents were provided the information sheets and informed consent forms which, upon agreement, were collected by the doctor and sent back to the research team. Focus groups were conducted between March and November of 2021. COVID-19 related guidelines were still active when the first two focus groups were conducted, so focus groups had to be conducted online. We used the Zoom application to connect remotely to the rehabilitation center, where children sat together behind a computer. Although ideally all focus groups would have been conducted face-to-face, this online alternative was deemed suitable and sufficiently reliable, as is demonstrated in recent research comparing both formats (Jones & Abdelfattah, 2020; Stewart & Shamdasani, 2017). As consent forms had been completed previously, we immediately started with the completion of a short demographic and pain-related questionnaire, which had been sent to the rehabilitation center by post prior to the focus groups. Upon completion of the questionnaires by all participants, we started the focus group, led by the primary author. The third focus group was held six months after the first two, when COVID-19 related guidelines had been eased, allowing researchers into the rehabilitation center. As such, the third focus group was held face to face, rather than online. Both online focus groups, as well as the face to face focus group, took around

90 minutes to complete. All focus groups were conducted in Dutch. Audio-recordings of the focus groups were transcribed verbatim afterwards. Participants were reimbursed €35 for their participation in the study.

Analysis method

Following IPA guidelines (Pietkiewicz & Smith, 2014), data analysis commenced with multiple readings of the transcripts while notes were made concerning researcher observations or reflections – a first stage of exploratory coding. In a further stage, notes were transformed through abstraction into themes, after which themes were clustered based on conceptual similarities. Transcripts from the focus groups with pain free children and children with chronic pain were analyzed separately from each other. To establish the recurrent nature of the generated themes, in line with previous work applying IPA to focus group methodology (Flowers et al., 2001; Love et al., 2020; Palmer et al., 2010), we chose to retain themes only when they were shared across all focus groups within the respective pain category of participants, and when at least half of participants in a group shared similar thoughts or feelings regarding the theme. While IPA is a method centered around idiography, it is nevertheless important to establish the recurrence of themes reflecting shared understandings, and remove idiosyncratic understandings (Smith et al., 2009). Notably, neither threshold led to the exclusion of themes, with all generated themes being shared across the focus groups within the relevant pain category. Final themes most representative of injustice notions are reported in the results section, along with representative phrases that were translated into English.

To establish credibility of analyses, we relied on the core features for acceptable IPA as outlined by Smith (2011). The first feature, to have a clear focus, was addressed in this study by designating the research topic to a very specific notion in specifically pain-related injustice perceptions. The second feature, to have strong data, was addressed by providing the most illustrative quotations as possible to clearly phenomenologically characterize the core of the generated themes. The third feature, rigor, was addressed by providing sufficient amount of quotations, spread across cases (here: both across groups and across participants), to indicate the breadth of the themes. Furthermore, as mentioned above, guidelines for recurrence were adopted to ensure the themes to reflect shared understandings. Rigor of the analyses was established further as the secondary author of the manuscript (FB), who has previous experience with conducting IPA (Baert et al., 2020), independently coded the first ten pages of each of the focus group transcripts, serving as a check of the credibility of the analyses performed by the first author. Establishing that the coding by the primary author (FD) lined up with the coding of the initial sections by the secondary author, served as a form of quality control of the qualitative analyses. Having a more experienced co-author supervise the analysis process is in line with typical IPA processes (Baert et al., 2020; Cox et al., 2022; McParland, Eccleston, et al., 2011; Smith et al., 2009) and strengthened the quality of the research. The fourth feature, sufficient space for elaboration of each theme, was addressed by providing high-level generated themes, rather than by breaking down the themes into its possible constituent parts. Instead, themes were generated through the clustering of phenomenological explications. This ties in to the fifth feature, analysis being interpretative and not just descriptive. This was addressed by drawing on the experiential core of the situations described by the participants, instead of by merely describing the specific situations they went through. The sixth feature, pointing to both convergence and divergence, was addressed by pointing out possible contradictions within the narratives as provided by the participants. Finally, the seventh feature, careful writing, was addressed by thorough reviewing of the manuscript by all co-authors.

Results

Pain free children

Study sample descriptives

Demographics and pain information of the pain free children are reported in Table 2. Children had a mean age of 12.31 (*SD* = 1.49), with 56.3% boys. Children indicated experiencing pain only occasionally, with an average of 18.88 days of pain over the past 6 months (*SD* = 43.70). However, this average includes one participant who indicated 180 days of pain in the last 6 months upon completion of the questionnaire, despite no mention of chronic pain having been made during earlier screening of inclusion criteria through telephone. The participant still took part in the focus group, but her having chronic pain was pointed out during this focus group as to make a clear distinction with the pain experiences of other participants, and her experiences were not taken into account during the analyses.

Focus group findings

As children were pain free and without experience of chronic pain, pain accounts largely focused on acute pain experiences such as pain occurring during sports or other physical activities, or pain as a result from small accidents. Two major injustice-related themes were generated based on the two focus groups with pain free children,: 1) ‘Someone else is at fault’, and 2) ‘I am in pain and he is not’. These two themes focus respectively on the two primary processes by which the children would appraise (acute) pain as unjust: respectively, attribution of blame and social comparison. Across themes, the issue of ‘deservingness’ seemed to play a crucial role. The children seemed to feel that pain cannot be ‘deserved’ if another is to blame for it, nor can it be if similar situations, e.g., two children falling in similar circumstances, do not lead to similar outcomes, e.g., one child breaking their leg and the other being unharmed. Accompanying injustice reflections focused on minor acute pain experiences rather than the severe consequences of pain.

‘Someone else is at fault’

The majority of the discussion about the potential of pain to be experienced as unfair centered around the presence or absence of attributions of blame. Typically, participants stated that, when another person could be clearly indicated to be at fault for the participant experiencing pain, the pain would feel unfair. The end result, experiencing pain itself, was not necessarily viewed as unfair – it was mostly dependent on who or what caused it and a potential sense of deservingness. This can be seen in the following quotation:

> Yeah, one of those people threw me into a bouncing castle and I landed with my nose against someone and it was then broken, that wasn't my fault so I was kind of angry. [Interviewer: Because someone else caused that. Now if you had tripped yourself, would...] Yes, then I would have thought it was fair, just because it was it was my fault. (Group 2, participant 7)

The participant described being hurt in a situation that they had no control over, with blame being assigned specifically to the person who threw them into the bouncing castle. This aspect made the pain feel unfair to the participant. This is highlighted specifically by the admission that, had they caused this pain on their own, for example by simply tripping over something and falling, that would not have resulted in feelings of injustice. This sentiment was echoed by a participant from the other focus group with pain free children:

> I've already had pain [before], but I haven't really felt like that's unfair. Because yes, they can't do anything about that of course. So I think that - yes, for me. I've had to walk on crutches before, but at the time I didn't really think that was unfair, because yes it's also my fault and not their fault so yeah. [Interviewer: Who do you mean with ‘they’? Other people or?] Yes, other people. Yes. [Interviewer: What had happened that you were on crutches? Had you fallen or so?] Yes, I was playing and I had jumped and I do

> not know why, but I had jumped to hard and suddenly I had to walk on crutches, because yes, usually it hurt. (Group 1, participant 4)

Here, the participant described a moment where they had injured themselves, but no one else was to blame for this. As such, the participant expressed not having experienced feelings of injustice about this at the time. These quotations indicate that if participants had no one to blame for the onset of an acute episode of pain, no injustice appraisals appeared to arise. However, having someone to blame was not always sufficient. Indeed, for an action and its consequences to feel unfair to them, a perception or suspicion of ill intent, or at the very least negligence, had to be present, whereby the pain was inflicted in an undeserving way. An example can be seen in the quotation below, continuing on the previously discussed quotation:

> [Interviewer: And say that someone would have pushed you, and that that would have caused you to fall and to need crutches. Would you have found that to be unfair then?] Well I would not find that unfair, because well. If he had done it on purpose, I would think that was unfair, but if he hadn't done it on purpose it would have been an accident and... then, there's nothing he can do about it. Then I don't really have a reason to find that unfair. (Group 1, participant 4)

This suggests that participants mostly thought about acute pain and injustice through the lens of intention rather than merely the consequences. If the other simply caused them to experience pain by accident, they still described the situation as unfortunate, but not as unfair. It is notable that, in the very first quotation in this section, the participant blamed someone who threw them into the bouncing castle, likely without the intention to cause pain. However, it is crucial to point out the words chosen here by the participant in the quotation above: “there’s nothing he can do about it”. This implies that, while intent to hurt can obviously be a source of blame, so can negligence. Indeed, the participant who was thrown into the bouncing castle, seemed to blame the person for not having been careful enough, rather than to imply that they were thrown with intent to cause to pain.

Attention was also drawn to the role of locus of control. Participants seemed to feel that, if they themselves were to blame for their pain, one could say that they ‘deserved’ it, because it was in their control to prevent it. If another was to blame, control was lost, and they could not be held accountable for the consequences, and as such should not be deserving of the pain. This is illustrated well by the following quotation from a participant, who specifically pointed at the human tendency to experience anything one cannot control as potentially unjust:

> That's just the way life is I think. I just think you're always going to reason that if it's out of your control, that you're going to find it unfair or unjust. Think that's usually the case anyway. (Group 2, participant 5)

This, however, does create a tension with the role of intent as described above. For example, when another person was the cause of an accidental trip, control was still lost, despite no attribution of malicious intent or negligence and accompanying blame having been possible. Participants seemed to resolve part of this tension by directing their anger of experiencing pain at the pain itself, rather than at another person, or by positively reframing the experience as undeserved yet fair. In other words, for participants, this just seemed to be what life is like, and that was not necessarily experienced as unfair. An example of this can be found in the quotation below, with a participant going through their immediate angry reaction to their painful experience and contrasting it with their retrospective reasoning that they got through it without assigning blame:

> For example when I had broken my hip… Now I'm over it, then I had constant pain and now I don't. Then it was annoying, you can't think clearly about it. Now that I think about it afterwards, I think that's fair, not that I deserved it, but that it

> happened and I'm also glad that it didn't happen to someone else. (Group 2, participant 2)

‘ I am in pain and he is not’

The second major source of potential injustice appraisals that was generated based on the focus groups was social comparison. Experiences were compared with other people in similar situations who somehow did not experience the same results as they do. Participants gave examples relating to injustice outside the context of pain, such as being born into poverty or simply having a bad life event happen to you that is beyond your control, and these thought processes translated to pain examples as well, as illustrated by the quotation below:

> For example, if you fall and the other one also falls and you are in more pain than the other one, I think that is unfair. (Group 1, participant 2)

Here, the participant described very specifically how, in very hypothetical terms, arbitrarily seeming to experience more pain than someone else who went through the same situation that caused the pain, can be a source of feelings of unfairness. What follows from this is the apparent expectation of a very clear link between cause and effect: If one person is in more pain than another, while no factors can be designated to be at cause for this, that constitutes injustice. The same type of reasoning was echoed by another participant from the same group:

> I mean then, if you have something and your friend has the same thing but not as bad. So you break your leg from jumping two meters or so and someone else does the same and has nothing. Like, he didn't bruise anything or so. (Group 1, participant 7)

This participant considered a hypothetical situation where they and a friend would jump from the same height, yet only one of them would get injured because of this. This type of ‘bad luck’ can easily be designated as arbitrary distribution of outcomes, leading to feelings of unfairness. Similar to the theme ‘Someone else is at fault’ described above, the pain in itself did not seem to be what is unfair here – it was only made so through comparisons with others. Whereas the theme ‘Someone else is at fault’ necessitated the (intentional) involvement of another to constitute injustice, this was not the case here: mere upward comparisons with others who are perceived to have more favourable circumstances could make it so. While this creates a clear difference with the previous theme, we might still view the experience as similar at its source, that is, a perceived lack of control, stemming from a sense of arbitrariness. We might interpret this as follows: Life is predictable only insofar as certain ‘rules’ or procedures are followed – typically named procedural (in)justice. While events constituting procedural injustice are most typically interpersonal (i.e., others violate a set of rules, whether explicit or unwritten, which causes blame and consequentially an experience of unfairness), it seems that participants generalized this to what might be called a ‘cosmic’ level as well, that is, the world is supposed to behave identically for everyone. If not, control over the world is lost, and so is equality:

> Yes, you have that and he doesn't. Then you are angry, because you want everything to be the same between the other person and you. (Group 1, participant 8)

Children with chronic pain

Study sample descriptives

Demographics and pain information of the chronic pain sample are reported in Table 3. Children had a mean age of 15.40 (*SD* = 1.18), with 86.7% girls. Participants indicated experiencing pain almost every day, with an average of 168.53 days of pain over the past 6 months (*SD* = 23.07). Common pain conditions included stomach pain (*n* = 5), headache (*n* = 3), joint pain (*n* = 2), and back pain (*n* = 2).

Focus group findings

Overall, participants indicated that rather than the pain sensation itself, it is the consequences of that pain that make them perceive their condition as unfair. While the pain itself was clearly not to be reduced to a mere trivial experience, they often indicated that it is something that they could get used to or learn to cope with – it remained terrible, but they did know what to expect and consequently how to navigate the pain episodes. Only rarely was the pain experience itself considered to be an example of injustice. There were two distinct core themes: 1) ‘People don’t see my pain’, and 2) ‘I am missing out because of my pain’. Central to these themes is the notion that children with chronic pain most of all want equal opportunities. They want to live their lives as normally as possible and have the same opportunities as everyone else despite their pain. While the pain itself may be manageable, the consequences often are not:

> I am much less annoyed by my pain than by its consequences. Of course, it is the pain that has to be dealt with to avoid the consequences, but talking about the pain is not going to help because it's there anyway. But talking about the consequences, explaining I feel this way, that can help. (Group 2, participant 4)

In the above quotation, the participant described that the sensation of pain, and the effects that such pain sensations may cause, are quite separate based on how they might be managed. Specifically, they mention that ‘talking about pain’ cannot help, meaning that it cannot be meaningfully influenced. Instead, the pain itself is something that has to be lived with. On the other hand, the various consequences of pain, which will be detailed thematically below, can be ‘talked about’; that is, these consequences are understood be more easily subject to change based on reactions by others than the seemingly unavoidable nature of the pain sensations themselves. Another participant expressed the idea similarly, by pointing out that the link between pain sensations in themselves and the resulting consequences is rather contingent, and that those consequences are a crucial source of feelings of unfairness and a difficult life:

> I also think it's not just the pain itself, because ultimately when we have pain it's not that our lives should be so much harder than the rest if we all had fair opportunities, but because we can't go to school there's even more unfairness in it than just, why are we in

> pain. In the end, it's a natural thing that no one is prepared for, yes sometimes there's nothing you can do about what happens, and yet it feels unfair. (Group 3, participant 5)

‘People don’t see my pain’

One theme stood out among all others in all focus groups conducted with children with chronic pain, and dominated all conversations: the feeling of their pain experiences being invalidated, i.e., not being seen or not being taken seriously. This theme was commonly reported. Participants felt that their pain experiences were often invalidated by different groups of people, ranging from family, to friends, to teachers, and even to doctors. Common to most of the stigmatizing reactions they faced was the perception that their pain reports are in some way not genuine, whether they are making up the pain, faking, or exaggerating it. Such stigmatizing reactions are exemplified by the following quotation:

> After a while you also feel like the annoying fly. Here it's less so because everyone has something, but for example at school, sometimes I felt like I would faint so I had to take the elevator, then they said ‘You’re lucky’. But that's not lucky, I also want the stairs. Really they don’t understand. I also had to go to the toilet constantly for a while, but people don't understand that, even teachers, they think you just want to avoid a test, or don't want to go to class and then they refuse. That's also very hard mentally, I'm almost sitting here weeping and they won't let you go. Then you think, I don't care. Then you also think, what have I done now, I go to the toilet in the middle of the class, that's not allowed normally, and then you get complaints about that too. Then you think, I can't do anything right. (Group 3, participant 2)

The participant described how many people, both peers and teachers, can be doubtful about their pain experiences, even suggesting that they are lucky to not have to take the stairs. They express a very specific inability to make others understand how they really feel, that in fact, they feel quite the opposite of lucky. Similar hesitations as expressed by peers about their pain experiences can be found in the quotation below, where a participation described such hesitation as especially painful when expressed by a friend:

> One of my best friends, I was already sick for half a year, then she asked me, ‘I want you to look at me straight and tell me if you are really sick or pretending not to go to school’, that is very painful. (Group 2, participant 4)

This lack of understanding can become very concrete when it comes to experiences at school, as academic processes can be largely impacted. Another participant described feeling a lack of understanding by their school in their efforts to push them to return to school:

> I had to do my exams and I really couldn't, I was pushed so hard to go back to school, then I did get angry at my school, obviously people here don't see what I have and how serious it is. (Group 2, participant 3)

At the heart of these stigmatizing accusations seemed to be the nature of the chronic pain condition common to most participants. They remarked that their condition lacks a clear (medical) cause and that most people find it difficult to accept this – indeed, participants realized that the typical pain experience for pain free people is acute pain, where causes are readily available and often accompanied by a visually noticeable injury, whether externally visible or on medical imaging. The type of chronic pain experienced by the participants was not necessarily accompanied by any clear injury or other visual signifiers of their being ill or injured. This seemed to lead to participants experiencing stigmatizing reactions from others, who seemed to feel that they may be making up or exaggerating their pain, possibly to create excuses to avoid difficult parts of life. Participants lacked, to use their own words, ‘proof’ of their pain to disprove these suspicions. This concern was demonstrated in the quotation below:

> If that's on a scan, for example, then you really have that exact proof. Look this is it. With chronic pain it's not like that. With us, for example, there is no scan of your body that you can show, for example, that yes, this is wrong. And for me, that's the most

> frustrating thing, that I can't prove that there is something wrong. (Group 1, participant 1)

Without simple proof of their pain, such as with people who break a bone which can be clearly visually identified by others, their pain experiences can be cast into doubt. Another participant brings up the same idea, pointing out how their lack of looking like typical people in pain leads to invalidating responses by others:

> Why should you, if someone has a bump on the head, take it into account and accept that he has pain, and if not, not. I think that's unfair, I also have pain and that's different pain and you don't see pain but I feel it. I'd rather have a bump on my head than the pains I normally feel. (Group 2, participant 4)

In addition to feeling invalidated by school and peers, participants regularly described similar invalidating experiences in interactions with medical professionals. Once again, the lack of proof seemed to be at the core of this experience of invalidation, with medical professionals often still subscribing to biomedical views on pain, rather than adopting a biopsychosocial model. In the quotation below, one participant described their invalidating experience in a medical setting:

> I had it mostly in the hospital. First I had a doctor who did nothing. He did all the tests that were there, but he said 'there's nothing wrong, nothing this, nothing that' all the time. I then changed doctors. That doctor literally told me to go to psychiatry or an institution, because he thought I was making it all up. Family members also thought like that, 'none of that is true' and 'you're just saying that to seek attention'. It's just literally said to my face and that hits very hard. (Group 1, participant 2)

Related to this is another issue: Because participants were not able to show proof that they really are in as much pain as they indicate, they had to resort to strategies aimed at avoiding or reducing invalidation, for instance, by displaying sufficient pain behaviours for others to take them seriously. We might see this as trying to conform to the idea that lay people have of what people in pain typically look or act like. The quotation below spoke to the variability of pain and the fact that pain patients do not always conform to the typical sick role, making it difficult for others to understand.

> After a while, first it starts with, ‘we have no explanation for it’, and after a while you just stop saying it [that you are in pain]. Then they also don't hear it often enough, ‘today I can't do this and that’, ‘why is it suddenly there today’, then it seems like it [the pain] comes out of nowhere. They miss that complaining, because they complain when they have pain. It's not as if you go to the hospital every week, that also costs a lot of money, you only go when it's really necessary, then there are sometimes three months between, then it seems like nothing has happened. (Group 3, participant 5)

When participants had a serious pain episode and cannot help but show extreme pain behaviours, such as crying, lying on the floor, or fainting, they indicated that these moments often helped convince others that their pain is genuine after all. This was demonstrated by the following quotation:

> Also because I did not show it [the pain], but if I did show it when there was no other way, then it [the understanding] came. I think it takes time. (Group 2, participant 4)

However, showing pain behaviours is at odds with participants wanting to live their lives as normally as possible. Participants indicated fear of being perceived as nagging, or at other times, that their pain comes and goes episodically, which again seems to go against the lay expectation that people in pain suffer mostly continuously. In the quotation below, a participant described how the absence of typical pain behaviours led to more invalidating responses by others.

> Meanwhile, you can hide it so hard that no one sees it and people think, she has nothing at all, why is she acting so ridiculous, while we have a lot of pain but they don't see it. (Group 3, participant 7)

This can even lead to the feeling that, in moments that they feel better, having fun can be a source of even more skepticism from others. Indeed, as demonstrated by the quotation below, participants felt that when they did have fun, others took this as evidence that their pain was not really as bad as they were making it out to be, or that it had healed. Here, the participant expressed a conflict between needing a painkiller to be able to deal with the pain and have positive moments with friends, and such positive moments being seen as evidence that a painkiller is not necessary at all:

> Because for me that's the case with friends, here too, we're chatting and I ask for a painkiller and ten minutes later I'm laughing, and then they say, ‘you can't come and ask for a painkiller when you're laughing’, that really takes away my pain, friends and active things are really things that take away my pain because then I don't think about that all the time. Then people say, yes you can do active things, but you can't go to school or ask for a painkiller but you are jumping and dancing, yes that is also very frustrating. (Group 2, participant 1)

‘I am missing out because of my pain’

A major and commonly shared injustice theme among participants was that their pain leads them to miss out on social, recreational, and educational activities, whether as a hobby, at school, or with peers. Participants stated that it is sad they cannot take part in their hobbies like they used to and cannot live a normal life. This is in stark contrast to seeing peers still engage in the activities that they themselves often performed prior to living with chronic pain, serving as a reminder of the experiences and opportunities that they are missing out on because of their pain. This was demonstrated well by the following quotation:

> Or also like you see on Instagram that there's a party somewhere or something that you can't attend because you know that afterwards it will hurt you too much and yeah. Just having an adolescent life, we can't, for example. We have to watch constantly that we have pains so that's not possible or, yeah. You see your friends do all kinds of things and then I think, yeah, I can't do it and that bothers me. (Group 1, participant 2)

Here, the participant pointed out how adolescent life often consists of activities such as social gatherings, and in recent times, also accompanying social media references to such events. As a person living with chronic pain, the participant has to give great attention to their pain and its management, which leads them to not easily be able to attend social gatherings and similar activities. Being confronted with this via social media only heightens the feeling of not only missing out, but an inability of not missing out at all through the pain. This sentiment was similarly pointed out by another participant, who specifically names the identification of not being a healthy child as a source of injustice, with the accompanying reduced opportunities in life:

> For me, it's just that I think it's unfair that I'm not a healthy child, that I can't do everything that others can. (Group 1, participant 3)

This is not to say that children with chronic pain can never participate. However, even when they do, the presence or even possibility of pain weighs heavily. Pain management or avoidance strategies, or merely the presence of pain itself, can impact their level of involvement in activities. In the quotation below, a participant described that even when they can engage in dancing, which they were able to do very well prior to living with chronic pain, they can still not give their all. Even more so, engaging in a hobby where they are confronted with others who remind them of what they used to be able to do prior to the pain, can be very hurtful and a source of injustice.

> It hurts so much that you can hardly do anything and even if you can, you can't do it completely. Like now, I've been dancing for 11 years, I danced at the top level, now I can't even do my dances for one hour. Then it's very unfair when someone else in your group can do it, without pain, and that's very hard to see. Others can do it without the pain and I have to do it with the pain, that it just isn't possible. And why me, why did I get the pain. (Group 2, participant 1)

A distinct interpersonal dimension to this theme is that participants felt as though their sense of autonomy is threatened by their status as a chronic pain patient and how peers react to this. Friends might anticipate that they might find it hard to join an event because of their pain, and would not bother asking them to join. Participants stated that they understood that often this might be well-intended, yet they experienced it as a violation of their autonomy. They themselves wanted to be the ones to make these decisions. Most of all, they wanted equal opportunities to those who do not live with chronic pain, and wanted to live life as much as possible on their own terms. One participant described how, after a while, peers do not invite them anymore to social activities, which removes their autonomy:

> I think that sometimes it is good to take it into account but I also understand what [other participant] says, that it is sometimes annoying, that you prefer to indicate it yourself if you can’t come, that you prefer to try everything and otherwise find a solution yourself. I've also had friends stop asking me because they know it's exhausting, but you still want to have the choice. (Group 2, participant 2)

While not being invited may in some situations be linked with the skepticism and accompanying invalidation as described in the previous theme, this does certainly not necessarily have to be the case. Indeed, the participant above described that friends may simply stop asking them to come due to their understanding of the differing levels of exhaustion that activities may bring to someone living with chronic pain. This was echoed by another participant, with both pointing out the importance of autonomy in deciding themselves what activities they will have to miss out on:

> I would just find it very annoying that they meet on the sly because I can't go. I prefer that they give me the choice, usually I go along and sit on a bench, and I participate for ten minutes, but then at least I am there and I do not miss all the fun. That's happened a few times that they didn't ask me along, then you find out and then I did feel good enough to go along that day. And when you say that, the reaction is, ‘you're too tired anyway,’ that's not the reaction you want. They don't want trouble, they don't want me to put it on them if I'm in a lot of pain then, they want to protect me, that's good but no one can determine that for myself. (Group 2, participant 1)

Finally, pain also reduced the opportunity for engaging in their education. Their pain condition often led them to having to miss out on classes, not being able to take tests, or, even while they were at school, not being able to focus on the classes as much as they would be without the pain. Regardless of how much effort they put into school, having to live with chronic pain and regularly missing classes because of this, inevitably means missing out on the same learning opportunities that are offered to their peers, as described by a participant in the quotation below:

> Sometimes it’s like, ‘you just stay at home so you don't have to take exams’. Then I think, I would much rather be there and do my tests because afterwards you have to catch up on the subject matter and that is ten times harder than just taking a test. (Group 2, participant 1)

As such, it is not merely missing out on class activities, but also the feeling of having to try exponentially harder than peers to attempt to compensate for their absences. Another participant described how, even when adjustments are made to be accommodating towards them because of their chronic pain, this may still miss the mark. Even when a teacher takes out extra time for them to be able to pose questions about classes they were not able to attend, this cannot compensate for what is being missed out on:

> It's everything on top of it, what comes with it. Now it could be that you were sick three days in a week, and you try just as hard in school, but because you were sick you were absent and then you have to transcribe the course and in the end you know less than the rest because they were able to ask questions, hear the explanation in full. That's also unfair, because if you ask a teacher something it happens in two minutes while the rest get a whole hour for that. (Group 3, participant 6)

Discussion

This study explored the previously unexamined phenomenology of child pain-related injustice appraisals in pain free children and pediatric chronic pain patients. Two injustice-related themes were generated based on the focus groups with pain free children: 1) ‘Someone else is at fault’, and 2) ‘I am in pain and he is not’. Two injustice-related themes were generated based on the focus groups with pediatric chronic pain patients: 1) ‘People don’t see my pain’, and 2) ‘I am missing out because of my pain’.

Pain free children recognized that the experience of pain can sometimes be perceived as unfair, and offered two different processes by which such appraisals might arise: blaming others for causing pain and making upward social comparisons. When pain felt particularly ‘undeserved’ and arbitrary, children perceived that rules about how the world should function are violated. In particular, children indicated experiencing a lack of control and notice what might be considered ‘cosmic’ procedural injustice, leading to an inequality in distribution of outcomes. This is in line with previous research showing that children already form strong inequality aversion from the age of 7-8 (Fehr et al., 2008; Jose, 1990; Sutter, 2007), as well as literature surrounding ‘just world beliefs’, i.e., an individual's view of the world as just, predictable, and controllable; violations of this view can engender feelings of injustice (Dalbert, 2009; Lerner, 1980). Indeed, injustice literature outside the context of pain has shown that lacking a sense of control over one’s surroundings is associated with a higher sensitivity to injustice (Žitný & Halama, 2011).

While pain free children solely talked about how pain itself can feel unfair, children living with chronic pain almost invariably talked about how everything *except* the pain itself can feel unfair. Although acceptance was not explicitly measured, most children seemed to show a degree of acceptance towards their pain in the focus groups. While it is important to note that all children with chronic pain attended a rehabilitation center, which may have affected their pain acceptance, participants noted that it was something they simply had to learn to cope with. Rather, it was the stigmatizing reactions of others and subsequent feelings of invalidation that formed the source of their lived injustice experiences and interfered with their attempts to come to terms with their condition. Participants held the belief that others fail to understand and subsequently discredit their pain because they cannot show proof, nor do they display typical pain behaviours. Indeed, adult stigma literature notes that chronic pain is taken less seriously in the absence of medical evidence, leading to social exclusion, poorer treatment by medical professionals, and feelings of invalidation (de Ruddere et al., 2012, 2016; de Ruddere & Craig, 2016). Recent research in an adult chronic low back pain sample found injustice appraisals to mediate the association between chronic pain stigma and both pain severity and physical function (Penn et al., 2020), stressing the conceptual link between stigma and injustice appraisals. Nevertheless, injustice themes from the children with chronic pain were not limited to stigma. Other violations of equality of opportunity or outcomes are similarly at the source of injustice appraisals, e.g., not being able to participate in their hobbies as they used to, perceiving a lack of equal chances at school, or choices being taken away from them. Even when such equal chances may be present, the pain prevents equality of outcomes, such as when the children with chronic pain are unable to perform their school activities similarly to pain free children.

Children with chronic pain often indicated that it would be helpful if the school provided accommodations for their situation. This may be viewed as a need for equity: different resources being allocated to vulnerable populations to allow the same opportunity.

Importantly, themes generated from pediatric pain patients showed little overlap with themes generated from pain free children. As pain free children hold no lived experiences of chronic pain, they do not hold lived experiences of its consequences either, including stigmatization due to chronic pain, being discredited, or experiencing a lack of opportunities. Similarly, themes generated from the focus groups with pain free children such as blame were barely discussed or quickly discarded by the pediatric pain patients, perhaps due to having had to learn to accept the pain itself. Based on these divergent focus group findings, and the view of the pediatric pain patients that the often interpersonal consequences of the pain outweigh the pain itself, we suggest that the conditions that give rise to child injustice appraisals might not be viewed as a spectrum ranging from acute to chronic pain. Instead, the conceptualization of pain-related injustice as drawn from the pediatric focus group themes indicates a clear distinction with the account of pain free children, suggesting that the injustice experiences resulting from living with chronic pain are qualitatively distinct from the potential injustice experiences resulting from dealing with acute pain as a pain free child. While injustice as a notion is readily recognized by pain free children, viewing it in the context of pain seems to be rather trivial to them and rarely pain-specific as opposed to reflections made by pediatric pain patients.

Previous research into the phenomenology of pain-related injustice appraisals among adults with chronic pain and parents of pediatric pain patients shows similar themes. In line with current findings, parents of pediatric pain patients view their child’s condition as unjustly invalidated and hold a strong desire to obtain a diagnosis for their child, serving as proof of their child’s pain (Baert et al., 2020; Neville et al., 2019). Qualitative work with adult chronic pain patients likewise concludes chronic pain to be as much a social as a medical problem (McParland, Eccleston, et al., 2011). Similar themes include invalidation, stigma, and seeking equality. Another typically recurring theme concerns engagement with the financial benefit system, clearly unique to an adult's life; analogously, themes such as children's participation at school do not translate to adults' experiences and demonstrate the need to view children's phenomenology of pain-related injustice as unique.

Comparing the pediatric pain focus group themes with the content of the current main measure of child pain-related injustice appraisals, i.e., the IEQ, we note that neither IEQ subscales, i.e., 'severity/irreparability of loss' and 'blame/unfairness', readily reflect the themes observed in the focus groups. Indeed, as described above, 'blame' is a concept barely touched upon by the pediatric pain patients and may be mostly useful for acute pain experiences or accident-related injuries. As the original IEQ authors suggest a unitary approach to the measure (Sullivan et al., 2008), measure items are compared with focus group themes instead. While some items reflecting invalidation are offered (e.g., "Most people don't understand how severe my condition is"), they represent a minor share of the total items, with other items mostly being of an intrapersonal nature (e.g., "Nothing will ever make up for all that I have gone through"). The current findings suggest that questionnaire items ought to more concretely emphasize perceptions of interpersonal injustice and be specifically shaped to child situations, while being especially mindful of the conceptual distinction between the injustice notions held by pain free children and pediatric pain patients. Indeed, the differential focus group findings imply that measures assessing child pain-related injustice appraisals may not generalize from acute to chronic pain populations, providing a possible explanation of either the absence of or diminished associations between child pain-related injustice appraisals and pain-related outcomes in pain free children as opposed to pediatric pain patients (Daenen et al., 2021, 2022). Findings further inform the potential development of a new questionnaire to adequately reflect child-specific notions of chronic pain and injustice, by capturing themes such as feeling left out, not being granted equal opportunities, or the inability to express one's pain without fear of being judged or stigmatized. Nevertheless, while current findings indicate that IEQ items may need to be adapted to more accurately reflect child phenomenology of injustice, existing findings from using the IEQ should not readily be discarded, as multiple items are in line with themes generated from this study. Instead, tailoring items may mainly benefit the more fine-grained contrasting of acute and chronic pain, as well as the interpretation of potential subscales.

Several limitations are noted. First, while efforts were made to have samples of comparable ages, recruitment feasibility led to the chronic pain sample being older than the pain free sample. It may be possible that experiences from younger children with chronic pain would have differed compared to the generally older sample in our study. Second, the sample of pediatric pain patients included only children who at the time were attending a rehabilitation center, which might have influenced their levels of acceptance and reflection about their own pain experiences as compared to children with chronic pain who do not receive similar support. Third, the sample showed limited diversity, with all participants being Flemish and White, raising potential concerns about the cross-cultural generalizability of the current findings. Fourth, two focus groups with pediatric pain patients had to be run in an online format. Although online synchronous focus groups are considered valuable alternatives to face-to-face interviews (Iacono et al., 2016; Janghorban et al., 2014), the fact that not all focus groups were conducted in the same setting may be worth considering when interpreting the findings.

In conclusion, this study offers the first exploration of the phenomenology of child pain-related injustice appraisals, among both pain free children and pediatric pain patients. Findings highlight the interpersonal nature of lived injustice experiences not fully captured by current child pain-related injustice measures, and suggest that injustice notions may not be extrapolated from a chronic to an acute pain context.

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Tables

Table 1

Interview schedule.

Introduction

1 Why did you choose to participate in this research?

2 What is pain, according to you?

3 What impact might pain have, according to you?

4 What feelings does pain cause?

5 What does unfairness mean to you?

6 Do you think life, in general, is fair?

7 Have you had pain that you thought was unfair?

8 When could pain be unfair?

9 What do you think and feel when pain could be unfair?

10 How do you deal with pain that is unfair?

Conclusion

Table 2

Healthy sample demographics and pain information

Group	Participant	Age	Sex	Days of pain	Type of pain
1	1	12	M	10	Unclear
1	2	11	M	0	/
1	3	12	F	180	Joint
1	4	12	M	0	/
1	5	10	F	1	Stomach
1	6	10	M	6	/
1	7	10	M	0	/
1	8	12	M	3	Stomach
2	1	13	F	10	Achilles
2	2	14	F	18	Headache
2	3	13	F	7	Neck
2	4	15	M	30	Knee
2	5	13	M	2	Stomach
2	6	14	F	15	Joint
2	7	13	M	10	Throat
2	8	13	F	10	Joint

Table 3

Chronic pain sample demographics and pain information.

Group	Participant	Age	Sex	Days of pain	Type of pain
1	1	16	F	150	Headache
1	2	15	F	180	Back
1	3	16	F	180	Back
1	4	15	F	180	Headache
2	1	17	F	180	Skin
2	2	12	M	98	Stomach
2	3	15	F	180	Joint
2	4	15	F	180	Headache
3	1	16	F	180	Skin
3	2	16	F	180	Neck
3	3	16	F	180	Joint
3	4	16	M	180	Stomach
3	5	16	F	180	Stomach
3	6	16	F	150	Headache
3	7	14	F	150	Headache