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Baert, F.; McParland, J.; Miller, M.M.; Hirsh, A.T.; Wallace, E.; Dickson, A.; Trost, Z.; Vervoort, T.

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Abstract

Background. In line with research highlighting the role of observer appraisals in understanding individuals' pain experience, recent work has demonstrated the effects of *parental child- and self-oriented injustice appraisals* on child pain-related outcomes. However, research on parental injustice appraisals is in its infancy and lacks a valid and context-specific operationalization of what parental injustice appraisals of child pain precisely entail. The current study presents an in-depth qualitative analysis of parental child- and self-oriented appraisals of injustice in the context of their child's chronic pain. **Methods.** Twenty-one mothers of children living with chronic pain participated in one of five focus group interviews conducted in Ghent (Belgium), Glasgow (Scotland) and Indianapolis (USA). **Results.** The interviews were subjected to interpretative phenomenological analysis, which revealed three key justice-related themes, labelled 'You shouldn't be in this much pain', 'The problem's probably with the mother' and 'At least it's not cancer'. Maternal injustice appraisals focused mainly on the child rather than the self and reflected various perceived barriers to their efforts to provide quality of life for their child. A fourth theme labelled 'Not everybody gets a healthy child' reflected maternal strategies to effectively cope with the child's condition and the associated appraisals of injustice. **Conclusions.** The current findings attest to the relevance of (child- and self-oriented) injustice in the parental experience of caring for a child with chronic pain and provides insight into the specific content and scope of these appraisals. As such, this study provides valuable insights to further research in this area.

Mothers' appraisals of injustice in the context of their child's chronic pain: An Interpretative Phenomenological Analysis.

F. Baert.¹, J. McParland², M. M. Miller³, A. T. Hirsh³, E. Wallace⁴, A. Dickson², Z. Trost⁵ & T. Vervoort¹

¹ *Department of Experimental-Clinical and Health Psychology, Ghent University, Belgium*

² *Department of Psychology, Glasgow Caledonian University, Glasgow*

³ *Department of Psychology, Indiana University – Purdue University Indianapolis*

⁴ *Department of Anaesthesia, Royal Hospital for Children, Glasgow*

⁵ *Department of Physical Medicine and Rehabilitation, Virginia Commonwealth University*

Corresponding author: Fleur Baert, Department of Experimental-Clinical and Health Psychology, Ghent University, Henri Dunantlaan 2, 9000 Ghent, Belgium.

Electronic mail may be sent to Fleur.Baert@UGent.be

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Significance: the current study is the first to present an in-depth qualitative analysis of parental appraisals of injustice in the context of their child's chronic pain condition. The findings provide valuable insights into the phenomenology of this construct and may inform future research and assessment methods. Further, the themes reported in this study may contribute to clinical practice, as they may raise awareness of parental concerns regarding their child's pain management.

1. Introduction

The experience of pain is common in childhood and is usually temporary. However, a considerable proportion of children report chronic, long-term pain that has a significant impact on their everyday lives (e.g., impaired functioning, school absence and general distress) (Perquin et al., 2000; Forgeron et al., 2006; Huguet & Miro, 2008; King et al., 2011). This impact extends beyond the child into the everyday social context in which children live their lives, most immediately affecting their parents (Eccleston & Malleson, 2003; Eccleston et al., 2004; Jordan et al., 2007; Goubert et al., 2008; Jordan et al., 2016), siblings and peers (Guite et al., 2007; Jaaniste et al., 2013). This impact may manifest in e.g., distress or burden, marital tension, reduced social or professional functioning,... Research increasingly recognizes the social and interpersonal context in which pediatric pain occurs (Engel, 1980; Gatchel et al., 2007; Karos, 2017; Karos et al., 2018). Evidence suggests that how an observer (e.g., parent, family caregiver) appraises another individual's (chronic) pain is an essential component of the patients' pain experience (Jacob et al., 1993; Cano et al., 2005; Hadjistavropoulos et al., 2011; Mohammadi et al., 2016; Vervoort & Trost, 2017; Fauchon et al., 2017). For instance, parental catastrophic or other illness-related appraisals can negatively impact children's pain-related outcomes (e.g., pain intensity, disability, school absence) (Chambers et al., 2002; Crombez et al., 2003; Eccleston et al., 2004; Goubert et al., 2006; Goubert et al., 2008; Hechler et al., 2011; Caes et al., 2011; Caes et al., 2012; Mullins et al., 2016).

More recently, research has also examined the impact of parental pain-related injustice appraisals, an appraisal cognition comprising elements of the severity and irreparability of loss due to pain and a sense of blame or unfairness (Sullivan et al., 2008; Mohammadi et al., 2016), on both child and parental functioning (Mohammadi et al., 2016; Miller et al., 2016; Miller et al., 2018; Baert et al., 2019). This research has shown higher levels of parental injustice appraisals to be associated with greater child pain intensity, disability, and quality of life. In

terms of parental functioning, higher levels of injustice appraisals may undermine parental well-being by inducing greater stress and burden (Mohammadi et al., 2016) which, in turn, may hinder effective parental caregiving. This research indicates there are potentially clinically important implications of this research and highlights the need for more research in this area. Specifically, research is needed to understand the *nature* of parental injustice appraisals in the context of pediatric chronic pain. Currently, what is known about parental perceptions of injustice is based on the use of the Injustice Experience Questionnaire (IEQ; Sullivan et al., 2008; Sullivan et al., 2012; Yamada et al., 2018) which was developed for use in adult chronic pain samples to measure injustice appraisals in relation to blame, loss and unfairness related to personal pain experience. More recent evidence suggests that parents tend to think about their child's pain in a more diverse way, encompassing both their perspective of themselves as parents as well as their child (Baert et al., 2019). There is also good evidence to suggest that parents think about their child's pain in a way that implies unique sources of injustice that may be relevant to the parent, such as fighting for resources, the child's condition being questioned, and the perceived inability to fulfill one's parental role (Jordan et al., 2007; Jordan et al., 2016). However, such experiences have yet to be considered and investigated in terms of perceived pain-related injustice.

Thus, there is an important knowledge gap regarding the nature and operationalization of parental appraisals of injustice about child chronic pain that needs to be addressed to progress research in this field. This study sought to conduct in-depth qualitative research with parents of children with chronic pain to explore *parents'* views of the meaning of injustice in this context – for themselves and for their child.

2. Method

2.1. Participants

Participants were 21 mothers of children living with a chronic pain condition (see table 2 for basic demographic information for each participant). The main inclusion criterion for the current study was occupying a primary caregiver role (i.e., mother or father) for a child or adolescent who had experienced pain for a minimum duration of six months. Twenty-one mothers (no fathers) volunteered to partake in one of five focus group discussions conducted at Glasgow Caledonian University ($n_1 = 5$; $n_2 = 6$), Indiana University - Purdue University Indianapolis ($n_3 = 3$; $n_4 = 2$) and Ghent University ($n_5 = 5$). As only mothers signed up for the present study, participants will be referred to as ‘mothers’ from this point forward.

Focus group methodology was chosen over individual interviews given the explorative nature of the study and the added experiential reflection this allows (Tomkins et al., 2010; Guest et al., 2017; Guest et al., 2017). Further, this may have created a more supportive, non-judgmental and safe environment for sharing experiences, which could benefit the richness of the data. The number of focus groups was deemed sufficient as evidence suggests that between three to six focus groups can capture 90% of themes related to a topic (Guest et al., 2017). Efforts were aimed at recruiting four to eight participants in each focus group (Kitzinger, 2005), which was achieved in three out of five groups. Although not quite reaching our target (due to participant no-shows), the sample size in the Indianapolis groups (i.e., two and three participants) were deemed sufficient as evidence indicates that meaningful data can be obtained in focus groups of this size (Githaiga, 2014).

2.2. Procedure

Ethical approval for each study site was obtained from each respective ethical board. In Glasgow, participants were recruited through the Royal Children’s Hospital by identifying parents through their children’s medical records from the chronic pain cohort managed within the paediatric pain service. Study invitation letters were sent to a random sample of 120 families who met study criteria. Participants who were interested in participating then contacted the

researchers. Here, focus group interviews were conducted by JMcP and each focus group interview took around 90 minutes to complete. In Indianapolis, participants were recruited through the Riley Children’s Hospital Pain Clinic Registry by contacting eligible parents by phone. Here, group discussions were facilitated by AH and MM and each group also lasted around 90 minutes. In Ghent, participants were mothers of children who had participated in a previous study and who had indicated that their child suffered from chronic pain. These participants were contacted by phone to screen for interest in partaking. This group interview was conducted by TV and AE. All participants provided written informed consent and completed a brief set of demographic questionnaires prior to attending the group discussions. All interviews were audio-recorded and transcribed either by the researchers or an external transcription service. Participants each received a financial reimbursement (€25, £25, \$25).

2.3. Interview schedule

A semi-structured interview schedule was designed and used to facilitate the group discussions. The schedule was developed by three members of the research team (JMcP, TV and ZT) in consultation with a group of university students who took part in a pilot focus group discussion to test the interview structure. The interview schedule comprised questions relating to mothers’ experiences of parenting a child with a long-term pain condition and focused particularly on perceived unfairness in the context of pain. Mothers were prompted to report on this perceived unfairness from their own perspective as a parent (i.e., self-oriented injustice appraisals) and from their child’s perspective (i.e., child-oriented injustice appraisals). The schedule was structured to contain opening questions, key questions and closing questions (see Table 1). Probing questions were included to facilitate the discussion when needed. All questions were displayed on a screen.

Opening questions

- 1 What interested you to participate in this study?
- 2 What does “unfairness” mean to you?
- 3 Do you think that life in general is fair?

4	What is it like for you to be the parent of a child who has a long-term pain condition?
Key questions	
5	When you think about your child's pain condition, to what extent do you think that life is unfair?
6	When you think about your child's pain condition, to what extent do you think that life is unfair for you as a parent?
7	When you think about your child's pain condition, to what extent do you think that life is unfair for your child?
Closing questions	
8	(Verbal summary of the content of the discussion) Did I correctly describe what you discussed today? Is there anything you think is missing from the discussion?
9	What was the group experience like for you?

Table 1. Semi-structured interview schedule

2.4. Method of analysis

Each transcript was analyzed using the steps of interpretative phenomenological analysis (IPA) as outlined by Smith, Flowers and Larkin (2009). IPA is well-suited to examining the concept of injustice among parents within the pediatric pain context. It is phenomenological in nature (i.e., concerned with the lived experience of the phenomenon), is idiographic (i.e., attempts to gain access to participants' own understandings and experiences and maps commonalities across accounts) and is inductive in nature (enabling unanticipated topics or themes to emerge). Further, IPA is particularly well-suited to investigate novel and under-explored topics (Smith, 1996; Smith, 2004; Noel et al., 2016) and therefore fits the objective of the current study.

As the Ghent group was conducted in Dutch, this transcript was first translated and double-checked by two members of the research team, after which each step of the analytical process was conducted in English. The first and second authors led the analysis, analyzing all of the transcripts and providing credibility checks along with authors AD and TV to ensure coding was performed appropriately. Initially, each transcript was repeatedly read to increase familiarity. Then, each transcript was subjected to exploratory coding where key words, phrases and underlying meanings were interrogated. Emerging themes were then developed from the exploratory codes and were clustered together into groups to identify emerging themes within each group. Themes that were reported by at least half of the participants in a group were

identified as recurrent themes. Then, in order to aggregate results across transcripts, shared recurrent justice-related themes across the groups were identified and illustrated with quotations from the transcript. An experienced IPA researcher (AD) oversaw the analysis process. The most salient justice-related themes across groups, with accompanying quotations that provide the most insightful examples of each theme, are reported here.

3. Results

3.1. Description of the study sample

Demographic information for each participant is reported in Table 2. The mothers had a mean age of 43 years ($SD=7.0$). Their children had a mean age of 14 years ($SD=2.6$); 33.3% ($n=7$) of their children were boys and 66.7% ($n=14$) were girls. All mothers were White and mothers in the Belgian, Scottish and US groups had a Belgian, Scottish and American nationality, respectively. The children were diagnosed with a variety of conditions and reported various types of pain, with $n = 16$ (76.2%) of the children reporting multiple pain sites. The average duration of experienced pain was 54.1 months ($SD=40.40$, range 15-156 months) Most frequently reported pain types were joint pain, headache, back pain, and abdominal pain (Table 2). The average duration of children's pain was 54 months ($SD = 40.40$, 15-156 months). The majority of the children ($N = 18$, 85.8%) was receiving medication for their pain at the time of the study.

Location	Group	Participant	Age mother	Age child	Sex child	Child pain condition
<i>Belgium</i>	1	1	38	11	M	Knee pain
		2	42	18	F	Migrain
		3	49	20	F	Neuropathic pain
		4	37	11	M	Migrain
		5	51	16	F	Back and knee pain
<i>Scotland</i>	1	1	40	15	F	Back and abdominal pain
		2	45	16	M	Unknown
		3	45	12	M	Neck, back and knee pain

		4	53	15	F	Chest pain
		5	43	15	F	Arm pain
		6	36	9	F	Hip pain
	2	1	39	15	F	Abdominal and hip pain
		2	51	14	F	Joint, spine and shoulder pain
		3	48	14	F	Headache, back, chest and abdominal pain
		4	32	14	M	Spine and chest pain
		5	49	14	M	Joint pain
<i>United States</i>	1	1	38	13	F	Neck and joint pain
		2	42	12	F	Headache, chest and abdominal pain
		3	31	13	M	Abdominal pain
	2	1	56	18	F	Headache and joint pain
		2	50	13	F	Headache, abdominal and joint pain

Table 2. Demographic and clinical information for participating mothers and their children.

Note: Participant number IDs accompany the selected quotations below.

3.2. Focus group findings

Overall, maternal reports of injustice mainly revolved around the child’s situation rather than the mother’s experience. The occurrence of child pain and its impact on the child’s life were explicitly acknowledged as unfair. However, the scope of maternal injustice accounts reached beyond this, with mothers reporting a strong desire to provide an enriching quality of life for their child. Further, many barriers were reported, evoking a sense of frustration and helplessness at being unable to improve their child’s well-being. Encountering such barriers was explicitly referred to by mothers as a “battle” where they fought for their child’s well-being, which gave rise to both child-oriented and self-oriented appraisals of injustice. Four key injustice-related themes emerged in this context: (1) You’re making it up (2) The problem is probably with the mother, (3) At least it’s not cancer and (4) Not everybody gets a healthy child.

3.2.1. “You’re making it up”

In the mothers’ view, when seeking support and understanding from others, the child was often wrongfully disbelieved and the authenticity and extent of their suffering – reported either by the child or the mother – was questioned. The perception of unfairness stems from a

violation of the maternal belief that the child's reports should be taken seriously and that appropriate action should be undertaken to support the child. This skepticism came from different sources such as school staff, family and peers, but most frequently and intensely from health care professionals. The child's voice was not heard; rather, providers conveyed a strong sense of skepticism and questioned the legitimacy of the pain complaint.

"The one thing, talking about what the professionals... when they say you shouldn't be feeling this way. (...) you shouldn't be feeling this bad. You shouldn't be this sore. They should never say that. It's...obviously, if somebody's coming to you, and telling them, I'm in pain. I'm in this much pain, it never goes away. It shouldn't be a case of, "Well, you shouldn't feel like that." Why don't you listen to what the child is saying instead of saying, "No, you shouldn't feel like that"?" (Group 2, participant number unknown)

Mothers appeared to have different views about the mechanisms underlying this wrongful delegitimization of their child's pain. One mechanism that was discussed involved the idea that the child is inexperienced and, thus, does not understand what pain is. That is, the child is thought to lack a valid frame of reference that is necessary to reliably reflect and report on their own pain experience. Mothers considered this perception among providers to be one contributing factor to providers' invalidating stance toward the child's report of pain and to their tendency to dismiss the child as imagining or faking the pain:

"Um, yeah. I just think that if you're an adult that if...if some...and it's a pain thing, they will listen to you because they believe that you're...you understand more what pain is. But I think that, um, when my daughter was first diagnosed, she was primary six, primary seven. And it was that whole dismissive, "Well, you're just a child. You don't know how bad your pain is and you're making it up." (Group 4, participant 2)

As indicated in the quote above, the child is considered to be 'just a child', reflecting a belittling tone on behalf of the health care professional and maybe even a sense of inferiority, where a child lacks the capacity to report on their own bodily sensations.

Other dynamics related to how child pain, especially idiopathic pain, is inconsistent with the societal view of illness. Mothers discussed discrepancies between others' expectations of illness and how the child's condition manifested itself. For instance, the notion of illness without an identifiable medical origin was difficult for people to understand. Other discrepancies related to the invisibility of pain and the fluctuating nature of the child's pain symptoms.

“So when you're in chronic pain you should, well you're almost obligated to look horrible, to not dress appropriately and to just lay in bed all day. People can accept that, and if that's not the case they doubt you and be like “Is it really true?” And I'm sure that's the case for adults as well, not just for children.”
(Group 5, participant 2)

As illustrated in the quote above, pain was considered valid and was accepted by others only insofar as it aligned with their expectations and preconceived notions. If the child was not consistently showing the (expected) outer appearance and behaviors of someone who is very ill, others seemed to doubt the validity of the pain.

In addition to the delegitimization of the child's suffering being acknowledged as unfair, the consequences of this delegitimization were also perceived in this way, particularly when there was concern that the child would not receive the care they should be receiving:

“Um, (Clears throat) I felt that, um, my child's pain when I was attending the hospital and attending the consultants that it was a case of that I felt as if they didn't really believe that there was a pain issue. And the easy option was we'll prescribe them a pain relief rather than actually getting to the bottom of what the pain is and how it was actually affecting my child.” (Group 2, participant 4)

The above quote reflects the parental concern that these health care professionals were not doing their job, which is examining the child and diagnosing their pain. Rather, this mother suspects the doctors resort to the 'easy option' of wrongfully dismissing the child's pain.

In some instances, mothers even harbored a sense of blame towards health care professionals, as if their perceived lack of action allowed the child's pain to progress to a further stage that could have been prevented, had they taken the pain seriously from the start.

“Yes we kind of feel like that, because if the doctors would have taken us seriously from the start, we might not be in this situation right now. But that's, well, they were just minimizing things just because they thought something else was going on, but once they examined all that and they couldn't find anything, well a few months had passed by then and that, I feel, is kind of their fault. (Group 5, participant 2)

Mothers further discussed how the lack of validation from health care professionals sometimes affected their own perceptions of the legitimacy of their child's pain, causing them to question their child's pain experience. They seemed torn between the child's pain reports and the authority of health care professionals.

“Um, unfairness means to me is I actually feel it's unfair that my daughter, um, has been questioned. It's as if they don't believe that she is in pain and you constantly have to force the issue. And it gets to the stage where you actually start to question it yourself, um and you start to... I'm not saying you become stroppy (slang for argumentative) with your child, but you actually question and say 'are you in that much pain' because you've been questioned back by the medics who are actually looking at her.” (Group 2, participant 4)

The above quote reflects how the mother's initial unconditional belief in her child's pain reports is being challenged. Influenced by authority figures, such as health care professionals, it seems as though the mother is internalizing some of their doubts and suspicions.

3.2.2. “The problem is probably with the mother”

Whether the child's pain was recognized as valid or not, the root of the child's pain condition was at times thought to be with the mother. This was reflected in different types of accusations either from clinicians, family members or others that were directed at the mothers

as they were seeking support for their child, resulting in a sense of undeserved blame. In some cases, mothers felt accused of having done something to cause or maintain their child's pain:

“And I think that (Sighs) I don't know. I know that I've experienced as well just comments that imply that you're in some way to blame for your child's ill health, um, even when the doctors say that nothing you can do or nothing that you have done has influenced it, that there's.... I think there can be a bit of kind of underlying blame.” (Group 1, participant 4)

In other instances, the child's symptoms were thought to arise from dysfunctional interactions with the mother (e.g., giving the child too much or too little attention) rather than from a medical condition. The child's symptoms were unfairly misattributed to the mother's actions, which prevented the child from receiving the correct diagnosis and treatment. This dynamic is reflected in the following discussion, where the mother was labelled as an overanxious parent and encouraged to seek psychological help:

“It got to the point where they told me that it was actually in my head. And that it was me that was creating the problem for my son and sent me to a psychologist. Um, and we still battled for two years after that because they just kept on dismissing everything, um, that I said. Um, that he'd get no help because they kept.... Um, actually seeing on my file one day with capital letters that had OVERANXIOUS PARENT. So they had made a judgment on me which prevented my child to get help for all that time.” (Group 2, participant 5)

The quote above reflects how the mother felt she had to battle an unfair and unjustified label she was given which seemed to contribute to the dismissal of her child's pain. This speaks to the risk associated with the parental role as advocate for the child: if the parental role is questioned, this may hinder proper treatment for the child.

In some cases, these perceived dysfunctional interactions were thought to be related to an actual mental illness in the mother, where the child's symptoms were considered the result of the mother's pathological needs and actions.

“I remember thinking they must think I’ve got that, is it Munchausen’s? Because I’m always at the doctors’, I’m always bringing her (Pause) with the same thing and it’s like, “You’ve been told before. There’s nothing wrong with her...” (Group 1, participant 2)

The use of the term “*Munchausen’s*” indicates the mother’s concern that she is perceived as using her child’s condition to satisfy her own need for attention and therefore her maternal intentions are questioned.

Mothers also discussed that the treatment they received from health professionals made them judge themselves and their own sense of parenthood:

“I think what’s unfair are these people that are supposed to help you, make you feel as if you’re totally ... And you come out doubting yourself. Like they just...they make you feel like you’re the worst parent in the world. They make you...I think because we’ve already said that earlier on they make you doubt your child. They push a wedge between you and your child because you then start to think, is this me? Is this her? What’s really going...am I doing something wrong? Is it me that’s making her sore? And you just sit and you have all this running around your head continuously all the time.” (Group 2, participant 1)

A sense of blame is apparent in the quote above. It reflects a sense of betrayal where those the mother seeks help from make her feel as though she is not fulfilling her parental role.

The mothers’ perception of being blamed for their child’s pain was perceived as highly unfair, both for the child and for the parent, particularly when people make judgements about a situation they are unfamiliar with:

“I think unfairness sometimes means a lot of understanding on other people’s parts. Um, especially if your child doesn’t look like there’s anything wrong with them. I think it’s unfair for people to judge or assume that they’re faking it or um the parents are just pampering or being over protective, because they don’t understand the situation. I think that’s unfair not only for the child but it’s unfair for the parent. Because people look at them and they make a judgement they don’t really understand or know anything about.” (Group 4, participant 2)

3.2.3. “At least it’s not cancer”

A sense of inequality was discussed in relation to how the child's pain is perceived and treated compared to the health conditions of other children. Not only was the presence of the pain condition in the child perceived as random and undeserved, the procedures dictating treatment-related and other decisions were often also seen as arbitrary and unfair.

“Unfairness means to me, why does my daughter deserve to be in pain? Why does my daughter's pain deserve not to be treated? What has she done to deserve to have chronic pain? She's an innocent; she's never done anything to anybody. Um (Pause) unfairness to me is why is somebody else's pain controlled better? That maybe makes me sound a bit nasty. Um, (Coughs) but you're like awake at night wondering just why all the time. Just why her?” (Group 2, participant 1)

The quote above illustrates the mother is preoccupied with the question, “Why?”, in relation to the onset and treatment of her child's condition. At the root of the appraisal of injustice is the notion that the child is an innocent and therefore does not deserve to experience pain. This is central to the mother's appraisal of injustice.

The mother recognizes that her child's pain seems to evoke less understanding and support than other conditions, to which the child's condition is often explicitly compared. It seemed that because pediatric conditions exist that are considered worse than pain, the child's suffering was denied, their condition was not considered deserving of sympathy and the mother's right to express her feelings and struggles was negated. Rather, according to others, she should be grateful and happy that her child does not have a condition like cancer. Mothers discussed feeling that this downward social comparison is forced upon them by doctors, family members, and others, whereas now their perceived entitlement that all children are treated with equal care and attention is violated.

“But when your child's in pain, that's where it ends isn't it, there's nothing there and if, after about a week or two, you'd say 'Well, my child is in pain' then it's like 'Yes, well, but at least it's not cancer'. (...) So just because your child isn't going to die, that doesn't mean it's not difficult for you as a parent. When you watch your child suffer, when she/he is crawling over the floor in pain that hurts just as much

as it does for parents who have a child with cancer. Alright, our child isn't going to die but the impact of pain and suffering and the fact that you can't do anything about it, you can't deny that either." (Group 5, participant 2)

In the quote above, it seems that only the life-threatening nature of an illness such as cancer justifies emotional suffering on the part of the parent, whereas the child's physical suffering does not. In fact, non-life-threatening pain conditions are deemed irrelevant in comparison to cancer and this dynamic is perceived to lead to an unfair distribution of resources and support.

Although comparisons between their child's pain and other, life-threatening conditions is perceived as unfair and something to be protested, this dynamic also evokes a tension between feeling grateful that the child does not have a more serious condition on the one hand and longing for the understanding and validation that comes with a more serious illness:

"I'm really grateful, genuinely grateful that she doesn't have cancer. Um (Pause) but there is a certain recognition and understanding that goes along with... that that is not acknowledged with pain or you know, other conditions that are... (...) I would keep saying that I'm very, very grateful that she's not got cancer. But at least if you've got that kind of label you feel like you know, there's a certain amount of kind of maybe understanding that goes with that and maybe sympathy, you know, that would kind of go with that." (Group 1, participant 5)

In the quote above, the mother repeating how she is grateful her daughter does not have cancer suggests she feels the need to defend herself in relation to others as she is seeking support that only a label of a serious illness seems to justify.

Although mothers discussed the pernicious effects of having downward social comparisons forced upon them, they also noted that when they can engage in these comparisons freely and of their own accord, that it helps them maintain a more adaptive sense of perspective. This strategy facilitates active coping within the context of social comparison, helps them move forward, and mitigates their less adaptive unfairness evaluations. It allows them to focus more

on what their child has or can still accomplish rather than what they have lost. This is illustrated in the quote below:

“I have to say, it helps if you put things into perspective. The pain my son is experiencing, that’s actually, well it’s, I have to say he can just go to school, he plays sports even though quite often he has to stop playing and that’s, well... When I arrive to pick him up and he’s sitting there, I just think it’s so sad, but I always think “Well there’s so many people who have it much worse”. So I find that to be very helpful, putting things into perspective.” (Group 5, participant 4)

The specific conditions that were considered unjust seemed to shift depending on the perspective taken and the points of reference that were present within the child and parents’ direct environment. Salient experiences or encounters with other individuals who are perceived to be worse off help the mothers to reconsider the standard against which the unfairness of their own situation is evaluated. This strategy of perspective taking is considered helpful when the mother comes to this realization spontaneously rather than when it is imposed by others.

“There are certain days where you know, things pop up that you know, it’s so unfair that he has this, it’s so unfair. And then there’s days where you know, you have a doctor’s appointment here and you have to get bloodwork and for whatever reason you have to go to Haematology and you see these little two-year-olds with no hair because they have cancer and it’s terminal and all that and you’re thinking, that’s unfair. There’s nothing unfair about my child having days when he’s not in pain, having those good days where these children likely may not live to see you know, where my child’s been lucky enough to do that.” (Group 3, participant 2)

3.2.4. “Not everybody gets a healthy child”

Although the unfairness of their child’s pain situation is generally acknowledged, mothers often actively resist engaging with these appraisals, as they recognize not only the futility of getting caught up in them but also their negative emotional impact. Instead, mothers discuss a broad range of coping strategies, consciously choosing to allocate their time and

energy differently, refusing to think negatively and attempting to positively reappraise the situation.

“I think that you deal with the cards life hands to you and you make the best of it. And you go on from there. You know, it’s—I agree, it’s a waste of time to worry about whether it’s fair or not. The fact is that it is what you have. And if you waste all your time sitting around feeling sorry for yourself because it’s not fair, that reflects off on the kids... So, you just don’t worry about it. You just—I mean, you can’t change it. So, all you can do is make the best of it, and do what you need to do to get them through it. It is what it is. I just don’t waste my time worrying about whether it’s fair or not fair because I can’t change it. Just deal with it. (Amused)” (Group 4, participant 2)

In the quote above, the mother frequently uses the word “just” (e.g., “just don’t worry”, “just deal with it”), implying a level of simplicity to it. Rather than this actually being an easy task, it seems to reflect the mother’s attempts to not get caught up in the unfairness too much and focus on managing the situation.

Instead of ruminating on the unfairness of their situation, mothers consciously prioritize more adaptive alternative beliefs (e.g., everybody has their struggles) that promote actively coping (e.g., proactivity) with their child’s condition.

“It’s just, how you deal with it. And everybody is dealing with struggles like you said. You just have to move forward and you know, this is how we live and I’m okay with that. We just have to deal with it. Some days are harder than others but we’ve got to move forward.” (Group 3, participant 1)

Other mothers perceive injustice and adverse life events as an inherent part of life, their occurrence being something one cannot control. For them, this promotes acceptance and shifts their focus away from an agenda of control and instead towards one of emotional resilience and active engagement in life.

“Um, but I don’t think it’s a fair place, but I think we have to just make the most out of what we’ve been given, um, and move forward and instill in our kids that yeah, there are injustices in the world, there

are bad people in the world, bad things are going to happen, but you've got to decide how you're going to react to it." (Group 3, participant 2)

Mothers were mindful of the fact that life endeavors, particularly having children, come with an inherent degree of uncertainty. Here, the notion of unfairness was sometimes considered irrelevant as long as mothers were able to assume the caregiver role and to access the resources required to do so. As such, unfair life events were not necessarily the greatest source of injustice to these mothers; rather, injustice was rooted in being denied the opportunity to effectively respond to these events. This idea is illustrated in the quote below.

"I mean, we wanted kids, and we brought them into the world. So, there's no fair or unfair about that. I mean, we asked for a child and you make the best of what you get. I mean, not everybody gets a healthy child. It is what it is. I don't think there's any fair or unfair as long as you can provide them the medical care that they need. That's as fair as it's going to get." (Group 4, participant 2)

Discussion

The present study sought to examine appraisals of injustice among parents of children with a chronic pain condition. Twenty-one mothers were recruited into the study. Within the overarching narrative of mothers attempting to provide a valued quality of life for their child, three key injustice-related themes were identified: 'You're making it up', 'The problem is probably with the mother' and 'At least it's not cancer'. These themes reflect violations of maternal expectations regarding the medical and interpersonal treatment of their child's pain and of themselves as parents. A fourth theme, 'Not everybody gets a healthy child', acknowledged but resisted injustice in this context, representing a mechanism buffering the impact of injustice.

Mothers unanimously reported their child's pain being unjustly delegitimized, most frequently in interaction with health care professionals and regardless of whether the child or the parent provided the report. The child, assumed to be too inexperienced to know what pain is, was accused of 'faking' or 'imagining' their pain. To counteract this dynamic, mothers

assumed the role of advocate and protector. However, in seeking care for their child, mothers were often accused of causing or maintaining the pain themselves, whereby their intentions as caregiver were wrongfully questioned. Further, even when acknowledged as legitimate, the child's condition was often compared to other, serious pediatric conditions (e.g., cancer), rendering the child less worthy of sympathy or support in the opinion of others and contributing to the improper or mistreatment of the child's pain and the continued suffering of the child. Previous studies in pediatric chronic pain have observed a strong parental desire for a diagnosis, even one indicative of serious pathology, as this would evoke sympathy and support from others (Jordan et al., 2007; Jordan et al., 2011; Neville et al., 2019). However, the notion of unfair comparison by others found here presents a novel aspect to the parental experience.

While the presence of pain and responses from others were recognized as a source of injustice, mothers also recognized that ruminating on unfairness was not helpful and did not facilitate their efforts to manage the child's pain and promote pain accommodation (i.e., the child's perceived ability to live a satisfying life despite pain) (Jacob et al., 1993). Rather, various strategies were adopted to counter these injustice evaluations such as benefit finding or cultivating positive over negative affect, some of which have been observed in previous work (Noel et al., 2016).

This is the first published phenomenological exploration of parental appraisals of injustice regarding their child's pain, thus contributing to existing knowledge in several ways. These results support preliminary findings highlighting the relevance of injustice in the parental experience of pediatric chronic pain (Miller et al., 2016; Miller et al., 2018; Baert et al., 2019). In line with earlier work (Monin & Schultz, 2009; Mohammadi et al., 2016), parental negative illness-related appraisals may challenge or even undermine parental functioning and subsequently impact negatively upon child well-being. This has repeatedly been observed in studies examining parental catastrophizing about child pain, where high catastrophizing parents

reported more impaired adjustment and children reported greater pain intensity, disability and distress (Goubert et al., 2006; Goubert et al., 2008; Hechler et al., 2011; Caes et al., 2012). As such, the current findings provide further insight into parental injustice appraisals as risk factors in both parental and child adaptation to pediatric chronic pain above and beyond parental catastrophizing. Further, beyond instances of distributive and procedural injustice (Folger, 1987; Greenberg & Cropanzano, 1993; Skarlicki & Folger, 1997; Ferris et al., 2012; Colquitt & Rodell, 2015) (e.g., appraisals relating to the presence of pain or the unfair distribution of resources such as treatment or support), the current study emphasizes the centrality of *interpersonal injustice*. Mothers felt that their child as well as themselves were unfairly or disrespectfully treated by others in various ways. In the broader pain literature, negative or threatening interpersonal experiences such as invalidation or stigmatizing responses have been identified as detrimental factors in patients' pain experience (Jordan et al., 2007; Jordan et al., 2011; McParland et al., 2010; McParland et al., 2011; De Ruddere & Craig, 2016) simultaneously leading to increased pain sensitivity and reduced pain communication. Acknowledging and addressing such social experiences may be of particular importance in pain management (Peeters & Vlaeyen, 2011; Karos, 2017; Karos et al., 2018).

Further, these results provide further evidence for the distinction between parental *child- and self-oriented appraisals of injustice*. Although parental narratives mainly revolved around perceiving injustice towards their child (i.e., child-oriented injustice), explicit references were also made to self-oriented injustice experiences. This is most clearly represented in the form of the mother not being acknowledged in her role as caregiver or even accused of causing or maintaining the child's pain. Such self-oriented appraisals of injustice among caregivers have only once been addressed in relation to adult pain (Moninn & Schultz, 2009; Mohammadi et al., 2016) but may be of particular importance in the pediatric context as these appraisals may impact both the parent and the child. In the current study, the experience of injustice

significantly affected maternal well-being, causing distress, self-doubt and feelings of frustration and depression. These narratives support earlier work suggesting that self-oriented injustice appraisals in family caregivers are associated with greater psychological distress (Mohammadi et al., 2016). From an affective-motivational perspective (Vervoort & Trost, 2017) it may be argued that such experiences (e.g., being accused of harming their child) conflict with valued identity-related goals (e.g., being a caring mother), resulting in negative emotional states. Further, given their role as caregiver, an excessive focus on such self-oriented injustice appraisals may shift a parent's focus away from the child's needs and as such compromise effective caregiving behavior. However, no research has thus far addressed such behavioral dynamics.

These results likewise shed light on potential *buffering mechanisms* attenuating the impact of parental injustice appraisals, allowing parents to focus on effective caregiving and pain management. In line with existing work on chronic pain acceptance (Jensen et al., 1991; McCracken, 1998; McCracken et al., 2010; Simons et al., 2011), maternal coping with child pain, particularly moving beyond questions of fairness, allowed mothers to allocate their time and energy more effectively towards a more positive and facilitatory perspective on their child's condition. Interestingly, the mothers' tendency to frame the world as unfair or unjust suggests that observing the suffering of others may influence the observing party's beliefs about fairness in the world. This finding also challenges the idea that a stronger belief in a just world (Lerner & Miller, 1978; Lerner, 1980; Chasteen & Madey, 2003) (i.e., the notion that people generally get what they deserve and deserve what they get) necessarily attenuates the relationship between pain or illness and psychological distress and health behaviors (Dalbert, 1999; Dalbert, 2002; Lench & Chang, 2007; Lucas et al., 2008; McParland & Knussen, 2010). Although speculative, it is possible that the effect of such just world beliefs is moderated by the chronicity and controllability of experienced illness or adversity. However, this account is highly

speculative and more research is required to confirm or disconfirm it or to shed light on other strategies at play in this context.

Lastly, when working towards the development of reliable assessment methods for use in clinical practice and to further research in this field, qualitative material such as that presented here offers valuable insights. In fact, the current findings highlight a number of key issues in the parental injustice experience that are not captured in the adult, intrapersonal framework as proposed by Sullivan and colleagues (Sullivan et al., 2008). Specifically, no explicit reference is made to interpersonal injustice, even though its importance for patients' well-being has been documented in previous work (Walker & Pettigrew, 1984; Jordan et al., 2007; Jordan et al., 2011; McParland et al., 2011; Ferris et al., 2012; Karos, 2017; Wernicke et al., 2017; Karos et al., 2018). Given this interpersonal dimension and the fact that maternal accounts described frequent negative interactions with health care providers, research may also benefit from studies focusing on other perspectives than that of the parent (e.g., health care professionals). Together with these previous findings, the current study calls into question the approach of simply extrapolating the existing adult framework to a parental perspective on pediatric pain – context specific content needs to be added to more fully capture this construct.

The current findings should be considered in light of a number of limitations. First, the sample included only mothers. Based on studies examining mothers' and fathers' parenting experiences, it is possible that paternal injustice appraisals emphasize different experiences (Jordan et al., 2007; Jordan et al., 2011; Hechler et al., 2011). Relatedly, given the qualitative nature of the current study, these findings may not generalize to other populations. Second, the sample had limited racial and ethnic diversity. This may be particularly relevant as certain minority groups may have been exposed to additional intra- and inter-personal injustices above and beyond those related to chronic pain (Green et al., 2003; Anderson et al., 2009). Alternatively, although diversity in participants (i.e., mothers from three different countries)

can be an asset when identifying widely shared injustice appraisals among parents, there are limitations associated with cross-cultural samples. Participants' injustice experiences may have been shaped by contextual factors unique to their country of residence, such as health care and insurance systems. However, regardless of country and culture, there was substantial convergence in mothers' perceptions and experiences of injustice in relation to their child's pain condition. Third, no information was available on the presence of chronic pain in the mothers. Since maternal pain may have influenced how they conceived of injustice in the context of their child's pain, this could have informed the interpretation of the results. A last limitation pertains to applying IPA to focus group data, where group dynamics may hinder the production of detailed personal accounts. However, IPA is a flexible approach, applicable to various data collection techniques (including focus groups) allowing to capture individual narratives that are nestled within the group context (Jordan et al., 2007; Tomkins & Eatough, 2010; Jordan et al., 2011; McParland et al., 2011; Phillips et al., 2016).

In conclusion, the current study provides an in-depth analysis of parental injustice experiences relating to their child's chronic pain, highlighting issues not currently captured in available injustice measures. As such, these findings inform future research into and assessment of parental injustice appraisals in the context of pediatric pain.

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Fleur Baert (corresponding author): data-analysis, writing of the entire manuscript.

Joanna McParland: data collection, data-analysis, guidance throughout the writing of the manuscript.

Megan Miller: international collaboration, data collection, thorough review of the manuscript.

Adam Hirsh: international collaboration, data collection, thorough review of the manuscript.

Zina Trost: facilitating international collaboration, thoughtful suggestions to the manuscript.

Ewan Wallace: supporting recruitment of participants, thorough review of the manuscript.

Adele Dickson: providing expertise in qualitative data-analysis, thorough review of the manuscript.

Tine Vervoort: study design, data collection, assistance in IPA coding, thorough review of the manuscript.

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