

## ORIGINAL ARTICLE

# ‘A whirlwind of everything’: The lived experience of adolescents with co-occurring chronic pain and mental health symptoms

Jenny Corser<sup>1</sup> | Line Caes<sup>2</sup>  | Sharon Bateman<sup>1</sup>  | Melanie Noel<sup>3</sup>  |  
Abbie Jordan<sup>1</sup> 

<sup>1</sup>Department of Psychology, University of Bath, Bath, UK

<sup>2</sup>Division of Natural Sciences, University of Stirling, Stirling, UK

<sup>3</sup>Department of Psychology, University of Calgary, Calgary, Alberta, Canada

**Correspondence**

Abbie Jordan, Department of Psychology, Claverton Down, Bath, BA2 7AY, UK.

Email: [a.l.jordan@bath.ac.uk](mailto:a.l.jordan@bath.ac.uk)

**Abstract**

**Background:** Co-occurring chronic pain and mental health issues are prevalent in adolescents, costly to society and can lead to increased risk of complications throughout the lifespan. While research has largely examined paediatric chronic pain and mental health in isolation, little is known about the unique challenges faced by adolescents who experience these co-occurring symptoms. This idiographic study examined the lived experience of adolescents with co-occurring chronic pain and mental health symptoms to identify salient issues for this population.

**Methods:** Semi-structured telephone interviews were conducted with seven adolescents (11–19 years) self-reporting diagnoses of both pain and mental health issues for a duration of 3 months or longer. Participants were recruited from UK-based schools, pain clinics and charities. Interview transcripts were analysed using interpretative phenomenological analysis.

**Results:** Analyses generated two themes ‘a whirlwind of everything’ and ‘putting up fronts’, which describe how the experience of co-occurring chronic pain and mental health symptoms typically disrupted adolescents’ ability to regulate their physical, psychological and social wellbeing and identity. Adolescents described their symptom experience as like an internal storm over which they had no control. Such experiences required adolescents to embrace a variety of symptom management strategies, with adolescents reporting deliberate efforts to minimize their symptoms to external individuals.

**Conclusion:** Co-occurring pain and mental health symptoms may be experienced in similar ways to individually experienced pain or mental health symptoms, but together, the experience may be both more difficult to manage and more socially isolating.

**Significance:** Adolescents with co-occurring chronic pain and mental health symptoms describe the experience as if there was a storm inside of them disrupting

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their sense of physical, emotional and social wellbeing. This inner chaos interferes with their self-identity and relationships with others. Challenges articulating their experiences, and negative encounters associated with their symptoms, further impact feelings of isolation and difficulties accessing support.

## 1 | INTRODUCTION

Pain is a common experience in childhood and adolescence, yet for some, acute pain experiences continue and become chronic. Rates of paediatric chronic pain are increasing, typically peaking in adolescence, with highest rates in adolescents (Gobina et al., 2019; Kamper et al., 2016; King et al., 2011; Roy et al., 2022). Evidence demonstrates wide ranging and often deleterious impacts of adolescent chronic pain at individual, interpersonal and societal levels (Jones et al., 2020; Jordan et al., 2017; Murray et al., 2020). In particular, chronic pain in adolescence is associated with poorer academic achievement, vocational function and relationship quality, as well as perceived stigma across all social domains (Murray et al., 2020; Wakefield et al., 2021). Severely disabling chronic pain is associated with more impaired quality of life, greater use of medication and medical services and increased school absence (Huguet & Miró, 2008). Mental health issues (anxiety, affective and behaviour disorders) have been found to be risk factors for the development of chronic pain in adolescence (Leino-Arjas et al., 2018; Tegethoff et al., 2015b) and conversely, paediatric chronic pain is shown to heighten lifetime risk of psychopathology (Noel et al., 2016).

Although a causal link is not clear, literature suggests the relationship between chronic pain and mental health issues in adulthood may originate during childhood or adolescence (Von Korff et al., 2005), identifying this as a critical developmental phase for further study. Tegethoff et al. (2015a) found that 35.3% of 6469 adolescents (13–19 years) reported at least one mental and one physical condition, regardless of socioeconomic factors, while another study found that 7 of 10 adolescents with psychiatric disorders also reported chronic pain (Mangerud et al., 2013). Crucially, two further studies have found that adolescents with chronic pain are at higher risk of developing depression and suicidality (Soltani et al., 2023; van Tilburg et al., 2011).

Impacts of co-occurring symptoms are important to investigate since the experience of mental health symptoms increases the risk of physical disease and injury and complicates help-seeking, diagnosis, treatment and prognosis (Prince et al., 2007; Turner & Kelly, 2000).

Mutually maintaining factors, including neurobiological (e.g. shared neural pathways) and psychosocial variables (e.g. cognitive biases, parental influence), have been proposed to explain the prevalence and co-occurrence of

pain with depression (Soltani et al., 2019), traumatic stress symptoms (Holley et al., 2016) and chronic pain in paediatric populations. Understanding the interaction between chronic pain and mental health symptoms in children and adolescents has been named as a top research priority in paediatric chronic pain (Birnie et al., 2019).

Existing research in this area has largely adopted a quantitative (nomothetic) approach, typically focused on understanding relationships between variables. Consequently, little is known to date regarding the nuances of the lived experience, indicating a need to develop a more detailed individualized (idiographic) understanding. This is important in terms of addressing how to better support adolescents in managing their symptoms and informing service development and referral processes. Meeting this important knowledge gap, this study addressed the following research question: ‘What is the lived experience of adolescents with co-occurring chronic pain and mental health symptoms?’

## 2 | METHODS

### 2.1 | Study design

This study is part of a larger, multi-method, longitudinal study comparing challenges faced by adolescents with and without chronic pain and mental health symptoms (both individual and co-occurring symptoms). The protocol for the larger study was registered with the Open Science Framework (Bateman et al., 2018). Using purposely selected qualitative data from the larger multi-method study, this study employs a qualitative cross-sectional design using semi-structured interviews to explore how adolescents experience and make sense of the co-occurring nature of pain and mental health symptoms at an idiographic level. This study is the first study to adopt a phenomenological approach to analysing data which focus solely on examining the co-occurrence of pain and mental health symptoms in adolescents.

### 2.2 | Participants

Data in this study comprised all data in the larger study which included adolescent participants (aged

11–19 years), who self-reported diagnoses of both chronic pain and mental health issues and who had completed the semi-structured interview at the initial recruitment phase. All study procedures were approved by the Psychology Research Ethics Committee at the University of Bath (ref 19-250) and by the National Health Service Ethics Committee (REC reference 19/YH/01).

Participants were recruited into the larger study from schools, pain clinics and via social media. Recruitment ran for 24 months from July 2019 onwards. The larger study comprised two online surveys to be completed at the time-point of recruitment: 0 months, (Time 1) and 12 months, (Time 2). These surveys included demographic questions, and self-report measures of pain, body esteem, catastrophizing, quality of life, mental health and relationships (Bateman et al., 2018). All participants who completed the survey at Time 1 were asked whether they were happy to be contacted about taking part in a follow-up interview with an aim of recruiting 20 participants to take part in the interviews. The sample size for the larger study was informed by the various characteristics of that study such as the nature of the study aims, researcher qualitative expertise and data quality richness (Vasileiou et al., 2018). Interested participants were then invited by email to take part in the follow-up interview and provided with links on Qualtrics (2022) to the interview study information sheet and consent form. Participants were contacted about taking part in the interviews once they had completed the brief Qualtrics survey to provide informed consent. Initial interviews were conducted with all consenting participants at Time 1 and repeated 12 months later at Time 2. A total of 15 participants were interviewed at Time 1 in the original larger study. This current study includes only those participants who were interviewed at Time 1 and who self-reported diagnoses of co-occurring chronic pain and mental health issues ( $n = 7$ ).

A total of seven participants were eligible for inclusion and were considered an ideal sample for an IPA analysis based on recommendations of the methodology which suggest small sample sizes aiming at depth rather than breadth (Smith, 2022, pp. 51–52).

Additionally, we used the concept of information power to guide sample size. Information power indicates fewer participants are required for the study when the study data are considered to be rich. Based on the idea of information power, our sample size was relatively small given the strength of our narrow study aim, dense specificity and strong dialogue, all of which strengthened information power in our study (Malterud et al., 2016). This sample size is congruent with other studies which have adopted a similar analytical approach (e.g. Kanstrup et al., 2019; Smith & Osborn, 2007).

The sample included seven adolescents of female sex (six identifying as female and one non-binary), aged between 15 and 18 years of age. According to the English Index of Multiple Deprivation (IMD) scores (Field Studies Council, 2023), the average decile of poverty was 5.17 ( $SD = 2.79$ ). Individual participant characteristics are shown in Table 1.

## 2.2.1 | Semi-structured interviews

Semi-structured interviews are the exemplary mode of data collection for IPA as they allow the participants the opportunity to speak freely and tell their own story (Smith & Larkin, 2009, pp. 56–57). The interview schedule (Table 2) was designed to explore the participants' experience of pain and mental health symptoms through the use of open-ended, non-leading questions and prompts (Brett & Wheeler, 2021; Smith & Larkin, 2009, pp. 59–62). Interviews explored the adolescents' experiences and meaning-making of their symptoms recognizing that the participants are individuals embedded within multiple systems (e.g. family, peers, school and healthcare systems). Interview questions focused on symptom experiences, the impact of symptoms on individuals' lives and management of co-occurring pain and mental health symptoms.

Interviews were conducted via telephone and ranged in duration from 25 to 53 min ( $M = 39$  min,  $SD = 10$  min). Telephone interviews offer synchronous contact with participants, and although lacking the quality of face-to-face interviews, have been shown to be a robust form of data collection (Johnson et al., 2021). Interviews were recorded using a digital audio recorder and were transcribed naturalistically by the research team, verified by S.B and anonymized.

As mentioned in the information sheet, participants received a £15 UK shopping voucher to thank them for their time.

## 2.3 | Data analysis

Interview data were analysed using IPA. This phenomenological methodology is appropriate for inductively exploring how individuals and homogenous groups understand and make sense of their lived experience. IPA is particularly fitting for broad research questions exploring under-studied areas. IPA has shown to be particularly useful for examining complex, ambiguous and emotionally laden topics such as the experience of chronic pain (Smith & Osborn, 2015).

TABLE 1 Participant characteristics.

Participant	Age (years)	School year	Pain diagnoses and symptom duration	(years)	History of pain treatment	Mental health diagnoses and symptoms duration	(years)	History of pain treatment
Jessie	15	11	Fibromyalgia	'a few years'	Physiotherapy, awaiting pain clinic <sup>c</sup>	Anxiety Stress Self-harm	'a long time'	Child and Adolescent Mental Health Service, mindfulness
Daisy	15	11	Hypermobility Chronic pain Scoliosis	5 <sup>a</sup> 5 -	Hypnotherapy, medication, sports massage, physiotherapy, awaiting pain clinic	Anxiety Depression	2 1	In-patient psychiatry, Child and Adolescent Mental Health Service
Maria	17	12	CRPS (foot)	6	Surgery, steroid injection, physiotherapy, hydrotherapy, pain clinic <sup>c</sup>	Anorexia Anxiety Self-harm	6 6 -	Psychology (via pain clinic)
Claire	17	12	CRPS (began in wrist, now global) Unexplained paralysis (leg)	6 <sup>a</sup> 1	Physiotherapy, occupational therapy, medication, in-patient pain clinic <sup>c</sup>	Anxiety Depression PTSD	6 6 3	Child and Adolescent Mental Health Service
Whitney	18	13	CRPS (leg)	4 <sup>a</sup>	Physiotherapy, hydrotherapy, in-patient and out-patient pain clinic <sup>c</sup>	Anxiety Depression	4 4	In-patient psychology and psychiatry, Child and Adolescent Mental Health Service, now transitioning to adult mental health service
Sarah	18	13	Chronic pain Hypermobility CRPS (leg/foot)	7-8 - 4	Physiotherapy, medication, pain clinic <sup>c</sup>	Anxiety Depression	2-3 1-2	Cognitive behavioural therapy, counselling at school, medication
Pippa	18	1st year university	Multiple chronic illnesses including: Chronic fatigue Fibromyalgia Hypermobility	- 4 <sup>b</sup> 1 -	Podiatry, physiotherapy, medication	Anxiety Depression	4 4	Cognitive behavioural therapy, mindfulness, counselling at school, interpersonal therapy (via adult service)

Note: All values taken from the transcripts to indicate what was self-reported at time of interview. Where values are missing, duration was not specifically declared.

<sup>a</sup>Symptom onset postinjury.

<sup>b</sup>Symptom onset postvirus.

<sup>c</sup>Pain clinic is multidisciplinary treatment and can include physiotherapy, occupational therapy, psychology, psychiatry and medical treatment.

**TABLE 2** Semi-structured interview schedule.

Getting started	<p>1. Can you tell me a little about yourself? <i>Prompts:</i> Are you in full time education? What do you enjoy doing?</p> <p>2. Can you describe your family situation? <i>Prompts:</i> Who do you live with?</p>
About You	<p>3. Can you tell me about any pain and/or mental health symptoms that you have? If the participant reports any symptoms, I will explain that I will use the term symptoms when discussing their diagnosis or condition from now on.</p> <p>4. Can you tell me about the journey from the start of your first symptom to now?</p> <p>5. How do these symptoms affect you? <i>Prompts:</i> How do these symptoms affect your physical and psychological wellbeing? Effect on relationships with others?</p> <p>6. How do you feel about your symptoms?</p> <p>7. How do you manage any symptoms you have?</p> <p>8. Can you tell me about any changes you have made to the way you behave that have been caused by your symptoms? <i>Prompts:</i> Emotional or physical? With friends or family? For instance, socially, in school or at home?</p> <p>9. Can you tell me about any ways your symptoms might affect your family and friends?</p> <p>10. What do your relationships with family/friends look like? <i>Prompts:</i> Can you think of any ways that your relationships are different from your friend's relationships?</p> <p>11. Are there any other ways in which your symptoms affect your life that you would like to share with me?</p>
Your Treatment	<p>I would like to ask you some questions about any treatment you are/have receiving/received</p> <p>12. Can you tell me about any treatment you have had for your symptoms? <i>Prompts:</i> How long did you have symptoms before receiving treatment? Can you describe any other methods that you have used to manage your symptoms? Can you tell me about any professionals you have seen for your symptoms?</p> <p>13. How do you feel about the treatments you have mentioned? <i>Prompts:</i> Can you please explain this in a bit more detail? What particular aspects of the treatment do you think worked well? What particular aspects do you feel did not work so well? Can you explain any ways that the treatment could be improved?</p> <p>14. Can you tell me what you think the future looks like for you? <i>Prompts:</i> In terms of your symptoms and treatment? What would you like the next steps to be in terms of treatment? How do you think you will be managing in the future if these symptoms do not change?</p> <p>15. Is there anything else you would like to share with me about your any areas of your treatment?</p>
Close	<p>That is all the questions that I have for you, is there anything you would like to add about anything we have discussed or anything else that you would like to share with me about your experience of pain and/or mental health symptoms?</p> <p>Thank you so much for taking part, I will ensure that you will not be able to be identified from anything you have said when this is written</p>

IPA is a dynamic process moving ideographically from individual experience towards a population level (Pietkiewicz & Smith, 2014). IPA explicitly acknowledges and uses double hermeneutics whereby the researcher's account is an interpretation of the participant's own interpretation. This focus on personal meaning-making before moving to group themes, allows for more detailed analysis than other qualitative approaches such as reflexive thematic analysis (Braun & Clarke, 2021). IPA also encourages a focus on language use and metaphor, concerned with cognitions and underlying meaning.

Analyses were conducted by J.C. and followed the detailed procedure outlined by (Smith & Larkin, 2009, pp. 79–107). The following description, however, uses updated terminology introduced by (Smith & Nizza, 2022).

For IPA 'the person becomes the universe of exploration' (Smith, 2021). As such, each transcript was studied individually, in turn. Although IPA has step-by-step

instructions, the process is fluid and cyclical involving multiple iterations of careful in-depth readings and reflective note-making. Analyses were conducted using Microsoft Word, employing columns alongside the main text to type notes.

The first stage was an idiographic analysis requiring immersion into each transcript one-at-a-time. The first stage involved reading and re-reading the text to gain familiarity and applying a pseudonym to the anonymized transcript. On subsequent readings, exploratory notes were made, examining the semantic content and language use. The researcher also highlighted text that seemed to be particularly impactful. Attention was paid to the text, line by line, noting everything of interest as well as writing questions and noting personal reflections. The next step was to construct experiential statements. This required an 'analytic shift' (Smith & Larkin, 2009, p. 91) to the initial notes in addition to the transcript itself. Experiential



statements were recorded in an additional column. The final step of idiographic analysis was to look for patterns clustering the experiential statements into personal experiential themes.

This process was repeated for each transcript in turn. Finally, the personal experiential themes were analysed together for patterns to create group experiential themes. The final group themes were named and defined. Themes are presented later in this report.

To ensure quality, the research team adopted quality principles which are specific to IPA as a methodology. These included constructing a compelling; unfolding narrative; developing vigorous experiential/existential accounts; close analytic reading of participants' words; and attending to convergence and divergence (Nizza et al., 2021). In addition, in accordance with the methodology, and in order to ensure trustworthiness, the researchers kept an audit trail including notes on each iteration of interpretation of the transcripts and a reflective journal. IPA demands explicit acknowledgement of the researchers' active role in the interpretation of the data. As such, it is noted here that the research team comprised novice and experienced qualitative researchers specialized in the area of paediatric chronic pain, some of whom also identified as parents and/or people with lived experience of chronic pain. Frequent supervision meetings with the lead supervisor, and feedback from colleagues and co-authors on each iteration of analysis and write-up allowed for credibility and validity checks through peer review (Johnson et al., 2020). To ensure transparency and rigour, this study declared the full procedure in the methods section and included quotations from all participants in the sample within the findings of this paper to ensure that all participants were represented in the results section (Smith & Larkin, 2009, p. 182; Yardley, 2000). While the larger study was pre-registered on the Open Science Framework (Bateman et al., 2018).

### 3 | RESULTS

The overall interpretation of the data was that co-occurring chronic pain and mental health symptoms were experienced as disruptive to the adolescents' wellbeing to the extent that it disturbed their sense of self and relationship with others. Inspired by a direct quotation from one participant, and language used by others, the themes are described using meteorological imagery and in particular, with reference to a storm.

Interpretations are supported by direct quotations. The following symbols were used as part of the naturalistic transcription:

(( )) indicates a long pause or gesture

(.) indicates a short pause

[ ] includes information added by the author for explanation

#### 3.1 | A 'whirlwind of everything'

The participants described their co-occurring pain and mental health symptoms as being binary (mental and physical), yet interconnected, resulting in an experience of being out of control over their physical and psychological wellbeing. The whirlwind metaphor was inspired by a statement made by Daisy, a 15-year-old, self-reporting diagnoses of hypermobility, chronic pain, anxiety and depression. She described a series of unexpected, and seemingly random, pain and mental health symptom flare-ups as a 'whirlwind of everything'. This was found to be a particularly resonant statement, or 'gem' (Smith, 2011) that informed the overall interpretation of the adolescents' co-occurring symptom experience. A gem is a particularly valuable word or statement, found as a result of close analytic reading of the participants' words, that can become pivotal in the analysis of the entire research corpus (Smith, 2011).

Physical symptoms including debilitating pain, hypersensitivity or numbness, discolouration and repeated dislocations were described as occurring unexpectedly, and often spreading throughout the body. Mental health symptoms including depression, anxiety, self-harm and eating disorders seemed also to vary in intensity, or 'come in waves' (Pippa: 18 years old, reporting chronic fatigue, fibromyalgia, hypermobility, anxiety, depression). The experience of co-occurring symptoms, like a meteorological whirlwind, appeared to create an instability or turbulence in the lives of these adolescents that was distressing and difficult to make sense of. Although their mental and physical symptoms could be spoken of as distinct, these co-occurring symptoms were often experienced as connected, as described by Maria.

I feel like they [her symptoms] sort of like control my life in a way ((pause)) um because I can't really do anything without considering the two [pain and mental health] and one will impact the other so if one of them is really bad then the other one will get worse

(Maria: 17 years old, reporting CRPS, anorexia, anxiety, depression, self-harm)

Extending the element-based imagery, Sarah used the image of waves to highlight the complex intertwining of pain and mental health symptom experiences. Important to

Sarah's experience was the idea of temporality, noting that even after her pain may abate, the impact on her mental health symptoms would endure, clearly demonstrating their interwoven nature .

So it kind of tends to follow a pattern with my pain, so if my pain gets really bad, erm then for the first day when it's really bad, my mental will kind of be ok, but by the next day if it's still really bad, then I start to feel quite like intense either anxiety or low mood and then the kind of mood stuff is harder to shift cos then if the pain kind of starts to get a little bit more manageable, then it tends to be the mental health issues kind of stay for a bit longer. So it's kind of like, if it's like on a graph, then it would kind of be like up and down wave, but the erm mental health wave would be kind of shifted to the right [on the y axis, or timeline]

(Sarah: 18 years old, reporting chronic pain, hypermobility, CRPS, anxiety, depression)

Describing the relationship between pain and mental health symptoms as open ended highlighted the unpredictable nature of the 'whirlwind' in its sudden ability to knock the adolescent off balance. This unpredictable nature created a sense that participants could not trust their own ability to maintain a sense of balance, or self-regulate. Whitney described this unpredictable, inconsistent, yet overwhelming symptom experience as causing her to be in a permanent state of hypervigilance, afraid of potential triggers for her symptoms.

I'm pretty much constantly aware of my surroundings (.) I'm on high alert of potential threats um (.) and over time it's got worse (.) so now I could be looking for threats that are highly unlikely to even happen um (.) which is exhausting

(Whitney: 18 years old, reporting CRPS, anxiety, depression)

At times, this constant fear of flare-up of either pain and/or mental health symptoms gave the impression of being haunted by the possibility of recurrence as if the symptoms were controlled by a separate entity, happening *to* them not *of* them. Despite being an internal experience, within themselves, they seemed to perceive that there was something outside of themselves in control. For some participants, symptoms were described as occurring independently of the individual and other outside influences, highlighting a sense of disconnection from their minds and bodies in relation to their symptoms. This is exemplified by Daisy when she said,

"It's anything like my knee my neck, anything can be alright but equally they can be awful it just depends how much they [her joints] want to do it". A distinction between self and pain and mental health symptoms is interesting in terms of adolescents' perceived self-control when these symptoms became overwhelming and cognitively intrusive. Sarah described how, when her symptoms were at their worst, she no longer felt in control of her own actions and effectively pushed towards self-harm.

If it's really bad my head gets a bit kind of fucked then I erm, might end up self-harming but it's almost like I'm really spaced out and kind of half-conscious with what I'm doing, so it's not like I'm fully in control at that point

(Sarah: 18 years old, reporting chronic pain, hypermobility, CRPS, anxiety, depression)

As with Sarah's account above, Claire described her symptoms as leading to a dissociative state, suggesting a possible lack of responsibility for her actions as she perceived that it was her symptoms, rather than herself, that influenced her actions, again suggesting that the symptoms could be experienced as if a separate entity that seems to be in control of her behaviour.

I'm not really sure because when obviously my symptoms are really bad I don't tend to remember it but like it happens in the moment but then after I don't really have any recollection of it, but I think that's quite a hard question to answer because I don't really know how I behave when I'm like it

(Claire: 17 years old, reporting CRPS, unexplained paralysis, anxiety, depression, PTSD)

Perceptions of a lack of agency over their symptoms impacted the participants' sense of who they were within the whirlwind experience. Whitney explicitly stated, "I wouldn't be the person I am today if I didn't have complex regional pain syndrome or depression or anxiety... if I didn't have all of this I would find it a lot easier". There was a sense of insecurity in who the 'I' in the storm was, especially as this new identity was the direct product of experience rather than design. It was as if the co-occurring symptoms had disrupted Whitney's inner sense of wellbeing to the point that it reshaped her identity. In particular, experiencing pain and mental health symptoms impacted the extent these adolescents could engage in activities that they identified with: for example, Whitney described herself as a confident theatre performer, Jessie as a gym lover and Pippa as a semi-professional horse rider. Alongside forming an important

part of their identity and providing enjoyment, these missed activities provided a sense of purpose, friendship opportunities, a sense of achievement and ambitions for the future. They informed who they recognized themselves to be, and the whirlwind experience of pain and mental health symptoms shook them up and figuratively took the wind out of their sails. In the quotation below Sarah described the impact of co-occurring symptoms on her life with a sense of loss and defeat as if the whirlwind had compromised her capacity for success: “I felt like I had potential but then my symptoms were the thing that kind of got in the way of that”.

### 3.2 | Putting up fronts

The previous theme describes the inner lived experience of adolescents with co-occurring pain and mental health symptoms as that of a whirlwind, like a turbulent and destructive storm. This symptom experience made the adolescents feel vulnerable, and this inner whirlwind experience also had external impacts: adolescents each described experiences of being bullied, shamed and blamed by others because of their symptoms. This theme continues the meteorological imagery in describing the adolescents' relationship with their outer social worlds. Weather fronts are described by the UK Met Office (Meteorological Office) as “a boundary between two air masses. [They] can be thought of like the frontline in a battle” (Met Office, 2022). Applying this to the context of the study's narratives, a front can be understood as a horizon where experiences of self and other meet, as well as a construction of defence, or concealment. For example, Maria perceived that her symptom experience resulted in an enhanced sense of vulnerability, and she noted a tendency to react defensively, “I know that I've become a lot more touchy and stuff, so if someone says something really small then I'll just get really angry”. Alternatively, to *put on a front* can also reference an act of pretence, this is exemplified by Claire who admitted she consciously hid her true feelings from others, “I will have a smile on my face cos I just put on a mask every day, because I don't like showing people how I feel”. In this sense, this theme explores a level of complexity that the adolescents described in terms of how they try to relate to others while experiencing pain and mental health symptoms.

The adolescents in this study described adapting various protective behaviours depending on the situation, manipulating the degree to which the symptoms were expressed to different audiences. This is exemplified in Sarah's account below where she acknowledges the importance of context (e.g. school vs. home) to the way she represents herself in relation to her symptoms. Such a need to be mindful of the extent to which she would allow

others to see the ‘real’ Sarah was exhausting and required careful thought, further reinforcing a sense of isolation from peers.

Erm, yeah, I think so. Erm there are some environments where I'll like hide it [pain and mental health] more and try and like kind of fit in, but that's then like really tiring and so like sometimes in school, I would erm try and kind of hide that side of me that's more cautious, or having to think everything seems too much and trying to like manage something, so I'd hide it more then, that, that has quite a big impact on you because you get really tired from it and isolated as well cos...you're not really living it outwardly it's just in your head, you're kind of thinking through things, but I think at home it's pretty much, and it's probably not changed as much, cos I can be more honest.

(Sarah: 18 years old, reporting chronic pain, hypermobility, CRPS, anxiety, depression)

This sense of isolation from others and perceived lack of protective social relationships highlights the wider social context in which the participants experienced their co-occurring pain and mental health symptoms. The experience of co-occurring symptoms made the participants feel different and often isolated them from their peers, “I felt kind of you know, not normal” (Pippa: 18 years old, reporting chronic fatigue, fibromyalgia, hypermobility, anxiety, depression). It was often difficult to make sense of, let alone describe, their experience to others, providing a broader social mirror in which these participants compared themselves with others. There was also a perceived tension between not wishing others to know about their pain and mental health symptoms, for fear of stigma, invalidation and social isolation, and yet finding it challenging to censor that part of themselves.

Sometimes self-censorship was important to protect participants from stigma, other times it was to protect others from the burden. For Maria, hiding the experience of her symptoms meant not being able to fully connect with others. She talked about her symptom experience as “what I've been through” implying a journey of hardship. To overcome the isolation of their experience, and to fully relate with others, especially in more intimate relationships, sharing the experience was important.

Yeah, it is a bit difficult because like um, I don't always want these people to know about what I've been through and stuff but it's kind of like difficult to hide it forever especially if



I'm going to be really good friends with someone so it can be quite frustrating and I've got really anxious recently because um I've recently got a boyfriend and he didn't know about any of this stuff and I just didn't know how to tell him

(Maria: 17 years old, reporting CRPS, anorexia, anxiety, depression, self-harm)

While self-censoring was an important issue with peers, in contrast, when relating to healthcare professionals and teachers, participants described advocating for their symptoms to be recognized in order to seek support. As with their peer interactions, negative experiences such as blame, dismissal and rejection in these situations sometimes led to barriers with future engagements. The adolescents described becoming sceptical, losing confidence and finding it difficult to trust providers and putting up fronts of protection.

Sometimes these fronts were more active, for example Claire perceived her confrontations with teachers and healthcare providers as a battle, "I ended up having to fighting for myself and fighting for my grades", and other times, distrust led to disengagement for self-protection.

I'd kind of go through a phase of just being like "No I really don't trust anyone" and they definitely kind of made me less trustworthy in any treatments and kind of became more and more sceptical

(Sarah: 18 years old, reporting chronic pain, hypermobility, CRPS, anxiety, depression)

Participants mentioned examples of experiences that led them to build and maintain these fronts of protection, including difficulties expressing or accepting ideas relating to a connection between their pain and mental health symptoms. Indeed, particularly difficult was making sense of and communicating the relationship between their symptoms with healthcare professionals specialized in a single discipline. Maria, for example, expressed frustration about care she received in a mental health in-patient setting for her anorexia and self-harm symptoms. They appeared not to recognize her pain symptoms which she felt were integral to her mental health.

I think that they [healthcare professionals] need to like take into consideration my pain a bit more, because they- all they focused on is have I eaten everything, is my weight okay, they don't think about like how I actually feel about my pain about everything and how it's linked, they just sort of jump to the emotional

side and whether there is physical pain and it's frustrating sometimes

(Maria: 17 years old, reporting CRPS, anorexia, anxiety, depression, self-harm)

Jessie, on the other hand, was offered psychological treatments for her pain symptoms, but in a way that did not make sense to her. In the quotation below it appears that Jessie was confused by an apparent tautology in the explanation given to her about how her pain and mental health symptoms may be linked as it was communicated to her in a way that seemed to undermine both her pain and mental health concerns, and she consequently did not fully engage in the mindfulness treatments.

And I've seen neurologist and they've said yeah stress there's nothing else you can do about it apart from try and be less stressed

(Jessie: 15 years old, reporting fibromyalgia, anxiety, stress, self-harm)

In contrast, home was a space where adolescents did not perceive a need to hide their true sense of self and the impact of living with co-occurring pain and mental health on their lives. For some adolescents, this sense of removing, or at least reducing, the social front they adopted elsewhere was intentional and driven by a desire to enable their families to understand the adaptations they had to make due to living with co-occurring pain and mental health symptoms. In the quotation below it is as if Jessie deliberately takes down the front to reveal the whirlwind inside, and even to bring her family into the experience.

Um I think they're [her family] affected quite badly because just when I'm not feeling great I am quite snappy with people and I want to force people to understand what I'm feeling

(Jessie: 15 years old, reporting fibromyalgia, anxiety, stress, self-harm)

However, for others, this sense of relaxation at home was not intentional, instead reflecting a sense of no longer being capable of managing the effort involved in putting on a front. Similar to Sarah's description above of the efforts involved in censoring the 'whirlwind' from others, here Claire described the fragile nature of the efforts to 'bottle everything up' in attempts to contain her inner experience. She noted that home could be the place of release, where fronts could be taken down, leaving her whirlwind uncontained.

if something minor goes wrong, I will automatically just have a massive mental breakdown because that's like the little push I needed to have like a massive breakdown because I tend to bottle everything up so that I don't have to show what I'm feeling to people and particularly in front of my family I end up having the meltdowns and the breakdowns in front of them ((laughs)) which isn't, which isn't great

(Claire: 17 years old, reporting CRPS, unexplained paralysis, anxiety, depression, PTSD)

The language used by Claire above highlights an interesting tension between a sense of needing to be strong and stoic to avoid stigmatization, while experiencing incredible fragility and vulnerability. The relaxation of defences at home seemed to expose the family members to their symptom experience, disrupting the safety of the home environment, which was noticeable to the adolescents. This obvious negative impact on their family contributed to feelings of shame, blame and isolation as exemplified by Sarah.

Yeah, so definitely kind of feel like I put a lot more of a burden erm on people, family and friends, but definitely my family, I kind of definitely feel like I cause quite a lot of the kind of like negative stuff in our family, cos we're like, my parents are generally quite happy people but then kind of I find often that I'm like the main cause of if they're upset, or kind of feeling frustrated. Erm that has quite a big impact on you cus you're like the main reason of everything being a bit shit.

(Sarah: 18 years old, reporting chronic pain, hypermobility, CRPS, anxiety, depression)

This sense of being a burden on their loved ones led the adolescents to feel that they had to maintain their fronts even in the home or carry a further weight of guilt and shame for being the cause of disruption in the family. Consequently, the sense of social isolation resulting from their symptoms, and the absence of protective social relationships was exacerbated.

## 4 | DISCUSSION

This study was designed to explore the lived experience of adolescents with co-occurring chronic pain and mental health symptoms. Qualitative analysis of interview data

generated two main themes around a central metaphor of a storm: 'A whirlwind of everything' and 'Putting up fronts'. Indeed, symptoms were described as turbulent, confusing and overwhelming, to the extent that participants felt a lack of control over their physical, emotional and social wellbeing, and consequently experienced difficulties engaging with others.

A key take home message from our data is that co-occurring chronic pain and mental health symptoms are experienced as highly stressful: the experience of symptoms as uncontrollable, unpredictable and unexplained in combination with consequent impacts to their identities, and experiences of stigmatization and social isolation. This is consistent with other qualitative studies which examine the impacts and lived experience of chronic pain in adolescence (Bunzli et al., 2013; Heffernan et al., 2020), and adolescent mental health (Woodgate et al., 2021). Having both their physical and psychological functioning disrupted, the adolescents felt not only out of control of their general wellbeing, but also confused about their perceptions of their self-identity and how they related with the world around them.

Stressors that are unpredictable and uncontrollable while also threatening to one's social self have been shown to be among the most common and reliable triggers of hypothalamic-pituitary-adrenocortical activation (Dickerson & Kemeny, 2004) and 'toxic stress' (Nelson et al., 2022). The current paper focussed on the effects this symptom experience had on the adolescents both internally (or personally) and externally (interpersonally).

Internally, the participants in this study described feeling 'not normal' and reported negative interactions with others as a result of their symptoms leading to feelings of shame and self-censorship, with clear efforts to avoid the risk of further stigmatization and social isolation. Deliberately concealing elements of their identity in this way was a form of self-protection for adolescents, yet they noted feelings of isolation, as well as a burden of effort, as a result of this concealment. These unwanted effects align with research of concealable stigmatized identities suggesting that hiding reduces feelings of belonging (Newheiser & Barreto, 2014) which can have further implications for mental health (Arslan, 2021).

However, Evans (2017) argues that decisions to disclose or conceal one's invisible disabilities play a critical role in identity development (Evans, 2017). Given that adolescence is normatively described as an important phase for identity development (Erikson, 1993), the impact of how adolescents feel about their symptoms and express or shield them from others should be further explored and form an important part of clinical assessment.

With this insecure internal experience, interpersonal relationships were described as complex. In situations

that required them to express their experience, there were challenges in terms of sense-making. Difficulties articulating their symptoms, as well as understanding advice from others, led to barriers to support. This highlights the importance of developmentally appropriate pain neuroscience education (e.g. neurophysiological and psychological models of pain, information about how context informs pain perception), as well as education about mind/body interactions (Caes et al., 2017), and importantly, developing a sense of trust (Hardin et al., 2021). Complementary to our findings, a recent investigation into children and adolescents' experiences of pain communication with healthcare professionals highlighted challenges in interpreting advice that may illicit anger reactions (Lee et al., 2023). Considering the inner turmoil that the adolescents may be facing with co-occurring pain and mental health symptoms, advice from Lee et al's paper highlighting the value their participants placed on feeling reassured and cared for, and being asked about how their pain impacts their mental health, is particularly prudent (Lee et al., 2023). Indeed, the first national health standard for paediatric pain management recently developed in Canada calls for pain care that is trauma informed (Standards Council of Canada, 2023). Trauma-informed care approaches are in line with research from Moore et al. (2019) suggesting that building good relationships, delivered in safe spaces, with normalization of symptoms through social support have been found to be the most important factors in treating youth with mental health and long-term conditions (e.g. chronic pain). Furthermore, systemic influences on pain need to be considered beyond the patient–clinician relationship to include education for family members, schools and considerations of how pain and mental health issues are portrayed in mass media (Mueri et al., 2021).

Where the lines between personal and interpersonal impacts appeared less clear, was in the adolescents' homes. There was a sense that the unique environment of the home and family relationships created a space where the family could be vulnerable to the adolescents' symptom experience. This could be from the adolescent revealing their struggles to seek help, or just relaxing the burden of self-concealment that they carry in public. Either way, the findings suggest that the turmoil of the symptom experience may directly impact immediate family members and the family unit as a whole. The home is important to consider in studies of paediatric populations as it is described as a socio-physical environment, critical for self-regulation and relationship regulation for all family members (Sallay et al., 2019). Indeed, a recent qualitative study of the impact of paediatric chronic pain on parents, reports that parents describe the pain experience as 'constant and all-consuming' impacting various aspects of their lives, in a similar way as these findings describe the

'whirlwind' (Ngo et al., 2022). Parents with, versus without, chronic pain have been found to report significantly higher PTSD symptoms, and likewise their children report significantly higher PTSD symptoms and pain interference indicating intergenerational trauma is prevalent in paediatric chronic pain (Beveridge et al., 2018). Mothers of children with chronic pain (more so than fathers) report significantly impaired social and emotional functioning with mental health scores most impacted by the child having co-occurring depression (Benjamin et al., 2019). Additionally, close family members may influence the experience of pain by reinforcing illness beliefs including fear of pain or negative prognoses, often supporting the patient's self-limiting behaviour in efforts to help (McCluskey et al., 2011). The intergenerational influences are clearly complex and bidirectional, and can be both protective and risk factors (Ruiz & Marsac, 2021). Treatment and assessment of adolescents with co-occurring pain and mental health symptoms should be aware and sensitive to the nature of the relationships with close family members and it is important to include them in collaborative care where possible.

Limitations to this study should be noted. First, the data were taken on a single time point, with participants ranging in age 15–18 years with participants in high school, college and university presenting different socio-developmental stages. Considering that adolescence is a time of development, it might be prudent to have a narrower age range for more homogenous samples and comparison. Longitudinal designs would also be useful to explore interpersonal changes over time, for example, to see whether a sense of control over the symptoms changes over time; or how adolescents integrate their symptoms into their identities and how this impacts their experience; and to explore developments in how adolescents express their symptoms to others or make sense of them over time. Additionally, the chronic pain and mental health diagnoses were self-reported. The participants declared them to be officially diagnosed, however, these were not verified against their medical records. While verification of medical records would add to the credibility of the study, given that the study focussed on the lived experience of co-occurring symptoms, and it often takes time for an official diagnosis, if one is obtained at all, this does not change the results or validity of analysis itself. Finally, all participants were biologically female and although the prevalence of chronic pain and mental health symptoms is higher in female adolescents (in terms of biological sex; Campbell et al., 2021; Gobina et al., 2019) results may not be representative of more diverse populations of adolescent chronic pain and mental health symptoms.

The findings add novel insight into how adolescents are impacted by the experience of co-occurring chronic pain

and mental health symptoms. They indicate that the experience can be overwhelming and distressing, impacting their sense of identity and relationships. Of particular note is that adolescents described hiding or concealing their symptoms from others to avoid stigmatization, although these behaviours did not have the intended effect and often resulted in feelings of loneliness. In addition, when adolescents did have to express their symptoms, they struggled to know how to do so effectively. Furthermore, due to relaxing their symptom concealment at home, impacts of the adolescents' symptom experience extended to their immediate families. The findings suggest several factors that may be critical to consider in their care and treatment, namely: consideration of how the adolescent makes sense of their symptoms, including family members in assessment and treatment, and improving developmentally appropriate health education including pain neuroscience and the mind-body connection. More broadly, the social ramifications and drivers of the challenges described by the participants in this idiographic study serve to highlight issues that may be structurally created and imposed, inviting future research to zoom out and examine systemic influences on the experiences of adolescent populations with co-occurring chronic pain and mental health symptoms.

## AUTHOR CONTRIBUTIONS

Jenny Corser contributed to analysis, writing, reviewing and editing. Line Caes contributed to writing, reviewing and editing. Sharon Bateman contributed to data collection, reviewing and editing. Melanie Noel contributed to reviewing and editing. Abbie Jordan contributed to conceptualization, methodology, analysis, writing, reviewing and editing.

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## CONFLICT OF INTEREST STATEMENT

None to declare.

## ORCID

Line Caes  <https://orcid.org/0000-0001-7355-0706>  
 Sharon Bateman  <https://orcid.org/0000-0001-9975-8572>  
 Melanie Noel  <https://orcid.org/0000-0003-3752-8055>  
 Abbie Jordan  <https://orcid.org/0000-0003-1595-5574>

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