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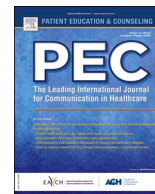
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## How children and adolescents with chronic pain describe their pain experiences: A qualitative systematic review

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### ABSTRACT

**Purpose:** To explore how children and adolescents with chronic pain describe their pain experiences.

**Method:** A systematic search of OVID Medline, CINAHL Complete, OVID Embase and APA PsycINFO (database inception to 19th August 2024) was conducted for qualitative or mixed-method studies investigating children's chronic pain experiences. Studies were excluded if focused on post-surgical or acute pain. Two independent reviewers screened studies, and disagreements resolved by a third reviewer. Methodological quality was assessed with the CASP checklist. Data from included studies were extracted and analysed using qualitative analysis.

**Results:** Forty studies were included, and 4 main themes were identified: 1. 'I'm missing out because of my pain'; in which children described frustration and isolation due to missing activities. 2. 'Things that help me to get by with my pain'; described a variety of children's coping mechanisms. 3. 'It hurts and no one else understands my pain'; where children felt frequently disbelieved about their pain severity, and 4. 'I keep trying to make sense of my pain'; in which children identified ways they seek to understand the cause and possible outcomes of their pain, including accessing health care services.

**Conclusions:** This review highlights how children describe their pain challenges in managing their day to day while emphasising the necessity of understanding and incorporating children's perspectives into research and practice.

**Practice Implications:** This review found that children were primarily concerned by how their pain affects their day-to-day activities and highlights the need to equip children with multiple strategies and promote autonomy in managing their pain. Additionally, further research is warranted into the ways that children understand their pain experience and seek information about their pain.

### 1. Introduction

Pain is a complex experience with many challenges in its diagnosis and management for children and healthcare professionals (HCPs). Chronic pain is defined as pain persisting or recurring for more than three months [1]. It is estimated, globally, around 38 % of children and adolescents experience chronic pain [2]. It is associated with medical conditions, such as cerebral palsy and juvenile idiopathic arthritis (JIA), and now listed as an individual classification in the International Classification of Diseases 11th Revision (ICD –11) [3]. Chronic pain's impact for children and adolescents includes decreased school attendance, disrupted academic performance and social participation, decreased physical function leading to reduced physical activity and

health issues, as well as overall anxiety, depression and reduced quality of life [4–6].

Children with chronic pain often experience referral delays to pain management services [7]. These delays may lead to children experiencing diagnostic uncertainty [8]. This uncertainty can further increase anxiety, impacting children's quality of life [8]. For example, of the children and adolescents referred for pain management services in Australia and Aotearoa (New Zealand), 60 % had experienced pain for more than 12 months [9]. Between initial pain onset, and pain management, children and families may develop their own concept of pain, own understanding of what pain is, how and why it occurs. This may lead to development of pain misconceptions, such as their pain must have an underlying aetiology cause, leading to further frustration and

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feelings of being misunderstood if no underlying aetiology can be identified. This pathway sometimes results in family service disengagement [10].

Existing literature about paediatric chronic pain mostly focuses on the experiences of children with specific conditions where chronic pain is a symptom, such as from Juvenile idiopathic arthritis (JIA), or post-surgical pain experiences [11,12]. It is important to look broadly at the way that children and adolescents talk about and understand their pain experiences given the prevalence and breadth of conditions that can result in chronic pain. Research about experiences and narratives of children’s chronic pain usually includes voices, insights and narratives of their parents, and, or HCPs [13]. There are limited reports exclusively on children’s chronic pain experiences of children without input from their families or their HCPs. Research comparing parent reporting of their child’s pain may not fully reflect the pain experience, in that parents often underreport their child’s pain [14]. Additionally, parent behaviours and pain understanding directly influence children’s pain experiences. Therefore, research including parent voices may influence the way the child reports pain, additionally, parent voice inclusion may influence researcher interpretation [15].

This review aimed to synthesise existing literature by focusing on qualitative accounts by children and adolescents about their pain experiences. Understanding the experiences and priorities of children is crucial for informing clinical practice and interventions that are considerate and inclusive of the child’s perspective.

## 2. Methods

### 2.1. Design

This is a systematic review of qualitative studies including thematic analysis. This design was selected to analyse existing literature and provide a comprehensive overview of the multi-faceted chronic pain experiences. The protocol was prospectively registered with Prospero (CRD42023433593). We reported findings following the Enhancing Transparency in Reporting the Synthesis of Qualitative Research statement (ENTREQ) [16], and PRISMA 2020 Checklist [17]. The team’s reflexivity statement is in Appendix C.

### 2.2. Eligibility criteria

Eligible studies used any qualitative research design, focusing on children and adolescents’ experiences of chronic pain. Where a study used mixed methods design, it was included if qualitative findings were reported and only the qualitative findings were coded and included in data analysis.

We included peer-reviewed studies, in English, reporting on participants up to the age of 19 years. At full-text review, studies including young people over the age of 18 years, with a mean age less than 18 years, were included. Included studies required participants to have experienced chronic pain (lasting  $\geq$  three months). When participants included both children and family, studies were included if the child and family contributed independently (e.g., interviewed separately). This was to avoid possible biases in reporting and how children chose to speak about their pain.

Studies were excluded if they focused on chronic pain post-surgery due to the potential different mechanisms and psychological impacts compared to non-surgical chronic pain [18]. Furthermore, studies were excluded if they focused on acute pain, related to chronic conditions or where experiences were described only by a family member, researcher, or HCP.

### 2.3. Search strategy

Four databases (OVID MEDLINE, Embase, EBSCO CINAHL, APA PsycINFO) were searched from inception to 19th August 2024. The

eligibility criteria were created using the Sample, Phenomenon of Interest, Design, Evaluation and Research type (SPIDER) tool [19] (Table 1). The full strategy for each database is available in Appendix A.

We used Covidence systematic review software (Veritas Health Innovation) to facilitate study screening. Two independent reviewers (JC and MS or CMW) screened titles and abstracts of studies. Subsequently, full texts of potentially eligible studies were reviewed by two independent authors (JC and MS or CMW). Disagreements were independently resolved by a third reviewer (VP or CMW). Finally, reference lists of included studies were manually searched for additional relevant studies, and citation tracking of included studies was completed by one author (JC) using Google Scholar, with relevant studies included.

### 2.4. Assessment of quality

The Critical Appraisal Skills Programme (CASP) for qualitative studies checklist was used to assess the methodological quality of included studies [20]. The CASP checklist includes 10 questions about the results relating to validity, trustworthiness, clarity and ethical considerations. One reviewer (JC) assessed each study, assigning the value of ‘yes’ or ‘no’ to each criterion 1–9. Criterion 10 was not assessed, as this related to the relevance of the study. A second reviewer (BT) independently assessed 20 % of the included studies (n = 8) with no discrepancies.

### 2.5. Data collection process

Data were extracted in Covidence by one author (JC). Extracted data was then checked by a second author (VP). Data extracted included: First author’s last name, year of publication, country, study aims, recruitment setting, sample size, participant information including age, diagnosis or site of pain, any measures of pain or quality of life, data collection method, data analysis method, and themes/subthemes generated by authors. The full text of each study was uploaded to qualitative data analysis software Atlas.ti (ATLAS.ti Scientific Software Development GmbH).

### 2.6. Data analysis

Data coding, extraction and synthesis was guided by Thomas (2008), thematic synthesis approach [21]. First, one author (JC) read and reread the included studies to develop an understanding of the content before inductively line-by-line coding the themes, subthemes, descriptive text, and quotes from each study. Then, through an inductive process, descriptive codes were refined with consideration of the included paper’s original themes and subthemes within Atlas.ti. Study segments quoting or referring to quotes by participants not relevant to inclusion criteria (i.e., HCPs, parents or young people older than 18) were not coded. As a result, some of the original themes from the original studies, such as ‘Mixed roles and values in parents’ pain reporting’ [42], are not represented in this review. Additionally, while each section was included in the coding process, themes and subthemes that were condition-specific, such as ‘Lives embedded with dyskinesia’ [45], are also not presented in the findings section of this review.

A second author (CMW) completed descriptive coding of 10 %

**Table 1**  
SPIDER tool used for this review.

SPIDER	Description
Sample	Children and adolescents 0–18 years of age with chronic pain (pain lasting 3 months or longer)
Phenomenon of interest	Experiences relating to chronic pain (lasting 3 months or longer)
Design	Focus groups, Interviews, diaries
Evaluation	Not applicable
Research Type	Qualitative and mixed methods studies

(n = 4) of included studies. Descriptive codes and similarities were reviewed and discussed by the full research team. These codes were refined and ultimately grouped according to similarity. Finally, these groupings were further developed into themes and subthemes used to form the final analytical themes. Final themes were determined based on their prevalence across included studies as well as their conceptual importance in children’s experiences of chronic pain. The full authorship team reviewed the groupings as well as the developed themes and subthemes from all studies.

Where studies described data collected from the same cohort, if there was an overlapping theme, they were combined into one record. Where studies reported different themes and analytical approaches, they were not combined.

### 3. Results

#### 3.1. Search results

There were 40 studies included in this review (Fig. 1) [22–60].

There were four different authorship groups using data from the same or similar cohort of children to publish two papers [47,48,53–56, 58,59]. Two of these authorship groups published studies with different participant perspectives relevant to our study aim [47,48,53,54] therefore, these were analysed separately. Whereas, the other two authorship groups published one study containing the majority of analysis relevant to our aim, with additional studies providing quotes and insights, therefore these were grouped into one record per authorship group [55,56,58,59].

#### 3.2. Included study characteristics

Included study characteristics are summarised in Tables 2 and 3. The sample sizes ranged from 3 to 53, ages ranged from 6 to 18 years and most studies included more females than males. Few studies included children under the age of 12 (n = 16). Thirteen studies included a pain measure, most measures were a variation of pain intensity, however,

there was inconsistency across the time period and type of scale. The most frequent recruitment site was outpatient pain clinics (n = 22).

### 3.3. Findings

The following themes were generated from our qualitative analysis. The authors reviewed themes across the conditions, demographics, contexts and settings included in Table 2. All themes spanned across multiple conditions, contexts and settings. Few studies included quotes from children under the age of 12.

#### 3.3.1. I’m missing out because of my pain

Children reported missing out across all life contexts, particularly sports, school and social settings [22,24,26,28–32,34–41,44–48,50,53, 54,56].

“I am much less annoyed by my pain than by its consequences.” (Age 15) [28]

Missing out on sporting activities such as football or hockey, physical education at school or other activities like rock climbing was a particular cause of frustration, disappointment and sadness.

“I was a ballerina since I was three years old. Slowly it [pain] started impacting ballet, but I kept up dance longer than I did school but eventually I had to drop out because the pain was too much.” (Age not specified, range: 13–19) [45]

In multiple studies, children highlighted their sport was something they had done for a large portion of their lives and was closely linked with their identity [21,27,28,30,33,44,56]. In Gremillion et al., 2022, children who had previously been very athletic described ongoing struggles with their sense of self after having to stop their sport due to pain, and subsequently gaining weight. This had a cascade effect on their self-esteem, often reducing their sense of accomplishment and opportunities for social engagement with peers [27–29,33,37].

In education settings, children described falling behind as their school attendance was impacted by pain or health care appointments during school hours [25,27,29,34,44,46,47]. While in classes, poor sleep the night before impacted energy and concentration levels [21,25,27,

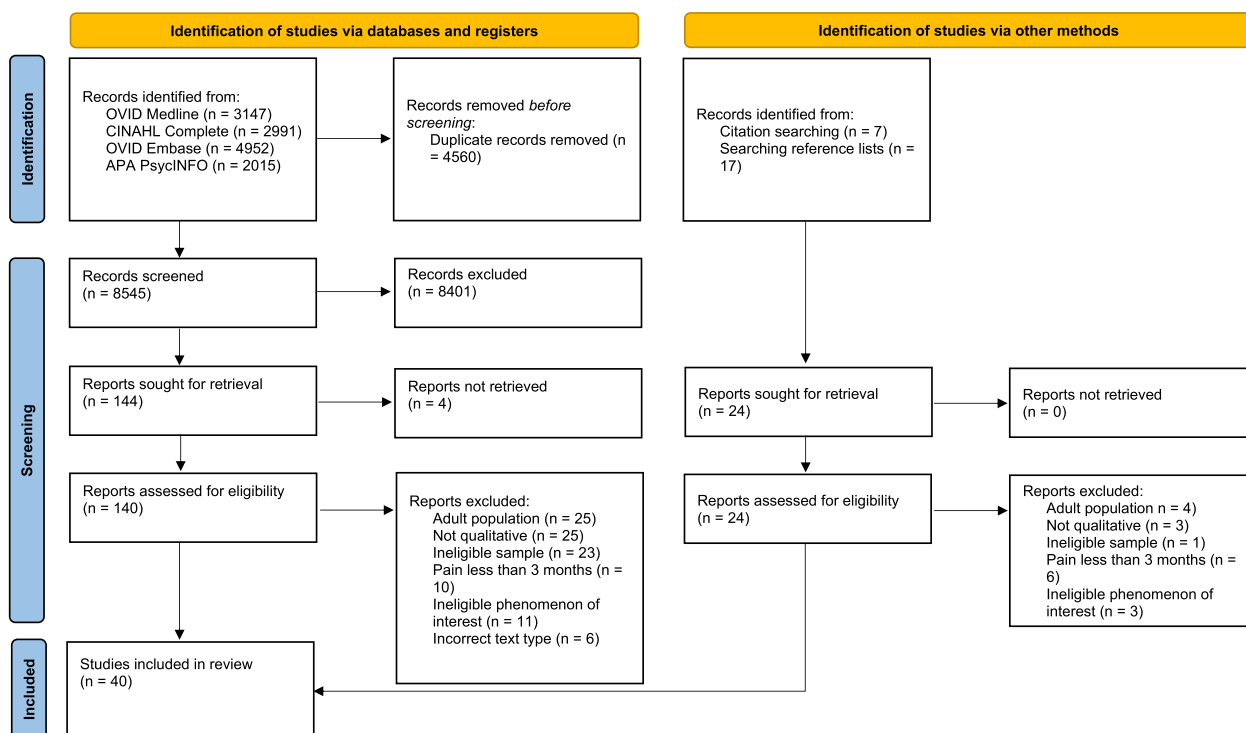


Fig. 1. PRISMA diagram.

**Table 2**  
Included study characteristics (Participants and setting).

Study ID	Country	Participants (sample size)	Participants (age in years)	Diagnosis/pain location <sup>a</sup>	Sex/gender identity <sup>b</sup>	Pain measures <sup>c</sup>	Recruitment setting
Alsaggaf, 2023 [22]	Saudi Arabia	10	12–16	Sickle cell anaemia, celiac disease, systemic lupus erythematosus, migraine, osteogenesis imperfecta, chronic sinusitis, headache, muscular dystrophy, juvenile rheumatoid arthritis (multiple sites), ulcerative colitis disease, Crohn's disease	5 female, 5 male	Pain intensity: mild to severe	Tertiary hospital
Borghgi, 2016 [23]	Brazil	6	6–17	Palliative care (epidermolysis bullosa, osteogenesis imperfecta, xeroderma pigmentosum and human T-cell lymphotropic virus /hereditary spastic paraparesis)	Not specified	Nil	Outpatient palliative care and pain clinic
Bradshaw, 2022 [24]	Ireland	5	9–16	Recurrent abdominal pain	3 female, 2 male	Nil	Paediatric speciality clinic
Carter, 2002 [25]	UK (not explicitly stated)	3	12–13	Knee pain, abdominal pain, back pain	2 female, 1 male	Nil	Via pain service healthcare professionals
Castle, 2007 [26]	Australia	6	14–24	Cerebral palsy + pain in hip, back, lower limbs, bladder, hand, wrist and shoulder	4 male, 2 female	Pain intensity on VAS scale 0–10 + Chronic Pain Questionnaire (location, VAS, types of aggravating activity, pain frequency, when? - before, during or after)	Tertiary paediatric hospital
Corser, 2023 [27]	UK (not explicitly stated)	7	15–18	Chronic pain + mental health issues Conditions: fibromyalgia, hypermobility, CRPS, chronic pain, scoliosis, unexplained paralysis and chronic fatigue Mental health conditions: (each had min 2 and all had anxiety) anxiety, anorexia, stress, self-harm, depression, PTSD	6 female, 1 nonbinary	Nil	Schools, outpatient pain clinic and social media
Daenen, 2023 [28]	Belgium	15	12–17	Joints, back, skin, stomach, neck, headache	13 female, 2 male	Nil	Outpatient speciality clinic
Dell'Api 2007 [29]	Canada	5	10–17	Flank and renal area, chest and abdominal pain	3 female, 2 male	Nil	Outpatient pain clinic
Donovan, 2019 [30]	USA	12	13–16	IBS	10 female, 2 male	Nil	Outpatient pain clinic
Ghio, 2022 [31]	UK	17	11–16	JIA	10 female, 7 male	Nil	Tertiary paediatric hospital
Gorbounova, 2022 [32]	USA	19	12–17	Chronic IBD pain	9 female, 10 male	Abdominal Pain Index	Outpatient specialty clinic
Gorodzinsky, 2013 [33]	USA	8	12–18	Functional abdominal pain, musculoskeletal pain, migraines, gastritis and post-concussive syndrome	7 female, 1 male	frequency and severity of pain (actual measure not described)	Outpatient pain clinic
Gremillion, 2022 [34]	USA	13	13–17	Headaches, generalised pain, abdominal pain, back pain, and lower extremity pain + BMI classification of obese	11 female, 2 male	Average pain over past 2 weeks on a 0–10 scale + worst pain intensity	Outpatient pain clinic
Heffernan, 2021 [35]	Ireland	12	12–17	Chronic headaches, musculoskeletal pain, back pain, neuropathic pain, and abdominal pain	9 female, 3 male	Pain Catastrophizing Scale, Child Version (PCS-C)	Outpatient pain clinic
Hilario, 2022 [36]	Portugal	7	7–17	Sickle cell disorder	4 female, 3 male	Nil	Outpatient pain clinic
Jacobson, 2011 [37]	USA	34	8–18	JIA or noninflammatory chronic pain migraines, chronic headaches, abdominal pain, and musculoskeletal pain (fibromyalgia, CRPS, chronic foot pain, progressive pseudo-rheumatoid chondrodysplasia, and chronic lower back pain)	28 female, 6 male	PROMIS pediatric version 1.0 short form formed basis of interview	Outpatient specialty clinics
Jones, 2022 [38]	UK	9	12–22	Chronic coccyx pain, chronic neuropathic pain, hypermobility, eczema, persistent leg pain, widespread chronic musculoskeletal pain, chronic back pain, chronic abdominal pain	8 female, 1 male	Nil	Outpatient pain service

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Table 2 (continued)

Jordan, 2018 [39]	UK	10	12–17	CRPS, JIA, localised idiopathic pain syndrome, diffuse idiopathic pain syndrome	7 female, 3 males	Nil	Outpatient pain services
Jordan, 2024 [40]	UK	10	15–19	Autism and CRPS, hypermobility spectrum disorder, hypermobility syndrome, chronic fatigue syndrome, Charcot-Marie-Tooth disease, Chronic widespread pain syndrome, EDS, POTS, symphysis pubis dysfunction, sacroiliac joint dysfunction, IBS, dysmenorrhea, OCD, gastroparesis, eosinophilic gastrointestinal disease, anxiety, depression, hyperthyroidism	6 female, 3 male, 1 agender	Nil	Tertiary paediatric pain service
Joslin, 2021 [41]	UK	21	11–18	Chronic musculoskeletal pain (lower limb, upper limb, back, neck and chest and multiple joints).	18 female, 3 male	Nil	Outpatient pain and specialty clinics
Killackey, 2023 [42]	Canada	19	8–18	Chronic pain no further specification	17 female, 2 male	Nil	Outpatient specialty clinics + social media
Lee, 2022 [43]	UK	26	6–18	JIA, chronic idiopathic pain syndromes including CRPS, EDS/hypermobility	15 female, 11 male	Nil	Outpatient specialty clinics
Linkiewicz, 2023 [44]	Canada	14	12–17	Chronic pain no further specification	9 female, 3 male, 1 nonbinary, 1 gender questioning	NRS + pain frequency	Outpatient pain clinics, social media and pain organisations
Mahon, 2023 [45]	Canada	15	13–19	Primary chronic pain	11 female, 4 male	Nil	Outpatient pain service
McKinnon, 2020 [46]	Australia	8	9–16	Mixed or dyskinetic cerebral pals and chronic pain in various body locations	2 female, 6 male	Faces pain scale revised (0–10), Childhood Arthritis and Rheumatology Research Alliance Body diagram (21 defined regions)	Outpatient pain clinic
Meldrum, 2009a [47]	USA	45	10–18	Headaches, myofascial pain (anywhere that is not head), functional neurovisceral pain disorder, CRPS, fibromyalgia	32 female, 13 male	VAS (0–10)	Outpatient pain clinic
Meldrum, 2009b [48]	USA	53	10–18	Headaches, myofascial pain (anywhere that is not head), functional neurovisceral pain disorder, CRPS, fibromyalgia	36 female, 17 male	Nil	Outpatient pain clinic
Neville, 2019 [49]	Canada	20	10–18	CRPS, headaches, stomach pain, nephroptosis, costochondritis	15 female, 5 male	Pain intensity (0–10)	Outpatient pain clinic
Neville, 2022 [50]	Canada	20	13–20	Chronic pain without an underlying disease	13 females, 7 males	Pain intensity (0–10)	Outpatient pain clinic
Parsons, 2023 [51]	UK	24	11–24	CRPS, Chronic pain, craniopharyngioma, scoliosis, chronic migraine, ankylosing spondylitis, joint hypermobility syndrome, fibromyalgia, EDS, psoriatic arthritis, Crohn's disease, bone marrow oedema, dystonia	21 female, 1 male, 1 trans male, 1 nonbinary	Nil	Outpatient pain clinics, pain charities and social media
Pate, 2019 [52]	Australia	8	8–12	Back pain, neck pain and headaches	3 female, 5 male	Nil	Outpatient pain clinic waitlist, flyers and email bulletins
Sallfors, 2001 [54]	Sweden	22	6–17	JCA	16 female, 6 male	Nil	Outpatient specialty clinic
Sallfors, 2002 [53]	Sweden	22	6–17	JCA	16 female, 6 male	Nil	Outpatient specialty clinic
Shaygan, 2021 [55]	Iran	14	12–17	Chronic pain	9 female, 5 male	NRS (0–10)	Schools
Shaygan, 2022 [56]	Iran	14	12–17	Chronic pain	9 female, 5 male	Nil	Schools
Szwimer, 2020 [57]	Canada	8	14–17	Chronic back pain, abdominal pain, hand pain, pelvic pain, orofacial pain, wide-spread pain, fibromyalgia, and/or arthritis	8 female	Nil	Outpatient pain clinic
Wakefield, 2021 [59]	USA	18	12–17	AMPS, abdominal pain, Pain Amplification Syndrome, back pain, chest pain, IBS, CRPS, fibromyalgia, neck pain and migraine	16 female, 1 male, 1 gender-fluid	Nil	Outpatient pain clinic

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Table 2 (continued)

Wakefield, 2022 [58]	USA	18	12–17	AMPS, abdominal pain, and Pain Amplification Syndrome, back pain, chest pain, IBS, CRPS, fibromyalgia, neck pain and migraine	16 female, 1 male, 1 gender-fluid	Nil	Outpatient pain clinic
Wallbing, 2023 [60]	Sweden	20	14–15	Chronic pain	18 female, 2 male	Nil	Schools

<sup>a</sup> CRPS = complex regional pain syndrome; JIA = juvenile idiopathic arthritis; IBS = irritable bowel syndrome; AMPS = Amplified Musculoskeletal Pain syndrome; EDS = Ehlers-Danlos Syndrome; IBD = inflammatory bowel disease; BMI = body mass index; JCA = juvenile chronic arthritis; PTSD = post-traumatic stress disorder; RAP = Recurrent abdominal pain; POTS = postural orthostatic tachycardia syndrome; OCD = obsessive-compulsive disorder; Kingdom; NRS = Numeric rating scale; USA = United States of America; UK = United Kingdom

<sup>b</sup> Some studies only reported % of female participants, we have assumed the remaining % identify as male

34]. Students with significant final exams or nearing graduation were particularly worried about grades and test results [27,34,38,44,46,49].

*“I would worry more during the year like at school stuff...like, oh god, like, how did you do in that test or how am I going to do in my end of year exams.”* (Age not specified, range: 12–17) [35]

Students who frequently missed school also described being excluded from activities with friends and having to find new friends [25, 27,29,35,37,38]. Furthermore, even when invited, social gatherings and parties were often too difficult to attend, and as a result, children stayed home and missed out [23,25,29,37].

*“I am lonelier. I have left my friends and hang out alone ... I feel that I am losing out, I don't get to do what my friends do and decompress from the stresses in life”* (Age not specified, range: 10–17) [29]

Most children described feelings of isolation or loneliness as part of their pain experience [21,25,28,35,37,41,43,45,57]. Seeing their friends at parties or out after school on social media furthered these feelings of missing out and isolation [27,29].

### 3.3.2. Things that help me to get by with my pain

Children described using a myriad of tools and strategies to manage their pain [22–24,26–31,33–36,38–47,49,51–54,56,57,60]. They leaned on their support systems for help, used medical and alternative pain management techniques when the pain became “too much” many chose to distract themselves or try to sleep off the pain.

Children displayed resilience as they looked to adapt and modify their activities motivated by participation inability [22,25,28,30,37,53, 55,56]. For example, some children described switching sports for other lower-impact activities such as gardening or swimming, while others adopted assistive technologies to maximise their independence. Some children took a ‘push through the pain’ approach, determined their pain would not stop them from doing the things they wanted and needed to do [21,23,25–28,30,34,38,40,42,44–46,53,55,56].

*“I try to not let it stop me from doing anything, I try to just kind of get on with it, and like it's going to happen anyway so I'm better off doing something or not.”* (Age not specified, range: 9–16) [24]

Children described using various pain management strategies including relaxation and mindfulness, gentle exercise, topical ointments and herbal teas, massages, hot and/or cold therapy and medications. Additionally, children described finding relief in participating in activities they enjoyed such as drawing, painting, reading, listening to music, playing video games and bird watching. Other children found comfort in religion or playing with their pets. Despite the multitude of strategies, children highlighted that there were times they felt their pain was just too much, and they needed to wait it out by resting or sleeping [21,25, 30,34,36,42,45–49,52,53,55,59].

In addition to these pain management strategies, children spoke extensively about their support systems acknowledging the crucial role of family, friends and other trusted people in helping them manage their pain [21–23,25,29,30,32,33,38,39,41,43,45,48,52,53,55].

*“I like my mother to talk to me or tell me stories because in this way, I forget my pain”* (Age 12) [56]

Help and support came from many different people and in many

different forms. At home, siblings played the role of trusted confidants and helped with homework and personal care tasks like brushing hair or bathing [29,30,32,41,54], while parents provided comfort and support, as well as options for pain relief [29,32,45].

In addition to family support, peer relationships or support groups with children with chronic conditions were highly regarded [29,43,52, 53]. Open discussion and opportunities to empathise with each other about their pain helped reduce feelings of loneliness and missing out [33,43,52,53].

*“There's a deeper level of understanding when you're talking to someone who's also going through the same things – especially who can also offer you support in a way that someone who doesn't have [chronic pain] maybe can't necessarily.”* (Age 17) [44]

Pain-free friends were also a source of support [21–23,25,27,32,33, 35–38,40,44,45,47,52–55,57,59]. Children noticed where their friends made the extra effort to include them or plan so they could be involved.

### 3.3.3. It hurts and no one else understands my pain

Children described their pain as all-consuming and many felt this was a weight they would have to carry forever, and they would never feel like themselves again [25,26,28,29,32,49]. Children were deeply affected by their pain. They described feeling self-conscious, anxious, ashamed, stigmatised, and worried

*“The sadder you get the more it hurts ... That's it, basically ... The more negative your thoughts, the more it hurts”* (Age not specified, 6–17) [53]

While many talked about the negative impact their pain had on their sense of self, some talked about the positive impacts [22,35,38,39,42,47, 51]. In Parsons (2023), Lily (Age 17) describes how her pain has made her “more confident and independent”, and “much more resilient to setbacks.” [51].

Children were aware of the impact of their pain on their families [27, 29–32,46]. They were concerned by the impact, which augmented their feelings of shame and worry.

*“[My pain] stops them from doing things they want to do”* (Age 16) [31].

In addition to this awareness of disrupting their families, children also articulated that their pain often made them irritable and overwhelmed [23,26,29,36,39,47,52]. Sometimes this manifested as an angry or upset outburst after trying to suppress their emotions and pain [26,29,30,36,47,52].

*“The kids in my class are perhaps a bit shocked that I get mad sometimes. It could be that I'm thinking about it...so I almost snap at them.”* (Age not specified, range: 6–17) [53]

Many children talked about having to manage the pain beliefs of others. Children perceived very few people understood their pain experience and were often either overly concerned about the pain or completely dismissive of the experience. [25,28,30,34,35,38,43–45,47, 48,50,53,56,58,59]. Children felt continually dismissed by family members, teachers and health professionals, resulting in humiliation and hurt, especially when coming from a trusted person. Overall, children described how the fluctuating nature of pain often resulted in being perceived as lying or being lazy [24,27,28,30,33,42–44,46,48,57].

*“why were you able to do this a week ago but you can't do it today?” or*

**Table 3**  
Included study characteristics (methodology and findings).

First author, year	Study Aims	Data collection method	Data analysis method	Themes and subthemes <sup>a</sup>
Alsaggaf, 2023 [22]	To report on the experience of chronic pain, its impact on participation in everyday life, and strategies to manage chronic pain from the perspectives of young people and their parents in Saudi Arabi	Semi-structured interviews	Charmaz’s constant comparative analysis and Yin’s cross-case synthesis analysis	<ul style="list-style-type: none"> <li>❖ Experiencing chronic pain: Like a big rock on me I cannot bear it”                             <ul style="list-style-type: none"> <li>o Describing pain</li> <li>o Seeking help from healthcare professionals.</li> </ul> </li> <li>❖ Impact of pain on quality of life: Pain ruins everything”                             <ul style="list-style-type: none"> <li>o Impact on physical functioning</li> <li>o Impact on psychological functioning</li> <li>o Impact on social functioning</li> </ul> </li> <li>❖ Everyday strategies to manage chronic pain: I don’t let the pain disrupt my day                             <ul style="list-style-type: none"> <li>o Taking medications for pain</li> <li>o Self-care management strategies</li> </ul> </li> </ul>
Borghi, 2016 [23]	To understand how children and adolescents under palliative care manage pain in their daily lives and how they describe its intensity and quality	Semi-structured interviews	Thematic oral history methodological strategy	<ul style="list-style-type: none"> <li>❖ Describing pain</li> <li>❖ Seeking a life that is closer to normality, despite pain and disease</li> <li>❖ Using many alternatives for managing pain</li> <li>❖ Living with a damaged self-image</li> </ul>
Bradshaw, 2022 [24]	To explore parent’s and children’s experiences and perspectives of recurrent abdominal pain (RAP) and its potential causes, impacts and burden	Semi-structured interviews	Inductive Thematic Analysis	<ul style="list-style-type: none"> <li>❖ Perception, understanding and identification of recurrent abdominal pain                             <ul style="list-style-type: none"> <li>o Perception of causes</li> <li>o Pain identification, manifestation and development</li> </ul> </li> <li>❖ Contributing factors                             <ul style="list-style-type: none"> <li>o Internal factors</li> <li>o External factors</li> </ul> </li> <li>❖ Coping mechanisms/pain management strategies                             <ul style="list-style-type: none"> <li>o Strategies/techniques</li> <li>o Support systems</li> <li>o Child resilience and determination</li> </ul> </li> <li>❖ Impact and burden of RAP                             <ul style="list-style-type: none"> <li>o Emotional reaction and impact</li> <li>o Impact on sleep and school</li> <li>o Impact on quality of life</li> </ul> </li> </ul>
Carter, 2002 [25]	To explore, from the children’s and families’ perspectives, the impact of living with chronic pain.	Other: journal + loosely structured interview	Constructivist philosophy, thematic analysis	<ul style="list-style-type: none"> <li>❖ The quest for a diagnosis and referral fatigue</li> <li>❖ Professional judgement and disbelief</li> <li>❖ Communication or ventriloquism</li> <li>❖ Professionals who believe the family                             <ul style="list-style-type: none"> <li>o The experience of chronic pain.</li> <li>o Making sense of the pain.</li> <li>o Doing anything to get rid of the pain.</li> <li>o Fighting the pain.</li> <li>o Enlisting help.</li> <li>o Being in pain.</li> <li>o Looking ahead</li> </ul> </li> <li>❖ A whirlwind of everything</li> <li>❖ Putting up fronts</li> </ul>
Castle, 2007 [26]	To explore the experience and impact of chronic pain on the lives of adolescents and young adults with cerebral palsy	Semi-structured interviews	Phenomenology	<ul style="list-style-type: none"> <li>❖ The experience of chronic pain.</li> <li>❖ Making sense of the pain.</li> <li>❖ Doing anything to get rid of the pain.</li> <li>❖ Fighting the pain.</li> <li>❖ Enlisting help.</li> <li>❖ Being in pain.</li> <li>❖ Looking ahead</li> </ul>
Corser, 2023 [27]	To examine the lived experience of adolescents with co-occurring chronic pain and mental health symptoms	Semi-structured interviews	Interpretive phenomenological approach	<ul style="list-style-type: none"> <li>❖ A whirlwind of everything</li> <li>❖ Putting up fronts</li> </ul>
Daenen, 2023 [28]	To examine the phenomenology of pain-related injustice appraisals among both pain-free children and children living with chronic pain, to compare and contrast their experiences.	Semi-structured focus groups	Interpretive phenomenological approach	<ul style="list-style-type: none"> <li>❖ People don’t see my pain</li> <li>❖ I am missing out because of my pain</li> </ul>

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Table 3 (continued)

Dell'Api 2007 [29]	To understand how children perceived their interactions with health care professionals to have influenced their experience of chronic pain	Semi-structured interviews	Interpretive description	<ul style="list-style-type: none"> <li>◆ Seeing is believing                             <ul style="list-style-type: none"> <li>○ If they can't see it, it's not there</li> <li>○ They don't believe me</li> <li>○ Wiping their hands clean</li> <li>○ Sometimes they are helpful, sometimes they are not</li> </ul> </li> <li>◆ The search for understanding</li> <li>◆ Guarded alliance: living with scepticism</li> <li>◆ Fears for the future</li> <li>◆ Difficulties in living a normal life</li> </ul>
Donovan, 2019 [30]	To describe the experiences of adolescents with irritable bowel syndrome (IBS) from the perspective of adolescents, their parents, and health care providers who treat adolescents who have IBS	Semi-structured interviews	Social cognitive theory, deductive qualitative analysis	<ul style="list-style-type: none"> <li>◆ Disconnection from peers                             <ul style="list-style-type: none"> <li>○ Trying to fit in</li> <li>○ Adolescents with similar health conditions understand</li> </ul> </li> <li>◆ Strain on family relationships                             <ul style="list-style-type: none"> <li>○ Comfort of mom</li> <li>○ Relying on family for practical assistance</li> </ul> </li> <li>◆ Preserving Social Identity                             <ul style="list-style-type: none"> <li>○ Focus on maintaining normality</li> <li>○ Focus on managing pain</li> </ul> </li> <li>◆ IBD threat</li> <li>◆ Fear/worry</li> <li>◆ Biased attending</li> </ul>
Ghio, 2022 [31]	To explore the coping goals and related personal models (cognitive and emotional profiles) of juvenile idiopathic arthritis of both the adolescents and their parent	Semi-structured interviews using In My Shoes (IMS) is a computer-assisted module interview tool	Qualitative cross-sectional study using Framework Method Analysis	<ul style="list-style-type: none"> <li>◆ Preserving Social Identity                             <ul style="list-style-type: none"> <li>○ Focus on maintaining normality</li> <li>○ Focus on managing pain</li> </ul> </li> </ul>
Gorbounova, 2022 [32]	(1) determine how youth with inflammatory bowel disease (IBD) and their parents appraise pain, and how their perspectives fit within CAMSA <sup>b</sup> , and (2) explore health care providers' understanding and communication about pain	Semi-structured interviews	Reflexive thematic Analysis	<ul style="list-style-type: none"> <li>◆ IBD threat</li> <li>◆ Fear/worry</li> <li>◆ Biased attending</li> </ul>
Gorodzinsky, 2013 [33]	To present the experiences of youth with chronic pain and their siblings, and their perspectives on how pain experiences influence family dynamics.	Semi-structured interviews	Not stated	<ul style="list-style-type: none"> <li>◆ Desire for closeness</li> <li>◆ Interference with vacations or activities</li> <li>◆ Sibling disbelieves pain</li> <li>◆ Sibling gets away with more</li> <li>◆ Sibling more independent</li> <li>◆ Sibling neglected or frustrated</li> <li>◆ Sibling supportive or protective of patient</li> <li>◆ Sibling verbal conflict</li> <li>◆ Sibling worsens pain</li> <li>◆ Impact of chronic pain on relationships</li> <li>◆ Impact of pain on self-perception</li> <li>◆ Using food to cope with pain</li> <li>◆ Perceived relationship between pain and weight after onset of pain</li> <li>◆ Attitudes toward physical activity</li> <li>◆ Barriers to physical activity</li> <li>◆ Supports to physical activity</li> <li>◆ The worry ripple: mind, body, and behaviour                             <ul style="list-style-type: none"> <li>○ worry content: personal competence and health</li> </ul> </li> <li>◆ The pain mystery: living in a scribble of black</li> <li>◆ The resist or avoid conundrum.</li> <li>◆ The use of non-medical strategies to deal with chronic pain</li> <li>◆ Food as a way to deal with uncertainty</li> <li>◆ (Not) being different</li> <li>◆ The impact of hospitalizations</li> <li>◆ Anger, anxiety, and depressive symptoms</li> <li>◆ Fatigue</li> <li>◆ Pain interference</li> <li>◆ Peer relationships</li> <li>◆ Tug of war: push and pull                             <ul style="list-style-type: none"> <li>○ The shifting sands of peer relationships</li> <li>○ Restricted choices</li> </ul> </li> </ul>
Gremillion, 2022 [34]	To better understand the challenges experienced by adolescents with co-occurring chronic pain and obesity, with a specific focus on physical activity	Semi-structured interviews	Interpretative Phenomenological Analysis.	<ul style="list-style-type: none"> <li>◆ Impact of chronic pain on relationships</li> <li>◆ Impact of pain on self-perception</li> <li>◆ Using food to cope with pain</li> <li>◆ Perceived relationship between pain and weight after onset of pain</li> <li>◆ Attitudes toward physical activity</li> <li>◆ Barriers to physical activity</li> <li>◆ Supports to physical activity</li> </ul>
Heffernan, 2021 [35]	To qualitatively explore beliefs about and experiences of worry and pain among a purposeful sample of adolescents with chronic pain	Semi-structured interviews	Critical realist ontology and contextualist epistemology, thematic analysis	<ul style="list-style-type: none"> <li>◆ The worry ripple: mind, body, and behaviour                             <ul style="list-style-type: none"> <li>○ worry content: personal competence and health</li> </ul> </li> <li>◆ The pain mystery: living in a scribble of black</li> <li>◆ The resist or avoid conundrum.</li> <li>◆ The use of non-medical strategies to deal with chronic pain</li> <li>◆ Food as a way to deal with uncertainty</li> <li>◆ (Not) being different</li> <li>◆ The impact of hospitalizations</li> <li>◆ Anger, anxiety, and depressive symptoms</li> <li>◆ Fatigue</li> <li>◆ Pain interference</li> <li>◆ Peer relationships</li> <li>◆ Tug of war: push and pull                             <ul style="list-style-type: none"> <li>○ The shifting sands of peer relationships</li> <li>○ Restricted choices</li> </ul> </li> </ul>
Hilario, 2021 [36]	To provide insights into the lives of a small group of children and young people with sickle cell disorder who suffer from chronic pain and of their parents.	Semi-structured interviews	Thematic Analysis	<ul style="list-style-type: none"> <li>◆ The resist or avoid conundrum.</li> <li>◆ The use of non-medical strategies to deal with chronic pain</li> <li>◆ Food as a way to deal with uncertainty</li> <li>◆ (Not) being different</li> <li>◆ The impact of hospitalizations</li> <li>◆ Anger, anxiety, and depressive symptoms</li> <li>◆ Fatigue</li> <li>◆ Pain interference</li> <li>◆ Peer relationships</li> <li>◆ Tug of war: push and pull                             <ul style="list-style-type: none"> <li>○ The shifting sands of peer relationships</li> <li>○ Restricted choices</li> </ul> </li> </ul>
Jacobson, 2011 [37]	To describe children's understandings of the health domain constructs and elucidate verbal and conceptual aspects of self-reported pain-related functioning, which shape disclosure and reporting.	Semi-structured interviews	Team-based thematic and content analysis	<ul style="list-style-type: none"> <li>◆ Fatigue</li> <li>◆ Pain interference</li> <li>◆ Peer relationships</li> <li>◆ Tug of war: push and pull                             <ul style="list-style-type: none"> <li>○ The shifting sands of peer relationships</li> <li>○ Restricted choices</li> </ul> </li> </ul>
Jones, 2022 [38]	To explore how adolescents make sense of their experience of chronic pain in the context of development.	Other: Interviews + 12-month qualitative diaries	Critical realist, Reflective TA	<ul style="list-style-type: none"> <li>◆ Tug of war: push and pull                             <ul style="list-style-type: none"> <li>○ The shifting sands of peer relationships</li> <li>○ Restricted choices</li> </ul> </li> </ul>

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Table 3 (continued)

Jordan, 2018 [39]	To examine how adolescents make sense of their own development in the context of living with chronic pain	Semi-structured interviews	Interpretive phenomenological approach	<ul style="list-style-type: none"> <li>❖ An externally imposed lens on identity</li> <li>❖ Paradoxes of developmental progress</li> </ul>
Jordan, 2024 [40]	To understand how autistic adolescents and their parents experience pain, manage pain and perceive the psychological treatment of chronic pain.	Semi-structured interviews	Inductive reflexive thematic analysis	<ul style="list-style-type: none"> <li>❖ Overstimulated and striving for control</li> <li>❖ Not everyone fits the mold</li> </ul>
Joslin, 2021 [41]	To establish which outcomes young people identify as important and why; and if their outcome preferences change during the course of treatment	Semi-structured interviews + participatory activity drawing timeline	Thematic Analysis	<ul style="list-style-type: none"> <li>❖ Perfect storm</li> <li>❖ Turning points                             <ul style="list-style-type: none"> <li>o Relationships</li> <li>o The environment</li> <li>o Pivotal moments</li> </ul> </li> <li>❖ Disconnect and free</li> <li>❖ Turning points</li> <li>❖ Absorbing and shifting: the</li> <li>❖ Toll of the pandemic on the family system                             <ul style="list-style-type: none"> <li>o Absorbing the loss of coping mechanisms</li> <li>o Shifting roles to respond to the pandemic</li> </ul> </li> <li>❖ Social ambiguity and abandonment                             <ul style="list-style-type: none"> <li>o Social sacrifice</li> <li>o Feeling abandoned by the healthcare system</li> </ul> </li> <li>❖ Building community resilience: familial adaptation to the pandemic                             <ul style="list-style-type: none"> <li>o Family cohesion</li> <li>o Confidence and self-management</li> </ul> </li> </ul>
Killackey, 2023 [42]	To describe the experiences of youth living with chronic pain and siblings and parents of youth living with pain during the COVID-19 pandemic.	Semi-structured interviews	Reflexive thematic analysis	<ul style="list-style-type: none"> <li>❖ Co-ordination of pain communication                             <ul style="list-style-type: none"> <li>o Expectation of pain communication</li> <li>o Purpose of pain communication</li> <li>o Mixed roles and values in parents' pain reporting</li> <li>o Methods in pain communication</li> <li>o Specific questions asked about pain</li> </ul> </li> <li>❖ Barriers to pain communication                             <ul style="list-style-type: none"> <li>o Appropriate timing of pain communication</li> <li>o Difficulties finding the terminology to express pain</li> <li>o Feeling nervous, scared and/or overwhelmed</li> <li>o Pain uncertainty</li> <li>o Pain dismissal</li> </ul> </li> <li>❖ Facilitators of pain communication                             <ul style="list-style-type: none"> <li>o Informal conversations</li> <li>o Feeling reassured and cared for</li> <li>o Familiarity</li> <li>o Communicating and managing the emotional impact of pain</li> </ul> </li> <li>❖ Dissatisfaction with pain communication                             <ul style="list-style-type: none"> <li>o Challenges interpreting pain advice</li> <li>o Anger at healthcare professionals' pain management explanations</li> </ul> </li> </ul>
Lee, 2022 [43]	To explore children and adolescents' experiences of pain communication in the context of paediatric rheumatology consultations.	Semi-structured interviews	Framework analysis	<ul style="list-style-type: none"> <li>❖ Being misunderstood                             <ul style="list-style-type: none"> <li>o Being and feeling othered</li> <li>o A pain to explain</li> <li>o The need to filter out a big part of your life</li> </ul> </li> <li>❖ They would understand me</li> </ul>
Linkiewicz, 2023 [44]	To explore the peer support needs of adolescents with chronic pain	Semi-structured interviews	Inductive reflexive thematic analysis	<ul style="list-style-type: none"> <li>❖ Being misunderstood                             <ul style="list-style-type: none"> <li>o Being and feeling othered</li> <li>o A pain to explain</li> <li>o The need to filter out a big part of your life</li> </ul> </li> <li>❖ They would understand me</li> </ul>

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Table 3 (continued)

Mahon, 2023 [45]	To explore patients' perception of their primary chronic pain origins and to understand the effects diagnosis and ongoing treatment may have on the adolescent's feeling of wellness	Semi-structured interviews	Interpretive Description (ID)	<ul style="list-style-type: none"> <li>o Shared knowledge and experiences</li> <li>o A safe space of belonging</li> <li>❖ Moving forward together in our pain journeys               <ul style="list-style-type: none"> <li>o Learning from each other</li> <li>o Being there for one another</li> </ul> </li> <li>❖ Psychological               <ul style="list-style-type: none"> <li>o Diagnostic uncertainty and uncertainty about the future</li> <li>o Depression and anxiety</li> <li>o Professional's scepticism</li> <li>o Importance of peer support</li> <li>o Importance of parental support</li> </ul> </li> <li>❖ Physiological               <ul style="list-style-type: none"> <li>o Effect on activities of daily living</li> <li>o Sleep</li> <li>o Exercise, sports, recreation</li> </ul> </li> <li>❖ Systematic               <ul style="list-style-type: none"> <li>o School</li> <li>o Lack of resources</li> <li>o Delays in referrals</li> </ul> </li> </ul>
McKinnon, 2020 [46]	To explore the lived experience of chronic pain and dyskinesia in children and adolescents with cerebral palsy	Semi-structured interviews	Mixed methods with qualitative Interpretative Phenomenological Analysis.	<ul style="list-style-type: none"> <li>❖ Lives embedded with dyskinesia               <ul style="list-style-type: none"> <li>o Lacking control</li> <li>o Negative emotional responses towards living with CP and dyskinesia</li> <li>o Normalization of dyskinesia within everyday lives</li> <li>o Physical challenges of living with dyskinesia</li> <li>o Self-reflecting to identify dyskinesia triggers</li> </ul> </li> <li>❖ Still learning strategies to manage their pain and dyskinesia               <ul style="list-style-type: none"> <li>o Self-adopting or learning strategies from parents</li> <li>o Seeking out 'child-friendly' treatment strategies</li> <li>o Problem-solving pain</li> <li>o Seeking comfort amongst family</li> <li>o Exerting control over their environment</li> </ul> </li> <li>❖ The real-world challenges of living with chronic pain               <ul style="list-style-type: none"> <li>o Pain a usual part of life</li> <li>o Negative emotional responses towards living with chronic pain</li> <li>o Feelings of social isolation</li> <li>o All-encompassing nature of severe pain</li> <li>o Pushing through pain</li> <li>o Hoping for a solution</li> <li>o The way pain really feels</li> <li>o Trust in caregivers</li> </ul> </li> </ul>
Meldrum, 2009a [47]	To examine the impact of pain-associated functioning limitations on children's lives and the strategies they develop to try to continue functioning	Semi-structured interviews	Mixed methods with qualitative grounded theory analysis	<ul style="list-style-type: none"> <li>❖ Functioning limitations               <ul style="list-style-type: none"> <li>o Adaptive behaviours</li> <li>o Passive behaviours</li> <li>o Stressed behaviours</li> </ul> </li> <li>❖ Isolation from peers</li> <li>❖ Realisation that focus on pain may increase pain perception</li> <li>❖ Worries about future</li> <li>❖ Hiding pain from others</li> <li>❖ Functioning strategies               <ul style="list-style-type: none"> <li>o Getting on with things</li> <li>o Planning ahead</li> <li>o Body awareness</li> </ul> </li> </ul>
Meldrum, 2009b [48]	To better understand the impact of chronic or recurrent pain on children within the context of their own lives and experiences, using qualitative	Semi-structured interviews	Grounded theory and narrative analysis	<p>Themes:</p> <ul style="list-style-type: none"> <li>❖ The choice to hide pain from parents and friends               <ul style="list-style-type: none"> <li>o Hiding pain from friends</li> </ul> </li> </ul>

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Table 3 (continued)

	analysis, and to suggest the applications of the narrative method to clinical practice			<ul style="list-style-type: none"> <li>o Hiding intensity or frequency of pain from parents</li> <li>o Reluctance to discuss pain with anyone</li> <li>❖ A sense of isolation and difference from peers and classmates</li> <li>❖ Pain as an obstacle to personal activities and goals</li> <li>❖ Fears about how pain will affect the future</li> <li>❖ Perceived lack of physician understanding</li> </ul>
				<p>Narratives:</p> <ul style="list-style-type: none"> <li>❖ The constant patient - the medical narrative</li> <li>❖ The invalid - defeated by the pain</li> <li>❖ The weary soldier - fighting constant stress</li> <li>❖ The stoic - "pushing through" the pain</li> <li>❖ The positive thinker - one step at a time</li> <li>❖ The decision maker - the major rewrite</li> </ul>
Neville, 2019 [49]	To examine diagnostic uncertainty in both youth with chronic pain and their parents	Semi-structured interviews	Reflexive thematic analysis	<ul style="list-style-type: none"> <li>❖ The function of a diagnosis</li> <li>❖ Haunted by something missing</li> <li>❖ The search for an alternative diagnosis</li> </ul>
Neville, 2022 [50]	To explore the experiences of youth with chronic pain and their parents during the COVID-19 pandemic	Semi-structured interviews	Reflexive thematic analysis	<ul style="list-style-type: none"> <li>❖ Mistrust in the medical system.</li> <li>❖ Temporality, mental health, and pain</li> <li>❖ Coping with pain during a global pandemic</li> <li>❖ Impact on care</li> <li>❖ Re-appraisal in the context of development and pandemic life</li> </ul>
Parsons, 2023 [51]	To explore how adolescents experience, understand and perceive flourishing in the context of living with chronic pain	Other: Diary + interviews (n = 10)	Inductive reflexive thematic analysis	<ul style="list-style-type: none"> <li>❖ Appreciating the moment</li> <li>❖ Becoming a better version of myself</li> </ul>
Pate, 2019 [52]	To explore the concept of pain in children with and without persistent pain.	Semi-structured interviews including drawing activities	Thematic analysis	<ul style="list-style-type: none"> <li>❖ My pain-related knowledge                             <ul style="list-style-type: none"> <li>o varied knowledge of pain's purpose, pain-related anatomy and pain mechanisms</li> <li>o Influences of age</li> </ul> </li> <li>❖ Pain in the world around me                             <ul style="list-style-type: none"> <li>o Contextual influences on a child's concept of pain</li> <li>o Perceptions of how other people respond to pain</li> </ul> </li> <li>❖ Pain in me                             <ul style="list-style-type: none"> <li>o Experiences of any pain/injury</li> <li>o The impact of having persistent pain</li> <li>o The physical is obvious, but the emotional is hidden</li> </ul> </li> <li>❖ Communicating my concept of pain                             <ul style="list-style-type: none"> <li>o Verbal communication</li> <li>o Individual engagement</li> </ul> </li> </ul>
Sallfors, 2001 [54]	To gain a deeper understanding of how children with juvenile chronic arthritis cope with their chronic pain condition.	Semi-structured interviews	Grounded theory method	<ul style="list-style-type: none"> <li>❖ Making me different                             <ul style="list-style-type: none"> <li>o Controlling strategies</li> <li>o Avoidance strategies</li> <li>o Cognitive strategies</li> <li>o Compliance with the treatment</li> <li>o Seeking social support</li> <li>o Recovering</li> </ul> </li> </ul>
Sallfors, 2002 [53]	To elucidate the life situation and psychosocial processes of living with chronic pain in children suffering from juvenile chronic arthritis	Semi-structured interviews	Grounded theory method	<ul style="list-style-type: none"> <li>❖ Oscillating between hope and despair</li> <li>❖ Disturbed order</li> <li>❖ Dependency</li> <li>❖ Ambivalence</li> </ul>

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Table 3 (continued)

Shaygan, 2021 [55]	Overall study aim: To evaluate a smartphone-based pain management application regarding the feasibility, adherence, participant satisfaction, and effectiveness on pain intensity and quality of life in adolescents with chronic pain Qualitative aim: To produce a more complete picture of pain management strategies adopted by adolescents	Semi-structured interviews	Qualitative content analysis	<ul style="list-style-type: none"> <li>◆ Uncertainty about the future</li> <li>◆ Physical management                             <ul style="list-style-type: none"> <li>○ Medical methods</li> <li>○ Traditional medicine methods</li> </ul> </li> <li>◆ Psychological management                             <ul style="list-style-type: none"> <li>○ Avoidance-based management</li> <li>○ Courageous management</li> </ul> </li> <li>◆ Interpersonal resources                             <ul style="list-style-type: none"> <li>○ Family support</li> <li>○ Social support</li> </ul> </li> </ul>
Shaygan, 2022 [56]	To explore the experience of chronic pain among adolescents	Semi-structured interviews	Conventional Content Analysis	<ul style="list-style-type: none"> <li>◆ Perceived suffering                             <ul style="list-style-type: none"> <li>○ Internal reactions to pain</li> <li>○ External/Observed reactions to pain</li> </ul> </li> <li>◆ Attempt to conquer pain                             <ul style="list-style-type: none"> <li>○ Factors affecting pain management</li> <li>○ Physical strategies for pain management</li> <li>○ Psychological strategies for pain management</li> </ul> </li> <li>◆ Hopes for support                             <ul style="list-style-type: none"> <li>○ Family support</li> <li>○ Peer support</li> <li>○ Social support</li> <li>○ Spiritual management</li> </ul> </li> <li>◆ Three Factors Improving One's Ability to Live                             <ul style="list-style-type: none"> <li>○ Creating a safe internal space</li> <li>○ Accepting the incurability of chronic pain</li> <li>○ Envisioning a positive future</li> </ul> </li> <li>◆ Hindrances to One's Ability to Live Well                             <ul style="list-style-type: none"> <li>○ Facing the unpredictability of chronic pain</li> <li>○ Facing the uncertainty of chronic pain</li> </ul> </li> </ul>
Szwimer, 2020 [57]	To inquire into the experiences of female adolescents living with chronic pain in order to enhance our understanding of how chronic pain affects their personal lives	Semi-structured interviews	Interpretative Phenomenological Analysis	<ul style="list-style-type: none"> <li>◆ Social motivations to conceal pain                             <ul style="list-style-type: none"> <li>○ Avoidance of judgment</li> <li>○ Avoidance of being a social burden</li> <li>○ Desire to be treated normally</li> </ul> </li> <li>◆ Harmful consequences of concealment                             <ul style="list-style-type: none"> <li>○ Social isolation</li> <li>○ Cognitive burden</li> </ul> </li> <li>◆ Felt stigma                             <ul style="list-style-type: none"> <li>○ Pain dismissal</li> <li>○ Faking or exaggerating</li> <li>○ Mental health stigma</li> </ul> </li> <li>◆ Anticipated stigma and concealment</li> <li>◆ Internalized stigma</li> <li>◆ Sources of pain-related stigma                             <ul style="list-style-type: none"> <li>○ Pain invisibility</li> <li>○ Lack of chronic pain knowledge</li> <li>○ Lack of understanding</li> <li>○ Controllability</li> </ul> </li> <li>◆ Becoming myself again                             <ul style="list-style-type: none"> <li>○ Trust as a pillar for growth</li> <li>○ Making sense of my life with pain</li> <li>○ Putting myself into the world again</li> </ul> </li> </ul>
Wakefield, 2021 [59]	To examine the nature of concealment as a coping strategy used by adolescents with primary chronic pain	Semi-structured focus groups	Inductive content analysis	<ul style="list-style-type: none"> <li>◆ Felt stigma                             <ul style="list-style-type: none"> <li>○ Pain dismissal</li> <li>○ Faking or exaggerating</li> <li>○ Mental health stigma</li> </ul> </li> <li>◆ Anticipated stigma and concealment</li> <li>◆ Internalized stigma</li> <li>◆ Sources of pain-related stigma                             <ul style="list-style-type: none"> <li>○ Pain invisibility</li> <li>○ Lack of chronic pain knowledge</li> <li>○ Lack of understanding</li> <li>○ Controllability</li> </ul> </li> <li>◆ Becoming myself again                             <ul style="list-style-type: none"> <li>○ Trust as a pillar for growth</li> <li>○ Making sense of my life with pain</li> <li>○ Putting myself into the world again</li> </ul> </li> </ul>
Wakefield, 2022 [58]	To identify and describe pain-related stigma among adolescents with chronic pain and their parents	Semi-structured focus groups	Directed content analysis	<ul style="list-style-type: none"> <li>◆ Felt stigma                             <ul style="list-style-type: none"> <li>○ Pain dismissal</li> <li>○ Faking or exaggerating</li> <li>○ Mental health stigma</li> </ul> </li> <li>◆ Anticipated stigma and concealment</li> <li>◆ Internalized stigma</li> <li>◆ Sources of pain-related stigma                             <ul style="list-style-type: none"> <li>○ Pain invisibility</li> <li>○ Lack of chronic pain knowledge</li> <li>○ Lack of understanding</li> <li>○ Controllability</li> </ul> </li> <li>◆ Becoming myself again                             <ul style="list-style-type: none"> <li>○ Trust as a pillar for growth</li> <li>○ Making sense of my life with pain</li> <li>○ Putting myself into the world again</li> </ul> </li> </ul>
Wallbing, 2023 [60]	To illuminate adolescents' experiences of Help Overcoming Pain Early (HOPE), a person-centred intervention delivered in a school setting by school nurse	Semi-structured interviews	Content analysis	<ul style="list-style-type: none"> <li>◆ Becoming myself again                             <ul style="list-style-type: none"> <li>○ Trust as a pillar for growth</li> <li>○ Making sense of my life with pain</li> <li>○ Putting myself into the world again</li> </ul> </li> </ul>

<sup>a</sup> Themes + subthemes or methodological equivalent i.e. categories and subcategories

<sup>b</sup> CAMSA = Cognitive-affective model of symptom appraisal

“why aren't you getting out of bed? You're just lazy, ” when you're not lazy, you're just in too much pain or you just don't have that energy” (Age 17) [44]

The shame and hurt of sharing their pain story when they were so

frequently dismissed and perceived to be a liar resulted in children being far less likely to talk about their pain. Many chose to not share when they were in pain for fear of being misunderstood or treated differently [27, 30,33,35,42,43,45,46,57,58]. Keeping their pain a secret exacerbated

pre-existing feelings of loneliness and isolation. This theme emphasises how managing other people's pain beliefs augments the burden of living with chronic pain for children.

### 3.3.4. *I keep trying to make sense of my pain*

Children described having their own questions about their pain, particularly around the cause of the pain and how long the pain would last [29,35,43,45,47–49,53,56,57].

*“Why isn't it going away?” (Jessica); “When will it stop?” (Tara); “When's this going to end?” (Celine).”* (Ages not specified, 12–17) [35]

The advice of HCPs was one of the ways children and their families tried to make sense of and manage their pain [28,29,35,41–43,45,47,49,53,54,58].

*“I tried to deal with it myself first and then I went to them [professionals]. Because it just got too bad for me ... to overcome on my own.”* (Age 14) [26]

Children reported mixed experiences of the healthcare system. Positive experiences included when children felt believed and listened to [23,28,42,59]. Children appreciated when asked about their hobbies and interests in addition to their pain. This helped them to develop a trusting relationship with their HCP where they felt comfortable and encouraged. When supported and empathised with, children felt hopeful about the future and could focus on their goals. These goals varied, some dreamed of being pain-free while some just wanted to be able to return to playing sports with their friends.

Not all experiences of the healthcare system were positive. Children described going back and forth between doctors, ongoing tests, being poked and prodded, disbelieved, dismissed and unsupported [27,28,34,40–42,44,46–48,52,53,57]. One boy described his stay in hospital as *“It was literally torture”* [35]. Children reported seeing a variety of HCPs and receiving conflicting information resulting in confusion and frustration [42,44,47,48]. Children didn't feel listened to and as a result, they felt the HCP did not understand them or their pain [24,26,27,42,47,48].

*“They would only talk and talk and talk [without listening]”.* (Age not specified, range: 10–18) [48]

Children who did not feel supported did not trust the HCP had found the 'correct diagnosis' and remained worried about their diagnosis and prognosis [21,48,58]. Some worried that due to not understanding the whole picture the HCP had missed something sinister such as cancer or something that would result in premature death [29,48,49,53,56,58]. For children who had ongoing questions about their pain, they reflected on their previous knowledge and experiences trying to understand their pain better. Previous experiences included family members who had had pain and previous experiences of pain [28,57].

*“My aunt had pain too you know. She died of a heart attack last year ... I hope that I don't have what she had.”* (Age not specified, range: 10–17) [29]

This suggests the information children receive from their HCPs is only one part of the way children understand their pain experience.

## 3.4. Quality assessment

There were 14 (35 %) studies meeting all nine of the evaluation criteria used for this review [34,38–41,43,46,51,53,54,57,58,60]. The full results of quality assessment are shown in Appendix B with all studies identified as moderate to high quality. Common quality concerns observed were studies not sufficiently reporting ethical approvals and/or consideration of the relationship between the researcher and the participants.

## 4. Discussion and conclusion

### 4.1. Discussion

This review identified four key areas based on a thematic analysis of 40 studies reporting on children's chronic pain as described by the child. These studies published across 23 years describe children's diverse

conditions from different countries and settings. These studies report similar ongoing impacts of chronic pain; children feel they are missing out, they use a variety of techniques, they feel hurt by and misunderstood about their pain and when seeking health care input, they have mixed experiences furthering their feelings of worry. The final themes represent concepts that were consistently identified across the studies, highlighting their prominence in the literature. To the best of our knowledge, this is the first systematic review to look exclusively at the child's experience of chronic pain. We have revealed new insights into children's perceptions of their family dynamics and the way children draw on previous experience to understand their pain.

HCPs and families have been rightfully included in research exploring children's chronic pain [13,61]. A large systematic review investigated how children and their families experience and understand their condition as well as pain services and treatments [13]. The findings of our review similarly highlight the impact of chronic pain on the child and their families. By limiting our focus to children, we have been able to further explore the concerns of children about the impact of pain on their day-to-day lives as well as highlight children are aware and worried about the impact of their pain on their families.

Children were worried about their pain and felt others did not understand or believe their pain experience. Furthermore, children were motivated to gain an understanding of their pain and often relied on their own experiences and knowledge to fill gaps in their understanding particularly when HCPs could not provide an explanation the child was also confident in. Children reporting mixed experiences in the healthcare setting is not surprising given the significant challenges in the assessment and management of chronic pain [62,63]. However, our review highlighted when children had questions their HCPs did not answer, they used other knowledge to 'fill in the gaps'. While this sometimes results in more questions than answers, it does highlight consultations with HCPs are only one of many ways children gain information related to their chronic pain. Further research is required to investigate the sources of information about chronic pain available to children and how they use this information to build their understanding of the cause and prognosis of their pain/condition. Peer mentoring programs are being explored as an information-sharing method for children with JIA [64]. Preliminary research on peer support for children and adolescents with chronic pain shows high engagement and children report increased confidence in managing their symptoms [64,65].

Children and adolescents' experiences of chronic pain have both similarities and notable differences when compared to the experiences of adults. Adults often reflect on higher-order impacts of pain such as limitations on their occupation or activities they could previously perform [66,67]. Children focus more acutely on the loss of recreational opportunities particularly those involving friends. While school may be considered an occupation for children, their concerns often centred around missing out on things and how that made them feel different from their peers rather than on their occupational responsibilities. Adults are also more likely to manage their pain independently sometimes using illicit drugs or alcohol [66]. Both adults and children report feeling hurt, worries and ashamed, concealing their pain in certain settings and mixed experiences of the healthcare system [66]. However, adults likely have a more established sense of self and may spend less time conceptualising their pain while children are actively trying to understand it as well as navigate the effects on their day-to-day life. Despite the inclusion criteria for this review being from birth to 18 years most studies focused on adolescents' experiences. Younger children who are just starting school may experience chronic pain in similar ways, however further research is required to explore these experiences. Completing interview-based research with children under the age of six may be difficult as they may not have yet developed the necessary language skills required to participate [68]. For younger children creative or art based research methodologies may be more appropriate [69,70]. These approaches have been successfully used with older children



to draw timelines of their pain [41] or describing experiences while seeking health care services [71], rather than interview only.

It is important to consider the limitations of this review. We limited our search and inclusion criteria to studies published in English; therefore, we may have missed insightful studies published in other languages. Most of the initial coding and data analysis was completed by one author with, 10 % coded by a second author. While this was managed through iterative analysis with the full research team the impact of this is unknown. Participants were mostly recruited from health services which means they were already engaged with the healthcare system, potentially creating bias in responses. Their experiences may differ from someone who has not engaged with any health services. Few included studies focused on the experience of one condition, such as cerebral palsy, in which chronic pain may be one of multiple symptoms each of which contributes to their experience, therefore, some of the experiences described in our research may have been influenced by symptoms other than pain. Lastly, we did not exclude studies on methodological quality resulting in the inclusion of some with limited methodological details. It is unknown what impact that has on our findings. Given the robustness of the quality assessment tool and all included articles being medium to high quality, we do not expect the methodological concern identified to have impacted the way the themes and quotes were analysed within this review.

Our qualitative content analysis identified gaps where the child's voice had not been centred particularly around their concerns about the impact of their pain on their families, their feelings of being misunderstood and not believed and the way that children and adolescents try to make sense of their pain in the absence of a diagnosis that they trust. This approach revealed these experiences occur across conditions and settings which may not have been emphasised in individual studies or studies that included both HCPs and family perspectives.

#### 4.2. Conclusion

This review provides insight into children's own experiences of chronic pain. It reinforces children are burdened by their pain and its consequences and emphasises the diversity of coping strategies used by children to manage their pain.

Moreover, this review highlights children feel weighed down by having to manage the beliefs and expectations of family, friends, teachers and HCPs about their chronic pain. Additionally, while children describe seeking HCP advice it is only one part of many ways children understand their pain.

#### 4.3. Practice implications

Our review highlights the importance of researching the child narrative to support HCPs in providing child-centred care. Children are primarily concerned by the impact their pain has on their ability to participate in school, sports and social activities.

Our review also highlights children use a variety of treatment strategies to manage their pain. Providing children with multiple tools and encouraging patient agency in their management encourages independence and autonomy.

This review furthers the existing literature on the burden of children's pain by revealing the additional load children bear in managing the expectations and beliefs of those around them. Trusted adults such as

parents, teachers and HCPs may be able to alleviate some of the burden of self-advocacy.

Finally, this review elucidates the need for further exploration of children's narratives both at a clinical and academic level. Children draw on previous knowledge and experiences to make sense of their pain and their condition. To provide a high level of care, HCPs must seek to understand the child's perspective by building rapport and listening to the child in front of them. Additionally, future research should explore whether younger children, who may use different expressive modalities, experience similar challenges, as current research has largely focused on adolescent perspectives. Diverse methods such as diaries or drawings may assist both researchers and HCPs to better understand the child's experience.

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#### Declaration of Generative AI and AI-assisted technologies in the writing process

During the preparation of this work the authors used ChatGPT in order to improve the readability of the appendices. After using this tool/service, the authors reviewed and edited the content as needed and take full responsibility for the content of the published article.

#### CRediT authorship contribution statement

**Cylie M Williams:** Writing – review & editing, Visualization, Validation, Supervision, Software, Resources, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Verity Pacey:** Writing – review & editing, Writing – original draft, Visualization, Validation, Supervision, Resources, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Jessica Coventry:** Writing – review & editing, Writing – original draft, Visualization, Project administration, Methodology, Formal analysis, Data curation, Conceptualization. **Mitchell Smith:** Writing – review & editing, Project administration, Data curation, Conceptualization. **Binh Ta:** Writing – review & editing, Visualization, Validation, Supervision, Resources, Methodology, Conceptualization. **Elizabeth Sturgiss:** Writing – review & editing, Visualization, Supervision, Resources, Methodology, Formal analysis, Conceptualization.

#### Declaration of Competing Interest

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Verity Pacey is an author of this systematic review and also the senior author on one of the included papers (Pate et al, 2021). There are no other competing interests to declare.

#### Acknowledgements

None.

Appendix A

Table A.1  
Electronic database search strategies

Ovid Medline: Search Date 19th August 2024		
Search Number	Search Terms	Result
1	Chronic pain/ or (pain adj1 (persist* or chronic or long term or recurrent)).mp.	61,870
2	exp Child/ or child*.mp.	2655,891
3	exp Adolescent/ or adolescent.mp.	2284,112
4	Minor/ or minor.mp.	237,251
5	juvenile*.mp.	97,626
6	p?ediatric*.mp.	475,981
7	(Young adj2 (person* or people)).mp.	37,268
8	youth*.mp.	95,695
9	Teen*.mp.	32,738
10	boy*.mp.	159,954
11	girl*.mp.	157,062
12	kid.mp.	2267
13	experience*.mp.	1233,625
14	perception*.mp.	493,799
15	(describ* or description).mp.	2102,533
16	perceive.mp.	31,796
17	explain*.mp.	566,986
18	communicat*.mp.	465,638
19	(narrative* or narration).mp. or Narration/	78,271
20	2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12	4200,049
21	13 or 14 or 15 or 16 or 17 or 18 or 19	4406,187
22	1 and 20 and 21	3147
CINAHL Complete: Search Date 19th August 2024		
Search Number	Search Terms	Result
S1	(MH "Chronic Pain") OR pain N1 ("persist*" OR "chronic" OR "long term" OR "recurrent")	49 261
S2	(MH "Child+") OR child*	1041,727
S3	(MH "Adolescence+") OR "adolescent"	642,524
S4	(MH "Minors (Legal)") OR "minor"	35,628
S5	juvenile*	17,311
S6	p#diatric*	220,159
S7	Young N2 ("PERSON" OR "PEOPLE")	25,004
S8	YOUTH*	67,028
S9	TEEN*	20,836
S10	boy*	50665
S11	girl*	52,655
S12	kid	10,206
S13	experience*	575,951
S14	perception	199,665
S15	("describ*" or "description")	449,733
S16	perceive	18,248
S17	explain*	123,226
S18	communicat*	251,327
S19	(MH "Narratives") OR "narration" or "narrative**"	57,050
S20	S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12	1500,787
S21	S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19	1369,936
S22	S1 AND S20 AND S21	2991
Embase: Search Date 19th August 2024		
Search Number	Search Terms	Result
1	chronic pain/ or pain.mp. adj1 (persist* or chronic or long term or recurrent).mp.	148,648
2	exp child/ or child*.mp.mp.	3658,083
3	exp Adolescent/ or adolescent.mp.	2061,754
4	minor.mp. or "minor (person)"/	364,705
5	juvenile*.mp. or exp juvenile/	4810,870
6	Pediatrics/ or p?ediatric*.mp.	897,222
7	(Young adj2 (person* or people)).mp.	64,544
8	youth*.mp.	138,654
9	teen*.mp.	53,834
10	boy/ or boy*.mp.	275,434
11	girl/ or girl*.mp.	266,826
12	kid.mp.	4769
13	experience.mp. or exp personal experience/ or experience/	1393,940
14	perception*.mp.	586,030
15	(describ* or description).mp.	3477,402
16	perceive*.mp.	393,445
17	communicat*.mp.	832,757
18	exp narrative/ or narrative*.mp. or narration.mp.	102,624
19	2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12	5489,610
20	13 or 14 or 15 or 16 or 17 or 18	6026,130
21	1 and 19 and 20	4952
PsycINFO: Search Date 19th August 2024		

(continued on next page)

**Table A.1** (continued)

Ovid Medline: Search Date 19th August 2024		
Search Number	Search Terms	Result
Search Number	Search Terms	Result
1	Chronic pain/ or (pain adj1 (persist* or chronic or long term or recurrent)).mp.	26,770
2	child*.mp.	935,882
3	Early Adolescence/ or adolescent.mp.	440,395
4	minor.mp.	26,938
5	juvenile*.mp.	42,881
6	p?ediatric*.mp.	63,422
7	(Young adj2 (person* or people)).mp.	41,319
8	youth*.mp.	140,892
9	Teen*.mp.	27,551
10	boy*.mp.	87,751
11	girl*.mp.	86,230
12	kid.mp.	1007
13	experience*.mp.	866,230
14	perception*.mp.	625,648
15	(describ* or description).mp.	607,932
16	perceive.mp.	48,220
17	explain*.mp.	255,382
18	communicat*.mp.	381,376
19	Narratives/ or narrative*.mp.	93,886
20	2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12	1322,562
21	13 or 14 or 15 or 16 or 17 or 18 or 19	2242,525
22	1 and 20 and 21	2015

**Appendix B**

**Table B.1**  
Quality Assessment using CASP

	Clear statement of aims	Appropriate methodology	Appropriate research design	Appropriate recruitment strategy	Data collection addresses issue	Researcher-participant relationship	Ethical issues considered	Rigorous data analysis	Clear statement of findings
Alsaggaf, (2023)	No	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Borghi, (2016)	Yes	Yes	Yes	Yes	Yes	No	Yes	No	No
Bradshaw, (2022)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Carter, (2002)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Castle, (2007)	Yes	Yes	Yes	No	Yes	No	Yes	Yes	Yes
Corser, (2023)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Daenen, (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Dell' Api, (2007)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Donovan, (2019)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Ghio, (2022)	Yes	Yes	Yes	Yes	Yes	No	No	No	No
Gorbounova, (2022)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Gorodzinsky, (2013)	No	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Gremillion, (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Heffernan, (2021)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Hilario, (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Jacobson, (2011)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Jones, (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Jordan, (2018)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Jordan, (2024)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Joslin, (2021)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Killackey, (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Lee, (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

(continued on next page)

Table B.1 (continued)

	Clear statement of aims	Appropriate methodology	Appropriate research design	Appropriate recruitment strategy	Data collection addresses issue	Researcher-participant relationship	Ethical issues considered	Rigorous data analysis	Clear statement of findings
Linkiewich, (2023)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Mahon, (2023)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
McKinnon, (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Meldrum, (2009)	Yes	Yes	Yes	Yes	Yes	No	No	No	No
Meldrum, (2009)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	No
Neville, (2019)	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Neville, (2022)	No	Yes	Yes	Yes	Yes	No	Yes	No	No
Parsons, (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Pate, (2019)	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes
Sallfors, (2001)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Sallfors, (2002)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Shaygan, (2021)	Yes	Yes	Yes	No	No	No	Yes	Yes	Yes
Shaygan, (2022)	No	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes
Stinson, (2008)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Szwimer, (2020)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wakefield, (2021)	No	Yes	Yes	Yes	Yes	No	No	No	No
Wakefield, (2022)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes
Wallbing, (2023)	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes

Appendix C

JC & VP (Physiotherapists), MS, CMW (Podiatrists) and ES (GP) aimed to highlight children’s views on chronic pain, acknowledging that our clinical backgrounds may have influenced interpretations. VP, ES, and BT have extensive qualitative research experience; BT is also a linguist and conversation analyst. Our clinical expertise informed data extraction and analysis, which was conducted iteratively with team discussions to ensure balance.

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