

## ORIGINAL ARTICLE

# How does pain work? A qualitative analysis of how young adults with chronic pain conceptualize the biology of pain

Hayley B. Leake<sup>1,2</sup>  | G. Lorimer Moseley<sup>1</sup>  | Lexa K. Murphy<sup>3</sup>  |  
 Caitlin B. Murray<sup>4,5</sup>  | Tonya M. Palermo<sup>4,5</sup>  | Lauren C. Heathcote<sup>6</sup> 

<sup>1</sup>IIMPACT in Health, University of South Australia, Kaurna Country, Adelaide, South Australia, Australia

<sup>2</sup>Centre for IMPACT, Neuroscience Research Australia, Sydney, New South Wales, Australia

<sup>3</sup>Department of Psychology, Seattle University, Seattle, Washington, USA

<sup>4</sup>Center for Child Health, Behavior & Development, Seattle Children's Research Institute, Seattle, Washington, USA

<sup>5</sup>Department of Anesthesiology and Pain Medicine, University of Washington, Seattle, Washington, USA

<sup>6</sup>Health Psychology Section, Department of Psychology, Institute of Psychiatry, Psychology and Neuroscience, King's College London, London, UK

## Correspondence

Hayley B. Leake, IIMPACT in Health, The University of South Australia, GPO Box 2471, Adelaide 5001, SA, Australia. Email: [hayley.leake@unisa.edu.au](mailto:hayley.leake@unisa.edu.au)

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## Abstract

**Background:** Pain science education (PSE) is commonly integrated into treatments for childhood-onset chronic pain. A core component of PSE is learning about, and often reconceptualizing, the biology of chronic pain. Yet, few interventions have been developed specifically for young adults and little is known about how young adults conceptualize the biology of pain. This study used a qualitative methodology to examine how young adults with childhood-onset chronic pain understand the biology of pain, and the language they use in this meaning-making process, which may inform future interventions tailored to this age group.

**Methods:** We identified a cohort of young adults with childhood onset chronic pain, and a subset of 17 young adults with continuing chronic pain completed individual, semi-structured interviews. Telephone interviews were audio-recorded, transcribed verbatim and analysed using reflexive thematic analysis.

**Results:** We generated four themes that capture participants' conceptualizations of the biology of pain: (1) Something is wrong with the body, (2) An injury has not healed, (3) Nerves fire when they should not, (4) An overactive stress system.

**Conclusion:** These conceptualizations, and the language used by young adults with childhood-onset chronic pain to describe them are discussed. Recommendations are provided for how PSE interventions can be tailored for young adults.

**Significance:** This study provides new qualitative insights reflecting a variety of ways that young adults with childhood-onset chronic pain conceptualize pain. Some conceptualizations of pain align with modern pain science principles (altered function of nervous and endocrine systems) while others conflict (unhealed injury). Health professionals can use these findings to tailor their pain education interventions by leveraging concepts that 'stick' for youth, being aware of, and interrogating, common misconceptions, and offering language and metaphors familiar to youth.

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## 1 | INTRODUCTION

Understanding how individuals conceptualize their pain is a foundational component of many interventions for chronic pain. Clinicians establish an individual's understanding of pain, and use this to guide the appropriateness and content of pain science education (PSE). The aim of PSE is to align an individual's understanding of pain with modern pain science principles (Moseley & Butler, 2017), in order to encourage engagement in non-pharmacological evidence-based management for chronic pain—such as exercise (Harrison et al., 2019) and psychological interventions (Fisher et al., 2018)—that may otherwise appear counterintuitive to recovery.

There is value in identifying patterns of how people with chronic pain make sense of pain. By establishing patterns in pain conceptualizations, and in language and metaphor use, we can identify how to best communicate pain concepts to people with chronic pain. Furthermore, uncovering common misconceptions about pain can help guide the development of educational resources. For example, adults with chronic pain have described the belief that pain is a sign of damage (Darlow et al., 2015) and that painful activity will result in functional loss (Bunzli et al., 2015). Resources have been developed to counter those misconceptions about pain, from books (Butler & Moseley, 2013), to mass media campaigns (Suman et al., 2021). However, these investigations and resources have been conducted in samples of older adults with chronic pain. Young adults may not share the same conceptualizations of pain as older adults, considering that older adults commonly describe that their pain is caused by age-related degeneration (Bunzli et al., 2015). Currently, no studies have explored how young adults conceptualize pain, despite chronic pain being a prevalent concern for this cohort (Murray et al., 2021). Up to a third of children and adolescents experience chronic pain (King et al., 2011) and over half will continue to live with chronic pain into young adulthood (Kashikar-Zuck et al., 2010). For those young adults with childhood-onset chronic pain, the (already complex) transition to young adulthood presents unique challenges, for example, an increased expectation to assume responsibility for managing pain (Higginson et al., 2019). Decisions about pain management may be influenced by how young adults with childhood-onset chronic pain conceptualize the meaning of their pain.

Capturing thoughts on the biology of pain is central to understanding how young adults with childhood-onset chronic pain conceptualize pain. Young people with chronic pain commonly seek a biological explanation for their pain (Neville et al., 2019). Throughout childhood, young adults with childhood-onset chronic pain are likely exposed to a variety of biological explanation about pain. These explanations may align or conflict with

contemporary explanations for the biology of chronic pain, whereby a pain experience does not necessarily represent ongoing harm to the body, but instead reflects processes such as nerve hypersensitivity, central sensitization, neuroplasticity and brain modulation of nociceptive signals. The aim of this study was to use qualitative methods to understand how young adults with childhood-onset chronic pain understand the biology of pain, and the language they use in this meaning-making process.

## 2 | METHODS

### 2.1 | Research design

This study was conducted as part of a larger observational study with long-term (6-year) follow-up of young adults with a history of chronic pain in childhood. One article has been published from this dataset to document healthcare transitions of young adults with chronic pain (Murray et al., 2022). This study aimed to determine how young adults with childhood-onset chronic pain, make sense of the biology of pain. We conducted semi-structured interviews to generate deep, rich insights into individual experiences.

The interviews were developed and analysed in line with Braun and Clarke's thematic analysis approach (Braun & Clarke, 2006). Our methodology adopted a critical realist ontology (Braun & Clarke, 2013) and a contextualist epistemology (Madill et al., 2000) that assumes that the real and knowable world is only partially accessible to researchers because of the unavoidable influence of social and cultural structures (Moller et al., 2021). When conducting research with this approach, we must maintain an awareness of these influences while continuously seeking to understand the knowable truth behind them. Our approach also acknowledges the researchers' expertise and motivating theoretical frameworks as a valuable part of analytic knowledge production.

This study is reported in accordance with the Standards for Reporting Qualitative Research (O'Brien et al., 2014).

### 2.2 | Participants

Young adults with childhood-onset chronic pain were identified from their participation in an ongoing long-term follow-up study (Murray et al., 2022). That cohort included 273 youth (ages 11–17 years) with a range of chronic pain conditions (e.g. head, abdomen and musculoskeletal pain) who were originally recruited from 15 interdisciplinary paediatric pain clinics across the United States and Canada. A 6-year follow-up survey was conducted to identify participants that were at least

18 years old and had current chronic pain for at least 6 months. All 273 youth who took part in the original study were above the age of 18 at the time of recruitment and were contacted via email, text or phone. A total of 84% ( $N = 229$ ) of the original cohort completed the 6-year follow-up study (36 were unable to be reached, six declined due to lack of availability and two failed to complete their surveys after consenting). Of the 229 young adults who completed the follow-up survey, 189 (82.5%) indicated having current chronic pain and were thus eligible to take part in this interview study. Of the 189 eligible youth, a subset of 26 were identified using purposeful, criterion-based sampling to identify a maximally diverse sample in terms of demographics (e.g. age, ethnicity, sex and country of residence) and pain-specific variables (e.g. type and severity of chronic pain). Of the 26 youth that were identified and invited to participate, 18 consented (six declined, two could not be reached; recruitment rate of 69%). One participant's interview could not be analysed due to poor audio quality. Therefore, for this study, we analysed data from 17 young adults (13 female; mean age = 20.7 years; range = 18–24 years) with childhood-onset chronic pain. Youth had mixed pain types, and an average pain duration of 11.4 years. Demographic characteristics of participants are presented in Table 1. The sources from which youth described learning about pain are described in Table 2.

## 2.3 | Procedure

Ethical approval for this study was provided from the Seattle Children's Hospital Institutional Review Board prior to any research procedures. Consent was provided online through REDCap (Research Electronic Data Capture; Harris et al., 2009), a secure web-based data collection platform. Semi-structured telephone interviews were conducted in Seattle, United States with LM and ranged in duration from 19 to 56 min (average = 35 min). Interviews were audio-recorded and transcribed orthographically in Microsoft Word. Identifying information was removed from the transcripts and participant numbers were used for data analysis. Participants were compensated with a \$25 (USD) gift card for their time.

## 2.4 | Data collection

### 2.4.1 | Demographic characteristics

#### *Demographic characteristics*

Participants reported on their age, sex, race, ethnicity and country of residence.

**TABLE 1** Demographic characteristics of young adults with childhood-onset chronic pain ( $n = 17$ )

	<b>N (%)</b>	<b>M (SD)</b>
Age at interview, years		21.2 (1.7)
Sex		
Female	13 (76.5)	
Male	4 (23.5)	
Country		
USA	13 (76.5)	
Canada	4 (23.5)	
Ethnicity/race		
Non-Hispanic, White	12 (70.6)	
Hispanic, Non-white (e.g. Latin American)	1 (5.9)	
Black	2 (11.8)	
American/Indian/Alaska Native/Aboriginal	2 (11.8)	
Highest level of education		
Some high school	2 (11.8)	
High school graduate/ equivalence	6 (35.3)	
Some college	6 (35.3)	
Associates degree (2-year college)	0	
Bachelor's degree (4-year college)	3 (17.6)	
Pain duration, years		11.4 (3.8)
Pain location/type		
Musculoskeletal	8 (47.1)	
Multiple types	4 (23.5)	
Neuropathic	2 (11.8)	
Abdominal	2 (11.8)	
Headache	1 (5.8)	
Pain intensity (BPI)		4.76 (1.95)
Pain interference (BPI)		4.47 (2.22)
Pain frequency		
Daily	11 (64.7)	
4–6×/week	2 (11.8)	
2–3×/week	2 (11.8)	
1×/week	2 (11.8)	
Depression (PHQ-9, range: 0–27)		9.59 (4.30)
Anxiety (GAD-7, range: 0–21)		8.53 (3.48)
Seeing a healthcare provider for pain management at the time of interview	9 (53)	

Abbreviations: BPI, Brief Pain Inventory; GAD, Generalized Anxiety Disorder; PHQ, Patient Health Questionnaire.

**TABLE 2** Sources of pain knowledge

Sources of pain knowledge	Examples
Healthcare professionals	Doctors, pain clinic and pamphlets
Online research	Social media, Google, YouTube and Internet
School	Class project, anatomy class
Personal experience	Trial and error, learnt from doing
Learning from other people's experiences	Talking to other people with chronic pain

**TABLE 3** Semi-structured interview schedule

Question number	Question and prompt
1	Tell me about your thoughts on the purpose of pain? <i>In other words, explain to me why you think humans have a system that creates pain?</i>
2	Can you describe everything you understand about the difference between acute and chronic pain?
3	Can you tell me everything you understand about the biological processes of pain? <i>In other words, what happens in your body when you feel pain? Can you tell me what happens to these processes when pain continues for a long time?</i>
4	In addition to biological processes, what other factors influence a person's experience of pain?
5	How did you learn the things you know about pain? <i>Are there any stories, metaphors, books or videos that you remember as being really useful when learning about pain? What did you like about them?</i>
6	How has learning about pain changed the way you manage your pain?
7	What do you think is the most important thing you have learnt about pain? <i>Why was this important?</i>

### Pain characteristics

Participants reported on pain intensity, pain duration, pain interference, pain frequency, and current pain location/type. *Pain intensity* and *pain interference* were assessed using the Brief Pain Inventory (BPI; Cleeland & Ryan, 1994). The BPI is an 11-item instrument designed to assess the severity of pain and the extent to which it interferes with various activities over the past 7 days. Pain intensity was assessed as average pain in the last week, ranging from 0 ('no pain') to 10 ('pain as bad as you can imagine'). The *pain interference* subscale comprises of seven items, each scored 0 ('does not interfere') to 10 ('completely interferes'). The interference subscale score is the mean of these seven items, where a higher score represents greater interference with daily activities. The BPI has demonstrated good internal consistency for pain severity and pain interference (Poquet & Lin, 2015).

### 2.4.2 | Semi-structured interview schedule

Semi-structured interviews focused on exploring participants' understanding of the science of pain, their experiences learning about pain, and their perceptions on the impact of learning about pain (see Table 3 for interview schedule). The interview schedule comprised open-ended questions and prompts to allow the interviewer to expand on points of interest as they were discussed. Piloting of the interview schedule with three young adults with

childhood-onset chronic pain assisted in developing and refining the wording of questions (pilot data not presented here).

To address the primary aim of this study, responses to most interview questions (Q1–4, 6, 7) were included in the reflexive thematic analysis. Those questions explored perspectives of the purpose of pain, differences between acute and chronic pain, how pain works in the body, what was important to learn about pain and the impact of learning about pain. To provide context for where participants learnt about pain, responses to question 5 ('How did you learn the things you know about pain?') were briefly summarized and included in Table 2. The raw data of responses to question 5 are included in Supplementary Materials.

## 2.5 | Data analysis

Data were analysed using reflexive thematic analysis, in accordance with Braun and Clarke's recommendations (Braun & Clarke, 2006). We used a primarily bottom-up, inductive approach to coding, whereby codes and resultant themes were developed based on the raw data without an a priori coding system. This approach ensured that results were grounded in the participant's interpretation of the biology of pain. We recognize that in this approach, the theoretical framework and clinical experience of the researchers influenced the thematic development process. Following transcription of the data (by research assistants not otherwise

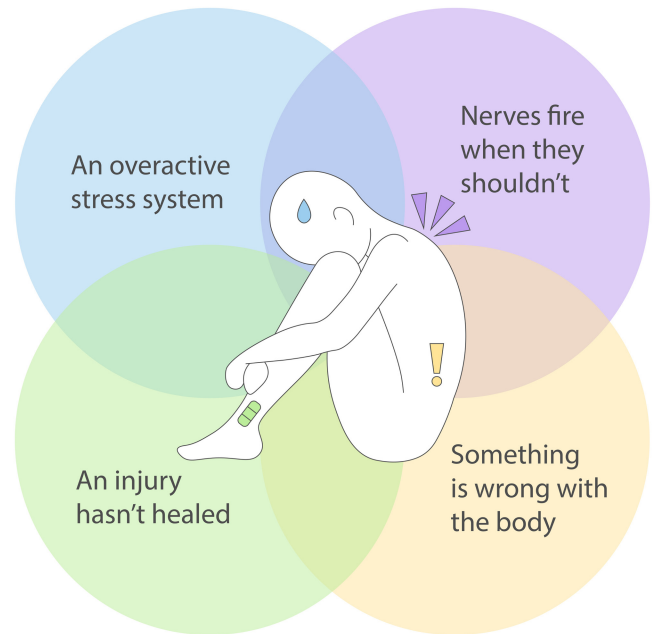
involved), and verification of the transcripts (by LM), the first author (HBL) familiarized herself with the data from all interviews through reading and re-reading transcripts. Through an iterative process, the data were recursively coded by HBL using NVivo (version 12; QSR International Pty Ltd, 1999). Coding focused on both semantic and latent features of the data, considering both what the participants said (i.e. content and meaning) and how they said it (i.e. language use). Codes were collated to identify candidate themes, that were iteratively reviewed and refined through discussion with co-authors (LCH and GLM) to generate final themes. For context, these researchers have backgrounds in physiotherapy (HBL, GLM) and psychology (LCH) and have published in the fields of chronic pain, paediatric pain and PSE. Excerpts of transcripts are provided as examples of each theme and selected to illustrate both the central components of each theme and the breadth and diversity of perspectives. In Results, at times we report quoted extracts using an analytical approach, whereby we interrogate what has been interpreted to be important about what participants said, and contextualize extracts in relation to the literature (Braun & Clarke, 2021).

## 2.6 | Quality criteria

We did not conduct coding in duplicate nor seek inter-rater reliability as those practices relate to a ‘small q’ or positivist ideal of obtaining ‘uncontaminated’ knowledge, by controlling subjective influences (Braun & Clarke, 2006). That approach is incompatible with our approach that recognizes subjectivity of the researcher, and takes this into account via contextualized analysis (e.g. the researcher’s context is explicitly described, acknowledging that it inevitably sculpts the knowledge produced). We met the following criteria for demonstrating quality of thematic analysis (Braun & Clarke, 2020): (1) a collaborative analysis (i.e. discussion between researchers) was used to develop a richer, more nuanced reading of the data, rather than to seek a consensus on meaning, (2) detailed transcriptions were checked against audio recordings for discrepancies, (3) equal attention was given to each data item in the coding process, (4) the coding process was thorough, inclusive and comprehensive and (5) most participants were represented with one quotation; no participants were represented with more than four quotations.

## 3 | RESULTS

We generated four themes related to how young adults with childhood-onset chronic pain understood the biology



**FIGURE 1** The relationship between the themes describing how young adults conceptualize the biology of pain.

of pain: (1) something is wrong with the body, (2) an injury has not healed, (3) nerves fire when they should not and (4) an overactive stress system (Figure 1).

### 3.1 | Theme 1: Something is wrong with the body

The first theme captures young adults’ descriptions that pain indicated a problem within the body. These accounts were generally vague, suggesting that pain signalled ‘something is wrong’ (P4) or ‘there’s some issue going on’ (P5) that was undesirable.

I think a lot of times pain kind of indicates a problem I guess is the way I would see it. Somethings going on that maybe shouldn’t be going on and that’s why you’re feeling the pain. (P16, abdominal pain)

Some youth provided a nuanced description of pain, by stating that pain could provide protection for impending danger to the body. Yet, this function of pain was caveated as applying only to healthy individuals.

I think that when humans are healthy, they have a system that creates pain to protect them from something that can hurt them further. (P17, musculoskeletal pain)

Although pain was often seen to indicate a problem in the body, a few participants suggested that pain could sometimes have no meaning at all. Meaningless pain was described as pain that ‘comes from nothing necessarily’ (P16). This label of meaningless pain may have been used to describe pain that has no obvious tissue-based cause. Yet, youth were sceptical that pain could truly be meaningless, instead adding that pain must be driven by an undiscovered problem in the body.

I think when we have pain in other areas, like the back, and it's there for no reason, I really do wonder if there's something going on in the body that's not good that hasn't been detected. Like soreness of a neck should be if the person slept wrong that blood flow will get cut off, sometimes that just happens. But if someone is often sore, then I think something is not quite right in the body. And I do think that's not normal. (P17, musculoskeletal pain)

Several participants explicitly used the terms ‘not normal’ when referring to a body with pain. Conceptualizing one's own body as abnormal may be internalized in such a manner that young adults themselves feel different from their pain-free peers. Abnormality of the body is especially salient for young adults, who often seek conformity to promote social bonding and belonging with peers. Negative body image and low self-esteem are also concerning issues for adolescents and young adults, that may be associated with viewing one's body or bodily functions as abnormal.

Um I guess [pain is] just a way of telling us that something's wrong. Something not right and our body wants us to be how it's supposed to be. A normal people body. (P13, multiple pain types)

Some participants suggested that the critical function of pain was to empower an individual to rectify a problem in the body. When pain persisted, and could not be relieved through action, it was considered useless. The term ‘useless pain’ appears to reflect a belief that chronic pain no longer serves its normal protective biological function, and is therefore a ‘useless’ (i.e. non-purposeful) signal. Identifying that chronic pain no longer serves a protective function, contrasts with beliefs that chronic pain is protecting from ongoing injury (see Theme 2), and presents as a positive and adaptive way that youth understand the function of chronic pain.

I think if you are unable to address the source of pain in some way, like if you're unable to actually react to it, the pain is kind of useless. Like, I think the whole purpose of pain is to alert the brain that there's some issue going on and that you should try to react to it to stop that issue. ... I would say pain in its simplest form is essentially an alert from the body telling you that something is wrong and ideally you should fix it to relieve that pain. (P5, abdominal pain and headache)

For one participant, believing that pain indicated an abnormality in their body motivated them to search for the ‘source of their pain’. During their pursuit, they described what has sometimes been termed in research as hypervigilance, or an attentional bias towards pain—that is, a tendency to select pain-related information over non-pain-related information. That their family did not share their enthusiasm to search for the source of their pain was perceived by the young person as a lack of empathy, which could have negative implications for family relationships.

I think it's been kind of like a bell curve in a sense where at first I didn't know anything. Then I learned about how pain like pain as a signal that something's wrong so then I became hyper aware of my pain and drove my family crazy anytime I had pain because I wanted to know what was causing it. Then I figured out that that was going to be exhausting, and no one really cared enough so I stopped. (P4, musculoskeletal pain)

Some participants believed that their pain indicated a serious problem. The most extreme example of this was a young adult describing that they believed their pain was an indication they were dying. However, the quote suggests that they had reconceptualized this function of pain as a young adult, now with a more nuanced understanding that pain does not always indicate a severe or life-threatening issue.

All pain is not severe; you're not going to die. Like it's temporary. Because when I was younger I used to think I was dying about the pain but it was just something minor. (P7, abdominal pain and headache)

Taken together, the theme ‘something is wrong with the body’ captures that young adults’ conceptualized pain as a sign that the body was abnormal. Young adults expressed a desire to understand what was happening in their body, and a dissatisfaction with explanations that pain lacked meaning. Without a clear explanation for pain, young adults attempted to fill the conceptual gap (i.e. does pain mean I am dying?) or searched for a cause of their pain.

### 3.2 | Theme 2: An injury has not healed

The second theme builds on the first theme by offering a conceptualization for what might be wrong with the body—that is, some participants described that pain was a sign that an injury had (unexpectedly) not healed. The ability for an injury to heal was portrayed as a normal response; a key feature of acute pain, but not chronic pain. For example, acute pain was ‘tied to a specific injury onset and an end’ (P1), whereas chronic pain was thought to occur when an injury had not *yet*, or could not *ever*, heal.

Acute pain is something that’s short term that’s normally a result of an injury. Um, something like chronic pain is something that’s going to last forever or last for a long amount of time and usually has to do with a medical condition or results of an injury, um where something is not gonna heal. I tend to think of acute pain like a paper cut which hurts in the moment but then it goes away and heals. But chronic pain is something that’s never going to fully heal and because of that you’ll have long term results. (P4, musculoskeletal pain)

A few participants described that healing was impossible in the context of their chronic pain. One participant suggested that some forms of bodily damage are incapable of healing; specifically, that scars do not heal. Clinically, a scar is considered the endpoint of a healing process, however, young people may have different expectations about the outcome of healing, for example, how the body should appear after it has healed (e.g. scar free), and what it means for an injury to be completely healed.

I think that overtime when you have created so much damage when something has happened so repetitively, you end up leaving damage or a scar in which it can’t be healed. (P13, musculoskeletal pain and headache)

One participant described that the key feature distinguishing injuries that heal, and those that do not, is their location—internal versus external. They conclude that, because you cannot fix internal injuries, they do not heal well. Because visual observation can be used to assess healing of external injuries, but not internal ones, young adults may instead use pain as a proxy for healing of internal injuries. This would lead to the conclusion that persisting pain, must indicate an unhealed injury. Their focus on fixing an injury, suggests a belief that intervention is always necessary for healing, rather than an accompaniment to increase the speed or quality of healing.

... when pain is in different areas like bone and muscle it can be a lot harder to heal out of those areas um because it’s not – it’s internal it’s not necessarily something external that can be fixed. So I think with chronic pain I think a lot of people struggle with that because it’s a lot harder to heal your bones, your nerves and your muscles. (P15, musculoskeletal pain)

One participant identified that their definition of pain, as an indicator of injury, did not fit for chronic pain. Yet, they were unable to bridge this conceptual gap with a coherent definition for chronic pain. A major challenge was to understand the cause of their pain.

Essentially, [pain is] how we know we’re injured so we know when to run away um or when we can’t do something. And I find unfortunately with that definition of pain it’s difficult to understand through a chronic pain idea, because if that’s a definition of pain and why we have it then we’re in a lot of trouble. And what do we do with that? We’re in a lot of trouble. I don’t – I don’t know. (P10, musculoskeletal pain)

One young adult described that there was little value in trying to heal their pain. Rather, there is greater perceived value in accepting the permanency of pain and learning to live with it. In this instance, it is likely that the terminology of ‘heal pain’ refers to resolving pain, rather than healing an injury to the body. Acceptance of pain as permanent was described by other participants, who suggested that chronic pain is ‘probably there forever’ (P13) or ‘something that you might just have to deal with for life’ (P16), or ‘doesn’t go away like at all’ (P2). This may be a realistic mindset, as chronic pain is a lifelong problem for some individuals.

Um instead of trying to heal it, try to cope with it. Because, like, when I was younger everyone would say, oh like you're going to be over your pain before you're eighteen, like, this is only temporary. I wish I would have prepared myself more knowing that I would have it long term because that's my reality now. (P15, musculoskeletal pain)

Taken together, the theme 'an unhealed injury' captured the belief that the failure of pain to fully resolve was an indication that an injury had not healed or was never going to fully heal, although a few young people described a lack of healing as a belief that pain would not resolve.

### 3.3 | Theme 3: Nerves fire when they should not

The third theme captures how nervous system functions relate to pain. The process of neurotransmission was a central aspect of this theme, in that several participants suggested that pain was intricately related to the way nerves transmit information. Most of these accounts used general language that nerves send 'messages' or 'signals'. Occasionally, participants specified that nerves send a 'message of pain' (P9), likely referencing the action of nociceptors.

So a lot of the times I know of, for the most part, [pain] has to do like with your nerves. Kind of just like the firing of your nerves. ... maybe I'm trying to think of a good way of explaining it but just like bring alert to the fact that you are in pain. You swell, your skin gets hot, and your nerves kind of just are sending out a sensation that you are in pain. (P16, abdominal pain)

Some young adults described that when pain persists, there is a problem in the way nerves transmit information. A few young people were general in their descriptions of what was wrong with the nervous system. For example, the following quote suggests that nerves go 'on the fritz', which is an idiom usually applied to machinery that is not operating correctly.

I'm not sure – do [nerves] go on the fritz? That's probably what happens right? I don't know. I imagine they do. Stop working so well. (P14, abdominal pain)

When asked to describe what happens when pain persists, one participant suggested that nerves send inaccurate messages. They described that when the brain receives messages that misrepresent the state of the body, it is unable to resolve problems in the body.

I'm pretty sure [nerves] get inflamed and um confused and so like start firing signals that aren't actually there so it doesn't know what's happening and the body gets confused and doesn't know how to fix anything .... (P10, musculoskeletal pain)

Other participants suggested that when pain persists, nerves send excessive messages. For example, stating that 'nerves are firing constantly instead of just when they need to' (P12). These descriptions align with the range of processes underpinning central and peripheral sensitization, where there is amplification of stimulus–response profiles within the nociceptive neuraxis. As justification for why the body creates excessive messages, one participant suggested that the mechanism that normally stops nerves sending messages is impaired in people with chronic pain.

But the chronic pain is – especially when you're trying to talk about people who have neuropathic pain and all that kind of stuff – it's like a continued sort of signal. It does not stop like acute pain when the inflammation goes down, or you get a cut and that heals. So, you're obviously not really having the same stimulation that you would with chronic pain where it's just a constant signal that just continues to go on. (P16, abdominal pain)

Other participants also described a mechanism that controlled when nerves send messages, instead using the metaphor of a switch. One participant suggested that sometimes pain was due to the 'pain switch' being permanently turned on, suggesting there was an unrestricted pathway for nerves to continue to send messages that result in pain.

... learning from my sister after her surgery, doctors explained it as the pain switch got flipped on permanently. ... In a sense [my sister] has pain but there's nothing wrong, but I have pain and there's something wrong, so I feel like it can sometimes mean that there's nothing wrong. But I guess at the same time it does mean that there's something wrong because her pain switch was flipped on. (P4, musculoskeletal pain)



When asked to describe how persistent pain works, rather than conceptualizing a switch in the nervous system being turned *on*, another participant suggested that pain was due to a switch being turned *off*. That is, they described a closed pathway, where pain occurred because no messages were being sent between the body and the brain. This diversity in how participants conceptualized the function of the switch highlights the complexity of understanding the role of the brain and nervous system in pain. It is likely that participants that described a switch in the nervous system, were exposed to similar content of pain education. That is, the concept of a *pain switch* seems analogous to the *pain gate*, which is a metaphor commonly used in paediatric pain education to explain mechanisms of pain transmission (Koechlin et al., 2020), originally based on the gate control theory (Melzack & Wall, 1965).

Um I mean the way I was kind of always told is sometimes in your spinal cord like that switch to send the message from your spinal cord to your brain gets like shut off so like the brain doesn't fully read – get the message to be able to stop the pain signal so the message of pain keeps getting sent from point of injury to the spinal cord and back and forth and back and forth. Um but yeah that's what I was told I think. (P9, neuropathic pain)

When describing increased sensitivity, some participants touched on the clinical phenomena of allodynia and hyperalgesia. For example, one participant described that sensitivity is why 'people feel pain in their hands when they touch things' (P15)—suggestive of allodynia, whereby pain results from a stimulus that does not normally provoke pain. The following participant described hyperalgesia; whereby increased pain is experienced from a stimulus that normally provokes pain:

Um I'd imagine that I think there's a lot more information um that results um in the body having more heightened sensitivity. Um it can result in having more pain more easily. (P1, musculoskeletal pain and headache)

One participant used the metaphor of a peanut allergy to describe their abdominal pain, suggesting that both involve exaggerated responses to (possibly inert) stimuli. The depiction of pain as an overreaction is similar to contemporary pain science descriptions of the pain system as 'overprotective' (Moseley & Butler, 2015).

Basically, the way I explain my stomach to people is sort of like a peanut allergy in the sense that the wires are crossed a bit and it overreacts to things. (P14, abdominal pain)

Taken together, the theme 'nerves fire when they shouldn't' highlights young adults' descriptions that chronic pain results from functional changes in the process of neurotransmission. Participants consistently described that, in the context of chronic pain, nerves send excessive, unnecessary and inaccurate messages.

### 3.4 | Theme 4: An overactive stress system

The fourth theme presents young adults' conceptualizations that the stress system is integral to why pain persists. Stress was discussed both as a perception and a physiological response. Often participants described a physiological stress response using the terminology of a fight or flight response. This is common vernacular to describe activation of the sympathetic nervous system in response to perceived threat. One young adult described that in their youth, they did not understand how stress influenced pain. This conceptual gap closed as they learnt about the biology of the stress system, specifically the sympathetic nervous system (i.e. 'fight or flight response') and the role of the hormone adrenaline. It is unclear if this young adult was exposed to these concepts in their youth and did not grasp them, or they were only introduced to them later in life.

Um I think learning about pain and how um the body can become stressed, and stress can lead to pain, has really helped me ... When I was younger, I didn't understand how stress causes pain. I understand how stress causes pain now, and how stress can cause pain from like fight or flight mode or adrenalin in your body. (P17, musculoskeletal pain)

One young adult suggested that the mechanism linking perceived stress with pain was changes to the nervous system and brain. Akin to descriptions of nerves in Theme 3, some young adults described that stress affects the brain, and causes the nervous system to malfunction—inferred in language that nerves are 'fried' and go 'haywire'.

Stress – eventually your nerves are being fried and so everything is going a little haywire.

Your body just can't register what's happening or emotional outbursts cause – or emotional problems cause distress in the brain that causes more pain and stuff like that I think. (P10, musculoskeletal pain)

One young adult identified that perceived stress could cause pain by increasing muscle tension. This young adult referred to pain in their muscles as physical pain. Physical pain is sometimes used in contrast with the term 'emotional pain' (P5), referring to negative emotions (e.g. depression). In the following excerpt, the young adult described feeling powerless to reduce the effect of perceived stress on their pain.

I noticed that when I am in more stressful situations or um more focused on the pain it feels like ten times worse and there is just nothing I can do about it. So by being in a stressful situation I feel tense. I am angry, uptight, and it's not doing much for my physical pain because I'm tensing up which is causing my muscles to hurt .... (P3, musculoskeletal pain)

Many participants inferred that they had agency over their stress system, and presumably also their pain. One young adult described that pain persists because of a sustained fight or flight response and that this could be controlled.

I also know that there's um a lot of discussion of chronic pain being a result of you not being able to come out of your fight or flight response; that your body never takes the time to stop if you don't stop. (P1, musculoskeletal pain and headache)

Understanding the biological link between stress and pain led some young adults to manage their pain using psychological strategies. Common psychological techniques that were described include breathing and relaxation strategies—for example, 'you develop techniques for being able to relax' (P5). For one young adult, the ability to manage pain with breathing techniques, allowed them to reduce their reliance on pharmacological strategies.

I feel like I have a better understanding of what causes the pain. Obviously, I've tried to avoid that but I'm more efficient about the way that I treat it and have a better grasp of not everything requires medication now that I understand exactly kind of what is going

on about the pain. I just know that I don't always have to take something I can breathe through it because it can be tied to emotions or your hormones and stuff like that. So, having a better idea of that has equipped with better tools to handle it better. (P16, abdominal pain)

Taken together, the theme 'an overactive stress system' captures that young adults' conceptualized that biological changes in the stress system drive pain. Mostly, young adults described sustained activation of the autonomic nervous system's fight or flight response; although stress was also said to impact neurotransmission, and muscle tension. This knowledge primarily functioned to support the use of psychological strategies to manage pain.

## 4 | DISCUSSION

### 4.1 | Summary of main findings

This qualitative study explored how young adults with chronic pain conceptualize the biology of pain. Through a reflexive thematic analysis of interview data, we generated four themes: (1) something is wrong with the body, (2) an injury has not healed, (3) nerves fire when they should not and (4) an overactive stress system. We provide recommendations for how these conceptualizations of the biology of pain could be used to tailor PSE for young adults with chronic pain.

The first theme was that pain indicated something was wrong with the body, yet, at times youth lacked an explanation for why. Some young adults described this by stating that chronic pain was 'useless'. The idea of 'useless pain' represents an adaptive way that youth conceptualize the function of chronic pain, in that it lacks its normal protective function. Yet for others, the suggestion that chronic pain could be meaningless was immediately rejected, stating instead that pain must indicate an undiscovered problem in the body. This innate need to explain what is happening in the body is also reflected in diagnostic uncertainty literature for both adults and adolescents with chronic pain (Neville et al., 2019; Pincus et al., 2018), whereby people with chronic pain describe wanting a further explanation for their pain beyond a diagnosis. Filling that void with the belief that pain indicated a problem in the body, made one participant hypervigilant towards their pain, which is concerning as hypervigilance is thought to play a critical role in the maintenance of chronic pain both directly (Eccleston & Crombez, 1999) and by facilitating worry,

fear and avoidance behaviours (Lau et al., 2018). Young adults may conceptualize a normal body as one where pain can be both explained and addressed. Certainly, societal norms suggest that pain denotes a fixable problem (Karos et al., 2018). Beliefs about underlying problems in the body are particularly relevant in young adulthood, when responsibility for healthcare shifts from parents/caregivers to the young adult (Higginson et al., 2019). In fact, the broader perception that persisting pain is a sign of an abnormal body is particularly relevant for youth because 'being normal' and belonging among one's peers is a salient concern for young adults (Barry et al., 2016). Shifting understanding from chronic pain as a marker of an undiscovered problem in the body via a coherent and contemporary biological explanation for pain, may help youth navigate their newfound healthcare responsibilities, reduce hypervigilance and promote a sense of belonging among peers.

The second theme was that pain meant an injury had not healed. This was distinct from the theme of an abnormal body insofar as it was associated with a clear understanding of an unresolved tissue injury. Recommendations for pain education for adolescents with chronic pain include concepts differentiating pain from tissue damage (Leake et al., 2019). Yet, it is possible that young people with childhood-onset chronic pain hold a mindset that their body is incapable of healing. Mindsets are core associations about the nature and workings of things and processes in the world (Crum et al., 2017). Indeed, if youth do hold a mindset that chronic pain indicates their body is incapable of healing, this would contrast against the normative view that 'young bodies heal quickly'. Yet that belief is consistent with previous literature of adults with chronic back pain who doubt the body's ability to heal, the likely time frames involved and the quality of any repair (Darlow et al., 2015). Children (8–12 years) with chronic pain describe pain not only in terms of injuries (Pate et al., 2019), but they also acknowledge that pain can be felt even after an injury heals (Ashar et al., 2021; Pate et al., 2020), although it is unclear if they apply that logic to their own pain condition. It is possible that if youth hold a mindset of their body as incapable of healing, this may limit engagement in therapies that threaten to perpetuate or worsen a perceived injury (e.g. moving the painful body part), or that appear unrelated to the perceived cause of pain (e.g. psychological therapies). Such themes have been observed in adults with chronic pain (Caneiro et al., 2021; Leake et al., 2021) and recovered adults report that shifting these beliefs played an important part in their recovery (Leake et al., 2021).

In this study, the term 'healed' is used in a variety of ways. Often young adults refer to 'healed' as complete repair of injured body tissue, however, they occasionally

use 'healed' as a reference to resolution of pain. In the wider literature, the meaning of the term 'healed' differs depending on the context of its use. For example, in cancer survivorship, 'healed' is described as a psychological construct, conceptualized as a shift away from suffering towards wholeness—set in contrast to the term 'cured' to denote biological improvement (i.e. remission of malignancy; MacDonald et al., 2021). In this sense, survivors of cancer can be cured but not healed. Similarly, in the context of palliative care, 'healed' refers to optimal quality of life, independent of the presence of disease. In this sense, it is possible to die healed (Mount, 2003). To effectively guide education about pain and healing, it will be important to understand how young adults individually conceptualize healing.

The last two themes attributed pain to problems in the nervous or endocrine system. Shifting focus from something being wrong from the tissues of the body to other bodily systems may be an adaptive way to understand the function of pain and may reflect learnings (although incomplete) from PSE. Such perspectives may improve engagement in evidence-based care. For example, learning about the biology of the stress system provided justification for some young people to engage in stress management techniques. In this study, the only treatments that youth linked to pain biology were psychological strategies, which may reflect our recruitment from a cohort that had been exposed to interdisciplinary paediatric pain treatment in childhood. These mindsets may also improve engagement in activity-based therapies, for example, reducing fear and worry about moving with pain. Alternatively, they may compound a sense of body abnormality. Although adult PSE studies suggest these mindsets promote participation in psychological, active and self-management strategies (Moseley & Butler, 2015), this remains to be tested in young adults.

The themes generated in this qualitative study represent that young adults with childhood-onset chronic pain conceptualize the biology of pain in a variety of ways. Some themes represent an alignment of youth's concept of pain with modern pain science—including 'nerves fire when they shouldn't' and 'an overactive stress system'. This may reflect that these messages are more readily acceptable by this cohort. Indeed, some young adults described that learning about the biological links between stress and pain equipped them with a wider range of options to manage their pain. However, while the theme 'an injury hasn't healed' conflicts with modern pain science principles and offers a potential treatment target for PSE for young adults. It is worth emphasizing that the young adults in this study had experienced chronic pain for an average of 11.4 years, during a time of important developmental milestones.

At that time, youth described learning about pain from a variety of sources, including healthcare professionals, online, at school, reflecting on their own and other people's experiences. Although we did not capture youth's concept of pain at the time of diagnosis, it is likely that the way youth conceptualized pain evolved over time and as a result of a variety of influences. This suggests that PSE should also be accordingly modified over time to align with youth's changing concept of pain.

## 4.2 | Recommendations for tailoring PSE for young adults

1. Be aware that young adults with chronic pain commonly hold misconceptions that pain indicates an unhealed injury. Identify and interrogate the root of this assumption. For example, in this study, youth identified scars as a sign that healing is impossible. Providing education about the biology of tissue healing could help to reconceptualize scars as the outcome of healing. Further, focusing education on the relationship between pain and healing could help decouple chronic pain with a failure to heal.
2. Some messages about the biology of chronic pain seem to 'stick' for young adults—leverage these. Young adults with chronic pain accept explanations about a hypersensitive nervous system (nerves fire when they should not) and an altered endocrine profile (an overactive stress system). Recognizing that these systems adapt can provide the biological underpinning that explains the altered function of chronic pain (i.e. that pain is protective, but chronic pain provides more protection is helpful).
3. Offer language and metaphors that are familiar and acceptable to young adults. For example, when describing the role of the endocrine system consider using language like 'fight or flight' and 'adrenaline'. When explaining that chronic pain does not serve a normally protective function, consider the metaphor of a 'peanut allergy'.
4. Seek clarification on the meaning of pain-related language used by youth. One term with multiple meanings is 'healing'. Youth use 'healing' to describe the body's ability to repair tissue, and to describe resolution of pain. By distinguishing between these meanings, clinicians will be better placed to guide pain education. For example, further exploration of the phrase 'my chronic pain won't heal' could reveal a belief that 'my body tissue won't repair which is driving my chronic pain'—this could be a target for pain education. Clinicians should also aim to clarify the meaning behind their language choices.

5. To further tailor PSE to young adults with chronic pain, future studies may utilize co-design methods to co-create curricula and resources. Future clinical trials are required to evaluate if re-appraisal of the biology of chronic pain to align with contemporary pain biology has positive impacts on pain-related outcomes for young adults with chronic pain, as has been demonstrated in studies with older adults (Moseley & Butler, 2015; Wager et al., 2018).

## 4.3 | Limitations

This research should be interpreted in light of limitations. The sample of participants were not naïve to pain education, as they had all received treatment in interdisciplinary paediatric pain clinics in childhood and were exposed to pain education. Given the goals of this study, there were no attempts to monitor the content nor extent of pain education that participants received. Future research might consider tracking how participant's understanding of pain matches their level of pain education or recruiting from young adults that are naïve to pain education to elucidate their beliefs. Furthermore, although participants in this sample had a range of pain types and levels of educational attainment, they were predominantly white, non-Hispanic, females from North America. Therefore, these accounts may not be representative of young adults with different gender identities, or ethnic/cultural backgrounds that face unique challenges (e.g. language barriers) that may affect how they conceptualize pain. Finally, replicating the current approach with youth who were no longer experiencing chronic pain in young adulthood might yield important information about refining the learning objectives of PSE, as it has for adults (Leake et al., 2021, 2022).

## AUTHOR CONTRIBUTIONS

All authors contributed substantially to this article. All authors discussed the results and commented on the article and approved the final version for publication. Hayley B. Leake contributed to conception and design, data analysis, interpretation of data and drafting the article. G. Lorimer Moseley, Caitlin B. Murray and Tonya M. Palermo contributed to interpretation of data, and critically revising the article for important intellectual content. Lexa K. Murphy contributed to data collection, interpretation of data and critically revising the article for important intellectual content. Lauren C. Heathcote contributed to conception and design, interpretation of data, and critically revising the article for important intellectual content.

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## CONFLICT OF INTEREST


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## ORCID

Hayley B. Leake  <https://orcid.org/0000-0002-6133-2186>

G. Lorimer Moseley  <https://orcid.org/0000-0002-3750-4945>

Lexa K. Murphy  <https://orcid.org/0000-0003-2644-4366>

Tonya M. Palermo  <https://orcid.org/0000-0001-6036-6715>

Lauren C. Heathcote  <https://orcid.org/0000-0003-2515-3102>

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## SUPPORTING INFORMATION

Additional supporting information can be found online in the Supporting Information section at the end of this article.

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