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A meta-ethnography of how children and young people with chronic non-cancer pain and their families experience and understand their condition, pain services, and treatments (Review)

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[Qualitative Review]

A meta-ethnography of how children and young people with chronic non-cancer pain and their families experience and understand their condition, pain services, and treatments

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ABSTRACT

Background

Chronic non-cancer pain in childhood is widespread, affecting 20% to 35% of children and young people worldwide. For a sizeable number of children, chronic non-cancer pain has considerable negative impacts on their lives and quality of life, and leads to increased use of healthcare services and medication. In many countries, there are few services for managing children's chronic non-cancer pain, with many services being inadequate. Fourteen Cochrane Reviews assessing the effects of pharmacological, psychological, psychosocial, dietary or physical activity interventions for managing children's chronic non-cancer pain identified a lack of high-quality evidence to inform pain management. To design and deliver services and interventions that meet the needs of patients and their families, we need to understand how children with chronic non-cancer pain and their families experience pain, their views of services and treatments for chronic pain, and which outcomes are important to them.

Objectives

1. To synthesise qualitative studies that examine the experiences and perceptions of children with chronic non-cancer pain and their families regarding chronic non-cancer pain, treatments and services to inform the design and delivery of health and social care services, interventions and future research.

2. To explore whether our review findings help to explain the results of Cochrane Reviews of intervention effects of treatments for children's chronic non-cancer pain.

3. To determine if programme theories and outcomes of interventions match children and their families' views of desired treatments and outcomes.

4. To use our findings to inform the selection and design of patient-reported outcome measures for use in chronic non-cancer pain studies and interventions and care provision to children and their families.

The review questions are:

1. How do children with chronic non-cancer pain and their families conceptualise chronic pain?

2. How do children with chronic non-cancer pain and their families live with chronic pain?

3. What do children with chronic non-cancer pain and their families think of how health and social care services respond to and manage their child's chronic pain?

4. What do children with chronic non-cancer pain and their families conceptualise as 'good' chronic pain management and what do they want to achieve from chronic pain management interventions and services?

Search methods

Review strategy: we comprehensively searched 12 bibliographic databases including MEDLINE, CINAHL, PsycInfo and grey literature sources, and conducted supplementary searches in 2020. We updated the database searches in September 2022.

Selection criteria

To identify published and unpublished qualitative research with children aged 3 months to 18 years with chronic non-cancer pain and their families focusing on their perceptions, experiences and views of chronic pain, services and treatments. The final inclusion criteria were agreed with a patient and public involvement group of children and young people with chronic non-cancer pain and their families.

Data collection and analysis

We conducted a qualitative evidence synthesis using meta-ethnography, a seven-phase, systematic, interpretive, inductive methodology that takes into account the contexts and meanings of the original studies. We assessed the richness of eligible studies and purposively sampled rich studies ensuring they addressed the review questions. Cochrane Qualitative Methods Implementation Group guidance guided sampling. We assessed the methodological limitations of studies using the Critical Appraisal Skills Programme tool. We extracted data on study aims, focus, characteristics and conceptual findings from study reports using NVivo software. We compared these study data to determine how the studies related to one another and grouped studies by pain conditions for synthesis. We used meta-ethnography to synthesise each group of studies separately before synthesising them all together. Analysis and interpretation of studies involved children with chronic non-cancer pain and their families and has resulted in theory to inform service design and delivery. Sampling, organising studies for synthesis, and analysis and interpretation involved our patient and public involvement group who contributed throughout the conduct of the review. We used the GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research) approach to assess our confidence in each review finding. We used a matrix approach to integrate our findings with existing Cochrane Reviews on treatment effectiveness for children's chronic non-cancer pain.

Main results

We synthesised 43 studies sampled from 170 eligible studies reported in 182 publications. Included studies involved 633 participants. GRADE-CERQual assessments of findings were mostly high (n = 21, 58%) or moderate (n = 12, 33%) confidence with three (8%) low or very low confidence. Poorly managed, moderate or severe chronic non-cancer pain had profound adverse impacts on family dynamics and relationships; family members' emotions, well-being, autonomy and sense of self-identity; parenting strategies; friendships and socialising; children's education and future employment prospects; and parental employment. Most children and parents understood chronic non-cancer pain as having an underlying biological cause and wanted curative treatment. However, families had difficulties seeking and obtaining support from health services to manage their child's pain and its impacts. Children and parents felt that healthcare professionals did not always listen to their experiences and expertise, or believe the child's pain. Some families repeatedly visited health services seeking a diagnosis and cure. Over time, some children and families gave up hope of effective treatment. Outcomes measured within trials and Cochrane Reviews of intervention effects did not include some outcomes of importance to children and families, including impacts of pain on the whole family and absence of pain. Cochrane Reviews have mainly neglected a holistic biopsychosocial approach, which specifies the interrelatedness of biological, psychological and social aspects of illness, when selecting outcome measures and considering how chronic pain management interventions work.

Authors' conclusions

We had high or moderate confidence in the evidence contributing to most review findings. Further research, especially into families' experiences of treatments and services, could strengthen the evidence for low or very low confidence findings. Future research should also explore families' experiences in low- to middle-income contexts; of pain treatments including opioid use in children, which remains controversial; and of social care services. We need development and testing of family-centred interventions and services acceptable to families. Future trials of children's chronic non-cancer pain interventions should include family-centred outcomes.

PLAIN LANGUAGE SUMMARY

Children with chronic non-cancer pain and their families' experiences and understanding of their condition, pain services and treatments: a meta-ethnography

What is the aim of this synthesis?

The aim of this Cochrane qualitative evidence synthesis was to find out how children and young people who have chronic pain and their families: 1) think about chronic pain; 2) live with chronic pain; 3) think of how health and social care services treated their pain; and 4) what they want from services and treatments. To answer these questions, we searched for, analysed and brought together the findings of all the relevant qualitative studies looking at these topics. This qualitative evidence synthesis links to 14 Cochrane Reviews assessing the effect of treatments on children with chronic pain.

What was studied in this synthesis?

Around 20% to 35% of children and young people worldwide have pain lasting 12 weeks or more (we call this chronic pain). It can lead to poorer health, quality of life, and stop them participating in school and social activities. Chronic pain can lead to higher use of healthcare services and treatments. If a child's chronic pain is not successfully treated it can continue into adulthood. In many countries, there are few services for managing children's chronic pain and current services are inadequate. United Kingdom and global clinical guidelines for managing chronic pain and 14 recent Cochrane Reviews on treatment effectiveness for children's chronic pain identified a severe lack of high-quality research to inform chronic pain management in children. In this qualitative evidence synthesis, we pulled together the different findings from published research studies, which asked children with chronic pain and their families about what it is like to live with chronic pain, their experiences of health care or what they want to get from treatments, to try to understand more about children's chronic pain in order to improve health care. Young people with chronic pain and their families, pain charities, healthcare professionals such as doctors, and research experts worked with us throughout the review to help us make decisions, analyse studies and tell others our findings.

The funder of this research was the National Institute for Health Research in the United Kingdom.

What are the main findings of this synthesis?

We identified 170 eligible studies and included 43 of the most relevant studies, 39 from high-income countries and four from low- to middle-income countries. The included studies involved a total of 633 participants. These studies primarily explored the views and experiences of adolescents with chronic non-cancer pain and their parents in the United Kingdom. Moderate or severe chronic pain negatively affected a child or young person's whole family, family life and their social lives. Children and their families wanted to know the cause of the pain and have it resolved, but they found it difficult to get help and treatments that worked from health services. Sometimes healthcare professionals did not believe the child was in pain or listen to how pain affected them. Some families made many repeated visits to health services seeking a diagnosis and cure. Often families were left to deal with chronic pain on their own, which could negatively impact the whole family. Over time, some children and families realised their pain was unlikely to be cured and so focused on living well with pain or gave up hope of effective treatment.

How up-to-date is this synthesis?

We searched for studies that had been published up to September 2022.

SUMMARY OF FINDINGS

Summary of findings 1. GRADE-CERQual Summary of qualitative findings table

#	Summarised review finding	GRADE-CERQual assessment of confidence	Explanation of GRADE-CERQual assessment	References
01. IMPACT OF CHRONIC PAIN ON FAMILY LIFE				
1	Poorly managed, moderate and severe chronic pain was overwhelming, and took over family life and affected family dynamics. The routines and activities of the whole family were restricted and limited by managing the pain and its consequences.	High confidence	No/Very minor concerns regarding methodological limitations, coherence and adequacy, and Minor concerns regarding relevance	Atkin 2001; Atoui 2015; Brandelli 2021; Britton 2002a; Britton 2002b; Brodwall 2018; Carter 2002a; Dyson 2011; Forgeron 2008; Gaughan 2014; Guell 2007; Jones 2020; Khanom 2020; McDonagh 2021; McKinnon 2020; Sorensen 2017; Suder 2016
2	In high-income contexts, pain meant children and their families had to manage many uncertainties regarding their changing routines and family life, diagnosis and prognosis, and the child's future prospects, e.g. of finding employment or attending university. For fluctuating pain conditions, the fear and uncertainty around when and how intensely children would experience pain was always present, which limited families' activities even when the child was not in pain. Some children with fluctuating pain conditions were able to gather energy from moments with less or no pain, which helped them to deal with everyday life.	High confidence	Minor concerns regarding methodological limitations, adequacy and relevance, No/Very minor concerns regarding coherence	Ahlqwist 2012; Jordan 2016; Khanom 2020; Maciver 2005
02. IMPACT OF PAIN ON FAMILY MEMBERS				
3	Poorly managed, moderate and severe chronic pain had mostly negative psychosocial impacts on all family members. Children and parents felt depressed, afraid of the possible cause of the pain, and grieved the loss of their life before pain. Children and young people felt socially isolated and different from peers. Parents felt anxious, helpless and frustrated at being unable to help their child feel better. There was a greater impact on members who were more involved in caring for the child with pain, usually mothers. Siblings who did not have chronic pain felt neglected by their par-	High confidence	No/Very minor concerns regarding methodological limitations, coherence and adequacy, Minor concerns regarding relevance	Atkin 2001; Atoui 2015; Brandelli 2021; Britton 2002a; Britton 2002b; Brodwall 2018; Carter 2002a; Cartwright 2015; Dyson 2011; Forgeron 2008; Gaughan 2014; Guell 2007; Jones 2020; Jones

	ents and resentful of the child with pain but also concerned about them.			2022; Jordan 2016; Khanom 2020; McDonagh 2021; Maciver 2005; McKinnon 2020; Njifon 2019; Rossato 2007; Sorensen 2017; Suder 2016; Waite-Jones 2008; Williams 2008
4	In high-income contexts, parents felt deeply afraid of what might be causing the pain, of witnessing their child in pain, that treatments would not work and that their child would not get better to enjoy a fulfilling life. The constant fear caused parents to always be on call for their child, which was also detrimental to parents' well-being.	High confidence	Minor concerns regarding methodological limitations and relevance, No/Very minor concerns regarding coherence and adequacy	Gaughan 2014; Jones 2020; Jordan 2016; Maciver 2005
5	In high-income contexts, parents, siblings and adolescents with chronic pain reported that some good things had happened because of the impact of chronic pain. The main caregiver, usually the mother, felt they became closer to their child and that their relationship had improved. Siblings without chronic pain also felt that their family relationships had become closer than in other families, and they became more compassionate to others. Some adolescents with chronic pain acknowledged that their experiences made them a better person, better equipped to live life, and more mature.	Moderate confidence	Moderate concerns regarding methodological limitations and coherence, Minor concerns regarding adequacy and relevance	Brandelli 2021; Britton 2002a; Jones 2020; Jones 2022; Jordan 2016; Suder 2016; Waite-Jones 2008
6	In high-income contexts, primary caregivers, usually mothers, experienced reduced ability to have a life outside their home, they stopped paid employment and/or lost their career and curtailed their social life to focus on caring for their child.	High confidence	Minor concerns regarding methodological limitations, coherence, adequacy and relevance	Brandelli 2021; Brodwall 2018; Gaughan 2014; McDonagh 2021
03. IMPACT ON SELF-IDENTITY				
7	Children saw themselves as different from peers because they felt unhealthy, restricted by pain, socially isolated, dependent and were treated differently by peers. Some children regarded their chronic pain as abnormal, because it affected their ability to lead a normal life, and as something to pity. Children did not want to be seen as unhealthy and different by their peers, and they wanted to belong to a group of friends.	High confidence	No/Very minor concerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance	Atkin 2001; Atoui 2015; Britton 2002a; Cartwright 2015; Dyson 2011; Forgeron 2008; Gaughan 2014; Guell 2007;Jordan 2018; Khanom 2020; Njifon 2019; Rossato 2007; Suder 2016;

				Waite-Jones 2008; Williams 2008
04. IMPACT ON SIBLINGS				
8	In predominantly high-income contexts, siblings who did not have chronic pain felt neglected and helpless, which could lead to them behaving dismissively towards the child with pain and even questioning the legitimacy of their pain. Siblings competed for parental time and affection. Siblings blamed the child with pain for dominating their parents' attention, but they also showed concern and affection for them. Siblings' negative feelings improved overtime as they developed the skills to adjust socially and emotionally.	Low confidence	Minor concerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy and relevance	Brandelli 2021; Britton 2002a; Brodwall 2018; Gaughan 2014; McDonagh 2021; Njifon 2019; Waite-Jones 2008
9	Some siblings, even younger siblings, took on caring responsibilities for children with chronic pain, which limited their freedom. For example, some siblings were expected by their parents to adopt a parenting role for the child with chronic pain, including supervising their medical care, which siblings resented. Other siblings provided personal care for the child with chronic pain such as helping them to dress, lifting them out of the bath and carrying them downstairs.	Moderate confidence	No/Very minor concerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy and relevance	Atkin 2001; Atoui 2015; Njifon 2019; Waite-Jones 2008
05. IMPACT ON PARENTING				
10	Parents learnt on their own to adapt their parenting to help their child deal with the pain while trying to still maintain their child's autonomy. Parents provided support and care while being firm when necessary, for example making their child go to school despite pain. Successfully adapting their parenting was hindered by a lack of understanding of how they could help their child, and the lack of resources and support from health services and their social network.	High confidence	No/Very minor concerns regarding methodological limitations, coherence and relevance, Minor concerns regarding adequacy	Atkin 2000; Atkin 2001; Brodwall 2018; Gaughan 2014; Jordan 2016; Maciver 2005; Smart 2005
06. ADAPTING FAMILY LIFE TO PAIN				
11	For poorly managed and severe chronic pain, families focused on trying to control the impact of pain on family life using many strategies. Strategies included families gathering information about pain, following treatments, adjusting their routine to accommodate pain and its management, and self-managing pain to be able to join in activities. These strategies meant that family life then became more restricted because it was completely organised around managing and avoiding exacerbating the pain.	High confidence	No/Very minor concerns regarding methodological limitations, relevance and coherence, Minor concerns regarding adequacy	Ahlqwist 2012; Atkin 2000; Atkin 2001; Atoui 2015; Carter 2002a; Forgeron 2008; Guell 2007; Rossato 2007

12	Over time, parents and children learnt to adapt to unresolved pain because they felt like they had no other choice. Consequently, families and children started to focus on living well with pain. For instance, parents (mothers) learnt to deal with the unpredictability of pain; helped their child to live with their new condition; and developed ways of dealing with the child's fear about the future. Children found new ways to do daily activities, e.g. using mobility aids.	High confidence	Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, adequacy and relevance	Baert 2020; Britton 2002a; Britton 2002b; Carter 2002a; Guell 2007; Jones 2020; Rossato 2007; Sorensen 2017; Suder 2016
07. SOCIAL SUPPORT				
13	In high-income contexts, peers, friends and the extended family provided practical, financial and emotional support, which helped parents and children deal with the impact of pain on their lives, and enhanced quality of life and adherence to treatments. Contact with peers and friends helped children feel normal, which provided them with hope and reassurance. Parents (mainly mothers) longed for others to understand their own suffering but lacked a social support system. Mothers grew apart from friends due to their caring role.	Moderate confidence	Moderate concerns regarding methodological limitations and adequacy, No/Very minor concerns regarding coherence, Minor concerns regarding relevance	Baert 2020; Brandelli 2021; Britton 2002a; Cartwright 2015; Waite-Jones 2008
14	Recurrent school absences and pain prevented children from engaging with friends when at school which made it difficult for children to maintain friendships, contributed to their lack of support and increased their sense of social isolation.	Moderate confidence	No/Very minor concerns regarding methodological limitations, Minor concerns regarding coherence and relevance, Moderate concerns regarding adequacy	Atkin 2000; Atkin 2001; Atoui 2015; Dyson 2011; Jones 2022; Williams 2008
08. CONDITION-SPECIFIC PEER SUPPORT				
15	In high-income contexts, meeting others with similar conditions helped adolescents feel less isolated because they were able to share experiences and provide mutual support. In contrast, other adolescents did not want peer support from other children with chronic pain because they did not want to be reminded of their pain or because they believed others would not have similar experiences. Parents preferred support from other parents of children with similar conditions, who they described as a great comfort and vital source of information.	Moderate confidence	No/Very minor concerns regarding methodological limitations, coherence and relevance, Moderate concerns regarding adequacy	Cartwright 2015; Forgeron 2008; McDonagh 2021; Williams 2008
09. DISCLOSURE OF PAIN				
16	In predominantly high-income contexts, parents avoided disclosing their child's pain to friends and extended family for a range of	High confidence	Minor concerns regarding methodologi-	Atkin 2001; Atoui 2015; Baert 2020; Britton

	reasons. For instance, parents found chronic pain hard to understand and explain, they were afraid of being judged on their parenting skills or disbelieved, or they anticipated a lack of sympathy for a condition that is not life-threatening. Lack of disclosure could negatively affect how much support parents received from their friends and wider family. However, when they did disclose their child's pain, their social networks did not always understand or believe the pain and were not empathetic, sometimes blaming them for poor parenting, e.g. being over-protective parents. Children also often avoided disclosing their pain, although girls and younger children were more likely to disclose and share their problems than boys and adolescents. Children also avoided disclosing their pain to help manage how others perceived them, to avoid having to deal with the prejudice and discrimination of others, such as derogatory comments, and because the pain was invisible and hard to explain.		cal limitations, coherence and relevance, No/Very minor concerns regarding adequacy	2002a; Dyson 2011; Forgeron 2008; Gaughan 2014; Guell 2007; Jones 2020; Khanom 2020; Sorensen 2017; Suder 2016
10. WHAT CHILDREN AND FAMILIES WANT FROM SERVICES				
17	In high-income contexts, at the onset of the child's chronic pain, children and their families initially sought services hoping for a cure for the pain, which they assumed must have an underlying physical cause. Parents expected doctors to undertake objective medical tests, such as physical examinations, X-rays and high technology scans, to reveal the physical cause of their child's pain and to clinically treat and cure the pain.	High confidence	Minor concerns regarding methodological limitations and relevance, No/Very minor concerns regarding coherence and adequacy	Brodwall 2018; Carter 2002; Dell'Api 2007; Gaughan 2014; Jordan 2007; Kanstrup 2019; Maciver 2005; McDonagh 2021; Neville 2019; Smart 2005; Sorensen 2017
18	In high-income contexts, families searched for a cause and/or diagnosis to better understand the pain, to enable treatment and as proof of a genuine illness, i.e. proof that their pain was real and was believed by health professionals. However, receiving a diagnosis was not a source of hope for all families; for instance, for children with a pre-existing chronic condition, an additional chronic pain diagnosis increased their worry. A diagnosis such as chronic pain or complex regional pain syndrome without knowing the cause could also be unsatisfactory to families because it did not help them understand why the child had pain.	High confidence	Minor concerns regarding methodological limitations and relevance, No/Very minor concerns regarding coherence and adequacy	Brodwall 2018; Carter 2002; Gaughan 2014; Guell 2007; Jordan 2007; Maciver 2005; McDonagh 2021; McKinnon 2022; Neville 2019; Smart 2005
11. REPEATED VISITS TO HEALTH SERVICES				
19	In high-income contexts, searching for a diagnosis and the cause of pain, and/or pursuing effective pain management, can lead children and their families to make repeated return visits to health services or health professionals to repeatedly refer families to different services often with long waiting periods. Waiting for diagnosis	High confidence	Minor concerns regarding methodological limitations and relevance, No/Very minor	Carter 2002; Castle 2007; Jordan 2007; Khanom 2020; Maciver 2005; McDonagh 2021;

	and effective pain management resulted in families experiencing long periods of uncertainty frustration, despair and loss of faith in professionals and services.		concerns regarding coherence and adequacy	Neville 2019; Wong 2016
12. EXPERIENCES OF HEALTH SERVICES AND CARE				
20	In high-income contexts, interactions with health professionals were a source of dissatisfaction and stress for many families. Children perceived that professionals ignored their experiences of living with pain and that professionals had given up on them. Mothers felt that professionals rarely addressed during medical appointments the emotional impact their child's treatment had on them. It was distressing when health professionals did not believe the child was in pain. Parents, particularly mothers, felt they were being blamed for their child's pain when there was no obvious cause, or when health professionals indicated the cause might be psychological and/or social. Parents and children highly valued health professionals who listened to, understood and believed the impact chronic pain had on them and their family life, which could reduce their distress and isolation and give them hope.	High confidence	No/Very minor concerns regarding methodological limitations, coherence and adequacy, Minor concerns regarding relevance	Baert 2020; Brandelli 2021; Britton 2002a; Brodwall 2018; Carter 2002; Castle 2007; Dyson 2011; Forgeron 2008; Hunt 2003; Maciver 2005; McDonagh 2021; McKinnon 2020; Nutkiewicz 2008; Smart 2005; Sorensen 2017
21	In high-income contexts, children being referred to a pain clinic confirmed to them and others that their pain was a real illness, and was a source of hope, and emotional and practical support.	High confidence	Minor concerns regarding methodological limitations and adequacy, No/Very minor concerns regarding coherence and relevance	Baert 2020; Carter 2002; Jordan 2007; Maciver 2005; Suder 2016
22	In high-income contexts, the transition from children's to adult health services was worrying and difficult for young people. Young people were likely to need a gradual shift to independence in managing their care. During transition to adult services, children with sickle cell disease had experienced adult hospital wards as unwelcoming and had had poor care during unscheduled hospital visits and in non-specialist hospital wards for painful episodes.	Moderate confidence	No/Very minor concerns regarding methodological limitations and coherence, Minor concerns regarding adequacy and relevance	Forgeron 2008; Renedo 2019
13. EXPERIENCES OF SERVICES ASSESSING AND MANAGING CHRONIC PAIN				
23	In high-income contexts, children and parents perceived that non-specialist health professionals did not always manage chronic pain effectively. Issues included professionals refusing to prescribe analgesics due to lack of knowledge of an underlying genetic condition; professionals showing scepticism about the child's pain severity and pain experiences; limited treatment time to focus on	High confidence	No/Very minor concerns regarding methodological limitations, coherence and adequacy, Minor concerns regarding relevance	Brodwall 2018; Carter 2002; Jordan 2007; McDonagh 2021; McKinnon 2022; Renedo 2019; Smart 2005; Wong Neville 2019; Wong 2016

	pain management; and disjointed organisation of care between professionals from different services.			
24	In high-income contexts, when a child had a learning disability or an underlying condition, such as cerebral palsy or Down syndrome, the health professionals focused on the condition or disability rather than the whole child. Consequently, the child's pain was overlooked and not treated.	High confidence	Minor concerns regarding methodological limitations and adequacy, No/Very minor concerns regarding coherence and relevance	Carter 2002b; Carter 2017; Hunt 2003; McDonagh 2021; McKinnon 2022
25	In high-income contexts, parents, usually mothers, perceived that their expertise in assessing their child's pain, particularly for younger children and those with communication difficulties, was not always recognised by health professionals.	High confidence	No/Very minor concerns regarding methodological limitations and coherence, Minor concerns regarding adequacy and relevance	Carter 2002a; Carter 2002b; Maciver 2005; McDonagh 2021
14. EXPECTATIONS OF TREATMENTS AND SERVICES				
26	In high-income contexts, effective communication by health professionals, including management of family expectations of treatments, was important for effective pain management and to support families' psychosocial needs. Good communication and expectation management result in a trusting relationship. However, sometimes families had their expectations of a cure raised by professionals, but cure was not achieved.	Moderate confidence	Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence and adequacy, Minor concerns regarding relevance	Baert 2020; Dell'Api 2007; Carter 2002; Carter 2002a; Maciver 2005; Suder 2016
15. WHAT CHILDREN AND FAMILIES WANT FROM CHRONIC PAIN TREATMENTS				
27	In high-income contexts, some treatments were not acceptable to all children and families. Families often saw psychological treatment as stigmatising, for instance as evidence that health professionals did not believe their pain was real, and they considered it their last choice of treatment. Children wanted tailored treatments from pain clinics, which they did not feel they received. Pain-causing therapies, e.g. physiotherapy or injections for juvenile idiopathic arthritis, or those with unpleasant side effects, seemed counter-intuitive to parents and caused the family extreme distress.	High confidence	Minor concerns regarding methodological limitations and relevance, No/Very minor concerns regarding coherence and adequacy	Brandelli 2021; Britton 2002b; Carter 2002; Maciver 2005; McKinnon 2022; Nutkiewicz 2008; Sorensen 2017
28	Although there was very little evidence concerning interventions, in high-income contexts parents valued interventions that helped them adapt their parenting skills and valued gaining information about chronic pain and how to better help their child deal with	Very low confidence	Moderate concerns regarding methodological limitations, adequacy and relevance,	Ahlqwist 2012; Gaughan 2014; Kanstrup 2019

	pain. Children and their parents valued treatment in a group setting because the group interaction with others with similar conditions helped them to feel less isolated, and to appreciate their individual differences. However, treatment in a group setting could lead to a sense of guilt in children when confronted with others with more severe pain. Children also valued an intervention that helped them change their focus from reducing pain to learning how to live with it. Children and young people liked physiotherapy because it helped them develop an awareness of their bodies and capabilities, gave them a greater understanding of their pain, helped to reduce their fear of exercise and facilitated treatment engagement and adherence.		No/Very minor concerns regarding coherence	
16. CHILDREN AND THEIR FAMILIES MANAGING PAIN ON THEIR OWN				
29	In high-income contexts, sometimes children and their families had to manage pain on their own. For instance, when they had disengaged with unsatisfactory services, which were unwelcoming and/or provided poor pain management; as a supplement to, or when they had no effective, prescribed medical treatments; or when they chose not to consult a doctor at all.	Moderate confidence	Minor concerns regarding methodological limitations and relevance, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy	Atkin 2000; Atkin 2001; Helvig 2013; McKinnon 2022; Renedo 2019; Wong 2016
30	In high-income contexts, parents, usually mothers, felt responsible for, and had an important role in, helping their child to manage their pain. The extent of parental involvement varied depending on the complexity of the condition and the child's age. Parents helped their child learn to recognise different types of pain and thus what type of pain management strategy they should use, helped their child avoid pain triggers, used distraction and reward during pain episodes, interpreted their child's non-verbal pain cues in order to assist with pain management, and provided help with basic needs.	High confidence	Minor concerns regarding methodological limitations, relevance, No/Very minor concerns regarding coherence and adequacy	Brandelli 2021; Brodwall 2018; Carter 2002b; Carter 2017; Hunt 2003; McDonagh 2021; McKinnon 2022; Renedo 2019; Smart 2005; Wong 2016
31	In high-income contexts, parents of children with neurological conditions felt they had to find a balance between managing pain and their child joining in family activities. These parents had to make difficult decisions with little help from health professionals, including whether and how much medication to administer their child at home because side effects could interfere with the child's participation in family life and/or cause health problems.	Moderate confidence	Minor concerns regarding methodological limitations and relevance, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy	Carter 2002b; Carter 2017; McKinnon 2022
32	In predominantly high-income contexts, parents had a key role ensuring their child was adhering to pain management treatments at	Moderate confidence	Moderate concerns regarding methodolog-	Borghi 2014; Brandelli 2021; Britton 2002b;

	home. Families were more likely to follow a treatment programme if it was associated with reduction in pain and increased autonomy for the child. Aspects that could negatively affect adherence were the side effects of medications, treatments that were monotonous, repetitive, painful and/or time-consuming and interventions that had negative impacts on family life and activities.		ical limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy and relevance	Carter 2002a; Gaughan 2014; McKinnon 2022
17. PREJUDICE AND DISCRIMINATION IN HEALTH SERVICES				
33	In high-income contexts, children and parents perceived or reported experiencing prejudice and discrimination in health services, which led to poor health service delivery and care and inadequate pain management. Discrimination included professionals having poor knowledge of their child's condition (sickle cell disease) and failing to convey even basic information to families about it; professionals focusing on the child's learning disability (Down syndrome) at the expense of investigating possible chronic pain; and children with Down syndrome receiving inferior care compared to children without Down syndrome. Care was particularly poor for children with Down syndrome and communication difficulties.	Moderate confidence	No/Very minor concerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy, Minor concerns regarding relevance	Atkin 2000; Atkin 2001; McDonagh 2021; Renedo 2019
18. PREJUDICE AND DISCRIMINATION IN SCHOOL				
34	In predominantly high-income contexts, some school policies and practices facilitated children's inclusion in education, others undermined their education. For instance, in some schools, children did not receive help from teachers to catch up on missed schoolwork, which undermined children's ability to succeed at school and some had to give up school early as a result. Other schools did provide extra support for children to catch up, such as learning advice outside of school hours, or offered adapted school hours.	Moderate confidence	No/Very minor concerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy, Minor concerns regarding relevance	Atoui 2015; Dyson 2011; Sorensen 2017; Williams 2008
35	In predominantly high-income contexts, children managing pain on their own was less successful in some circumstances, for example when the pain was severe. Also, children were unable to manage their own pain when the emotional and physical impacts of their underlying condition were severe. External barriers could prevent effective self-management, for example a lack of physical resources to manage pain, such as no hot baths in hospitals. School policies also undermined children's abilities to self-care thus triggering or worsening pain. School rules and practices such as refusing requests for water or breaks during classes and enforcing physical exercise classes in cold environments meant children with sickle cell disease were prevented from staying sufficiently hydrated and warm to avoid painful crises. In contrast, some children with juvenile idiopathic arthritis were granted exemptions	High confidence	No/Very minor concerns regarding methodological limitations, coherence, adequacy and relevance	Atkin 2000; Atkin 2001; Atoui 2015; Britton 2002a; Cartwright 2015Dyson 2011; Guell 2007; Renedo 2019; Waite-Jones 2008; Williams 2008; Wong 2016

	from physical exercise classes. Accommodations made by teachers, such as being excused from physical education, could be unwanted by children because it made them stand out as different from their peers.			
36	At school, children reported experiencing bullying, not being accepted, being judged and discriminated against by peers, peer disbelief in their pain, or peers' general ignorance and prejudice about their condition. Younger children found it harder to deal with discriminatory behaviour than older children who were more used to it and so had had time to develop coping mechanisms. In a country (Lebanon) where sickle cell disease has high prevalence, a study did not find evidence of bullying and marginalisation of children with the condition at school.	Low confidence	No/Very minor concerns regarding methodological limitations, Minor concerns regarding coherence and adequacy, Serious concerns regarding relevance	Atkin 2001; Atoui 2015; Dyson 2011; Williams 2008

Summary of findings 2. GRADE-CERQual evidence profile table

#	Summarised review finding	Methodological limitations	Coherence	Adequacy	Relevance	GRADE-CERQual assessment of confidence	References
01. IMPACT OF CHRONIC PAIN ON FAMILY LIFE							
1	Poorly managed, moderate and severe chronic pain was overwhelming, and took over family life and affected family dynamics. The routines and activities of the whole family were restricted and limited by managing the pain and its consequences.	No/Very minor concerns	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in 6 high-income countries (Australia, Canada, Ireland, Norway, UK, USA) and only 1 LMIC (Lebanon), therefore global relevance is uncertain	High confidence **Explanation:** No/Very minor concerns regarding methodological limitations, coherence and adequacy, and Minor concerns regarding relevance	Atkin 2001; Atoui 2015; Brandelli 2021; Britton 2002a; Britton 2002b; Brodwall 2018; Carter 2002a; Dyson 2011; Forgeron 2008; Gaughan 2014; Guell 2007; Jones 2020; Khanom 2020; McDonagh 2021; McKinnon 2020; Sorensen

							2017; Suder 2016
2	In high-income contexts, pain meant children and their families had to manage many uncertainties regarding their changing routines and family life, diagnosis and prognosis, and the child's future prospects, e.g. of finding employment or attending university. For fluctuating pain conditions, the fear and uncertainty around when and how intensely children would experience pain was always present, which limited families' activities even when the child was not in pain. Some children with fluctuating pain conditions were able to gather energy from moments with less or no pain, which helped them to deal with everyday life.	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because of three studies with no or minor limitations and one study with moderate limitations	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding adequacy because there are only 4 studies	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 2 high-income countries (Sweden, UK), therefore global relevance is limited/uncertain	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy and relevance	Ahlqwist 2012; Jordan 2016; Khanom 2020; Maciver 2005
02. IMPACT OF PAIN ON FAMILY MEMBERS							
3	Poorly managed, moderate and severe chronic pain had mostly negative psychosocial impacts on all family members. Children and parents felt depressed, afraid of the possible cause of the pain, and grieved the loss of their life before pain. Children and young people felt socially isolated and different from peers. Parents felt anxious, helpless and frustrated at being unable to help their child feel better. There was a greater impact on members who were more involved in caring for the child with pain, usually mothers. Siblings who did not have chronic pain felt neglected by their parents and resentful of the child with pain but also concerned about them.	No/Very minor concerns	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in 6 high-income countries and only 3 LMICs (Brazil, Cameroon, Lebanon), therefore global relevance is somewhat limited/uncertain	High confidence **Explanation:** No/Very minor concerns regarding methodological limitations, coherence and adequacy, and Minor concerns regarding relevance	Atkin 2001; Atoui 2015; Brandelli 2021; Britton 2002a; Britton 2002b; Brodwall 2018; Carter 2002a; Cartwright 2015; Dyson 2011; Forgeron 2008; Gaughan 2014; Guell 2007; Jones 2020; Jones 2022; Jordan 2016; Khanom 2020; McDonagh 2021; Maciver 2005; McKinnon 2020;

							Njifon 2019; Rossato 2007; Sorensen 2017; Suder 2016; Waite-Jones 2008; Williams 2008
4	In high-income contexts, parents felt deeply afraid of what might be causing the pain, of witnessing their child in pain, that treatments would not work and that their child would not get better to enjoy a fulfilling life. The constant fear caused parents to always be on call for their child, which was also detrimental to parents' well-being.	Minor concerns **Explanation:** Minor concerns regarding methodological limitations based on the assessment of 5 studies – 3 with low and 2 with moderate methodological limitations	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 2 high-income countries and no LMICs, therefore global relevance is limited/uncertain	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence and adequacy, and Minor concerns regarding relevance	Gaughan 2014; Jones 2020; Jordan 2016; Maciver 2005
5	In high-income contexts, parents, siblings and adolescents with chronic pain reported that some good things had happened because of the impact of chronic pain. The main caregiver, usually the mother, felt they became closer to their child and that their relationship had improved. Siblings without chronic pain also felt that their family relationships had become closer than in other families, and they became more compassionate to others. Some adolescents with chronic pain acknowledged that their experiences made them a better person, better equipped to live life and more mature.	Moderate concerns **Explanation:** Moderate concerns regarding methodological limitations because of 4 studies with moderate limitations and 2 with low limitations	Moderate concerns **Explanation:** Moderate concerns regarding coherence because data could have alternative interpretations such as the positive framing of challenging circumstances or adapting psychologically	Minor concerns **Explanation:** Minor concerns regarding adequacy because there is a moderate amount of data from only 6 studies	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 3 high-income countries and no LMICs, therefore global relevance is limited/uncertain	Moderate confidence **Explanation:** Moderate concerns regarding methodological limitations and coherence, Minor concerns regarding adequacy and relevance	Brandelli 2021; Britton 2002a; Jones 2020; Jones 2022; Jordan 2016; Suder 2016; Waite-Jones 2008

			to threatening experiences				
6	In high-income contexts, primary caregivers, usually mothers, experienced reduced ability to have a life outside of their home, they stopped paid employment and/or lost their career and curtailed their social life to focus on caring for their child.	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because of 2 studies with moderate limitations and 2 with low limitations	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding adequacy because 2 studies offered rich data and 2 offered thin data	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 4 high-income countries and no LMICs, therefore global relevance is limited/uncertain	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy and relevance	Brandelli 2021; Brodwall 2018; Gaughan 2014; McDonagh 2021
03. IMPACT ON SELF-IDENTITY							
7	Children saw themselves as different from peers because they felt unhealthy, restricted by pain, socially isolated, dependent and were treated differently by peers. Some children regarded their chronic pain as abnormal, because it affected their ability to lead a normal life, and as something to pity. Children did not want to be seen as unhealthy and different by their peers, and they wanted to belong to a group of friends.	No/Very minor concerns	No/Very minor concerns	Moderate concerns **Explanation:** Moderate concerns regarding adequacy because 7 out of the 13 studies that contributed to this finding were moderate for richness and overall there was a small amount of rich data	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 3 high-income countries and 3 LMICs, therefore global relevance is somewhat limited/uncertain	High confidence **Explanation:** No/Very minor concerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance	Atkin 2001; Atoui 2015; Britton 2002a; Cartwright 2015; Dyson 2011; Forgeron 2008; Gaughan 2014; Guell 2007; Jordan 2018; Khanom 2020; Njifon 2019; Rossato 2007; Suder 2016; Waite-Jones 2008; Williams 2008
04. IMPACT ON SIBLINGS							
8	In predominantly high-income contexts, siblings who did not have chronic pain felt neglected and helpless,	Minor concerns	Minor concerns	Serious concerns	Moderate concerns	Low confidence	Brandelli 2021; Britton 2002a;

	which could lead to them behaving dismissively towards the child with pain and even questioning the legitimacy of their pain. Siblings competed for parental time and affection. Siblings blamed the child with pain for dominating their parents' attention, but they also showed concern and affection for them. Siblings' negative feelings improved over time as they developed the skills to adjust socially and emotionally.	**Explanation:** Minor concerns regarding methodological limitations because 4 studies presented moderate concerns; 3 of them were regarding significant aspects such as recruitment and data collection. Three studies had low concerns.	**Explanation:** Minor concerns regarding coherence. Some concerns about the lack of explanation in primary studies about improved negative feelings over time.	**Explanation:** Serious concerns regarding adequacy because only 2 studies had rich data and this was a small amount	**Explanation:** Moderate concerns regarding relevance because 4 studies contained data of indirect relevance from parents; 5 studies were conducted in high-income countries and only 1 in a LMIC therefore global relevance is limited/uncertain	**Explanation:** Minor concerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy and relevance	Brodwall 2018; Gaughan 2014; McDonagh 2021; Njifon 2019; Waite-Jones 2008
9	Some siblings, even younger siblings, took on caring responsibilities for children with chronic pain, which limited their freedom. For example, some siblings were expected by their parents to adopt a parenting role for the child with chronic pain, including supervising their medical care, which siblings resented. Other siblings provided personal care for the child with chronic pain such as helping them to dress, lifting them out of the bath and carrying them downstairs.	No/Very minor concerns **Explanation:** Only 1 study had moderate concerns regarding methodological limitations and 3 had low concerns	No/Very minor concerns	Moderate concerns **Explanation:** Moderate concerns regarding adequacy because all 4 studies presented moderate richness and quantity of data related to this finding	Moderate concerns **Explanation:** Moderate concerns regarding relevance because only 2 studies focused on the experiences of siblings who did not have chronic pain. Two studies had indirect relevance because they presented the views of children with chronic pain. Two studies were conducted in the UK and 2 in LMICs, therefore global relevance is limited /uncertain	Moderate confidence **Explanation:** No/Very minor concerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy and relevance	Atkin 2001; Atoui 2015; Njifon 2019; Waite-Jones 2008
05. IMPACT ON PARENTING							
10	Parents learnt on their own to adapt their parenting to help their child deal with the pain while trying to still main-	No/Very minor concerns	No/Very minor concerns	Minor concerns	Minor concerns	High confidence	Atkin 2000; Atkin 2001; Brodwall

	tain their child's autonomy. Parents provided support and care while being firm when necessary, for example making their child go to school despite pain. Successfully adapting their parenting was hindered by a lack of understanding of how they could help their child, and the lack of resources and support from health services and their social network.	**Explanation:** Only 2 studies that contributed to this finding had moderate limitations, 5 studies had low limitations		**Explanation:** Minor concerns regarding adequacy because 3 publications were moderate regarding richness of data, 5 had rich data	**Explanation:** Minor concerns regarding relevance because studies were conducted in only 3 high-income countries and no LMICs, therefore global relevance is limited/uncertain	**Explanation:** No/Very minor concerns regarding methodological limitations and coherence, Minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	2018; Gaughan 2014; Jordan 2016; Maciver 2005; Smart 2005
06. ADAPTING FAMILY LIFE TO PAIN							
11	For poorly managed and severe chronic pain, families focused on trying to control the impact of pain on family life using many strategies. Strategies included families gathering information about pain, following treatments, adjusting their routine to accommodate pain and its management, and self-managing pain to be able to join in activities. These strategies meant that family life then became more restricted because it was completely organised around managing and avoiding exacerbating the pain.	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding adequacy because 5 studies had moderately rich data and 3 were very rich	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 3 high-income countries and 2 LMICs, therefore global relevance is somewhat limited/uncertain	High confidence **Explanation:** No/Very minor concerns regarding methodological limitations and coherence, Minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	Ahlqwist 2012; Atkin 2000; Atkin 2001; Atoui 2015; Carter 2002a; Forgeron 2008; Guell 2007; Rossato 2007
12	Over time, parents and children learnt to adapt to unresolved pain because they felt like they had no other choice. Consequently, families and children started to focus on living well with pain. For instance, parents (mothers) learnt to deal with the unpredictability of pain; helped their child to live with their new condition; and developed ways of dealing with the child's fear about the future. Children found new ways to do daily activities, e.g. using mobility aids.	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because 5 studies had moderate limitations and 3 studies had no or minor limitations	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in 3 high-income countries and 1 LMIC, therefore global relevance is somewhat limited/uncertain	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, adequacy and relevance	Baert 2020; Britton 2002a; Britton 2002b; Carter 2002a; Guell 2007; Jones 2020; Rossato 2007; Sorensen 2017; Suder 2016

07. SOCIAL SUPPORT

13	In high-income contexts, peers, friends and the extended family provided practical, financial and emotional support, which helped parents and children deal with the impact of pain on their lives, and enhanced quality of life and adherence to treatments. Contact with peers and friends helped children feel normal, which provided them with hope and reassurance. Parents (mainly mothers) longed for others to understand their own suffering but lacked a social support system. Mothers grew apart from friends due to their caring role.	Moderate concerns **Explanation:** Moderate concerns regarding methodological limitations because 3 studies had moderate concerns in important aspects, such as data collection and analysis and recruitment strategy. Two had low concerns.	No/Very minor concerns	Moderate concerns **Explanation:** Moderate concerns regarding adequacy because there was a small amount of moderately rich data for this finding	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 4 high-income countries, therefore global relevance is limited/uncertain	Moderate confidence **Explanation:** Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance	Baert 2020; Brandelli 2021; Britton 2002a; Cartwright 2015; Waite-Jones 2008
14	Recurrent school absences and pain prevented children from engaging with friends when at school, which made it difficult for children to maintain friendships, contributed to their lack of support and increased their sense of social isolation.	No/Very minor concerns **Explanation:** All studies had low concerns regarding methodological limitations	Minor concerns **Explanation:** Minor concerns regarding coherence because the data from 3 out of the 6 studies did not have a good fit with the review finding	Moderate concerns **Explanation:** Moderate concerns regarding adequacy because only 1 out of the 6 studies included rich data regarding this finding	Moderate concerns **Explanation:** Moderate concerns regarding relevance because studies were conducted in only 1 high-income country and 1 LMIC, therefore global relevance is limited/uncertain. Four studies focused only on adolescents, only 1 included children from age 5 years	Moderate confidence **Explanation:** No/Very minor concerns regarding methodological limitations, Minor concerns regarding coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance	Atkin 2000; Atkin 2001; Atoui 2015; Dyson 2011; Jones 2022; Williams 2008

08. CONDITION-SPECIFIC PEER SUPPORT

15	In high-income contexts, meeting others with similar conditions helped adolescents feel less isolated because they were able to share experiences and provide mutual support. In contrast, other adolescents did not want peer support from other children with chronic pain because they did not want to be reminded of their pain or because they believed others would not have similar experiences. Parents preferred support from other parents of children with similar conditions, who they described as a great comfort and vital source of information.	No/Very minor concerns **Explanation:** All studies had low concern for methodological limitations	No/Very minor concerns	Moderate concerns **Explanation:** Moderate concerns regarding adequacy because 2 of the studies included only thin data regarding this finding	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 3 high-income countries, therefore global relevance is limited/uncertain, and 3 studies focused only on adolescents	Moderate confidence **Explanation:** No/Very minor concerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy, and No/Very minor concerns regarding relevance	Cartwright 2015; Forgeron 2008; McDonagh 2021; Williams 2008
09. DISCLOSURE OF PAIN							
16	In predominantly high-income contexts, parents avoided disclosing their child's pain to friends and extended family for a range of reasons. For instance, parents found chronic pain hard to understand and explain, they were afraid of being judged on their parenting skills or disbelieved, or they anticipated a lack of sympathy for a condition that is not life-threatening. Lack of disclosure could negatively affect how much support parents received from their friends and wider family. However, when they did disclose their child's pain, their social networks did not always understand or believe the pain and were not empathetic, sometimes blaming them for poor parenting, e.g. being over-protective parents. Children also often avoided disclosing their pain, although girls and younger children were more likely to disclose and share their problems than boys and adolescents. Children also avoided disclosing their pain to help manage how others perceived them, to avoid having to deal with the prejudice and discrimination of others,	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because 6 studies had moderate limitations and 6 had low limitations	Minor concerns **Explanation:** Minor concerns regarding coherence because there are plausible alternative explanations that could have been further explored	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 5 high-income countries (Belgium, Canada, Norway, UK, USA) and 1 LMIC (Lebanon), therefore wider global relevance is uncertain	High confidence **Explanation:** Minor concerns regarding methodological limitations and coherence, No/Very minor concerns regarding adequacy, and Minor concerns regarding relevance	Atkin 2001; Atoui 2015; Baert 2020; Britton 2002a; Dyson 2011; Forgeron 2008; Gaughan 2014; Guell 2007; Jones 2020; Khanom 2020; Sorensen 2017; Suder 2016

	such as derogatory comments, and because the pain was invisible and hard to explain.						
10. WHAT CHILDREN AND FAMILIES WANT FROM SERVICES							
17	In high-income contexts, at the onset of the child's chronic pain, children and their families initially sought services hoping for a cure for the pain, which they assumed must have an underlying physical cause. Parents expected doctors to undertake objective medical tests, such as physical examinations, X-rays and high technology scans, to reveal the physical cause of their child's pain and to clinically treat and cure the pain.	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because 5 studies had moderate limitations and 5 had low limitations	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 6 high-income countries (Canada, Ireland, Norway, Sweden, UK, USA), therefore wider global relevance is limited/uncertain	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence and regarding adequacy, and Minor concerns regarding relevance	Brodwall 2018; Carter 2002; Dell'Api 2007; Gaughan 2014; Jordan 2007; Kanstrup 2019; Maciver 2005; McDonagh 2021; Neville 2019; Smart 2005; Sorensen 2017
18	In high-income contexts, families searched for a cause and/or diagnosis to better understand the pain, to enable treatment and as proof of a genuine illness, i.e. proof that their pain is real and is believed by health professionals. However, receiving a diagnosis was not a source of hope for all families, for instance for children with a pre-existing chronic condition, an additional chronic pain diagnosis increased their worry. A diagnosis such as chronic pain or complex regional pain syndrome without knowing the cause could also be unsatisfactory to families because it did not help them understand why the child had pain.	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because 5 studies had moderate limitations and 5 had low limitations	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 6 high-income countries (Australia, Canada, Ireland, UK, USA, Norway), therefore wider global relevance is limited/uncertain	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence and regarding adequacy, and Minor concerns regarding relevance	Brodwall 2018; Carter 2002; Gaughan 2014; Guell 2007; Jordan 2007; Maciver 2005; McDonagh 2021; McKinnon 2022; Neville 2019; Smart 2005
11. REPEATED VISITS TO HEALTH SERVICES							
19	In high-income contexts, searching for a diagnosis and the cause of pain, and/or pursuing effective pain management, can lead children and their	Minor concerns **Explanation:** Minor con-	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance be-	High confidence **Explanation:** Minor concerns regarding method-	Carter 2002; Castle 2007; Jordan 2007; Khanom 2020;

	families to make repeated return visits to health services or health professionals to repeatedly refer families to different services often with long waiting periods. Waiting for diagnosis and effective pain management results in families experiencing long periods of uncertainty frustration, despair and loss of faith in professionals and services.	cerns regarding methodological limitations because 4 studies had moderate limitations and 5 had low limitations			cause studies were conducted in only 5 high-income countries (Australia, Canada, China/Hong Kong, Ireland, UK), therefore wider global relevance is limited/uncertain	ological limitations, No/Very minor concerns regarding coherence and adequacy, and Minor concerns regarding relevance	Maciver 2005; McDonagh 2021; Neville 2019; Wong 2016
12. EXPERIENCES OF HEALTH SERVICES AND CARE							
20	In high-income contexts, interactions with health professionals were a source of dissatisfaction and stress for many families. Children perceived that professionals ignored their experiences of living with pain and that professionals had given up on them. Mothers felt that professionals rarely addressed during medical appointments the emotional impact their child's treatment had on them. It was distressing when health professionals did not believe the child was in pain. Parents, particularly mothers, felt they were being blamed for their child's pain when there was no obvious cause, or when health professionals indicated the cause might be psychological and/or social. Parents and children highly valued health professionals who listened to, understood and believed the impact chronic pain had on them and their family life, which could reduce their distress and isolation and give them hope.	No/Very minor concerns	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in 7 high-income countries (Australia, Belgium, Canada, Ireland, Norway, UK, USA) and no LMICs, therefore wider global relevance is uncertain	High confidence **Explanation:** No/Very minor concerns regarding methodological limitations, coherence and adequacy, and Minor concerns regarding relevance	Baert 2020; Brandelli 2021; Britton 2002a; Brodwall 2018; Carter 2002; Castle 2007; Dyson 2011; Forgeron 2008; Hunt 2003; Maciver 2005; McDonagh 2021; McKinnon 2020; Nutkiewicz 2008; Smart 2005; Sorensen 2017
21	In high-income contexts, children being referred to a pain clinic confirmed to them and others that their pain was a real illness, and was a source of hope, and emotional and practical support.	Minor concerns **Explanation:** Minor concerns regarding methodological lim-	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding adequacy because	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 3 high-income coun-	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns	Baert 2020; Carter 2002; Jordan 2007; Maciver 2005; Suder 2016

		itations because 3 studies had moderate limitations and 2 studies had no or minor limitations.		the finding is based on 5 studies and a moderate amount of rich data	tries (Belgium, UK, USA) and no LMICs, therefore global relevance is limited/uncertain	regarding coherence, Minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	
22	In high-income contexts, the transition from children's to adult health services was worrying and difficult for young people. Young people were likely to need a gradual shift to independence in managing their care. During transition to adult services, children with sickle cell disease had experienced adult hospital wards as unwelcoming and had had poor care during unscheduled hospital visits and in non-specialist hospital wards for painful episodes.	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding adequacy because the finding is based on 2 studies with a small amount of rich data. We have expertise in this area. There is universal evidence about transitions to adult services being problematic in the way described in this finding.	Moderate concerns **Explanation:** Moderate concerns regarding relevance because the studies focused on only sickle cell disease or musculoskeletal pain so relevance to other pain conditions is uncertain. Studies were conducted in only 2 high-income countries (Canada, UK), therefore global relevance is limited/uncertain. There is a much wider highly relevant literature on transitions to adult services, which was not captured in our search.	Moderate confidence **Explanation:** No/Very minor concerns regarding methodological limitations and coherence, Minor concerns regarding adequacy and relevance	Forgeron 2008; Renedo 2019
13. EXPERIENCES OF SERVICES ASSESSING & MANAGING CHRONIC PAIN							
23	In high-income contexts, children and parents perceived that non-specialist health professionals did not always manage chronic pain effectively. Issues included professionals refusing to prescribe analgesics due to lack of knowledge of an underlying genetic condition; professionals showing scepticism about the child's pain severity and pain experiences; limited treatment time to focus on pain man-	No/Very minor concerns	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 6 high-income countries (Australia, Canada, Hong Kong, Ireland, Norway, UK)	High confidence **Explanation:** No/Very minor concerns regarding methodological limitations, coherence and adequacy, and Minor concerns regarding relevance	Brodwall 2018; Carter 2002; Jordan 2007; McDonagh 2021; McKinnon 2022; Renedo 2019; Smart 2005; Neville 2019; Wong 2016

	agement; and disjointed organisation of care between professionals from different services.				and no LMICs, therefore global relevance is limited/uncertain		
24	In high-income contexts, when a child had a learning disability or an underlying condition, such as cerebral palsy or Down syndrome, the health professionals focused on the condition or disability rather than the whole child. Consequently, the child's pain was ignored and not treated.	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because 1 study had moderate limitations and 4 had minor or very minor limitations	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding adequacy because the finding is based on 5 studies and a moderate amount of rich data	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 3 high-income countries (Australia, Ireland, UK), therefore global relevance is limited/uncertain	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	Carter 2002b; Carter 2017; Hunt 2003; McDonagh 2021; McKinnon 2022;
25	In high-income contexts, parents, usually mothers, perceived that their expertise in assessing their child's pain, particularly for younger children and those with communication difficulties, was not always recognised by health professionals.	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding adequacy because the finding is based on only 4 studies but data were rich	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 2 high-income countries (Ireland, UK), therefore global relevance is uncertain/limited.	High confidence **Explanation:** No/Very minor concerns regarding methodological limitations and coherence, Minor concerns regarding adequacy and relevance	Carter 2002a; Carter 2002b; Maciver 2005; McDonagh 2021
14. EXPECTATIONS OF TREATMENTS & SERVICES							
26	In high-income contexts, effective communication by health professionals, including management of family expectations of treatments, was important for effective pain management and to support families' psychosocial needs. Good communication and expectation management result in a trusting relationship. However, sometimes families had their expectations	Moderate concerns **Explanation:** Moderate concerns regarding methodological limitations because 4 stud-	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 4 high-income countries (Belgium, Canada, UK, USA), there-	Moderate confidence **Explanation:** Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence and	Baert 2020; Dell'Api 2007; Carter 2002; Carter 2002a; Maciver 2005; Suder 2016

	of a cure raised by professionals, but cure was not achieved.	ies had moderate concerns and 2 studies had no or minor concerns.			fore global relevance is uncertain	adequacy, and Minor concerns regarding relevance	
15. WHAT CHILDREN AND FAMILIES WANT FROM CHRONIC PAIN TREATMENTS							
27	In high-income contexts, some treatments were not acceptable to all children and families. Families often saw psychological treatment as stigmatising, for instance, as evidence that health professionals did not believe their pain was real, and they considered it their last choice of treatment. Children wanted tailored treatments from pain clinics, which they did not feel they received. Pain-causing therapies, e.g. physiotherapy or injections for juvenile idiopathic arthritis, or those with unpleasant side effects, seemed counter-intuitive to parents and caused the family extreme distress.	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because 4 studies had moderate limitations and 3 studies had no or very minor limitations	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 5 high-income countries (Australia, Canada, Norway, UK, USA), therefore global relevance is uncertain	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence and adequacy, and Minor concerns regarding relevance	Brandelli 2021; Britton 2002b; Carter 2002; Maciver 2005; McKinnon 2022; Nutkiewicz 2008; Sorensen 2017
28	Although there was very little evidence concerning interventions, in high-income contexts parents valued interventions that helped them adapt their parenting skills and valued gaining information about chronic pain and how to better help their child deal with pain. Children and their parents valued treatment in a group setting because the group interaction with others with similar conditions helped them to feel less isolated, and to appreciate their individual differences. However, treatment in a group setting could lead to a sense of guilt in children when confronted with others with more severe pain. Children also valued an intervention that helped them change their focus from reduc-	Moderate concerns **Explanation:** Moderate concerns regarding methodological limitations because 2 studies had moderate limitations and 1 minor limitations	Serious concerns **Explanation:** Serious concerns regarding coherence because all the evidence on interventions has been grouped together into one finding, which has resulted in low coherence	Moderate concerns **Explanation:** Moderate concerns regarding adequacy because the finding is based on only 3 studies with limited data that was not very rich	Serious concerns **Explanation:** Serious concerns regarding relevance because the studies were conducted in only 2 high-income countries (Sweden, USA) and data were on a narrow range of treatments (acceptance and commitment therapy, physiotherapy, pain rehabilitation outpatient programme), therefore global relevance may be limited	Very low confidence **Explanation:** Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy and relevance	Ahlqwist 2012; Gaughan 2014; Kanstrup 2019

	ing pain to learning how to live with it. Children and young people liked physiotherapy because it helped them develop an awareness of their bodies and capabilities, gave them a greater understanding of their pain, helped to reduce their fear of exercise and facilitated treatment engagement and adherence.						
16. CHILDREN AND THEIR FAMILIES MANAGING PAIN ON THEIR OWN							
29	In high-income contexts, sometimes children and their families had to manage pain on their own. For instance, when they had disengaged with unsatisfactory services which were unwelcoming and/or provided poor pain management; as a supplement to, or when they had no effective, prescribed medical treatments; or when they chose not to consult a doctor at all.	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because 2 studies had moderate limitations	No/Very minor concerns	Moderate concerns **Explanation:** Moderate concerns regarding adequacy because there were 6 studies, 2 of which had a good amount of rich data	Moderate concerns **Explanation:** Moderate concerns regarding relevance because the studies focused on broader aspects of the pain experience rather than specifically on children and families managing pain on their own. Studies were conducted in only 4 high-income countries (Australia, China/Hong Kong, UK, USA), therefore wider global relevance is uncertain	Moderate confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance	Atkin 2000; Atkin 2001; Helvig 2013; McKinnon 2022; Renedo 2019; Wong 2016
30	In high-income contexts, parents, usually mothers, felt responsible for, and had an important role in, helping their child to manage their pain. The extent of parental involvement varied depending on the complexity of the condition and the child's age. Parents helped their child learn to recognise different types of pain and thus what type of pain management strategy they should use, helped their child avoid pain triggers, used distraction and reward during pain episodes, interpreted their child's non-verbal pain	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because 4 studies had moderate limitations and 6 studies had	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in 6 high-income countries (Australia, Canada, China/Hong Kong, Ireland, Norway, UK), therefore wider global relevance is uncertain	High confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence and adequacy, and Minor concerns regarding relevance	Brandelli 2021; Brodwall 2018; Carter 2002b; Carter 2017; Hunt 2003; McDonagh 2021; McKinnon 2022; Renedo 2019; Smart 2005; Wong 2016

	cues in order to assist with pain management and provided help with basic needs.	no or very minor limitations					
31	In high-income contexts, parents of children with neurological conditions felt they had to find a balance between managing pain and their child joining in family activities. These parents had to make difficult decisions with little help from health professionals, including whether and how much medication to administer their child at home because side effects could interfere with the child's participation in family life and/or cause health problems.	Minor concerns **Explanation:** Minor concerns regarding methodological limitations because 1 study had moderate limitations and 2 studies minor or very minor limitations.	No/Very minor concerns	Moderate concerns **Explanation:** Moderate concerns regarding adequacy because findings are based on 3 studies and a moderate amount of rich data	Minor concerns **Explanation:** Minor concerns regarding relevance because all studies were conducted in only 2 high-income countries (Australia, UK), therefore global relevance is limited/uncertain	Moderate confidence **Explanation:** Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance	Carter 2002b; Carter 2017; McKinnon 2022
32	In predominantly high-income contexts, parents had a key role ensuring their child was adhering to pain management treatments at home. Families were more likely to follow a treatment programme if it was associated with reduction in pain and increased autonomy for the child. Aspects that could negatively affect adherence were the side effects of medications, treatments that were monotonous, repetitive, painful and/or time-consuming and interventions that had negative impacts on family life and activities.	Moderate concerns **Explanation:** Moderate concerns regarding methodological limitations because 4 studies had moderate limitations including 3 with concerns about the rigour of data analysis	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding adequacy because there was a moderate amount of rich data	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 4 high-income countries (Australia, Canada, UK, USA) and 1 LMIC (Brazil), therefore wider global relevance is limited/uncertain	Moderate confidence **Explanation:** Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy and relevance	Borghi 2014; Brandelli 2021; Britton 2002b; Carter 2002a; Gaughan 2014; McKinnon 2022
17. PREJUDICE AND DISCRIMINATION IN HEALTH SERVICES							
33	In high-income contexts, children and parents perceived or reported experiencing prejudice and discrimination in health services, which led to poor health service delivery and care and	No/Very minor concerns	No/Very minor concerns	Moderate concerns **Explanation:** Moderate	Minor concerns **Explanation:** Minor concerns regarding relevance be-	Moderate confidence **Explanation:** No/Very minor con-	Atkin 2000; Atkin 2001; McDonagh 2021; Renedo 2019

	inadequate pain management. Discrimination included professionals having poor knowledge of their child's condition (sickle cell disease) and failing to convey even basic information to families about it; professionals focusing on the child's learning disability (Down syndrome) at the expense of investigating possible chronic pain; and children with Down syndrome receiving inferior care compared to children without Down syndrome. Care was particularly poor for children with Down syndrome and communication difficulties.			concerns regarding adequacy because the data are from only 4 studies and the studies focus only on sickle cell disease or Down syndrome	cause studies were conducted in only 2 high-income countries (Ireland, UK), therefore global relevance is uncertain	cerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance	
18. PREJUDICE AND DISCRIMINATION IN SCHOOL							
34	In predominantly high-income contexts, some school policies and practices facilitated children's inclusion in education, others undermined their education. For instance, in some schools, children did not receive help from teachers to catch up on missed schoolwork, which undermined children's ability to succeed at school and some had to give up school early as a result. Other schools did provide extra support for children to catch up, such as learning advice outside of school hours, or offered adapted school hours.	No/Very minor concerns	No/Very minor concerns	Moderate concerns **Explanation:** Moderate concerns regarding adequacy because the finding is based on only 4 studies with a small amount of rich data	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were conducted in only 2 high-income countries (Norway, UK) and 1 LMIC (Lebanon), therefore global relevance is limited/uncertain. Two studies focused only on sickle cell disease, 1 on epidermolysis bullosa and 1 on complex regional pain syndrome, so relevance to other pain conditions is uncertain	Moderate confidence **Explanation:** No/Very minor concerns regarding methodological limitations and coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance	Atoui 2015; Dyson 2011; Sorensen 2017; Williams 2008
35	In predominantly high-income contexts, children managing pain on their own was less successful in some circumstances, for example when the pain was severe. Also, children were unable to manage their own pain	No/Very minor concerns	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regard-	Minor concerns **Explanation:** Minor concerns regarding relevance because studies were	High confidence **Explanation:** No/Very minor concerns regarding methodological	Atkin 2000; Atkin 2001; Atoui 2015; Britton 2002a; Cartwright 2015Dyson

	when the emotional and physical impacts of their underlying condition were severe. External barriers could prevent effective self-management, for example a lack of physical resources to manage pain, such as no hot baths in hospitals. School policies also undermined children's abilities to self-care thus triggering or worsening pain. School rules and practices such as refusing requests for water or breaks during classes and enforcing physical exercise classes in cold environments meant children with sickle cell disease were prevented from staying sufficiently hydrated and warm to avoid painful crises. In contrast, some children with juvenile idiopathic arthritis were granted exemptions from physical exercise classes. Accommodations made by teachers, such as being excused from physical education, could be unwanted by children because it made them stand out as different from their peers.			ing adequacy because there was a moderate amount of rich data	conducted in only 2 high-income countries (China/Hong Kong, UK) and 1 LMIC (Lebanon), therefore global relevance is limited/uncertain	limitations, coherence, adequacy and relevance	2011; Guell 2007; Renedo 2019; Waite-Jones 2008; Williams 2008; Wong 2016
36	At school, children reported experiencing bullying, not being accepted, being judged and discriminated against by peers, peer disbelief in their pain, or peers' general ignorance and prejudice about their condition. Younger children found it harder to deal with discriminatory behaviour than older children who were more used to it and so had had time to develop coping mechanisms. In a country (Lebanon) where sickle cell disease has high prevalence, a study did not find evidence of bullying and marginalisation of children with the condition at school.	No/Very minor concerns	Minor concerns **Explanation:** Minor concerns regarding coherence because 1 study conducted in Lebanon had contradictory data	Minor concerns **Explanation:** Minor concerns regarding adequacy because the finding is based on only 4 studies but a moderate amount of rich data	Serious concerns **Explanation:** Serious concerns regarding relevance because a limited range of pain conditions, ages of children and countries are represented. Out of 4 studies, 3 are based only on sickle cell disease and 1 is based on epidermolysis bullosa; 3 studies focused only on adolescents. Studies were conducted only in 1 high-income country (UK) and 1 LMIC (Lebanon),	Low confidence **Explanation:** No/Very minor concerns regarding methodological limitations, Minor concerns regarding coherence and adequacy, and Serious concerns regarding relevance	Atkin 2001; Atoui 2015; Dyson 2011; Williams 2008

therefore global relevance is uncertain.

LMIC, low- and middle-income country

BACKGROUND

Description of the topic

Chronic pain in childhood is widespread: around 20% to 35% of children and young people worldwide are estimated to have chronic pain (King 2011), although a more recent global survey found that around 44% of adolescents reported chronic weekly pain (Gobina 2019). Frequent severe chronic pain of all types affects 8% of children (Perquin 2000); for approximately 5% of children, chronic pain results in moderate or severe disability (Huguet 2008). The 11th revision of the International Classification of Diseases (ICD-11) (WHO 2019) defines chronic pain as "pain that persists or recurs for more than 3 months" (Treede 2019). Chronic pain is recognised as a condition in its own right, but it is also a key feature of health conditions, such as inflammatory bowel disease and juvenile idiopathic arthritis. Most importantly, chronic pain is a significant clinical issue in children and adolescents with important negative consequences beyond the child's physical health, also affecting social, psychological and cognitive functioning, and quality of life (Merlijn 2006; Roth-Isigkeit 2005). Families are often highly involved in managing a child's chronic pain, playing both mediating and moderating roles (Donnelly 2020; Liossi 2016; Palermo 2014), as well as often experiencing stress and distress in their caring role (Jordan 2007; Jordan 2017; Law 2019; Palermo 2014). This review seeks to understand how children and young people with chronic non-cancer pain and their families conceptualise and live with chronic pain; explore their views and experiences of health and social care services and treatments in relation to pain management; and investigate what they consider as optimal pain management and what they want to achieve from interventions and services, with a focus on high-income countries. This review will be crucial to inform health and social care, and therefore improve pain management and hence the lives of children and young people.

How the health condition might affect people

Chronic pain has considerable negative impacts on children's health and quality of life; for instance, surveys have shown that the majority of adolescent children with chronic pain experience poorer physical, mental and social health (Gauntlett-Gilbert 2007), and perceive themselves to be behind their peers in many aspects of their development (Eccleston 2008). Chronic pain adversely affects social and family relationships (Jordan 2017); results in poorer school attendance (Logan 2008); and is associated with increased use of healthcare services and medication (Scottish Govt 2018). Healthcare costs of chronic pain in adolescents alone have an annual cost of about GBP 4000 million in the UK (Sleed 2005), and USD 19,500 million in the USA (Groenewald 2014). It also costs families to travel to healthcare appointments and to take time off work to care for their child, with some parents giving up work entirely to care for their child (Sleed 2005). Moreover, longitudinal research indicates a high risk of childhood chronic pain continuing into adulthood with further individual, healthcare and societal costs (Walker 2010).

To our knowledge, there is no single comprehensive theory of children's chronic pain that covers all the aspects of interest in this review (how children and families conceptualise pain, experiences of living with pain and of pain management services, and views of 'good' pain management and services) and that reflects the theoretical stance of the review team. Most of the existing theories have been developed within a specific field, which might narrow our understanding and perspective of how children experience chronic pain. For instance, psychological theories of children's chronic pain tend to focus only on specific aspects of the pain, such as what causes pain, or they adopt a child development approach to explaining children's understanding of their chronic pain (Carter 2014). More comprehensive theories that are not specific to children's chronic pain but which better reflect our theoretical approach to pain are biopsychosocial theories of chronic illness, which specify the interrelatedness of biological, psychological and social aspects of illness (Haslam 2021). To our knowledge, there do not appear to be any comprehensive biopsychosocial theories specifically about children's chronic pain; there is at least one which has focused only on clinical assessment and management of children's chronic pain, but not other aspects, such as how children and their families conceptualise and live with chronic pain (Bursch 1998).

There are also programme theories that specify how a complex intervention is thought to work (Noyes 2016a). Existing recent Cochrane effectiveness reviews have focused on pharmacological treatments of children's chronic pain: antidepressants (Cooper 2017c; de Bruijn 2021), non-steroidal anti-inflammatory drugs (Eccleston 2017), antiepileptic drugs (Cooper 2017d), opioids (Cooper 2017b), paracetamol (Cooper 2017a), or any pharmacological treatment (Martin 2017). These reviews have focused on how the medications work biologically, rather than a broader view of medication use in the 'real world' in terms of how people actually engage with medications. Cochrane Reviews of psychological or psychosocial interventions for children with chronic pain (Abbott 2017; Anie 2015; Fisher 2019) and psychological interventions for their parents have described how a range of psychological or psychosocial interventions, such as behavioural strategies, cognitive strategies and cognitive behavioural therapy, are thought to work (Law 2019). A Cochrane Review of dietary interventions for abdominal pain described how diet alterations work biologically (Newlove-Delgado 2017). Another review of physical activity for chronic musculoskeletal pain described a range of ways interventions might work (Leite 2023). Thus, most reviews have had a narrow view of how chronic non-cancer pain interventions work. However, many interventions in clinical practice are multidisciplinary, combining different kinds of treatments: biological, psychological and physical (Palermo 2012). It will therefore be important to further develop programme theories. Consequently, there is an opportunity for our review to contribute to theoretical development in this field.

Why is it important to do this review?

Despite the high prevalence and serious impacts of children's chronic pain, current services for managing children's chronic pain are inadequate (CMO 2009; Pain Summit 2012; Palermo 2019). The *Lancet* Commission 'Delivering transformative action on paediatric pain' stated that pain in children is frequently undertreated (Eccleston 2021). There is a lack of evidence from high-quality trials to inform clinical guidelines and thus guide chronic pain management (NICE 2018; Scottish Govt 2018; WHO 2020a), and insufficient knowledge of which outcomes are important to patients and their families to guide design of services and treatments and to inform future research (Cooper 2017b; Cooper 2017c; Cooper 2017d; Eccleston 2017; Fisher 2018). Seven Cochrane Reviews on the effectiveness of pharmacological treatments for children's chronic non-cancer pain (antidepressants (Cooper 2017c), non-steroidal anti-inflammatory drugs (Eccleston 2017), antiepileptic drugs (Cooper 2017d), opioids (Cooper 2017b), and paracetamol (Cooper 2017a)) or for recurrent abdominal pain (any pharmacological treatment) (Martin 2017); antidepressants (de Bruijn 2021)) identified a dearth of research to inform pain management, and highlighted the lack of patient-defined outcomes related to pain relief or improvement of function. This indicated an urgent need to identify outcomes of importance to children with chronic pain and their families to inform future trials and effectiveness reviews to guide pain management (Cooper 2017a; Cooper 2017b; Cooper 2017c; Cooper 2017d; de Bruijn 2021; Eccleston 2017; Martin 2017). Cochrane Reviews investigating psychological or psychosocial therapies for children with recurrent abdominal pain (Abbott 2017), or for sickle cell disease, found a lack of high-quality evidence (Anie 2015). Further, whilst psychological interventions that engage children with chronic pain or parents, or both, improve child outcomes (Fisher 2018; Law 2019), a family-system approach to chronic pain research appears to be lacking despite a call for this over a decade ago (Lewandowski 2007). A review of pharmacological, physical and psychological therapy intervention effectiveness for the World Health Organization (WHO) found a lack of evidence from high-quality trials (Fisher 2022). With high-quality evidence lacking, children are not receiving evidence-based pain management, which could result in poor short- and long-term outcomes in terms of pain and pain-related disability. Indeed, unaddressed pain in children is a risk factor for continued pain into adulthood (Walker 2010).

To design and deliver services and interventions that meet the needs of children and their families, it is crucial to understand how they experience and understand chronic pain of different kinds, which treatment outcomes are meaningful to them, and their views and experiences of health and social care services in relation to their pain management. Qualitative research is ideally suited to address these urgent and important questions. There is existing relevant qualitative research to inform these issues (e.g. Carter 2012; Jordan 2007; Jordan 2016; Maciver 2010; Neville 2019), but there were no existing or planned qualitative evidence syntheses of this research. We identified only two existing qualitative evidence syntheses, which were limited in focus. The two evidence syntheses looked at specific childhood chronic pain populations and topics: living with juvenile idiopathic arthritis (Tong 2012), and adolescent social relationships (Jordan 2017), and did not develop a theory to inform pain management; theory is important to guide the development of complex interventions, for example Skivington 2021. We therefore conducted a qualitative evidence synthesis using meta-ethnography (Noblit 1988), a methodology suited to developing theory, to investigate the diverse experiences and perceptions of children up to age 18 with chronic non-cancer pain and their families, and to generate theory to inform health and social care. This research should enhance our understanding of the experiences, perceptions and needs of children with chronic pain and their families in order to improve services and treatments, and hence children's health and quality of life. This meta-ethnography aimed to: help us better understand how children and families conceptualise and live with chronic non-cancer pain; inform whether a more family-orientated approach to chronic pain management is needed in order to help improve the quality, access and organisation of health and social care services; and identify child- and family-centred outcomes to help inform the selection and design of patient-reported outcome measures.

The Cochrane Pain, Palliative and Supportive Care (PaPaS) Group (papas.cochrane.org/) has prioritised research into children's chronic pain (Cochrane PaPaS 2018), and the International Association for the Study of Pain set its global theme for 2019 as "the year against pain in the most vulnerable" - a group which includes children - in order to raise awareness and improve pain assessment and management (IASP 2018). Furthermore, we developed this review with input from children with chronic pain and their families, pain and children's health charities, healthcare professionals and academic experts who confirmed the importance of our review aims and objectives.

Our review aimed to produce robust, novel evidence to inform and support the management of childhood chronic pain, which is important to health and social care services. This review should also lead to new conceptual insights and theories (which can change healthcare delivery and policy and inform treatments) (France 2019c; Noblit 1988), and indicate gaps in knowledge and hence new directions for chronic pain research (Campbell 2011).

How the review might inform or supplement what is already known in this area

Three review authors (EF, JN, MSB) conducted a qualitative evidence synthesis for WHO (WHO 2020c), in order to inform the revised guidelines for children's chronic pain management (WHO 2020b). The WHO 2020c synthesis took a global perspective on the management of children's chronic pain, with a particular focus on including research conducted in low- and middle-income countries (LMICs), and which incorporated the views and experiences of healthcare professionals, as well as those of children with chronic pain and their families. It focused solely on the views, perceptions and experiences of the risks, benefits and acceptability of three types of intervention: pharmacological, psychological and physical therapies. Our current qualitative evidence synthesis takes a broader perspective on chronic pain management, including how children and their families conceptualise and live with pain, and considers any kind of intervention or service; it does not explore the views of healthcare professionals (which were explored in the WHO synthesis) and does not focus extensively on LMICs. We will compare the findings of our synthesis to those of the WHO 2020c synthesis to help ensure that there is a global focus to meet global decision-makers' needs.

We will extend the findings of existing relevant Cochrane Reviews on the effectiveness of pharmacological interventions (e.g. Cooper 2017a; Cooper 2017b; Cooper 2017c; Cooper 2017d; de Bruijn 2021; Eccleston 2017; Martin 2017), psychological interventions (e.g. Abbott 2017; Anie 2015; Fisher 2018; Fisher 2019; Law 2019), dietary interventions (Newlove-Delgado 2017), and physical activity interventions (Leite 2023) for children's chronic pain by undertaking a stand-alone qualitative evidence synthesis that provides further clarity concerning phenomena of interest that supplement and add to the Cochrane intervention effectiveness reviews. Our meta-ethnography may also direct future effectiveness reviews to address outcomes of importance to children and their families. These are two of the important 'added-value' roles of qualitative evidence synthesis recognised by Cochrane (Noyes 2018a). There has been inadequate use of qualitative research evidence about children and their families' experiences of chronic pain in the form of qualitative evidence syntheses to inform the design of trials and the outcomes they measure, services and treatments. A more biomedical approach from the clinician's perspective is typically adopted in the Cochrane Reviews on managing children's chronic pain (Cooper 2017a; Cooper 2017b; Cooper 2017c; Cooper 2017d; de Bruijn 2021; Eccleston 2017; Martin 2017); yet a biopsychosocial approach is required (Faculty 2015). Qualitative research typically adopts a biopsychosocial perspective (Pope 2006), and is also well-suited to developing an understanding of the outcomes valued by children and families that could inform future trials and Cochrane Reviews of intervention effectiveness. Meta-ethnography is ideally matched to synthesising qualitative evidence on the complex issues related to children's chronic pain.

Note: we will use the term 'children' to refer to 'children and young people' throughout the review.

OBJECTIVES

1. To synthesise qualitative studies that examine the experiences and perceptions of children with chronic pain and their families regarding chronic pain, treatments and services to inform the design and delivery of health and social care services, interventions and future research.
2. To explore whether our review findings help to explain the results of Cochrane Reviews of intervention effects of treatments for children's chronic pain.
3. To determine if programme theories and outcomes of interventions match children and their families' views of desired treatments and outcomes.
4. To use our findings to help inform the selection and design of patient-reported outcome measures for use in chronic pain studies and interventions and care provision to children and their families.

Review questions

1. How do children with chronic non-cancer pain and their families conceptualise chronic pain?
2. How do children with chronic non-cancer pain and their families live with chronic pain?
3. What do children with chronic non-cancer pain and their families think of how health and social care services respond to and manage their own/their child's chronic pain?
4. What do children with chronic non-cancer pain and their families conceptualise as 'good' chronic pain management, and what do they want to achieve from chronic pain management interventions and services?

METHODS

Criteria for considering studies for this review

We developed the aim and review questions using the SPIDER acronym, as follows.

Sample: children, teenagers or infants with chronic pain, their siblings, brother, sister, parents, mothers, fathers, grandparents or other family members.

Phenomenon of interest: experience of any type of chronic non-cancer pain: musculoskeletal, migraine, headache, recurrent abdominal pain, juvenile idiopathic arthritis, complex regional pain syndrome (CRPS), fibromyalgia, endometriosis, inflammatory bowel disease, and so on.

Design: interviews, focus groups, case studies, surveys, observation, ethnography.

Evaluation: views, experiences, attitudes, perceptions, beliefs, conceptualisations, feelings, understandings of living with chronic non-cancer pain and of chronic pain services and treatments.

Research type: qualitative, mixed methods.

Types of studies

We included as eligible qualitative primary research studies of any design.

Topic of interest

We included studies focusing on the experiences and views of children with chronic non-cancer pain and their families towards chronic pain, health services and treatments. 'Child' is defined according to the UN Convention of the Rights of a Child (UNCRC) as a person under 18 years of age.

Inclusion and exclusion criteria are below. We decided the final criteria with our Patient and Public Involvement (PPI) group (12 children and young people with chronic non-cancer pain and eight parents purposefully recruited to be diverse) at the project outset and in line with qualitative evidence synthesis methods. We identified and read relevant articles and made decisions in collaboration with our PPI group to refine inclusion and exclusion criteria in order to ensure that a focused, manageable and meaningful synthesis was conducted to answer our research questions. In this way, we used an iterative process to select texts for synthesis.

Inclusion criteria were as follows.

- Published or grey literature, i.e. peer-reviewed journal articles, published reports, book chapters, books, PhD theses.
- Contained qualitative research data on chronic non-cancer pain, e.g. pain lasting for 12 weeks or more, relevant to the research questions.
- Reported the views of children with chronic non-cancer pain from three months up to age 18 years or their family members (e.g. parents/guardians, grandparents, siblings).
- Qualitative primary research studies of any design (e.g. ethnography, phenomenology, case studies, grounded theory studies) including mixed methods studies if it was possible to extract data that were collected and analysed using qualitative methods.
- Used recognisable qualitative methods of data collection and analysis.
- In any language.

Exclusion criteria were as follows.

- Acute pain, i.e. pain lasting for less than 12 weeks, such as that caused by medical procedures.
- Cancer pain.
- Pain in neonates and babies < 3 months old.
- Focused on end-of-life pain management.
- Non-empirical article, e.g. editorial, commentary, study protocol.

- Findings did not differentiate between participants with acute or chronic pain.
- Findings did not differentiate between adult and child participants.
- Studies that did not use qualitative methods for data collection and/or analysis (e.g. studies that analysed qualitative data quantitatively).
- Literature reviews.

The inclusion criteria were discussed and subsequently agreed with our Patient and Public Involvement (PPI) group.

Search methods for identification of studies

We conducted a rigorous search for published and unpublished ('grey' literature) studies via bibliographic databases and supplementary searches, as outlined below. We included grey literature as an important potential data source for all research questions. While peer review can be a marker of quality, unpublished studies, such as doctoral theses, can offer rich, high-quality data. In a meta-ethnography, lower-quality studies will contribute less in terms of data and conceptual insights and understanding than higher-quality studies to the synthesis findings (Noblit 1988), regardless of their peer-review status (see the 'Assessing the methodological limitations of included studies' section below). RT led the design and conduct of literature searches assisted by the research fellow (MSB) and Cochrane PaPaS. We conducted initial literature searches of all information sources between August and September 2020. We repeated bibliographic database searches from 20 September 2022 to 3 October 2022 to bring the review up-to-date prior to publication. Our PPI group informed which websites to search and which experts to approach for publication suggestions.

Electronic searches

We searched 12 bibliographic databases selected for their good coverage of qualitative research and spectrum of relevant disciplines. See Table 1.

Table 1. Bibliographic databases to be searched

Discipline/type of literature	Databases
Health and social care	CINAHL (Cumulative Index to Nursing and Allied Health Literature) (EBSCO) Embase (OVID) Child Development & Adolescent Studies (EBSCO) MEDLINE (including MEDLINE in Process and ePub ahead of print) (OVID) Social Care Online (SCIE – social care institute for excellence)
Psychological	PsycInfo (EBSCO)
Sociological	Social Sciences Citation Index (Web of Science)
Education	British Education Index (EBSCO)
Multidisciplinary	Scopus
Grey literature	HMIC (Health Management Information Consortium database) OpenGrey EThOS (British Library's e-theses online service)

The database search strategies for MEDLINE, HMIC and CINAHL are presented in Appendix 1. They combined three key search concepts:

- qualitative study designs;
- population: children and their families;
- phenomenon of interest: chronic non-cancer pain.

The strategy was informed by existing reviews that represented good practice for identifying the study design, population and/or phenomenon (Fisher 2018; Scottish Govt 2018), and tested against a set of key papers. We adapted the MEDLINE strategy to the remaining bibliographic databases listed in Table 1. We searched all databases from their inception without language restriction.

Grey literature

Grey literature searches were conducted on 28 September 2020. We identified grey literature by searching the following.

- Three bibliographic databases listed in Table 1 (HMIC, OpenGrey and EThOS).
- Websites of key organisations representing chronic pain health conditions, as informed by our PPI group. These included: The British Pain Society (www.britishpainsociety.org/), Department of Health (www.gov.uk/government/organisations/department-of-health-and-social-care), NIHR Journals Library (www.journalslibrary.nihr.ac.uk/#/), the Sickle

Cell Society (www.sicklecellsociety.org/), Versus Arthritis (www.versusarthritis.org/), the International Association for the Study of Pain (www.iasp-pain.org/), CRPS (Complex Regional Pain Syndrome) UK (crps-uk.org/), Fibromyalgia Action UK (www.fmauk.org/), Crohn's & Colitis UK (www.crohnsandcolitis.org.uk/), Reflex Sympathetic Dystrophy Syndrome Association (RSDSA) (rsds.org/), The European League Against Rheumatism (EULAR) network (www.eular.org/index.cfm), European Pain Federation (europeanpainfederation.eu/), Pain Relief Foundation (painrelieffoundation.org.uk/), Children's Health Scotland (www.childrenshealthscotland.org/), children's hospitals.

Searching other resources

Supplementary searches (Harris 2018) for published and unpublished research were conducted between 1 August 2020 and 17 December 2020 via:

- website searches as detailed in the section on grey literature;
- handsearching of the following key journals relevant to our research questions or qualitative health research from December 2018 to December 2020:
    - *BMC Pediatrics* (bmcpediatr.biomedcentral.com/);
    - *Clinical Journal of Pain* (journals.lww.com/clinicalpain/pages/default.aspx);
    - *European Journal of Pain* (europeanpainfederation.eu/european-journal-of-pain/);
    - *Journal of Pediatric Psychology* (academic.oup.com/jpepsy);
    - *Qualitative Health Research* (journals.sagepub.com/home/qhr);
    - *Social Science and Medicine* (www.springer.com/journal/44155/);
    - *Sociology of Health and Illness* (onlinelibrary.wiley.com/journal/14679566);
- contacting experts in the field for recommended studies, including ongoing research;
- checking the reference lists of included studies and relevant literature reviews for any further relevant studies.

Supplementary searches were *not* updated in 2022 due to resource limitations, with the exception of asking experts to suggest potentially relevant new studies.

Selection of studies

Search results were exported to EndNote and duplicates removed. We uploaded all remaining references to the Covidence systematic review management software (Covidence). One review author (MSB) conducted initial screening of retrieved references by title to exclude off-topic texts that were clearly not about childhood chronic pain, which was checked by a second, independent review author (RT). Following initial piloting and standardisation between review authors, two review authors (any two of MSB, RT, EF, IU, LF, AJ and JN) independently screened each reference by title and abstract, and then by full text to assess their relevance using the Covidence systematic review management software (Covidence). We resolved any disagreements through discussion or by referring to a third review author, if necessary.

The funder of this research has a key interest in the UK context of the National Health Service, therefore we focused particularly on studies conducted in this context. However, we included both UK and non-UK studies, including those conducted in low- to middle-income countries, to answer review questions 1, 2, 3 and 4 on how children and families conceptualise and live with chronic non-cancer pain and experience and conceptualise good pain management. We have indicated whether findings related to the UK or to other countries when reporting the review findings. We made decisions in light of the characteristics and content of the whole body of relevant studies and with our PPI group.

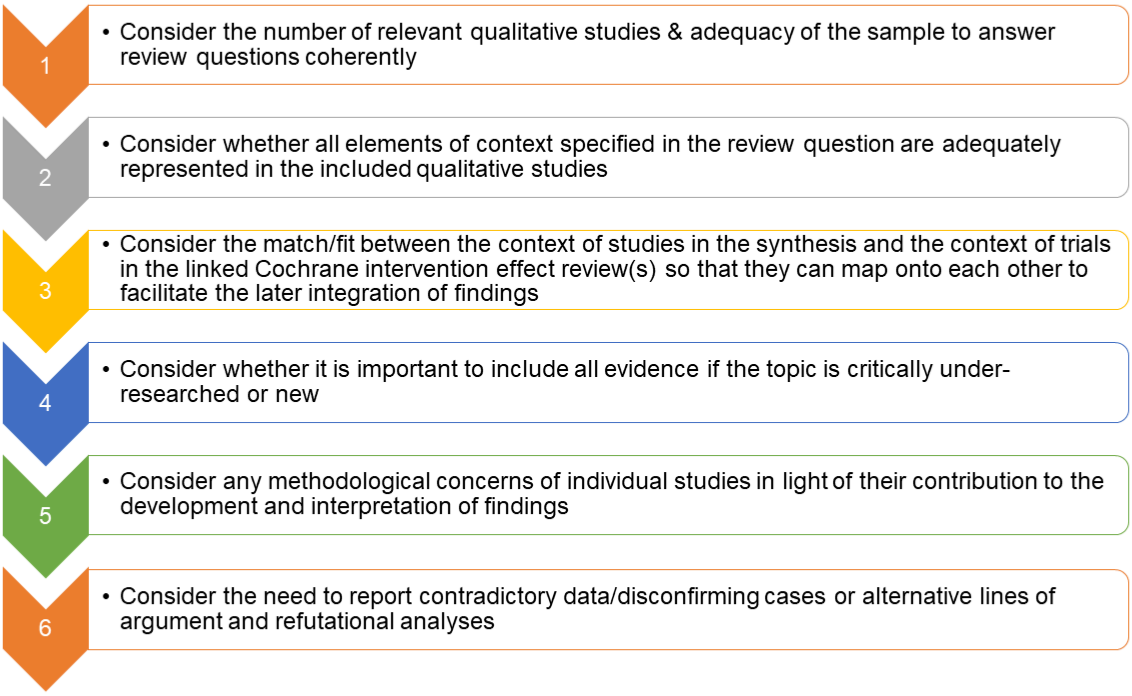
Language translation

The review team are proficient in English, Portuguese, Spanish, Dutch and French. Any titles, abstracts and full texts published in any other language were translated through Google Translate (Google Translate) to determine eligibility.

Sampling of studies

We purposively sampled our final set of included studies from all studies meeting our eligibility criteria. We used published guidance from the Cochrane Qualitative Implementation Methods Group (QIMG) on how to select a sample of studies to answer our review questions (see Figure 1 for QIMG key assessment criteria) (Ames 2019; Benoot 2016; Noyes 2018b) and input from our PPI and project advisory groups to develop a strategy for sampling studies, summarised in Figure 2. In short, our sampling approach prioritised conceptually rich UK studies, and then filled gaps in the data with less rich UK studies and both rich and less rich non-UK studies. Our rationale for this is described below.

Figure 1. Key criteria to consider when selecting studies to synthesise, adapted from Noyes and colleagues (Noyes 2018b).



1
- Consider the number of relevant qualitative studies & adequacy of the sample to answer review questions coherently

2
- Consider whether all elements of context specified in the review question are adequately represented in the included qualitative studies

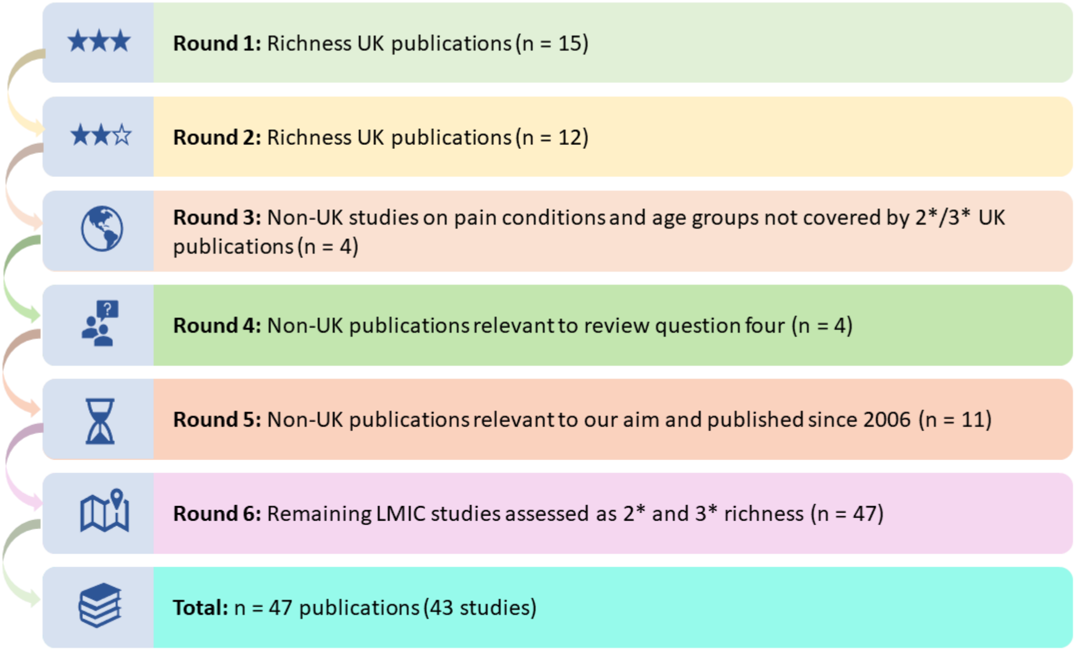
3
- Consider the match/fit between the context of studies in the synthesis and the context of trials in the linked Cochrane intervention effect review(s) so that they can map onto each other to facilitate the later integration of findings

4
- Consider whether it is important to include all evidence if the topic is critically under-researched or new

5
- Consider any methodological concerns of individual studies in light of their contribution to the development and interpretation of findings

6
- Consider the need to report contradictory data/disconfirming cases or alternative lines of argument and refutational analyses

Figure 2. Final sample



★★★ **Round 1:** Richness UK publications (n = 15)

★★☆ **Round 2:** Richness UK publications (n = 12)

Round 3: Non-UK studies on pain conditions and age groups not covered by 2*/3* UK publications (n = 4)

Round 4: Non-UK publications relevant to review question four (n = 4)

Round 5: Non-UK publications relevant to our aim and published since 2006 (n = 11)

Round 6: Remaining LMIC studies assessed as 2* and 3* richness (n = 47)

Total: n = 47 publications (43 studies)

A meta-ethnography warrants studies with a good or fair amount of rich and thick qualitative data and moderate to fair depth of context and setting descriptions (France 2019e). In a qualitative evidence synthesis, it is neither necessary nor desirable to include every relevant study to produce meaningful results because the purpose is to develop understanding of a phenomenon, not to make predictions or to produce a definitive conclusion about the effectiveness of an intervention (Ames 2019; Benoot 2016). Having too many studies, and therefore too much data, to synthesise can interfere with the ability to conduct an in-depth analysis and so result in a superficial analysis (Ames 2019).

To ensure that we were including studies that were the most adequate to address our review questions, we judged the conceptual richness of findings of the primary studies, that is whether the findings were explanatory rather than just descriptive (Popay 1998) and the contextual detail. We selected rich studies for inclusion (France 2019e). We adapted the Ames 2017 and Ames 2019 existing scale for assessing data richness, developed for qualitative evidence synthesis using thematic analysis, into a three-point scale to suit meta-ethnography to focus on conceptual richness and contextual 'thickness,' informed by Popay and colleagues' approach to judging richness (Popay 1998) and Cochrane QIMG guidance (Noyes 2022). Popay 1998 differentiated between descriptions that state facts in isolation from the context, intentions or circumstances (which we refer to as conceptually 'poor' or 'thin') and those that provide the context, intentions and meanings behind qualitative findings (which we refer to as conceptually 'rich' or 'thick'). The scale and user guidance were drafted, piloted and revised by the review authors. See Table 2 for our final richness scale.

Table 2. Adaptation of Ames richness scale developed for meta-ethnography

Richness Score	Measure	Example
1*	Thin or fairly thin qualitative data (findings) presented that relate to the synthesis objectives. **Little or nocontext** and setting descriptions	For example, a mixed methods study using open-ended survey questions, a more detailed qualitative study where only part of the data relates to the synthesis objectives, or a limited number of qualitative findings from a quant-qual mixed methods or qualitative study
2*	Fairly thick qualitative data (findings) that relate to the synthesis objectives. **Some/ moderate amount of context** and setting descriptions	For example, a typical qualitative research article in a journal with a smaller word limit and often using simple thematic analysis
3*	Thick or very thick qualitative data (findings) that relate to the synthesis objectives. **Fairly detailed or detailed/fairly large or large amount ofcontext** and setting descriptions	For example, data from a detailed ethnography or a published qualitative article with the same objectives as the synthesis that includes more in-depth context and setting descriptions and a more in-depth presentation of the findings

We first selected all the 3* UK studies for inclusion. We then explored any potential gaps in the data provided by these studies. We extracted basic information such as age and type of participants, pain condition, aims, setting and which of our review questions were addressed by their findings. These 3* UK studies only covered a limited range of pain conditions, and few provided information on review question 4, which indicated that the UK studies might not provide sufficient data to answer all our review questions. We also took into account the potential importance of the distinction between primary (e.g. fibromyalgia) and secondary pain conditions (e.g. sickle cell disease) when sampling studies.

We made further sampling decisions in collaboration with our PPI group and project advisory group, to ensure that the synthesis addressed what is of greatest importance to children and their families and considered the views of other key stakeholders including healthcare professionals. The PPI members supported our preferred option not to include poor UK studies (rated 1* for richness). They stated that we should include 2* as well as 3* UK studies and, therefore, continue with a meta-ethnography rather than conduct a thematic synthesis, which could incorporate less rich 1* findings. Project Advisory Group members, including PPI representatives, agreed it was important to include non-UK studies (i.e. studies not conducted in the UK), as long as they fitted our aim and review questions, to try to represent a wider range of pain conditions and of participants. We completed richness assessments only for those non-UK studies that met our sampling criteria; only those that were rated as 2* or 3* for richness (fairly or very rich data on our review questions) were included.

We referred to the PROGRESS-plus criteria (place of residence, race/ethnicity/culture/language, occupation, gender/sex, religion, education, socioeconomic status and social capital) when judging whether relevant populations were represented in the sample (O'Neill 2014). We used the four GRADE-CERQual domains (methodological limitations, adequacy, coherence, relevance) to guide the sampling process in order to develop the strongest findings for decision-making.,

In our final sample, we aimed to ensure a balance of heterogeneity and homogeneity of studies and conducted 'reciprocal translation' (looking for similarities in meaning), but also included contradictory findings through 'refutational translation' (looking for differences in meaning) (France 2019e). Refutational or contradictory data are important for developing comprehensive understandings and theory building (Booth 2013a). We had anticipated that including studies conducted in a range of countries might be an important element of identifying similarities and differences in the conceptualisation of chronic non-cancer pain and what 'good' chronic pain management looks like amongst different ethnic, national and cultural groups.

Summary of final sampling strategy

- Round 1 – We included all publications reporting UK studies ('UK publications') assessed as 3* for richness.
- Round 2 – We included all UK publications assessed as 2* for richness.
- Round 3 – We included non-UK publications focusing on pain conditions, palliative care and/or types and ages of participants (e.g. children under five years old) not well-represented in the sampled UK publications.
- Round 4 – We included non-UK publications from high-income contexts similar to the UK NHS and relevant to review question 4 (assessed by checking the aims and abstracts).
- Round 5 – We included non-UK publications whose aims were most closely related to our aim and review questions (assessed by their abstract), which had been published after 2006.
- Round 6 – We assessed the richness of all remaining LMIC studies in order to include those assessed as 2* or 3* for richness.

We repeated the sampling process following the update of our literature searches in September 2022.

Data extraction

At least two review authors read all the studies in full and read them again as needed throughout the analysis process (all authors read some studies). As analytic phases overlap, reading was not a one-off activity. We recorded study characteristics for all eligible studies (e.g. aim; methods of data collection and analysis; country; number and type of participants, e.g. patients, parents or other family members, gender, age, diagnosis, etc.). We referred to the PROGRESS-Plus criteria when extracting data on participant characteristics (O'Neill 2014). Further characteristics were recorded for the final included publications such as study design, recruitment setting, sampling method, methods of data collection and analysis, ethnicity, conflicts of interest and funders.

We uploaded full text PDFs of the included studies into NVivo qualitative data analysis software (QSR International 2018). We added each publication as an individual 'node' and we extracted all of its conceptual findings as 'subnodes'. We 'extracted' or coded each conceptual finding or theme, regardless of whether it appeared in the 'findings' or 'discussion and conclusions' sections, and labelled it with the author, study identification number and the concept/theme name. We also extracted authors' recommendations and 'interventions that worked' as subnodes for each paper. In total, we extracted data into 529 nodes. Some studies did not contain conceptual-level data but instead contained, for example, descriptive themes or rich descriptions – where possible for these studies, we interpreted the findings to develop new concepts and coded them at a new node. For studies identified in the updated searches, we compared the findings of included studies directly to our synthesis findings rather than extracting data in NVivo.

Assessing the methodological limitations of included studies

In addition to assessing the conceptual richness of studies, as described above, we also assessed the methodological limitations of the included studies. Two review authors (EF, MSB, IU, LF and/or three volunteer research assistants) independently assessed the methodological limitations of relevant studies using the Critical Appraisal Skills Programme (CASP) qualitative tool (CASP 2018). We did not exclude studies that were limited by poor methodological reporting because there is a distinction between quality of methodological reporting and quality of output/findings; however, we planned to exclude studies that we judged to be fatally flawed (e.g. methodologically unsound). Ultimately, the quality of studies was determined by the degree to which they contributed to the synthesis findings. We resolved any disagreements by discussion or by consulting a third review author when necessary. If a review author was the author of a relevant primary study, they were not involved in quality appraisal of that study to ensure an unbiased appraisal. We transparently recorded all decision-making and reasons for study exclusion in Microsoft Excel (Microsoft Corporation 2018a). We used the results of quality appraisal to inform GRADE-CERQual (Confidence in the Evidence from Reviews of Qualitative research) judgements of how much confidence can be placed in our synthesised findings.

We assessed methodological limitations according to the following domains:

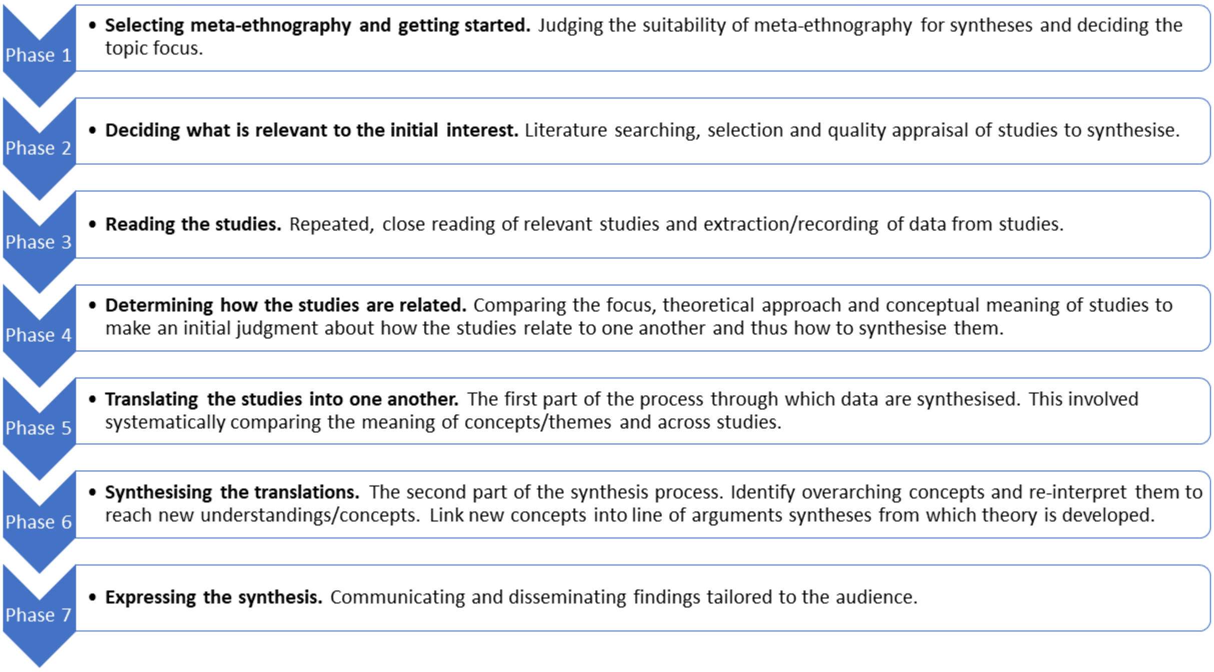
- Was there a clear statement of the aims of the research?
- Is a qualitative methodology appropriate?
- Was the research design appropriate to address the aims of the research?
- Was the recruitment strategy appropriate to the aims of the research?
- Were the data collected in a way that addressed the research issue?
- Has the relationship between researcher and participants been adequately considered?
- Have ethical issues been taken into consideration?
- Was the data analysis sufficiently rigorous?
- Is there a clear statement of findings?

We reported our assessments in a Methodological Limitations table (see Appendix 2).

Data management, analysis and synthesis

We conducted a meta-ethnography (Noblit 1988), as the available data in primary studies were sufficiently rich, following the eMERGe meta-ethnography reporting guidance (France 2019a; France 2019b; France 2019c; France 2019d), and QIMG guidance (Noyes 2018a). Meta-ethnography is suited to developing new understandings and theory (Noblit 1988), and can also indicate gaps in knowledge and thus new directions for research (Campbell 2011). A meta-ethnography involves interpreting the concepts, findings or themes from existing accounts of primary qualitative studies (e.g. those using in-depth interviews) in order to try to develop novel insights that were not apparent in any single study (France 2019c; Noblit 1988). It does not involve simply aggregating findings (Noblit 1988). The seven phases of meta-ethnography are described in Figure 3; although presented linearly, some phases run in parallel, and the process is iterative (Cunningham 2019; France 2019c; Noblit 1988). Meta-ethnography has a unique synthesis method that involves systematically comparing the meaning of concepts from primary studies; identifying new overarching concepts; and linking these in order to develop theory (Campbell 2011; France 2019c).

Figure 3. The seven phases of meta-ethnography (Noblit 1988).



Phase 1
- **Selecting meta-ethnography and getting started.** Judging the suitability of meta-ethnography for syntheses and deciding the topic focus.

Phase 2
- **Deciding what is relevant to the initial interest.** Literature searching, selection and quality appraisal of studies to synthesise.

Phase 3
- **Reading the studies.** Repeated, close reading of relevant studies and extraction/recording of data from studies.

Phase 4
- **Determining how the studies are related.** Comparing the focus, theoretical approach and conceptual meaning of studies to make an initial judgment about how the studies relate to one another and thus how to synthesise them.

Phase 5
- **Translating the studies into one another.** The first part of the process through which data are synthesised. This involved systematically comparing the meaning of concepts/themes and across studies.

Phase 6
- **Synthesising the translations.** The second part of the synthesis process. Identify overarching concepts and re-interpret them to reach new understandings/concepts. Link new concepts into line of arguments syntheses from which theory is developed.

Phase 7
- **Expressing the synthesis.** Communicating and disseminating findings tailored to the audience.

To determine the best way of grouping and organising included studies for synthesis, we became familiar with their content (France 2019e). We determined how the studies related to one another by comparing their aims, focus, characteristics and findings. In deciding our approach to organising studies for synthesis, we concluded that we could not classify studies into groups according to the type of participant or the children's age group because many studies included the views of children *and* parents and/or focused on a wide age range. Grouping studies by the type of pain or pain condition seemed to be a more feasible and logical approach. Therefore, we looked at existing systematic reviews of intervention effectiveness and qualitative evidence syntheses on children’s chronic pain to see how they had grouped studies by conditions, and consulted our healthcare professional Project Advisory Group and review authors to agree the groupings. We then grouped included studies by health condition, which resulted in a total of 11 groups:

- Juvenile idiopathic arthritis
- Abdominal pain
- Complex regional pain syndrome (CRPS)
- Sickle cell disease (SCD)
- Headache
- Neurological conditions
- Musculoskeletal conditions
- Skin conditions (epidermolysis bullosa)
- Dysmenorrhoea
- Mixed conditions
- Unspecified types of chronic pain

Translation and synthesis within condition groupings

Next, we ‘translated’ or synthesised each grouping of studies separately before synthesising them all together across groupings (Campbell 2011). Quality meta-ethnographies have used this approach successfully, and it enables synthesis of diverse studies (Campbell 2011). We used a synthesis method similar to that described by Campbell 2011, which compares concepts one by one, study by study (e.g. in chronological order), for each grouping of studies. This method has the following advantages over other methods: it does not impose an analytic framework on the data; it allows the researchers to stay close to the meanings and contexts of the original studies; and is faithful to Noblit 1988's original method (France 2019e). The process of translation is key to conceptual interpretation and synthesis, so it is important to adhere to the principles of translation (France 2019e).

One study was published in three publications containing similar findings (Maciver 2005; Maciver 2010; Maciver 2011), which were analysed together. Britton 2002a and Britton 2002b reported different participants’ perspectives from the same study, so findings were analysed separately. Another study was published in two publications presenting similar findings (Renedo 2019; Renedo 2020), which were analysed together.

We completed the translation and interpretation using an inductive approach, guided by data, and focused on meaning and context. To translate the studies into each other, we interpreted the conceptual data/findings from all NVivo nodes in chronological order from the earliest publication date. We interpreted and captured in NVivo memos the key meaning of each conceptual finding (from each node) while taking account of relevant contextual data. We gave each interpretive memo a unique identifying label with the pain condition, author's name, study number and concept/theme name. For the first three studies, two review authors (EF and MSB) interpreted each node independently, then discussed their interpretations and, if possible, agreed and recorded a joint interpretation or recorded their alternative interpretations in one memo. For the remaining studies, one review author interpreted the data (EF or/and MSB) from each node and recorded this in a memo; a second review author (EF and MSB, IU, RT, LC and/or AJ) read the data coded at the node, then read the first review author's interpretive memo and challenged, confirmed and/or added to the interpretation of the first review author. All authors kept an 'analysis journal' in a memo in NVivo to record any reflections, thoughts, issues or questions during the analysis. In total, 346 memos were created.

We used the interpretive data in the memos to compare concepts systematically, study by study, within each of the 11 condition groupings to identify or 'translate' concepts. In this study-by-study translation for each grouping, we read the interpretive memos in chronological order by publication date. We took the earliest study first, read the memos for each concept and compared their meaning to the memos for the second study looking for similar and contradictory concepts. We then compared these to the third study, and so on, until we had identified the full range of concepts. To help juxtapose the concepts, we used tables in a Microsoft Word document (Microsoft Corporation 2018b), one for each grouping (see Table 3). One review author (EF or MSB) carried out the initial translation for each grouping. A second and third review author (EF, MSB, IU, AJ, RT, LF, LC and/or JN) then read and challenged, confirmed and/or added to the translation. At least three review authors analysed (translated) the concepts to try to reach a new level of interpretation. We identified common and unique concepts within each grouping. For groupings with only one study, we looked for and identified any overarching concepts where possible. In addition, we held an online PPI analysis workshop in December 2021 to discuss, clarify and interpret preliminary findings from included primary studies.

To synthesise the translations, we then matched and merged the common and unique concepts (second-order constructs) to develop overarching third-order constructs expressing a new interpretation of the data, which went beyond the findings of the original publications. Britten 2002 coined the term 'third-order constructs,' thus further developing Schutz 1962's notion of 'first-order constructs' – i.e. lay understandings – and 'second-order constructs' – i.e. the interpretations of the first-order constructs by researchers. We achieved third-order constructs for some of the condition groupings, i.e where there were sufficient in-depth data. Additional Table 1 and Table 2 show, for each pain condition grouping, how we progressed from included study findings to third-order constructs illustrating the outcomes of our translation and synthesis of translations. We produced a textual synthesis in a narrative format for each of the constructs and, where possible, we also created diagrams showing how the new constructs linked to each other. We also referred back to any theory or model produced by the original authors of the publications to check we had taken account of the original meanings. The translation and synthesis process resulted in a total of 39 third-order constructs and 169 second-order constructs across all the groupings. An example is included in Table 3.

Table 3. Example of translation process of one concept (abdominal pain grouping)

Author's name **#study_** **name of the author's construct**	**Author's name** **#study_** **name of the author's construct**	**Common and unique second-order constructs - our interpretations**
Brodwall#5239_ desire for a specific diagnosis and discussion with a professional	Smart#3799_Interactions with doctors	Importance of diagnosis [for parents] [Brodwall#5239, Smart#3799]
The outcome most wanted by parents after examinations were detection of a somatic disease with a well-defined treatment. (…) Parents described as extremely sad and frustrating regarding the lack of diagnosis that could potentially lead to a treatment. Focusing on the pain could drive the family and the doctor into a vicious cycle of hunting for undetected causes instead of focusing on pain management. The anxiety that something dangerous may be overlooked may make the parents crave further examinations. (…) They wanted their child to have further medical examinations, and that this	Mothers (n = 22) visit doctors to establish whether a child was malingering (3 cases); to exclude a physical disease so that they could manage the pain themselves (13 cases); and to seek help in managing the pain (6 cases). Mothers (22) reported consulting doctors to establish whether a child was "malingering" (3 cases) [mothers]; to exclude a physical disease so self-manage the condition (13 cases); and to seek help with pain-management (6 cases). Mothers' view the interaction as satisfactory when they had been given a simple explanation for the pain as this acknowledged that the child was indeed genuinely ill and their concerns for their child were thus legitimate which removed any charge against their competence. Mothers perceived interactions with doctors to be satisfactory when a simple explanation for the child's pain had been offered. Such an explanation provided validation of (1)	Parents wished for a diagnosis that would enable treatment, were sad and frustrated with the lack of diagnosis and anxious it is 'something very serious'. Focusing on finding a diagnosis could be at the expense of pain management. Diagnosis legitimised and validated the pain.

should happen quickly in case it is 'something very serious'.	parental concerns, (2) legitimacy of the child's illness and alleviated any potential charges against maternal competence.	

Translation and synthesis across condition groupings

To translate and synthesise data across condition groupings, we conducted a series of four review author team analysis meetings including one hybrid in-person/online and three subsequent synchronous online meetings. In the first all-day meeting, six review authors (EF, IU, LF, MSB, RT and AJ) conducted a thematic analysis of the 39 third-order constructs and 169 common or unique second-order constructs created from the translation process. In order to do this, they were provided with the detailed narratives (the textual syntheses) for each of the constructs and a colour-coded summarised label for each construct, which stated the pain condition, the name of the concept, the contributing studies and a brief description of the construct. We thematically analysed the constructs into themes and then organised those themes into broader 'analytic categories' (thematic headings) according to shared meaning. Two review authors (RT and AJ) attended online and followed the analysis process using Padlet (a real-time collaborative web platform used to share and organise content) (Padlet 2022;en-gb.padlet.com/). A further three online team meetings using Google Jamboard (Workspace 2022; jamboard.google.com/), a digital interactive whiteboard, focused on refining the thematic analysis, drawing on the different perspectives and expertise of review authors.

Following the thematic analysis meetings, two review authors (MSB, EF) used Microsoft Teams Whiteboard (Microsoft Corporation 2018c) to create diagrams to express and further understand how themes and analytic categories were related. We discussed these analytic diagrams with all review authors in order to further develop our interpretive analysis and synthesis. Subsequently, we produced detailed textual syntheses for each analytic category. We continually further developed and refined our analysis and synthesis and discussed and clarified ambiguous or unclear findings with our PPI and Project Advisory Groups.

In order to clarify our analytic terminology, where we had been able to reach the level of new interpretation, we re-named the analytic categories of data from across all studies as 'third-order constructs,' e.g. 'pain organises the family system and the social realm.' These third-order constructs comprised 'second-order constructs,' e.g. 'adapted parenting,' which we had previously called 'themes.' We developed lines of argument – the 'overarching storylines' - to explain how all the final constructs linked together with the help of diagrams in Whiteboard and team discussion. These lines of argument together form our model and explanatory theory of children's chronic non-cancer pain and its management, which incorporates how children and families conceptualise chronic non-cancer pain, their experiences of living with the pain and how this impacts their use of pain management and health services.

For rigour and richer interpretation, all review authors were involved in the analytic synthesis. In addition, three young people with chronic non-cancer pain and two parents from our PPI group participated in an online data analysis and interpretation workshop in December 2021. We maintained a reflexive approach during analysis, for example when review authors had alternative interpretations of data, we recorded this.

We compared the findings of our synthesis to those of our prior WHO synthesis to help ensure that there was a global focus to the synthesis (WHO 2020c). Where studies reported gender/gender differences, we explored gender differences in the views and experiences of children and their parents.

Assessing our confidence in the review findings

Two review authors (MSB, EF) used the GRADE-CERQual approach to assess our confidence in each finding which a third review author (JN) checked (Lewin 2018; Noyes 2018a). GRADE-CERQual assesses confidence in the evidence, based on the following four key components.

- Methodological limitations of included studies: the extent to which there are concerns about the design or conduct of the primary studies that contributed evidence to an individual review finding (Munthe-Kaas 2018).
- Coherence of the review finding: an assessment of how clear and cogent the fit is between the data from the primary studies and a review finding that synthesises those data. Cogent means well-supported or compelling (Colvin 2018).
- Adequacy of the data contributing to a review finding: an overall determination of the degree of richness and quantity of data supporting a review finding (Glenton 2018).
- Relevance of the included studies to the review question: the extent to which the body of evidence from the primary studies supporting a review finding is applicable to the context (perspective or population, phenomenon of interest, setting) specified in the review question (Noyes 2018c).

After assessing each of the four components via the iSoQ 2022 software, we made a judgement about the overall confidence in the evidence supporting the review finding. We judged confidence as high, moderate, low or very low. The final assessment was based on consensus amongst three of the review authors (MSB, EF, JN). All findings started as high confidence, which we then downgraded if there were important concerns regarding any of the GRADE-CERQual components.

We used summary of qualitative findings tables to present summaries of the findings and our assessments of confidence in these findings, as shown in the Summary of findings 1. We used evidence profiles to present detailed descriptions of our confidence assessments, as shown in Summary of findings 2.

Integrating the review findings with the Cochrane intervention reviews

It is important for decision-making to develop an overall understanding of intervention effect, feasibility, acceptability and factors that create the context for barriers and facilitators to successful implementation. We therefore integrated our qualitative findings with the results of 14 relevant Cochrane intervention effectiveness reviews (Abbott 2017; Anie 2015; Cooper 2017a; Cooper 2017b; Cooper 2017c; Cooper 2017d; de Bruijn 2021; Eccleston 2017; Fisher 2018; Fisher 2019; Law 2019; Leite 2023; Martin 2017; Newlove-Delgado 2017), using quantitative/qualitative data integration methods from Cochrane QIMG (Harden 2018), to determine if the programme theories (i.e. how a complex intervention is thought to work; Noyes 2016a) and the outcomes of interventions matched families' views and expectations. We checked that the contexts (e.g. the population and setting) of the intervention studies were sufficiently similar to the contexts of the qualitative studies prior to integration (Noyes 2016b).

We created a matrix in Microsoft Excel (Microsoft Corporation 2018a) to juxtapose key outcomes and aspects of interventions that were important to children and families with the outcomes and focus of the reviews. We extracted all available data on the programme theories for all reviews into the matrix and two review authors (EF, KT) assessed whether these matched families' views, experiences and expectations and whether how the interventions were thought to work adopted a biopsychosocial perspective by identifying if they reported any biological, psychological or social mechanisms of action.

There are various points in overall meta-ethnography production at which integration can occur (Harden 2018; Noyes 2019). We integrated qualitative and quantitative perspectives during review question formulation and synthesis.

- Qualitative and quantitative review team membership and communication: members of our qualitative evidence synthesis review team (JN, EF, LC) had close contact and communication (during both this meta-ethnography and previous reviews) with key reviewers who have conducted and/or been the managing editor for the quantitative intervention effect reviews. For instance, we wrote funding applications with some of the quantitative reviewers, we shared search strategies and outputs for the WHO reviews, had joint meetings and consulted regularly to obtain early sight of the quantitative outcomes. The Cochrane PaPaS Managing Editor and quantitative intervention effect review authors also shared resources with our meta-ethnography team, such as draft intervention effects reviews, the new core outcome set and the Lancet Commission Report, which were used during quantitative/qualitative review data integration. Because of this close collaboration and the way that we designed the meta-ethnography to complement the Cochrane intervention effects reviews, this facilitated the subsequent quantitative/qualitative integration. This enabled us to establish a high level of coherence between the qualitative and quantitative evidence.
- Question formulation: we formulated the meta-ethnography review questions to address known gaps in the Cochrane intervention effectiveness reviews.
- Synthesis: we used a matrix approach adapted from one used previously in several Cochrane Reviews (for example, Munabi-Babigumira 2017). Our matrix explored whether potential implementation factors (patient values, preferences and desired outcomes, acceptability, feasibility) identified in our meta-ethnography were acknowledged or addressed in the intervention programme theories in the related Cochrane Reviews of intervention effectiveness.

Review author reflexivity

The review authors have varied professional backgrounds including sociology (IU, RT), psychology (EF, LF), health psychology (AJ, LC), family therapy (LF), nursing children with chronic pain (JN), physiotherapy with children who have chronic pain (MSB), occupational therapy (KT), development of evidence synthesis methodology (JN, EF, RT, IU), children's pain research (AJ, LC) and health services research (all). Five of us (JN, LF, AJ, MSB, KT) have clinical backgrounds, and seven of us (EF, IU, RT, LC, AJ, JN, LF) have social science backgrounds. Three review authors have personal experience of chronic non-cancer pain, which started in childhood or adulthood. We believe that children have a fundamental right to pain treatment and to be pain-free and that all pain is real and to be believed.

If a review author was the author of an included primary study, they were not involved in assessing its methodological limitations to ensure an unbiased appraisal; a senior team member took overall responsibility for the assessments of such studies. We maintained a reflexive approach during analysis and made clear any potential conflicts of interest, for example when interpreting any studies by our team that were included in the synthesis. AJ and LC have authored several qualitative study publications on children's chronic pain, but the other review authors are independent of that research. EF and JN conducted a qualitative evidence synthesis on interventions for children's chronic pain globally for WHO.

All review authors kept a reflexive stance during all the stages of the review process. The chief investigator and research fellow (MSB), who made the greatest time contribution to the review, kept a reflexive journal during the review process. The review process and progress was regularly assessed and discussed between the researchers and using PPI input. The PPI input throughout the review also minimised the risk of influencing our selection of studies, analysis, and the interpretation of the findings based on our preconceptions and backgrounds.

Based on our collective and individual experiences (as healthcare professionals, academics and researchers), we anticipated the findings of our review might reveal a mismatch between the current pain management treatments and services and the design and outcomes of trials research compared to the needs and wants of children with chronic non-cancer pain and their families. We anticipated that they might also show that the rhetoric of seeing chronic non-cancer pain as something that impacts the whole family is not borne out by people's experiences. We took a reflexive approach throughout the review by interrogating how our professional and personal assumptions could influence our interpretation of the data and our interpretation of our own findings.

Patient and public involvement and stakeholder engagement

The review included patient and public involvement and engagement. Public engagement is not synonymous with public involvement and, in the UK, it refers to sharing research information and knowledge with the public (Campbell 2020; INVOLVE 2012). We had a core patient and public involvement (PPI) group who provided detailed feedback, contributed to important decisions and to data analysis and interpretation during key stages of the meta-ethnography. We also sought views from the wider population of children with chronic pain and their parents/guardians beyond our core PPI group. In addition, we had a Project Advisory Group of stakeholders, including medical experts, academic experts, third-sector organisations, and children with chronic non-cancer pain and their families, who were involved at key time points. Aspects of the Project Advisory Group role included both involvement and engagement. The Advisory Group was tasked with providing strategic advice to the research team on four key areas:

1. methodological issues;
2. clinical and lived experience of chronic non-cancer pain;
3. study conduct;
4. dissemination.

We used the UK standards for Public Involvement, launched between 2018 and 2019, as a guide to ensure the quality and consistency of public involvement (UK 2019). PPI and Advisory Group members decided their level of involvement or engagement throughout the duration of the study. Patient and public involvement (PPI) played a central role across all stages of the meta-ethnography, from inception through to dissemination. PPI contributed to tasks such as helping with the development of the grant funding proposal; finalising the study design; deciding the name and the logo for the research; deciding which studies to include and how to organise them for synthesis; sharing their experiences in order to clarify, confirm or disconfirm findings; identifying important areas missing from existing research; and participating in the dissemination of findings. Further details of PPI and stakeholder engagement are provided in Appendix 3.

RESULTS

Eligible studies

A total of 6357 records were identified through database searching and 564 from other sources. After removing duplicates, a total of 4197 records remained and had their titles and abstracts screened against the eligibility criteria resulting in 620 full texts selected for assessment. After screening against the inclusion criteria, 438 full-text articles were excluded with reasons (i.e. 200 for ineligible publication type, 141 not chronic pain, 65 not in children, 17 were unavailable and 15 were duplicates). This process resulted in the inclusion of 182 publications reporting 170 studies published between 1998 and 2022 representing 25 countries as eligible for potential inclusion (i.e. prior to sampling). A PRISMA flow diagram (Figure 4) shows the search results and the results of screening and selecting studies for inclusion (Moher 2009). The majority of studies (n = 158) were conducted in high-income countries: 49 were conducted in the USA, 39 in the UK, 25 in Canada, eight in Sweden, five in Norway, eight in Australia, five in Spain, three in Ireland, three in Denmark, two in Switzerland, three in Portugal, two in France, two in The Netherlands, two in Germany, one in Belgium, one in Hong Kong and one in Saudi Arabia. One study was conducted across three countries – the USA, UK and Belgium (Baert 2020). Only 12 studies were conducted in low- to middle-income countries (LMICs) including four in Brazil, two in Iran, one in Nigeria, one in Cameroon, one in Ghana, one in Mexico, one in Malawi and one in Lebanon. The table of eligible studies presents key characteristics of sampled and unsampled eligible studies (Appendix 4).

Figure 4.

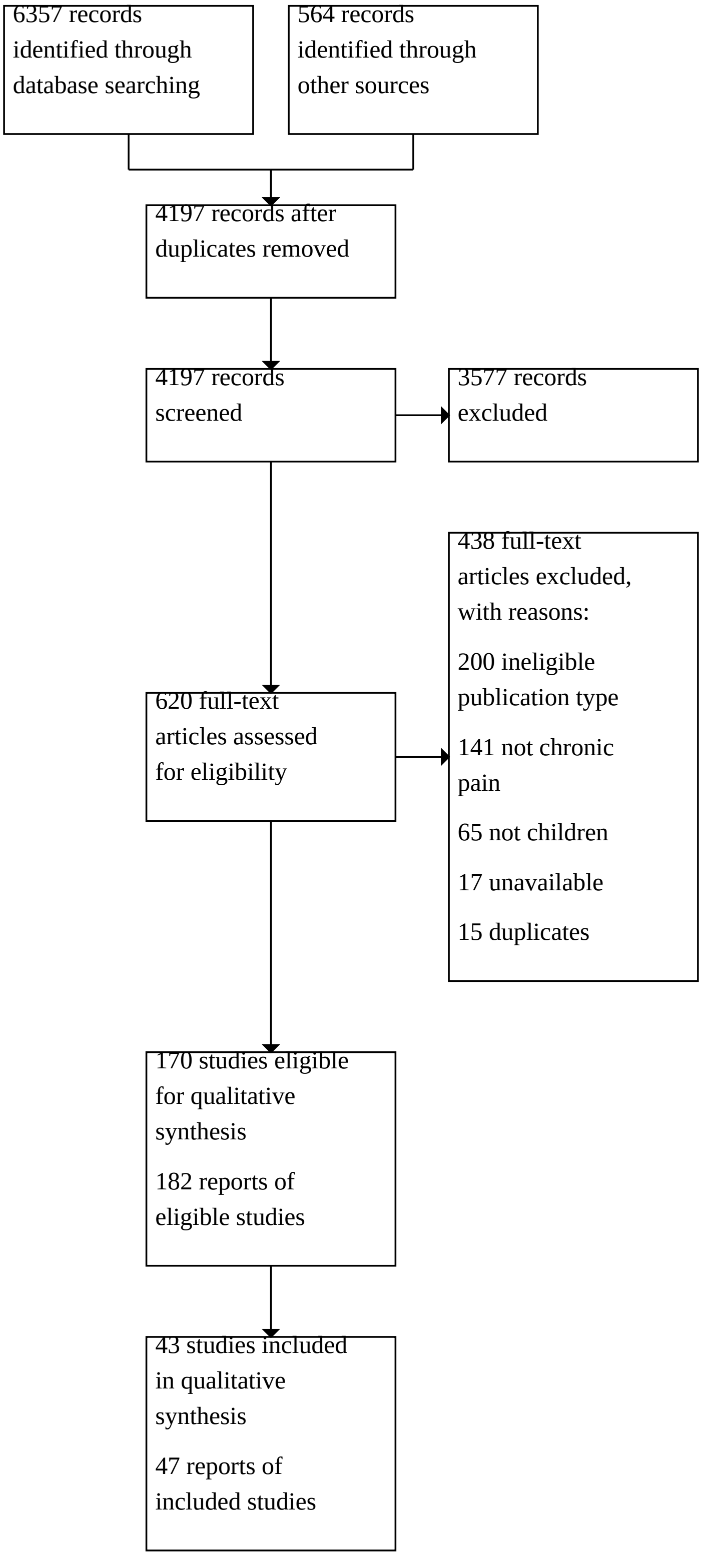

6357 records identified through database searching
564 records identified through other sources
4197 records after duplicates removed
4197 records screened
3577 records excluded
438 full-text articles excluded, with reasons:
200 ineligible publication type
141 not chronic pain
65 not children
17 unavailable
15 duplicates
620 full-text articles assessed for eligibility
170 studies eligible for qualitative synthesis
182 reports of eligible studies
43 studies included in qualitative synthesis
47 reports of included studies

Figure 4. (Continued)

A large proportion of eligible studies focused on the more severe, but fairly rare, conditions of juvenile idiopathic arthritis (JIA) (n = 32, 19%) and sickle cell disease (SCD) (n = 25, 15%). There were some common pain conditions that few studies focused on as their sole focus, such as recurrent abdominal pain (n = 11, 6%), musculoskeletal pain (n = 7, 4%), headache (n = 6, 3.5%) dysmenorrhoea (n = 3, 2%) and otitis media (earache) (n = 1, 0.6%). In terms of rarer pain conditions, only four (2%) studies focused solely on cerebral palsy, three (2%) on HIV/AIDs, two (1%) focused on complex regional pain syndrome (CRPS), two (1%) on epidermolysis bullosa, one on osteogenesis imperfecta (a bone disorder) and one (0.6%) on juvenile fibromyalgia. None looked at Ehlers-Danlos syndrome, a group of inherited conditions that affect connective tissue.

Evidence gaps in eligible studies

We identified gaps in the evidence from eligible studies with respect to the age range, types of pain, types of participants (e.g. children, parents, siblings) and countries covered. For example, we found only two (1%) studies focusing on infants under two years old (Asmussen 1999; Soni-Jaiswal 2016) and only 11 (6%) focusing on children aged from two up to five years old (Ajinkpang 2022; Brandelli 2021; Carter 2017; Gomez-Ramirez 2016; Hunt 2003; Iliyasu 2021; Leksell 2017; Panepinto 2012; Randall 2020; Santos 2018; van Scheppingen 2008; Yeung 2017). Only eight (5%) studies included siblings. Only 12 (7%) of studies were conducted in LMICs.

Sampling outcome

Following the iterative six-round sampling strategy described in the Methods and Figure 2, in Round 1 we sampled all 15 publications reporting UK studies ('UK publications') assessed as 3* for richness; in Round 2 we included a further 12 UK publications assessed as 2* for richness (the initial UK focus is in line with the funder's interests). We explored any potential gaps in the data provided by these studies. In Round 3 we included five non-UK publications (i.e. reporting studies not conducted in the UK), which focused on pain conditions (e.g. dysmenorrhoea, headache), palliative care or children's age groups that were not represented by the included UK publications (e.g. children under five years old) and that we assessed as 2* and 3* for richness (Borghi 2014; Brandelli 2021; McDonagh 2021; McKinnon 2022; Wong 2016). In Round 4 we identified nine non-UK publications relevant to review question 4 of which four were assessed as 2* and 3* for richness and were included (Ahlqwist 2012; Dell'Api 2007; Kanstrup 2019; Nutkiewicz 2008). In Round 5 we selected 11 publications published since 2006 that were most closely related to our aim and review questions, which were rated as 2* and 3* for richness (Atoui 2015; Brodwall 2018; Castle 2007; Forgeron 2008; Gaughan 2014; Helvig 2013; Neville 2019; Njifon 2019; Rossato 2007; Sorensen 2017; Suder 2016). In Round 6, we assessed the richness of all remaining LMIC studies resulting in no further included studies because they were all rated 1* for richness. This six-round sampling strategy (described in Figure 2) resulted in 47 publications reporting 43 studies included in the final sample, as reported in the PRISMA flow chart (Figure 4).

Included studies

We included 43 studies reported in 47 publications published between 2000 and 2022 in the analytic synthesis. Three are PhD theses (Maciver 2005; Suder 2016; Williams 2008), one is a report (Renedo 2020), and the remainder are peer-reviewed journal articles. One PhD study was published in three formats – a thesis (Maciver 2005) and two journal articles (Maciver 2010; Maciver 2011). Britton 2002a and Britton 2002b reported data from the same study, as did Renedo 2019 and Renedo 2020. Two studies were based on longitudinal data (Jones 2022; Renedo 2019; Renedo 2020). Appendix 4 presents detailed characteristics of the included studies. Twenty-three studies reported in 28 included publications were conducted in the UK, five studies in the USA, four in Canada, two in Sweden, two in Norway, two in Australia, one in Belgium and one in Hong Kong. Only four were in low- to middle-income countries (LMICs), including two in Brazil, (upper middle-income), one in Cameroon, (lower middle-income) and one in Lebanon (lower middle-income), according to the World Bank classification (World Bank 2023). (There is a three-country study (Baert 2020), so the total does not add up to 43 studies).

The included studies involved a total of 633 participants comprising 325 children and young people aged 5 to 18 years old, 291 parents of children aged 2 to 18 years old, and 17 siblings of children with chronic pain. Most (n = 28, 65%) included studies focused on only adolescent children aged 10 years or older. Seventeen studies focused on children under 10 years, but only three of these focused on children under five years old (Brandelli 2021; Hunt 2003; McKinnon 2022), and only five included children under 10 years, rather than their parents, as the research participants (Borghi 2014; Britton 2002a; Britton 2002b; Dyson 2011; Guell 2007; Rossato 2007). This means that the voices of children under 10 years old are not well-represented in the data and that the findings attributed to children and young people are more applicable to adolescents, except where stated.

Included studies involved a total of 197 mothers, 48 fathers, 164 girls with chronic pain and 53 boys with chronic pain. Over two-and-a-half times more girls than boys with chronic pain participated in included studies, hence the findings are more likely to represent the views and experiences of girls. This gender imbalance likely reflects that adolescent girls are more likely to be diagnosed with chronic pain than adolescent boys (e.g. Keogh 2021). In most of the studies that included parents, the sample was weighted towards mothers rather than fathers as representing the parenting view of the primary caregiver; as described above, almost three times more mothers than fathers took part in the studies. Five included studies focused on only mothers (Baert 2020; Brandelli 2021; Carter 2017; McDonagh 2021; Smart 2005), but only one included study focused solely on the views of fathers (n = 6) (Jordan 2016). Hence, the findings mostly report impacts on mothers' experiences and perceptions. We recognise that this may be a bias of study samples but also may represent the wider gendered nature of caring in the societies/countries represented in the included studies.

The majority of included studies – 26 (61%) of them – did not state the participants' ethnicity. Overall, 11 included studies (26%) involved a total of at least 129 non-Caucasian participants from a wide range of ethnic backgrounds (e.g. British Asian, Asian, Black British, Black Caribbean, Black African, African American, Latin American/Latino, Indian, Chinese, mixed origin, Lebanese Muslim, Palestinian Muslim) (Atkin 2000; Atkin 2001; Atoui 2015; Dyson 2011; Helvig 2013; Khanom 2020; Neville 2019; Njifon 2019; Nutkiewicz 2008; Williams 2008; Wong 2016); three of these were studies conducted in Lebanon, Hong Kong and Cameroon (Atoui 2015; Njifon 2019; Wong 2016). The total number of participants from non-Caucasian ethnic backgrounds is an underestimate because one UK study, Atkin 2000, reported the entire family's ethnicity only and a UK study did not state ethnicity explicitly (Renedo 2019; Renedo 2020), despite focusing on SCD, which predominantly affects people of African-Caribbean backgrounds. Six included studies stated that all participants were Caucasian (Baert 2020; Forgeron 2008; Jones 2022; Jordan 2016; Waite-Jones 2008). Details of the characteristics of included studies are in the table of eligible studies in Appendix 4.

The studies covered a wide range of conditions involving chronic pain including complex regional pain syndrome (CRPS), juvenile idiopathic arthritis (JIA), JIA associated with Down syndrome, sickle cell disease (SCD), headache, migraine, abdominal pain, musculoskeletal pain such as low back pain, epidermolysis bullosa, dysmenorrhoea, neurological conditions such as cerebral palsy, and unspecified chronic pain, although some studies (n = 12) focused on a mix of different pain conditions including some rare conditions.

The studies did not provide data or give an in-depth understanding of how families experienced pain assessment by healthcare professionals, their experiences of social care services and primary care, family attitudes to opioids for pain management, or use of pain management plans. Furthermore, there was a lack of conceptually rich studies that we could include in our final sample focusing on common types of pain, such as headache (n = 1), dysmenorrhoea (n = 1), musculoskeletal pain (n = 3) and abdominal pain (n = 2) or conducted in LMICs. See additional Table 3 for definitions and characteristics of chronic pain conditions in the included studies.

Assessment of methodological strengths and limitations

For the overall assessment of methodological limitations in the sample of 43 included studies, we judged 56% (n = 24) as having minor methodological limitations, and the remaining 44% (n = 19) as having moderate limitations. The full CASP assessments are shown in Appendix 2. We most commonly identified methodological limitations concerning if and how study authors took the relationship between researcher and participants into consideration. We also raised concerns when assessing whether ethical issues were adequately taken account of. In most studies, these limitations were because information was not reported rather than a definite lack of consideration of the specific domain. Overall, we judged most studies to have few methodological concerns regarding an appropriate study design. Participant recruitment strategies were mostly well or moderately well designed with only four studies assessed as having serious concerns. Data collection was generally well-conducted across studies with some exceptions. Data analysis was relatively well-conducted with only two studies having serious methodological limitations.

Assessment of conceptual richness of included studies

Overall, in line with our sampling strategy, we included only studies rated as 2* and 3* for richness in the sample. For linked studies that presented the same data, we conducted one combined richness assessment (Maciver 2005; Maciver 2010; Maciver 2011; Renedo 2019; Renedo 2020); but when different findings were presented, we conducted separate richness assessments (Britton 2002a; Britton 2002b), meaning there are 44 assessments for included studies/publications. Twenty-three (52%) were rated 3*, that is, they had rich (thick) or very rich qualitative findings related to our synthesis aim and review questions, and fairly detailed or detailed descriptions of the research context and setting. Twenty-one (48%) were rated 2*, that is, they had fairly rich (thick) qualitative findings relate to our aims and review questions and a moderate amount of context and setting descriptions. Within these categories there was variation in the richness and thickness of studies. Additional Table 4 shows the richness assessments of final included studies only. Studies we assessed for richness to aid sampling decisions and rated as 1* are shown in additional Table 5 (not all eligible studies were assessed).

Synthesis findings

Our findings are organised into five new interpretive constructs, which we call third-order constructs, using the language of Britten 2002, two of which ('families managing pain independently' and 'families' experiences and perceptions of specific interventions and treatments') are less well-developed because there were insufficient rich data. The third-order constructs are:

- pain organises the family system and the social realm;
- families struggling to navigate health services;
- families managing pain independently;
- families' experiences and perceptions of specific interventions and treatments; and
- children and families experiencing prejudice and discrimination.

All third-order constructs are comprised of second-order constructs. Additional Table 6 shows the development of the third-order constructs derived from our thematic analysis of translated findings (the common and unique findings we identified) from across all studies.

In the findings below, we present our further interpretation of the data in the cited publications. Throughout, we provide illustrative quotations from research participants and from the primary researchers' (the authors of included studies) interpretations. Where relevant, the data analysis and interpretation also incorporate insights from our PPI group.

Third-order construct: Pain organises the family system and the social realm

Data supporting this third-order construct originate from 37 publications representing 33 studies published between 2000 and 2022 (Atkin 2000; Atkin 2001; Atoui 2015; Baert 2020; Brandelli 2021;Britton 2002a; Britton 2002b; Brodwall 2018; Carter 2002; Carter 2002a; Carter 2002b; Cartwright 2015; Castle 2007; Dell'Api 2007; Forgeron 2008; Gaughan 2014; Guell 2007; Jones 2020; Jones

2022; Jordan 2007; Jordan 2016; Jordan 2018; Khanom 2020; Maciver 2005; Maciver 2010; McDonagh 2021; McKinnon 2022; Neville 2019; Njifon 2019; Renedo 2019; Renedo 2020; Rossato 2007; Smart 2005; Sorensen 2017; Suder 2016; Waite-Jones 2008; Williams 2008). Twenty-one of the 33 studies were conducted in the UK. These data come from studies focusing on the following conditions: SCD, CRPS, abdominal pain, epidermolysis bullosa, JIA, musculoskeletal conditions/pain, neurological conditions or a mix of pain conditions.

This third-order construct comprises seven second-order constructs: pain organises the family system; adapted parenting; pain's adverse psychosocial impacts on the whole family; pain forces families to manage uncertainty; pain forces adjustment and adaptation; pain's influence on disclosure, social support and social relationships; and school and the social realm.

Pain organises the family system and the social realm

A family system is defined as a complex social system constituted of people, which may include parents, the child, siblings and grandparents, who depend on each other for basic needs and emotional support. The impact of poorly managed, moderate and severe chronic pain on the family system was overwhelming; it took over family life and affected family dynamics, roles and relationships (Brandelli 2021; Britton 2002a; Britton 2002b; Brodwall 2018; Cartwright 2015; Gaughan 2014; Jordan 2016; Maciver 2005; Maciver 2010; Suder 2016; Waite-Jones 2008).

Our interpretation shows that pain had a powerful role in organising the family system, profoundly restricting and altering the whole family's routines and activities. For instance, families had to adapt to avoid exacerbating the pain, and to fit in time-consuming pain management, which made spontaneity difficult as pain was the context of, and set boundaries around, their daily activities (Atkin 2001; Brandelli 2021; Gaughan 2014; Guell 2007; Jones 2022; McDonagh 2021; McKinnon 2022; Njifon 2019; Rossato 2007; Waite-Jones 2008). Some families perceived the onset of pain as so intense that it split their lives into before and after pain, as a form of life-course rupture; one adolescent girl described it as *'coming into pain'* (Carter 2002a, p758). There were fewer data relating to well-managed and less severe pain, however pain's dominance and influence was less visible in those data relating to the lives of parents and families of children and young people with well-managed, or with less severe chronic pain, which highlights the importance of good pain management strategies to enable families to regain agency.

Children and young people described how pain led to loss of the freedom to govern their daily routines: inadequately controlled pain prevented them from attending school due to hospital appointments, symptoms or pain management, leaving them feeling consumed and overwhelmed by pain (Atkin 2001; Atoui 2015; Dyson 2011; Gaughan 2014; Jones 2020; Jones 2022). Pain isolated children and young people from their peers and friends, with risk of exacerbation needing to take precedence, or due to a loss of shared interests when pain prevented participation in hobbies and activities (Ahlqwist 2012; Brandelli 2021; Jones 2020; Jones 2022; Njifon 2019; Sorensen 2021). Pain forced increased dependency of the child on family members, which led to ambivalent feelings. For example, children and young people were grateful to their parents for being their main source of support, but also resented them for limiting their activities to avoid aggravating the pain (Atkin 2001; Atoui 2015; Jones 2022; Njifon 2019).

Pain negatively impacted children and young people's sense of identity (Ahlqwist 2012; Atkin 2000; Atkin 2001; Atoui 2015; Forgeron 2008; Jones 2022; Khanom 2020; Njifon 2019). Specifically, children and young people perceived themselves as different from peers as a result of feeling restricted, isolated and not 'healthy'. Additionally, studies showed that children and young people reported a sense of perceived difference from peers due to loss of their independence, parental overprotection, and having to undergo pain-related treatments and being treated differently to peers by others (e.g. by teachers) (Ahlqwist 2012; Atkin 2000; Atkin 2001; Atoui 2015; Forgeron 2008; Jones 2022; Khanom 2020; Njifon 2019; Williams 2008). Pain led some children and young people to not feel 'normal', because it restricted their ability to lead a normal life (Atkin 2001; Atoui 2015; Britton 2002a; Cartwright 2015; Forgeron 2008; Guell 2007; Rossato 2007; Waite-Jones 2008). Feeling different, and resenting this, affected children as young as seven years old (Britton 2002a). This excerpt of the authors' interpretation illustrates the impact of pain on children and young people's identity:

*"(pain) limited what they [children and young people with SCD] were able to do and shaped how others viewed them, and even how they viewed themselves" (*Atoui 2015*, p5).*

Pain also resulted in siblings feeling neglected by their parents and helpless as the whole family started to focus on the children and young people with pain (Brandelli 2021; Britton 2002a; Brodwall 2018; Gaughan 2014; McDonagh 2021; Waite-Jones 2008). Consequently, the impacts of pain could lead to siblings behaving dismissively towards the children and young people and even questioning the legitimacy of the other child's pain. Parents, and sometimes grandparents, felt responsible for preventing siblings from feeling neglected (Jordan 2007; McDonagh 2021). Siblings competed for parental time and affection, but whilst they blamed their sibling with pain for dominating their parents' focus, they also showed concern and affection for them (Britton 2002a; Waite-Jones 2008). These ambivalent feelings in the sibling without chronic pain became less negative as the sibling got older and developed the skills to adjust socially and emotionally (Waite-Jones 2008):

"I feel a bit different about it now. I have understood it more. Because I know what the problem is then it is a lot easier to understand and help." (19 years, older brother of children and young people with pain from JIA) (Waite-Jones 2008, p21).

Pain organised the activities of siblings, even younger children, by requiring them to take on caring responsibilities, which limited their freedom. This was raised as a particular issue in a study conducted in Cameroon where children and young people were routinely expected to adopt a 'parenting' role for younger siblings, including supervising medical care, which they resented (Njifon 2019). However, siblings becoming young carers was also apparent in studies in the UK (Atkin 2001; Waite-Jones 2008), and Lebanon (Atoui 2015).

Importantly, parents, particularly mothers who tended to be the primary caregiver, saw looking after their child's health as part of their parental role, so they assumed the main responsibility for helping their child to manage the emotional and physical consequences of pain. Consequently, pain had a stronger influence over the opportunities and choices of mothers than fathers (Atkin

2001; Atoui 2015; Brandelli 2021; Britton 2002a; Britton 2002b; Brodwall 2018; Cartwright 2015; Guell 2007; Maciver 2005; Maciver 2010; Njifon 2019; Rossato 2007; Smart 2005; Waite-Jones 2008; Williams 2008). Their child's pain also negatively impacted the identity of primary caregivers, particularly for more severe pain, which reduced their ability to have a life outside of the home; for instance, they stopped paid employment and/or lost their career (Gaughan 2014; McDonagh 2021); and curtailed their social life to focus on caring for their child (Brandelli 2021; Brodwall 2018):

"It can be quite wearing looking after them. And it's not just the worry, it's actually your life stops and you cannot do anything else." (Atkin 2000, page 61) (Mother of a child with SCD).

Having one parent in paid employment and the other being an unpaid carer for their child could affect parental relationships because the parents had very different stresses and demands on their time (McDonagh 2021). Some mothers did not confide their caring-related stress to their employed partner to avoid worrying them (McDonagh 2021).

Adapted parenting

Parenting style (often that of mothers) altered as a result of their child having chronic pain. Our analysis shows that parents were initially uncertain of how to parent in the presence of chronic pain and learnt on their own to adapt their parenting to help their child deal with the pain while trying to maintain their child's autonomy and family quality of life (Brodwall 2018; Gaughan 2014; Jordan 2016; Maciver 2005; Maciver 2010; Smart 2005). They had to change their perception of what parenting should look like and their role as parents. For instance, they learnt to provide support and care while being firm when necessary, e.g. making their child go to school despite pain (Gaughan 2014) (for further details see 'families managing pain independently'); and had to decide whether to let their child join in activities, as described by this mother:

"I can't wrap (daughter) in cotton wool, I've learned that, and it's wrong to do that, she should be allowed to lead as normal a life as possible, even though that you know that some of the activities that she's going to undertake are going to result in a lot of pain." (Maciver 2005, p278) (mother of children and young people with fibromyalgia and full body pain for 34 months).

Parents tried to find a balance between deciding how much to let their child engage in activities that might cause or worsen pain to ensure quality of life for their child and family, even for older children who should have been making their own choices as they matured developmentally (Maciver 2005). Things that hindered adaptation of their parenting approach were a lack of understanding about how they could help their child, and the lack of resources and support from health services and their social network (Atkin 2000; Atkin 2001; Brodwall 2018; Smart 2005).

Pain's adverse psychosocial impacts on the whole family

This second-order construct focusses on the emotional impacts of pain. Moderate to severe pain had adverse psychosocial impacts on all family members, to the extent that some parents and children and young people described living with chronic pain as traumatic - like surviving a traumatic event (Carter 2002a; Forgeron 2008; McKinnon 2022; Sorensen 2017; Suder 2016). Children and young people felt isolated, depressed, 'different' from peers and afraid of the possible cause of the pain, particularly when they had no diagnosis or did not know the cause of their pain (for further details see 'families struggling to navigate health services'). Pain in some adolescents with cerebral palsy, headache, CRPS, otitis media or musculoskeletal pain led them to wonder if they 'deserved' it (Castle 2007; Suder 2016).

Parents were deeply negatively affected emotionally; they experienced helplessness, frustration and guilt if they could not help their child feel better or find a cure, anxiety, distress and depression (Gaughan 2014; Jordan 2016; Maciver 2005; Maciver 2010), as expressed by this father:

"She (daughter) was depressed; I was starting to get depressed from it. It was absorbing our whole life.'' (father of child with chronic neuropathic pain)(Gaughan 2014, p250).

Parents also felt deeply afraid of what might be causing the pain, of witnessing their child in pain, that treatments would not work, and that the children and young people would not get better to enjoy a fulfilling life (Gaughan 2014; Jones 2020) (for further details see 'families struggling to navigate health services'). The constant fear caused parents to always be 'on call' (available at any time) for their child (Jordan 2016; Maciver 2005), which was also detrimental to parents' well-being:

"You don't really have a major life, you're always on call. There is always that, you know, whatever you do, or wherever you go, you know if you go to bed, you know you're going to be on call if something is going to be wrong, if he needs you, you've got to get up and do it." (mother of child with full body pain for 7.5 years) (Maciver 2005, p264).

Furthermore, parents grieved the loss of their lives before pain and the loss of 'normal' parenting (Maciver 2005). Our PPI group, both children and young people and parents, also expressed grief over losing the life they could have had without chronic pain.

There was a greater negative psychosocial impact on family members who were more involved in caring for the child with chronic pain (Atkin 2001; Atoui 2015; Britton 2002a; Britton 2002b; Cartwright 2015; Guell 2007; Jordan 2016; Maciver 2005; Njifon 2019; Rossato 2007; Waite-Jones 2008; Williams 2008). Children and young people felt responsible for, and guilty about, their family's distress and caring efforts (Atkin 2001; Atoui 2015; Njifon 2019), as this adolescent boy explained:

"She gets so upset when I am having a pain and it's not fair on her, like I don't want to make her worry. Because if she's upset I get upset for upsetting her." (Male age 13, pain from SCD) (Atkin 2001, p620).

Thus, our interpretation shows there can be a cycle of escalating distress amongst family members: the child is distressed due to pain, which causes distress to the parents and siblings, which further distresses the child. Furthermore, guilt and worry about parents could cause children and young people to hide or downplay their pain, which we hypothesise can pose difficulties for assessing and managing pain. Consequently, pain disrupts family communication systems and precludes sharing of worries with each other.

Seeking meaning in chronic pain

Parents and adolescents would rather not experience chronic pain but when they did live with it, they reported some positive consequences of chronic pain. The parent most involved in chronic pain management, usually the mother, perceived they became closer to their child and that their relationship had improved (Brandelli 2021; Britton 2002a; Jordan 2016). Some siblings felt that their family relationships had become closer than in other families and they had become more compassionate to others (Britton 2002a; Waite-Jones 2008). Additionally, some adolescents with chronic pain acknowledged that their experiences made them a better person, better equipped to live life and more mature (Jones 2020; Suder 2016). An adolescent with chronic back pain described having more time to be with friends because they had had to stop other extracurricular activities (Jones 2022). We suggest that these perceived positive consequences may be examples of 'benefit finding' (a form of cognitive adaptation to threatening circumstances) or an attempt to seek meaning in pain. For example, some young people worked towards framing their pain experience to try to portray some positive impacts, as expressed in the following account:

"Going through this pain and going through the program has almost made me a little more mature mentally because I have to be able to cope and get through my life. I have to get ready for adulthood. (…) I will survive, I meant there is so many different ways I could say it, but it's all going to come down to it's changed me for the better. It's perseverance, I can tolerate more pain I guess, that's a bad and a good thing. But it's just changed me a lot." (Suder 2016 p113), (17-year-old boy with chronic headaches)

Thus, the adolescent expressed some positive changes in himself, but also expressed ambivalence about the impact of pain on his life. This kind of behaviour also speaks to the resilience that these young people built up over time in response to pain as a serious adverse event. Our PPI group confirmed that they had experienced some of the positive consequences described above, except for children and young people having more time for friends. When pain was severe enough to prevent engagement in extracurricular activities it also prevented PPI members from socialising with friends; perhaps their alternative experience was due to differences in their pain conditions and pain severity.

Pain forces families to manage uncertainty

Pain meant children and young people and their families had to manage many uncertainties regarding their changing routines and family life, diagnosis and prognosis, and the child's future prospects, e.g. of finding employment or engaging in education. The child's uncertain future increased fear, and for parents, this was a strong motivator for searching for treatments and cures. For conditions with remission periods, such as low back pain or JIA, fear and uncertainty around when and how intensely they would have a pain flare were always present (Maciver 2005; Jordan 2016), which limited families' activities, as described by this mother:

"Definitely a lot of planning, and you are restricted in an awful lot you can do, so you have to just kind of, each day we know we could maybe go swimming because that's a good thing to do, but if it's a lot of walking we're not going to go there, so you have to just plan ahead, and we don't know if by tomorrow she's going to be in such severe pain that we'll have a day with her friends round to the house, you just have to juggle what each day is going to be like." (Mother of 11-year-old girl with pain from congenital hip dislocation for 3.5 years) (Maciver 2005 p263).

It was hard for children and young people and the family to adapt to the often-fluctuating nature of pain (Britton 2002a; Cartwright 2015).

Pain forces adjustment and adaptation

Family adjustment to moderate to severe chronic pain was a process over time: initially (in the early days of chronic pain) they wanted to hold on to (or return to), what study participants and study authors often referred to as, 'normal' life or 'normality,' i.e. what family life was like prior to the onset of pain (Atkin 2000; Atkin 2001; Atoui 2015; Britton 2002a; Cartwright 2015; Gaughan 2014; Guell 2007; Rossato 2007; Waite-Jones 2008). This finding also resonated with our PPI group.

In response to the pain, families focused on trying to control pain's impact on family life using many strategies, such as gathering information about pain; following treatments (for further details see 'families' experiences and perceptions of specific interventions and treatments'); adjusting their routine to accommodate pain and its management; and self-managing pain to be able to join in activities (Ahlqwist 2012; Forgeron 2008; Guell 2007). Paradoxically, family life then became completely organised around managing and avoiding exacerbating the pain, which subsequently resulted in further restrictions and changes to the whole family that dominated children and young people's childhood (Guell 2007). Children and young people felt like they were losing control over their bodies, routines and daily lives.

Our interpretation indicates that over time, parents and children and young people started to focus more on living well with pain rather than focusing their efforts on finding a cure, although not all families gave up on finding a cure. In general, families tried to resist pain's control, and find balance between managing/controlling pain and having a fulfilling family life (Britton 2002a; Britton 2002b; Guell 2007; Rossato 2007). For instance, parents (mothers) learned to deal with the unpredictability of pain; helped their child to live with their new condition; and developed ways of dealing with the child's fear about the future (Britton 2002a; Britton 2002b; Guell 2007; Rossato 2007). Children and young people found new ways to do daily activities, e.g. using mobility aids (Jones 2020). To regain some control and have quality of life, some children and young people chose to engage in valued activities despite the pain, which was also mentioned by our PPI group (Ahlqwist 2012; Forgeron 2008). As they got older, some adolescents changed their perception of their lack of engagement with activities because of pain as their choice rather than as something out of their control (Jones 2022).

Adolescents, many of whom had daily pain, saw their pain as unavoidable, all encompassing and always present, for instance, a 17-year-old boy with chronic headache described pain as *"it is part of me. Constant"* (Suder 2016 p114). Adolescents with neurological conditions or SCD perceived chronic pain as just another obstacle, as something else they had to deal with (Atkin 2001; Carter 2002b; Castle 2007). Similarly, some parents of children with neurological conditions and other chronic pain conditions saw adversity, such as pain, as part of life and something that was out of their control (Baert 2020; Carter 2002b; Castle 2007).

Over time, some parents and adolescents learnt to adapt to unresolved pain on their own by "getting on with it" (Carter 2002a, p758) because they felt like they had no other choice; they accepted that pain was inescapable and would not go away (Baert 2020; Carter 2002a; Cartwright 2015; Castle 2007; Sorensen 2017; Suder 2016), as this quotation illustrates:

"I figured like you don't have it (pain) and you're lucky, but if I have it I'm just going to get on with it, like you can't, there's nowhere it's going to go, you just have to like overcome it and be brave" (Cartwright 2015, p5), (Female, 13 years, one year since JIA diagnosis).

Families were able to accept and adjust to pain faster when healthcare professionals and services helped set expectations early on regarding treatment and the unlikely probability of a cure (for further details see 'families struggling to navigate health services'). We hypothesise that the effort and challenges involved in adapting to pain's presence might be a reason why families found strategies that helped them to shift their focus solely from controlling/curing the pain to learning to live well with it so helpful (for further details see 'families' experiences and perceptions of specific interventions and treatments').

Pain's influence on disclosure, social support and social relationships

Mothers described longing for others to understand their suffering, yet parents did not always disclose their child's condition to friends and extended family because of its complexity (e.g. CRPS), fear of being judged on their parenting skills or being disbelieved (Gaughan 2014). Mothers also reported difficulties disclosing their child's condition due to concerns around a lack of sympathy for a condition that was not life-threatening (Baert 2020; Jones 2020). This lack of disclosure could be detrimental to how much support parents received from their friends and wider family (Gaughan 2014). Mothers also described having grown apart from friends due to their caring role (Brandelli 2021). However, disclosure did not always lead to social support (Baert 2020; Gaughan 2014). When the family's wider social network of peers, friends and the extended family, such as non-cohabiting grandparents, did provide practical, financial and emotional support this helped parents and children and young people deal with the impact of pain on their lives, enhanced quality of life, and adherence to treatments (Britton 2002a; Cartwright 2015; Waite-Jones 2008).

Children and young people often avoided disclosing their pain, although this was age- and gender-dependent with girls and children under 12 years old being more likely to disclose and share their problems than boys and older children (Britton 2002a; Dyson 2011; Forgeron 2008; Guell 2007; Khanom 2020; Sorensen 2017). Children and young people, including those aged 7 to 10 years old, perceived that other people saw something wrong with them and that they were seen as their illness, which they did not want; they wanted to be seen as 'normal' and healthy by their peers and to belong to a group of friends (Britton 2002a; Cartwright 2015; Guell 2007; Jordan 2018; Suder 2016; Williams 2008), as expressed by this teenage girl:

"I want to do what normal teenagers do and not be reminded of my illness all the time. It keeps my mind off the pain and makes me forget about medication and physiotherapy every now and then. Also people think I am perfectly healthy when I participate in normal things—and that helps me forget about it" (Guell 2007, 2007 p890), (female with JIA).

Contact with peers and friends helped children and young people to feel 'normal' which provided hope and reassurance (Cartwright 2015). The definition of normal behaviour varied with the child's age because they were comparing themselves to their peers (Cartwright 2015; Guell 2007). In adolescence, being like peers was particularly highly valued. Normative constructions of adolescence involve individuation from parents but because of their pain this was delayed in some ways, thus increasing their sense of difference. Hiding and not disclosing their pain meant children and young people could manage how others perceived them to an extent and avoid people's 'disabling responses,' e.g. derogatory comments (Atkin 2001; Atoui 2015; Dyson 2011); however, we hypothesise that non-disclosure might also make children and young people's attachments with their peers and friends less deep and affect their ability to garner social support.

Meeting others with similar conditions helped adolescents with epidermolysis bullosa and JIA feel less isolated because they were able to share experiences and provide mutual support (Cartwright 2015; Williams 2008). In contrast, other adolescents with musculoskeletal pain did not want peer support from others with chronic pain because they did not want to be reminded of their pain or because they believed others would not have similar experiences since their pain was unique (Forgeron 2008). This was particularly reflected in the case of comorbidities. For instance, parents of children with arthritis linked to Down syndrome did not seek support from parents of children without Down syndrome because they believed they would not understand (McDonagh 2021). However, they described their interactions with parents of children with Down syndrome and arthritis as a great comfort and vital source of information (McDonagh 2021).

School and the social realm

School was a major part of most children and young people's lives. Having chronic pain meant difficulties engaging with the school environment, which affected children and young people's relationships with peers and friends, contributed to their lack of support, increased their sense of social isolation and adversely impacted their education, including for younger children under 10 years old (Atkin 2000; Atkin 2001; Atoui 2015; Dyson 2011; Jones 2022). Social isolation was a consequence of recurrent school absences due to pain, which made it difficult to maintain friendships, but was also the result of pain preventing children and young people from engaging with friends when at school (Jones 2022):

'My pain has stopped me from coming into school or being social in school. For example, I may be in a lot of pain and won't want to be a bother to anyone else. (Mark, 16, month two diary)' (Jones 2022, p5).

Most schools practices and policies did not operate in a way that supported children and young people with chronic conditions including chronic pain; this impaired children and young people's learning thus contributing to their uncertainty regarding their future job and further education prospects. Children and young people with SCD and those with JIA had to take special precautions at school, such as avoiding contact sports and crowded spaces, having more toilet breaks and keeping warm, which reinforced their sense of being different and not belonging (Atkin 2001; Atoui 2015; Dyson 2011). Children and young people also had to deal with stigma and the disabling attitudes of others, which were particularly noticeable in accounts of children and young people with epidermolysis bullosa and SCD, such as racism related to SCD (for further details see 'children and families experiencing prejudice and discrimination') (Atkin 2000; Atkin 2001; Williams 2008).

Several Canadian adolescents in a 2008 study reported how struggling academically at school due to their school's failure to modify rules and requirements interfered with their sense of wanting to be 'normal' (Forgeron 2008). In a 2020 UK study, going back to school was a key step to returning to normality and 'normal' life as it provided a refuge from hospital (Khanom 2020). These different experiences might be explained by differences in school policies, procedures and cultures in Canada and the UK or the recency of the studies given that study participants were of similar ages (11 to 17 years old) and all had musculoskeletal pain of similar severity.

Third-order construct: Families struggling to navigate health services

Thirty-six included publications from 32 studies published from 2000 to 2022 contributed data to this third-order construct (Ahlqwist 2012; Atkin 2000; Atkin 2001; Baert 2020; Brandelli 2021; Britton 2002a; Britton 2002b; Brodwall 2018; Carter 2002; Carter 2002a; Carter 2002b; Carter 2017; Dell'Api 2007; Forgeron 2008; Gaughan 2014; Guell 2007; Helvig 2013; Hunt 2003; Jones 2020; Jordan 2007; Kanstrup 2019; Maciver 2005; McDonagh 2021; McKinnon 2022; Neville 2019; Njifon 2019; Nutkiewicz 2008; Renedo 2019; Rossato 2007; Smart 2005; Sorensen 2017; Suder 2016; Wong 2016). Pain conditions in these studies included: unspecified chronic pain, headache, CRPS, mixed pain conditions, neurological conditions, musculoskeletal pain, abdominal pain, JIA and SCD. Studies were conducted in the UK (Atkin 2000; Atkin 2001; Baert 2020; Britton 2002a; Britton 2002b;Carter 2002; Carter 2002a; Carter 2002b; Carter 2017; Guell 2007; Hunt 2003; Jones 2020; Jordan 2007; Maciver 2005; Renedo 2019; Smart 2005), the USA (Gaughan 2014; Helvig 2013; Nutkiewicz 2008; Suder 2016), Canada (Brandelli 2021; Dell'Api 2007; Forgeron 2008; Neville 2019), Norway (Ahlqwist 2012; Brodwall 2018; Sorensen 2017), Sweden (Kanstrup 2019), Australia (Castle 2007; McKinnon 2022), Cameroon (Njifon 2019), Brazil (Rossato 2007), Ireland (McDonagh 2021), and Hong Kong (Wong 2016). There was a lack of data on experiences of social care services.

This third-order construct describes the difficulties families faced when navigating and interacting with health services, including getting stuck in a cycle of continually returning to services in pursuit of a diagnosis and curative treatment. Service fragmentation and numerous referrals without a clear care pathway resulted in frustration, unmet expectations, inadequate pain management and unmet needs. In contrast, a healthcare professional listening to and believing parents and children and young people's experiences of pain could reduce their distress and isolation and provide hope of resolution. This third-order construct comprises four second-order constructs: families' striving for diagnosis and a cure; family expectations of services influence experiences; chasm between health services and families' needs; and the importance of being listened to and believed by healthcare professionals.

Families striving for diagnosis and a cure

At the onset of the child's chronic pain, children and young people and their families initially hoped for and sought out curative treatment based on the assumption that there must be an underlying physical cause for the pain (Brodwall 2018; Carter 2002; Dell'Api 2007; Gaughan 2014; Jordan 2007; Kanstrup 2019; Maciver 2005; Neville 2019; Smart 2005; Sorensen 2017). This desired outcome of a cure motivated families to access health services. For painful chronic conditions, such as JIA and SCD, children and young people and/or parents also often hoped for a cure for the underlying condition (Atkin 2001; Rossato 2007). An exception was a family from Cameroon who believed that a 'cure' would result in the illness (SCD) simply passing to another family member (Njifon 2019).

Parents in high-income countries expected doctors to undertake objective medical tests (e.g. physical examinations, X-rays, high technology scans), which they hoped would reveal the physical cause of their child's pain, to prescribe pharmacological pain management and eventually find a cure (Brodwall 2018; Carter 2002; Dell'Api 2007; Gaughan 2014; Jordan 2007; Kanstrup 2019; Maciver 2005; McDonagh 2021; Neville 2019; Smart 2005; Sorensen 2017). Their expectations of services were frequently unmet, resulting in repeated visits to health services. Some families moved on from their search for a cure - either they gave up on a cure in the absence of one, or were told by healthcare professionals that a cure was unrealistic.

Our interpretation indicates that families searched for a cause and/or diagnostic label as a way to better understand their pain and to enable pain relief treatment or cure. Without a diagnosis, families could not access appropriate services. Many children and young people and families welcomed a diagnosis as proof of a 'genuine' illness (Brodwall 2018; Carter 2002; Guell 2007; Jordan 2007; Maciver 2005; McDonagh 2021; Neville 2019; Smart 2005), a confirmation that their pain was real and could be explained to others (peers and friends). Identifying a cause was important because it indicated the pain was 'real' (not imagined or invented), the pain was not disbelieved by others including healthcare professionals (Gaughan 2014; Maciver 2005; McDonagh 2021; Neville 2019), and it could enable effective treatment (McKinnon 2022). PPI input emphasised that both having a diagnosis and identifying the cause of pain were important, e.g. even with a diagnosis, if the cause is not known then treatment cannot target the cause of pain, although sometimes even when the cause was known there was no effective treatment. Our PPI group indicated that another positive consequence of a diagnosis was when it led to identifying a condition-specific peer support group. Without a known cause of, or diagnosis for, the pain, parents and children and young people worried and feared the cause may be life-threatening, e.g. cancer (Brodwall 2018; Dell'Api 2007; Helvig 2013; Neville 2019); children aged 10 to 12 years old tended to be more fearful than 13- to 16-year-olds that their pain might be life-threatening (Dell'Api 2007).

However, the path to diagnosis was not straightforward, and could lead to families making repeated visits to health services with no satisfactory resolution. Some families gave up on a cure in the absence of one or were told by healthcare professionals that a cure was unrealistic. However, some did not abandon hope of a cure, as this parent of a child with JIA described:

> *"The doctors say that there's no cure, but I'm sure that there is one, I don't believe it's possible that there's no cure for this disease. (F11)"* (Rossato 2007, *p560).*

Healthcare professionals tended to refer children onwards in the search for a cause/diagnosis, often with long referral waiting periods (Carter 2002; Jordan 2007; Maciver 2005; Maciver 2011;

Neville 2019). This meant families went through long periods of uncertainty, which generated more fear, hopelessness and anger. With each new referral families repeatedly experienced raised hopes but no resolution. This resulted in frustration, despair and loss of faith in healthcare professionals and services in what Carter 2002 referred to as 'referral fatigue', as shown in this quotation from a mother of a young person with chronic pain of an unknown cause:

*"After five months we have had no real diagnosis and not much in the way of effective treatment. (Mother, interview)" (*Carter 2002*, p32).*

Families became stuck in a continual cycle of attending and re-attending services in the search for diagnosis and cure. Although the Carter 2002 study is from 2002, the idea of referral fatigue resonated with our PPI group indicating it is still a current issue. This quotation from a 14-year-old girl with probable chronic idiopathic pain syndrome illustrates the frustration of not having a confirmed diagnosis and not having pain relief:

*"(I feel frustrated) probably at the fact that, there's nothing to cure it at the moment like I can't do anything to stop the pain, I can't do anything else, and the fact that it's, I haven't got a firm diagnosis. (P06, F14yrs, CIPS)" (*Khanom 2020*,p1792).*

Sometimes the medical tests and examinations carried out to help establish a cause for the pain were unsatisfactory to parents, e.g. test results revealed no clear cause, or no objective tests were conducted, as this quotation about a doctor from a mother of a child with chronic leg pain illustrates:

*"… I mean how can he see through somebody and say I know you've got a pain in your arm right this minute in time by looking at you? You'd have to do some kind of examination. I mean, is he some kind of magician or something? (FE1)" (*Maciver 2005*, p187).*

The lack of a physical examination of her child within the consultation resulted in this mother lacking confidence in the doctor's diagnosis or explanation. Such unsatisfactory medical encounters could lead families to seek alternative tests.

Even when families received a diagnosis (e.g. pain as a result of JIA, SCD or cerebral palsy), this did not always enable the effective pain management for which families hoped. Notably, children were often left in considerable pain because treatments did not work (cerebral palsy), it was seen as unnecessary to treat the pain (dysmenorrhoea), or when pain fluctuated in severity (musculoskeletal pain) (Castle 2007; Khanom 2020; McDonagh 2021; Wong 2016). Although families often desired a diagnosis for the child's pain symptoms, a diagnosis was not a source of hope for all families, for instance for one family whose daughter had a pre-existing chronic condition, the additional diagnosis of fibromyalgia increased their worry (Maciver 2005). A diagnosis such as 'chronic pain' or CRPS without a known underlying biological cause could also be unsatisfactory to families because it did not help them understand *why* they had pain (Neville 2019).

Our interpretation of the data reveals that families searched for a physical cause that could be cured through biomedical types of intervention reflecting a biomedical conceptualisation of the causes of pain and its management. Indeed, data in several studies provided further supporting evidence that a biomedical model of pain and pain management tended to predominate both in health services and in the minds of families, at least in high-income countries (Brodwall 2018; Carter 2002; Dell'Api 2007; Kanstrup 2019; Maciver 2005; Neville 2019; Nutkiewicz 2008; Sorensen 2017).

There were some refutational data from two studies that revealed that some parents were open to considering a more biopsychosocial (holistic) approach to understanding and managing their child's pain condition, which took into account biological, psychological and social aspects of pain. Indeed, mothers of children and young people with abdominal pain in a UK study accepted the possibility of a psychological basis of pain but they still felt they first had to rule out physical illness via medical consultations (Smart 2005). Furthermore, parents undergoing family Acceptance and Commitment Therapy in Sweden for their child's longstanding disabling pain conditions were open to a biopsychosocial model of pain (Kanstrup 2019). It is unclear why some mothers of children and young people with abdominal pain were open to biopsychosocial explanations. Some specialist pain services/treatments, like Acceptance and Commitment Therapy, helped parents to shift their understanding to a biopsychosocial model, which could alter their expectations of what treatment could achieve and allow them to shift their focus from a cure to ways to manage and live with the pain (Kanstrup 2019).

Family expectations of services influence experiences

When family expectations of services were not met, they became frustrated, angry and lost trust in services (Atkin 2000; Atkin 2001; Baert 2020; Carter 2002; Carter 2002a; Dell'Api 2007; Maciver 2005; Maciver 2011; Renedo 2019; Suder 2016). The complexity of navigating the healthcare systems had negative impacts on families as it left them to deal with the pain on their own. Indeed, when families perceived the outcome of accessing health services to be unsatisfactory (e.g. poor pain management or a lack of explanation for the pain), families would return to services, seek out alternative services and/or self-manage the pain as best they could with over-the-counter medications and self-care like rest, sleep, hot water bottles etc. (for further details see 'families managing pain independently') (Helvig 2013; Renedo 2019; Wong 2016).

Participants in some studies had experienced inpatient pain management programmes or specialist outpatient pain services with varied results (Jordan 2016; Jordan 2018; Maciver 2005; Maciver 2011; Suder 2016). In-patients with CRPS in one study had their expectations of a cure raised by professionals but cure was not achieved (Maciver 2005), as described by the mother of a child with CRPS:

*"… that's what I was told would happen, I wanted them to cure her because they told me they could cure her. (Mother 3)" (*Maciver 2005*, p223).*

These raised expectations negatively impacted how families experienced that particular programme, highlighting the important role of healthcare professionals setting expectations as part of pain management. Management of family expectations of treatments and effective communication by health professionals were important for effective treatment and to support families' psychosocial needs - it resulted in a trusting relationship (Baert 2020; Carter 2002; Carter 2002a; Dell'Api 2007; Maciver 2005; Maciver 2010; Suder 2016). Some members of our PPI group said that they wished healthcare professionals had managed their expectations from the outset, for example by telling them that there was no cure; this would have helped them focus sooner on ways to manage the pain instead and might have avoided the financial cost of the constant search for a cure as some of them tried various privately paid for treatment alternatives and medications.

Chasm between health services and families' needs

Children and young people and parents described that general practitioners (GPs) and other health professionals did not always manage the chronic pain effectively (Brodwall 2018; Smart 2005). Accounts from children and young people with SCD and parents of children and young people with Down syndrome or SCD highlighted that ineffective pain management often resulted from the lack of knowledge and awareness about pain associated with these genetic conditions amongst non-specialist healthcare professionals (Atkin 2000; McDonagh 2021; Renedo 2019), but also from discrimination (for further details see 'children and families experiencing prejudice and discrimination'). Parents of children with complex conditions, such as cerebral palsy, mentioned that (allied) healthcare professionals offered limited time for pain management as their focus was on other aspects of treatment (McDonagh 2021; McKinnon 2022). Young people also felt the healthcare professionals were sceptical about their pain severity and pain experiences causing them to feel "ignored", "abandoned" (Renedo 2019, p4), judged and misunderstood (Carter 2002; Renedo 2019). Children and young people also felt that healthcare professionals judged their pain relief needs based on how the children and young people expressed chronic pain, which might be different from how children and young people express acute pain. Some families said that general practitioners, emergency departments and general hospital wards had refused to prescribe analgesics (Carter 2002; Jordan 2007; Maciver 2005; Neville 2019; Renedo 2019), as illustrated by this quotation from a young person with SCD who had attended the general hospital:

*"It was a bad experience really (being on the ward) (…) The doctors just didn't really believe… not believe, but they thought I was like, faking, or like doing it to get medication (analgesia) as if I, like, was addicted to medication. (…) But I can be laughing but still in pain and that's what people need to understand, like nurses and doctors and even people in general: that I can be in pain, anyone can be in pain and, like, still be laughing because we know how to… people, like kids or, you know, kids know how to deal with the pain and we just try to distract ourselves. (O1 13-15 years old)" (*Renedo 2019*, p4).*

Gender bias also was present within the pain management approaches in one study. For instance, young girls with dysmenorrhoea were left with no adequate pain management as described in a study from Hong Kong. The majority of girls in the Hong Kong study did not trust Western medicine and used Chinese medicine or self-management techniques instead. Some girls did seek out Western medical practitioners as they did not receive help elsewhere, if the pain was so severe that it made them faint, or/and they wanted quick relief of symptoms by taking pharmacological medication rather than traditional Chinese medicines (Wong 2016). However, their pain was trivialised by Western doctors, as the girls were told that there was no cure and that it was 'normal pain' to be endured (Wong 2016).

There were also other reasons for poor chronic pain management. For children with underlying chronic conditions, sometimes treatment for the child's pain fell between gaps in clinical specialisms due to disjointed or siloed organisation of care, as this mother of a child with a neurological condition explained:

*"The specialists just look at the bit they're interested in; it's up to me to put it all together. The neuro are interested in epilepsy, and the gastro in his stomach but no-one is really responsible for tackling his pain. (M3)" (*Carter 2017*, p7).*

This fragmented care was frustrating for parents whose expert knowledge in assessing their child's pain was not always acknowledged by health professionals. Specifically, parents perceived that their expertise in assessing their child's pain, particularly for younger children and those with communication difficulties caused by neurological or genetic conditions, was not always recognised by health professionals: the underlying (e.g. neurological) condition was the professionals' focus rather than the whole child, meaning their pain was overlooked and not treated (Carter 2002b; Carter 2017; Hunt 2003; Maciver 2005; McDonagh 2021; McKinnon 2022). Parents' expert knowledge of their child's pain and lived experiences placed them in a position to advocate for their child when interacting with health services; they often felt they had to fight for effective pain management, resources and answers (Brandelli 2021; Jordan 2007; Maciver 2005; McDonagh 2021; McKinnon 2022):

*"'We realised that as parents we've all had to fight an awful lot to get our children anywhere, to get them diagnosed, to get them recognised, to get them treated ... If they had other parents who were ... less confident and less bolshy (assertive), then they would still be on the sofa at home in constant pain ... probably slashing their wrists by now,'' (participant 1, focus group 1)." (*Jordan 2007*, p52).*

Health services were sometimes portrayed as a different world for which parents needed a new vocabulary in order to navigate this world effectively and to be taken seriously by health professionals (Guell 2007). Parents felt that learning medical terminology associated with illness and treatments gave them more control over medical encounters (Guell 2007).

Being referred to a pain clinic could 'validate' the pain (i.e. confirm it was a real illness) and be a source of hope, and emotional and practical support when the healthcare professionals 'listened' (Baert 2020; Carter 2002; Jordan 2007; Maciver 2005; Maciver 2011; Suder 2016). It could, however, be very difficult to get referred to a pain specialist or specialist pain service (Carter 2017; Hunt 2003). In one USA study, children and young people aged 10 to 18 years old had consulted on average eight different doctors prior to being evaluated at a paediatric pain clinic (Nutkiewicz 2008). Difficulties navigating health services, in addition to the difficulties/challenges around receiving contradictory advice and guidance from health professionals, led families to seek out their own information, e.g. on the Internet, which could be helpful or distressing (Britton 2002b; Maciver 2005; Sorensen 2017).

In addition, the transition from children's to adult health services could be worrying and difficult for young people, which in many high-income countries happens around the age of 18 years old (Forgeron 2008; Renedo 2019). Young people aged 13 to 17 years old with musculoskeletal pain expressed negative feelings at the thought of moving to adult services and our interpretation is that they were likely to need psychological/emotional preparation for the move; one author suggested a gradual shift to independence in managing their care (Forgeron 2008). During transition to adult services, children and young people with SCD had experienced adult wards as 'unwelcoming' and had poor care during unscheduled hospital visits and non-specialist hospital wards for painful episodes (Renedo 2019). Our PPI group offered another perspective: having had poor experiences of paediatric services, some had decided to wait for treatment until they were old enough to use specialist adult services, which they perceived as far better.

Importance of being listened to and believed by healthcare professionals

Interactions with healthcare professionals were often a source of dissatisfaction and stress for many families. Children and young people perceived that professionals ignored their experiences of living with pain (Nutkiewicz 2008) and had ‘given up’ on them (Carter 2002; Maciver 2005; Maciver 2011; Sorensen 2017). Mothers felt that the emotional impact their child’s treatment had on them was rarely addressed during medical appointments (Brandelli 2021). Parents, particularly mothers, also felt they were being blamed for their child’s pain when there was no obvious cause for the pain, when healthcare professionals indicated the cause might be psychosocial (Baert 2020; Brodwall 2018; Carter 2002; Maciver 2005; Maciver 2011; McDonagh 2021; Smart 2005; Sorensen 2017), and/or that their child’s pain was not believed (Britton 2002a; Brodwall 2018; McDonagh 2021; Smart 2005), as this diary extract for a child with abdominal pain reveals:

“I’ve had pain in my stomach for nearly two years. It seems much longer ... One doctor told me that what she was seeing on examination and what she was being told were two different things. I was 11, and knew that I was being accused of lying. This made me really angry, because it didn’t help the pain (it actually got worse) and it really hurt me to be called a liar when the pain was very real. (Child, diary)” (Carter 2002, p34).

Parents and children and young people highly valued healthcare professionals who listened to and understood the impact chronic pain had on them and their family life, i.e. a healthcare professional who showed empathy. The experience of being listened to by a healthcare professional could reduce distress and isolation and provide hope for parents and children and young people (Castle 2007; Hunt 2003). This quotation from a mother of a child with CRPS conveys the importance of healthcare professional empathy:

“A good professional? Somebody who will also listen as well as give a medical opinion, somebody who doesn’t turn around and make you feel two inches tall when you try to tell them how your lifestyle is. (FE2)” (Maciver 2005, p186).

Being believed by the healthcare professional was also key. Pain was difficult for children and young people to describe in words and for them and others to understand because it is invisible (Suder 2016), which was corroborated by our PPI group. In the third-order construct ‘Families managing pain independently’ we show that not being listened to and believed can create a lack of control/autonomy over how to manage the pain – this could result in children and young people resorting to often ineffective self-management strategies.

Third-order construct: Families managing pain independently

Thirteen studies contributed to this construct (Atkin 2000; Atkin 2001; Brandelli 2021; Brodwall 2018; Carter 2002b; Carter 2017; Helvig 2013; Hunt 2003; McKinnon 2022; Renedo 2019; Smart 2005; Williams 2008; Wong 2016), which covered six conditions: SCD, headache, epidermolysis bullosa, abdominal pain, dysmenorrhoea and neurological conditions. There are gaps in our understanding of families’ management of children’s pain because there were few relevant data in the studies and many of the data were not very rich. This third-order construct is composed of data from two second-order constructs, which are focused on how families manage pain independently: pain self-management, and parents helping children and young people to manage pain.

Pain self-management

Self-care and self-management of pain occurred across a range of environments - at home, at school and even in the hospital (Atkin 2000; Atkin 2001; Renedo 2019). Children and young people and families decided to manage pain on their own for multiple reasons, and it usually occurred when:

1. they disengaged with unsatisfactory services that were unwelcoming and/or provided poor pain management;
2. as a supplement to, or when they had no effective, prescribed medical treatments (McKinnon 2022; Wong 2016); or
3. when they chose not to consult a doctor at all, e.g. for dysmenorrhoea (Wong 2016) or headache (Helvig 2013).

The decision to self-manage pain could give children and young people a higher level of autonomy in deciding how and when their pain was managed, which we interpret to indicate the need for services, e.g. hospitals, to flexibly support all kinds of pain management, including self-management, to support children and young people’s autonomy in pain management. In some instances, children and young people preferred to manage their pain at home, where they had access to resources (such as their own bed, hot water bottles, hot baths, television for distraction, family support etc.), which helped them to deal with their pain on their own (Atkin 2000; Atkin 2001; Renedo 2019).

Self-management of pain involved a lot of trial and error. Over time, with more experience and knowledge, children and young people’s pain self-management strategies improved, e.g. they learned what worked in terms of pain medications, self-massage, ointments, breathing techniques or distraction. Children and young people also learnt to differentiate different types of pain, which enabled them to understand what kind of pain relief was needed, as described by this young person:

“Only a few years ago, that’s when I was able to kind of cope better, and I had a better understanding of the kind of medicine I need, and if I need like the strongest out of the painkillers or just like a little bit. So I kind of developed and kind of grew on to how to take care of it myself. Until I reached this point, where I feel like I don’t need to go hospital sometimes, or sometimes I do, then... And as you grow older you’re going to be able to know the different types of pain also, like if it’s going to be a mild crisis, or if it’s going to be a really severe crisis.” (Female 16 to 18 years old, SCD) (Renedo 2019, p7).

However, children’s self-management of pain did not always work well, for example when pain was severe and the strategies ineffective, e.g. attempting to manage a vaso-occlusive SCD pain crisis with paracetamol or hot baths. Self-management and self-care were also affected by organisational policies, such as school policies that did not allow children to leave the classroom or be excused from physical education (also refer to 'prejudice and discrimination at school'), and lack of resources, e.g. hot baths in hospitals. Some children were unable to effectively self-manage because of the emotional and physical impact of the underlying condition causing pain (Atkin 2000; Atkin 2001; Renedo 2019; Williams 2008).

Parents helping children and young people to manage pain

Our interpretation reveals that parents, usually mothers, felt responsible for, and had an important role in, helping children and young people to recognise and self-manage their pain, supporting preventative self-care, and, if necessary, e.g. in the case of younger children and those with neurological conditions, managing pain on their child's behalf. Parents developed strategies to help their child manage pain at home, for example, they were fundamental in helping their child recognise different types of pain and thus selecting the most appropriate pain management strategy (Renedo 2019). Parents also used distraction and reward with their child during pain episodes and helped their child avoid pain triggers (Brodwall 2018; Smart 2005). They interpreted their child's non-verbal pain cues in order to assist with pain management, particularly for children with neurological conditions or learning disabilities who could not verbally communicate their pain, and girls with dysmenorrhoea, who were embarrassed to directly communicate their pain (Carter 2002b; Carter 2017; Hunt 2003; McDonagh 2021; McKinnon 2022; Wong 2016). Mothers in Hong Kong provided home remedies for their daughter's dysmenorrhoea (Wong 2016). Parental involvement ranged from very little (ignoring the pain as a management strategy to avoid positively reinforcing the pain) to extensive, depending on the complexity of the condition and the child's age. For example, mothers noticed that their constant involvement in treatment decisions for complex conditions such as JIA adversely affected the development of their child's self-management skills, consequently reducing the child's autonomy in managing their pain (Brandelli 2021).

Helping their child manage pain could involve parents (e.g. of children with neurological conditions) making difficult decisions on their own, such as finding a balance between managing pain and the child joining in family activities/routines, as this quotation illustrates:

"She's in less pain when she's in bed but that's not a life, just being in bed. She needs to be part of the family, up in her chair and being with us. That's a trade off." (Mother of 11-year-old girl with nerve pain) (Carter 2017, p8).

Deciding whether and how much medication to administer at home was often a dilemma for parents because side effects could interfere with the child's participation in family life and/or cause health problems (Carter 2002b; Carter 2017; McKinnon 2022). Parents often expressed feeling left on their own to make decisions with little help from health professionals (for further details see 'families struggling to navigate health services').

Third-order construct: Families' experiences and perceptions of specific interventions and treatments

Twelve studies contributed to this third-order construct (Ahlqwist 2012; Britton 2002b; Borghi 2014; Brandelli 2021; Carter 2002a; Gaughan 2014; Kanstrup 2019; Maciver 2005; McKinnon 2022; Nutkiewicz 2008; Sorensen 2017), covering the following conditions: JIA; musculoskeletal pain; CRPS; cerebral palsy (dyskinesia); epidermolysis bullosa; mixed pain conditions including rarer conditions such as osteogenesis imperfecta; unspecified chronic pain; or chronic pain from any cause. This third-order construct comprises two second-order constructs: experiences and perceptions of interventions and treatments, and adherence to and engagement with interventions and treatments.

Relevant data were limited, largely descriptive and heterogeneous, which adversely affected our ability to fully develop a coherent conceptual understanding. Overall, there was a lack of rich data in studies about family attitudes to and experiences of pain treatments. Studies focused on Acceptance and Commitment Therapy (ACT), a cognitive behavioural therapy (Kanstrup 2019); physiotherapy for musculoskeletal pain (Ahlqwist 2012); daily physiotherapy, splinting and medication for JIA (Britton 2002b); pharmacologic and nonpharmacologic JIA treatments (Brandelli 2021); interdisciplinary intensive pain treatment at specialist pain clinics/programmes for children and young people with CRPS or a range of painful conditions (Borghi 2014; Carter 2002; Carter 2002a; Gaughan 2014; Maciver 2005; Nutkiewicz 2008; Sorensen 2017); and complementary treatments such, as chiropractors, massage and mindfulness, used to help reduce pain associated with dyskinesia in cerebral palsy (McKinnon 2022).

Experiences and perceptions of interventions and treatments

Parents valued help with adapting their parenting skills and gaining information about the pain and how to better help their child (with CRPS and undiagnosed pain) (Gaughan 2014; Kanstrup 2019). Children and young people also appreciated gaining information about pain and having more autonomy in their pain management (Ahlqwist 2012; Kanstrup 2019) (for further details see 'families managing pain independently'). For example, physiotherapy treatments that helped children and young people with low back pain to develop an awareness of their bodies and capabilities gave them a greater understanding of their pain, which helped to reduce their fear of exercise and facilitated physiotherapy treatment (Ahlqwist 2012). Children and young people with longstanding disabling pain conditions valued strategies, learned through ACT, which helped them change the focus from reducing pain to learning how to live with it (Kanstrup 2019); specifically, this shifted their focus away from curative approaches, which was valued by children and young people as expressed through this account (see also 'pain forces adjustment and adaptation' in Section 4.6.1):

"After so many doctor's appointments you end up so focused on just getting rid of it, and now it's more like 'You're still going to feel pain and it'll still hurt when you do stuff but it's ok." (Kanstrup 2019, p16) (female with unspecified pain).

Children and young people with unspecified pain and their parents also valued ACT treatment because the group interaction with others with similar conditions helped them to feel less isolated, and to appreciate their individual differences (this links to 'pain organises the family system and the social realm') (Kanstrup 2019). Group ACT treatment also helped families to learn from how others pareonted when their child had pain:

"When you've got a sick child you become incredible overprotective er and that might not always be of benefit to your child, they do need to be allowed to live their own lives and do exciting things, and this other mum that I met, she let her daughter go inter-railing, with her sister I should add, but still, at that age, I thought was really cool, and it made me think, yeah, it makes sense." (Kanstrup 2019, p16) (mother of child with unspecified pain).

However, treatment in a group setting could lead to a sense of guilt in children and young people when confronted with others with more severe pain (Kanstrup 2019). Our interpretation indicates that the experiences and perceptions of children and young people and parents of specific interventions or treatments seem to be related, at least in part, to how well these addressed the negative impacts of pain on the family and their social realm (this links to 'pain organises the family system and the social realm').

Adherence to and engagement with interventions and treatments

Children and young people wanted tailored treatments from pain clinics (Nutkiewicz 2008), which they did not feel they received. Pain-causing therapies, e.g. physiotherapy or injections for JIA, or those with unpleasant side effects, seemed counter-intuitive to parents and caused the family extreme distress (Brandelli 2021; Britton 2002b; Maciver 2005; McKinnon 2022). Concerns over side effects are expressed by this parent of a child with cerebral palsy:

"It is a real hard process when a new medication is introduced ... He can't tell me if he's not feeling well; he can't tell me if he's sad. I do not need the extra stress of a medication being disruptive in our life. (Caregiver I)" (McKinnon 2022, p76).

Parents were essential to ensuring their child was adhering to pain management treatments at home (for further details see 'adapted parenting' and 'families managing pain independently'). This was particularly relevant for conditions such as JIA, which involved painful treatments that had to be administered and reinforced by parents (Brandelli 2021; Britton 2002b), as described by this mother:

"It's painful, very painful at times. You can see it's painful, but you've got to make her do it or you've got to do it for her. I think there's no choice in it. I've got no choice and she's got no choice." (Britton 2002b, p455) (mother of child with JIA).

However, not all parents enforced treatment adherence. Medication side effects and treatments that were monotonous and repetitive, painful and/or time-consuming negatively affected adherence (Borghi 2014; Brandelli 2021; Britton 2002b; Carter 2002a; McKinnon 2022); as described in 'pain organises the family system and the social realm', time-consuming management strategies were an important factor contributing to pain organising family life. Parents of children and young people with JIA and CRPS decided to what extent their child would follow a prescribed pain management treatment based on its impact, including side effects and the effect on family life and activities, versus the perceived treatment benefits (Brandelli 2021; Britton 2002b; Gaughan 2014; McKinnon 2022). This quotation illustrates a mother's dilemma:

'"... I think we could deal with the side effects easier if it was working. But when you see your child suffering with side effects for nothing it feels very pointless" (mother B, 12-year-old girl).' (Brandelli 2021, p6).

Families were more likely to follow a treatment programme if it was associated with reduction in pain and increased autonomy of the child (Brandelli 2021; Britton 2002b), as shown in this quotation from a mother of a girl with JIA:

"Her arthritis symptoms had settled down and she was doing much better, so I actually just stopped the medication. I was just like, 'I can't do this' because she was like the exorcist (horror film). I would give her the medication, and she would just barf (vomit) everywhere. And I figured she's not getting any of this. You know, I was very frustrated, I guess. And so we stopped the medication, and within 2 months, 3 months she had a big flare and needed joint injections again. So I learned my lesson" (mother A, 12-year-old girl) (Brandelli 2021, p6).

Thus, sometimes parents only recognised the value of a treatment after stopping it.

Some families rejected psychological treatments, which they perceived as stigmatising, for example, because they thought it indicated that healthcare professionals did not believe their pain was real. For many families, they only considered using psychological therapies after other medical treatments had failed (Carter 2002; Maciver 2005; Sorensen 2017). In sum, parents had a key role to play in their child's adherence to, and engagement with, treatment but aspects of the treatments, such as impacts on family life, could adversely affect adherence.

Third-order construct: Children and families experiencing prejudice and discrimination

This is a cross-cutting third-order construct that applies across the other third-order constructs, so we present it separately here and refer to it throughout the results section, as appropriate. Seventeen studies (reported in 18 publications) focusing on SCD, epidermolysis bullosa, JIA, dysmenorrhoea and abdominal pain contributed to this concept (Atkin 2000; Atkin 2001; Atoui 2015; Britton 2002a; Britton 2002b; Brodwall 2018; Cartwright 2015; Dyson 2011; Guell 2007; Jordan 2016; Maciver 2005; McDonagh 2021; Njifon 2019; Renedo 2019; Rossato 2007; Smart 2005; Waite-Jones 2008; Williams 2008; Wong 2016).

Children and families experiencing prejudice and discrimination was most apparent for children and young people with SCD (mainly in high-income countries) – in terms of experiencing racism in particular – and for children and young people with visible differences due to their condition or with a learning disability. Visible differences were apparent in children with JIA, whose mobility was affected (e.g. Waite-Jones 2008), and epidermolysis bullosa who often had visible severe blisters (Williams 2008). One study focused on children with Down syndrome and JIA (McDonagh 2021). Children and young people with SCD, mostly from African and Caribbean ethnic groups, reported not receiving timely and adequate pain relief, which they explained with reference to institutionally racist practices within the health service (Renedo 2019). However, prejudice and discrimination also applied to other less 'visible' chronic pain conditions, such as sexist attitudes of healthcare professionals to dysmenorrhoea (Wong 2016).

Discrimination and racism in health services

Children and young people with SCD and their parents experienced racist attitudes and behaviours in UK health services – this was apparent in three studies from 2000, 2001 and 2019 (Atkin 2000; Atkin 2001; Renedo 2019). Parents perceived that poor service delivery for SCD in the UK as compared to services for other common genetic conditions - including healthcare professionals having poor knowledge of SCD and failing to convey even basic information to families about SCD - was related to institutional racism (Atkin 2000), as described by the study author:

"Notions of racially-motivated unfavourable behaviour, negative attitudes and disinterest in a 'black' condition were implicit in many parents' accounts. For example some parents - mainly African-

*Caribbean - felt that if haemoglobinopathies affected more white children, there would be better service delivery. Mrs Prince compared the services available for what she regarded as a 'white' genetic condition, cystic fibrosis and those available to those with an SCD." (*Atkin 2000*, p65).*

Furthermore, inadequate pain control was a constant problem to which racism likely contributed (Atkin 2000; Atkin 2001), as shown in this excerpt of the study author's interpretation:

*"Racism can contribute to poor pain control and means that one of most distressful aspects of the illness remains untreated. Stereotypes of minority ethnic patients having a lower pain threshold are rife in the health services (Bowler 1993) and may be used to justify a lack of pain relief (Atkin et al. 1998). The lack of treatment can also be justified by another racial myth. Some people with SCD require powerful drugs for the control of pain. However, some doctors worry about their African-Caribbean patients becoming dependant on drugs (Stimmel 1993) and this can contribute to the significant under-treatment of pain." (*Atkin 2000*, p65).*

In the light of Atkin 2000 and Atkin 2001's analysis, we observed that racism was apparent in Renedo 2019's study, as shown is this excerpt:

*"These participants told us they felt judged and misunderstood. Some said they felt that they were perceived to be liars or "drug addicts" (O1). I6 said he overheard nurses talking about his pain not being that bad ("he just wants some morphine") but he did not complain about it, because "when you need help (…) you just accept it." (*Renedo 2019*, p4). (NB this quotation includes interpretation from the study authors).*

Although not labelled explicitly as racism by the authors or the study participants, examples of discriminatory attitudes included lack of respectful care for African-Caribbean children and young people in emergency departments and general hospital wards, healthcare professionals disbelieving the pain severity of SCD, not acknowledging requests for pain relief and not prescribing opioids when required (Renedo 2019) (which are part of the treatment recommendations for SCD in UK clinical guidelines (NICE 2012)).

"When I was in … admitted (…) they would like sometimes say, uh there's nothing wrong with her, uh she's lying about her illness (…) It was difficult especially 'cause I was in pain, like, I dunno… Why I would lie about something about coming to hospital? It doesn't even make sense. (Z1 16-18 years old)" (Renedo 2019, p4).

Parents of children with Down syndrome and JIA also perceived discrimination from healthcare professionals in a study in Ireland (McDonagh 2021). Parents of nonverbal children and young people with Down syndrome felt that their child was treated differently in comparison to other children resulting in them being excluded from services and ineffective pain management (McDonagh 2021). These parents described the GP as 'their biggest hurdle' (McDonagh 2021, p4) and perceived healthcare professional attitudes as dismissive and complacent, as elucidated by this parent:

"(He was not being examined) literally because he has Down syndrome. (…) I said, 'I still want to know what's wrong with him because maybe it will help us treat him,'… but they literally say, 'Well, he has a diagnosis (of Down syndrome).' (Blake)"(McDonagh 2021, p4).

Thus, it is evident that the parent perceived the doctor to be focused on the child's genetic condition at the expense of investigating possible chronic pain. Parents perceived that the services and care their child received were inferior compared to children without Down syndrome and that nonverbal children with Down syndrome received worse care than verbal children with Down syndrome, thus highlighting disability-related discrimination (McDonagh 2021).

Prejudice and discrimination at school

At school, children and young people with SCD and JIA encountered discrimination in the form of school policies and rules, and the attitudes of teachers and other pupils (Atkin 2001; Atoui 2015; Dyson 2011; Waite-Jones 2008). Having SCD pain (and other symptoms like fatigue) made learning challenging even when children and young people were present at school; school policies compounded this by not facilitating inclusion, e.g. children and young people did not receive help to catch up on missed schoolwork, were prevented from staying sufficiently hydrated and warm to avoid painful crises, and their need for frequent toilet breaks was not recognised or facilitated (Atoui 2015; Dyson 2011). In contrast, other children and young people with JIA, which is more prevalent amongst Caucasians, reported accommodations being made at school such as exemption from physical education (Britton 2002a; Guell 2007; Waite-Jones 2008).

At school, children and young people with SCD reported experiencing bullying, not being accepted, being judged and discriminated against by peers, including peer disbelief in their SCD pain (Dyson 2011). A study from 2001 reported children and young people also experienced their peers'/social network's general ignorance and prejudice about their condition including some people associating SCD with HIV/AIDS because they assumed that all people with blood disorders would be infected with HIV/AIDs from blood transfusions (Atkin 2001) - it is unclear whether this kind of assumption is a current issue since it was not mentioned in a more recent study (Renedo 2019). Prejudice and discrimination negatively affected children and young people's sense of identity and discouraged them from telling others about their SCD condition (Atkin 2001).

Bullying, teachers' disbelief of children and young people's pain, and unsupportive school policies made it harder for children to catch up on schoolwork and self-manage pain (Atkin 2001; Atoui 2015; Dyson 2011). Younger children found it harder to deal with discriminatory behaviour than older children and young people who were more used to it (and so had had time to develop coping mechanisms) (Atkin 2001). Perceived racism and discrimination in schools undermined children and young people's with SCD trust in these institutions and their staff and potentially undermined their abilities to self-care to avoid triggering pain (Atoui 2015; Dyson 2011; Renedo 2019), and to succeed at school (Atoui 2015; Dyson 2011).

Children and young people with SCD also experienced institutionalised racism in school, which was not directly linked to their condition, but which compounded their difficulties in succeeding at school, for example some teachers expected African Caribbeans to achieve less at school and to get poorly paid jobs (Atkin 2001). Only one SCD study, conducted in Lebanon (Atoui 2015), did not find evidence of bullying and marginalisation of children and young people at school, but the authors surmised that adolescents might have been reluctant to disclose any bullying or children in Lebanon are more accepting of disabled people. Alternatively, we propose that the relatively high prevalence of SCD in Lebanon might have contributed to a higher degree of awareness and acceptance than in the UK.

Such experiences extend beyond SCD. Siblings of children with JIA also experienced stigma and bullying from peers due to their sibling's health condition and witnessed their sibling with JIA being bullied (Britton 2002a; Waite-Jones 2008). Children and young people with epidermolysis bullosa also conveyed experiences of prejudice and stigma, for instance the peers of a teenage girl with epidermolysis bullosa ridiculed her school absence (Williams 2008):

*"she's been off for all this time cos her feet hurt". (Female, age 14) (*Williams 2008*, P76).*

Those with epidermolysis bullosa reported negative treatment from others, e.g. being stared at due to their blisters or because of mobility issues and, perhaps as a result, many suggested that their appearance was more important to them than the chronic pain associated with the condition.

Pain prevented them from doing physical activity and from walking normally and, consequently, they perceived that others did not see them as a 'proper person':

*"Kerry: Some people might think that I'm not a full person cos I can't do anything, do like all the things that other people can do. Cos I'm not like them they think that I don't count as a proper person." (*Williams 2008*, p47).*

Furthermore, the fluctuating nature of the skin condition meant others disbelieved the realness of their condition (Williams 2008). Disbelief in pain could be considered a form of prejudice.

Sex and inequality

Most studies did not conduct an in-depth gendered analysis, although a few studies identified some (subtle) sex differences between boys and girls with chronic pain (Atkin 2001; Atoui 2015; Njifon 2019; Sorensen 2017). Adolescent girls were more likely than adolescent boys to disclose their pain to and share their problems with friends in order to access social support (Atkin 2001; Sorensen 2017). Older adolescent boys were more likely to dissociate from illness as a way to cope, believing talking was futile because it did not change anything (Atkin 2001). The way adolescent girls and boys expressed their pain differed as girls tended to communicate it more openly through their feelings, e.g. crying, shouting or roaring out their pain, to help them cope emotionally (Sorensen 2017). In contrast, older adolescent boys regarded emotional responses such as crying as "a threat to their masculinity" and they felt guilty when they did cry (Atkin 2001, p622).

We identified that sexism was apparent in a Hong Kong study of dysmenorrhoea in which girls did not receive pain relief from Western doctors who portrayed the condition as 'normal' (Wong 2016) (described in more detail in 'families struggling to navigate health services'). Societal and cultural norms influenced their perceptions and understandings of pain – girls with dysmenorrhoea viewed their condition as something normal that they had to endure, a view that was reinforced and perpetuated by healthcare professionals (Wong 2016). Consequently, many girls only sought medical help if the pain was so severe that it made them faint (Wong 2016).

We identified that sex inequality in caring responsibilities was apparent in many studies from a range of countries, including LMICs, in which mothers did most of the work related to pain (Atkin 2001; Atoui 2015; Brodwall 2018; Cartwright 2015; Guell 2007; Jordan 2016; Maciver 2005; Njifon 2019; Rossato 2007; Smart 2005; Waite-Jones 2008; Williams 2008) – this is a bigger social issue that affects the experience of caring. This does not mean that fathers were unaffected by or uninvolved in caregiving - one study that focused on fathers (n = 6) of adolescents with chronic pain found that they also experienced difficulties achieving a balance between the competing demands of family needs, caregiving and work, even if they were not the main caregiver (Jordan 2016).

Lines of argument

We developed three interpretive lines of argument that link together the key findings from the third-order constructs into overarching 'storylines' or explanations:

- Dominance of biomedical perspective in how children and families conceptualised chronic pain and pain management
- Parents fundamental to effective pain management
- The journey of living with chronic pain

We then linked the three lines of argument into a model of families navigating chronic pain management.

Line of argument: dominance of biomedical perspective in how children and families conceptualised chronic pain and pain management

This line of argument pulls together data from the third-order and second-order constructs to show there were differences between how children and young people and their families conceptualised:

1. the impacts and experience of living with chronic pain, compared to
2. how they understood the cause of pain, and
3. how they understood the role of health services in management of the pain.

In terms of living with chronic pain, children and young people and their families described experiencing mainly negative physical, social and emotional impacts on their lives, such as the impact of pain on family life, social life, schooling and parental employment (as described in the third-order construct 'pain organises the family system and the social realm'). Thus, it can be seen that children and young people and their families expressed physical/biological, psychological and social impacts of chronic pain on their lives, which is consistent with a biopsychosocial model of pain.

Despite families recognising biopsychosocial *impacts* of pain, children and young people and parents tended to understand the *cause* of chronic pain, at least initially, as solely biomedical, i.e. pain has an underlying pathophysiological cause that can be identified, treated and/or cured. Families were not usually readily receptive to the idea of any psychosocial *causes* of, or influences on, chronic pain because they believed it implied that the pain was not 'real' or that parents were to blame for their child's pain, e.g. because of a dysfunctional family life or poor parenting. Consequently, many families did not want or understand the point of psychological pain treatment and saw it as stigmatising and a last choice. An exception is that some mothers of children with abdominal pain were open to the existence of psychosocial causes/influences, although it is not clear why (described in 'families striving for diagnosis and a cure'). It was mainly families for whom there was no identifiable or known medical cause of pain (which does not necessarily mean there was no biological cause) who were asked to consider possible psychosocial causes of pain. For children whose pain was caused by an underlying health condition, such as SCD, JIA or cerebral palsy, families were less likely to consider psychosocial causes of, or influences on, pain; these families may not have seen the value of psychosocial treatments either, given the cause of pain was a disease.

How children and young people and families initially conceptualised the role of health services in managing the chronic pain was based on a biomedical understanding that shaped their expectations of, and interactions with, services. Specifically, children and young people and families sought to find an underlying biomedical cause in order to access curative or palliative treatment (as described in the third-order construct 'families struggling to navigate health services'). Families who already knew the cause of pain was a disease also sought biomedical pain relief and in some cases a cure for the underlying disease from services. Some families did, however, want support with psychosocial impacts of pain on their lives but did not expect or recognise that health services might provide such support. In interactions with health services, this desire for biomedical treatment for chronic pain created a medical focus for families, and for healthcare professionals. However, their biomedical conceptualisation of the causes and appropriate treatment of pain was not static and could change over time. For example, families could realise over time that repeated clinical tests could not identify a physical cause and/or medical treatments did not resolve the pain, or they were told by healthcare professionals that no cause could be found, and/or there was no treatment or cure. (Even when an underlying physical cause had been identified, treatment could be ineffective or there could be no suitable treatment).

Line of argument: Parents fundamental to effective pain management

This line of argument resulted from interpreting third-order and second-order constructs (described in 'pain organises the family system,' 'adapted parenting,' 'parents helping children and young people to manage pain,' 'experiences and perceptions of interventions and treatments,' 'adherence to and engagement with interventions and treatments,' 'pain's adverse psychosocial impacts on the whole family' and 'pain self-management') and it explains the fundamental role of parents in implementing pain management strategies at home based on the impact on family life.

Because of the profound impacts of pain on the child and the whole family life, parents had to adapt their parenting approach to help their child to manage pain. Families carried out pain management at home on their own most of the time, which interrupted the family structures and routines. Indeed, most prescribed pain management strategies were time-consuming and disruptive of family life; some were also repetitive and painful or had other unpleasant side effects. Parents were fundamental to deciding whether and how children and young people followed any prescribed pain management and treatment strategies. This decision was usually made based on the amount of impact the treatment strategy had on family life and on the child. Parents, especially parents of children who could not communicate, developed expert knowledge in assessing when their child was in chronic pain. Parents were typically the main advocate for their child in interactions with healthcare professionals and services in order to access effective pain management. Parents often had to make difficult decisions about their child's pain management (particularly for complex conditions such as neurological conditions and JIA) but they were left feeling on their own to do so. Feeling that they could share this responsibility with healthcare professionals could help parents feel less alone.

Line of argument: The journey of living with chronic pain

This line of argument was developed with data from third-order and second-order constructs (described in the second-order constructs 'pain organises the family system and the social realm,' 'pain's adverse psychosocial impacts on the whole family,' 'pain forces adjustment and adaptation', 'families striving for diagnosis and a cure,' 'family expectations of services influence experiences,' 'chasm between health services and families' needs,' 'importance of being listened to and believed by healthcare professionals' and 'pain self-management'). It explores families' journeys starting from the onset of chronic pain, their struggle to navigate services seeking a cure, not having their needs and expectations met, and moving on either to prioritise living well with pain or to give up hope. We hypothesise that a biopsychosocial perspective of pain management could help improve how families experience pain management and services.

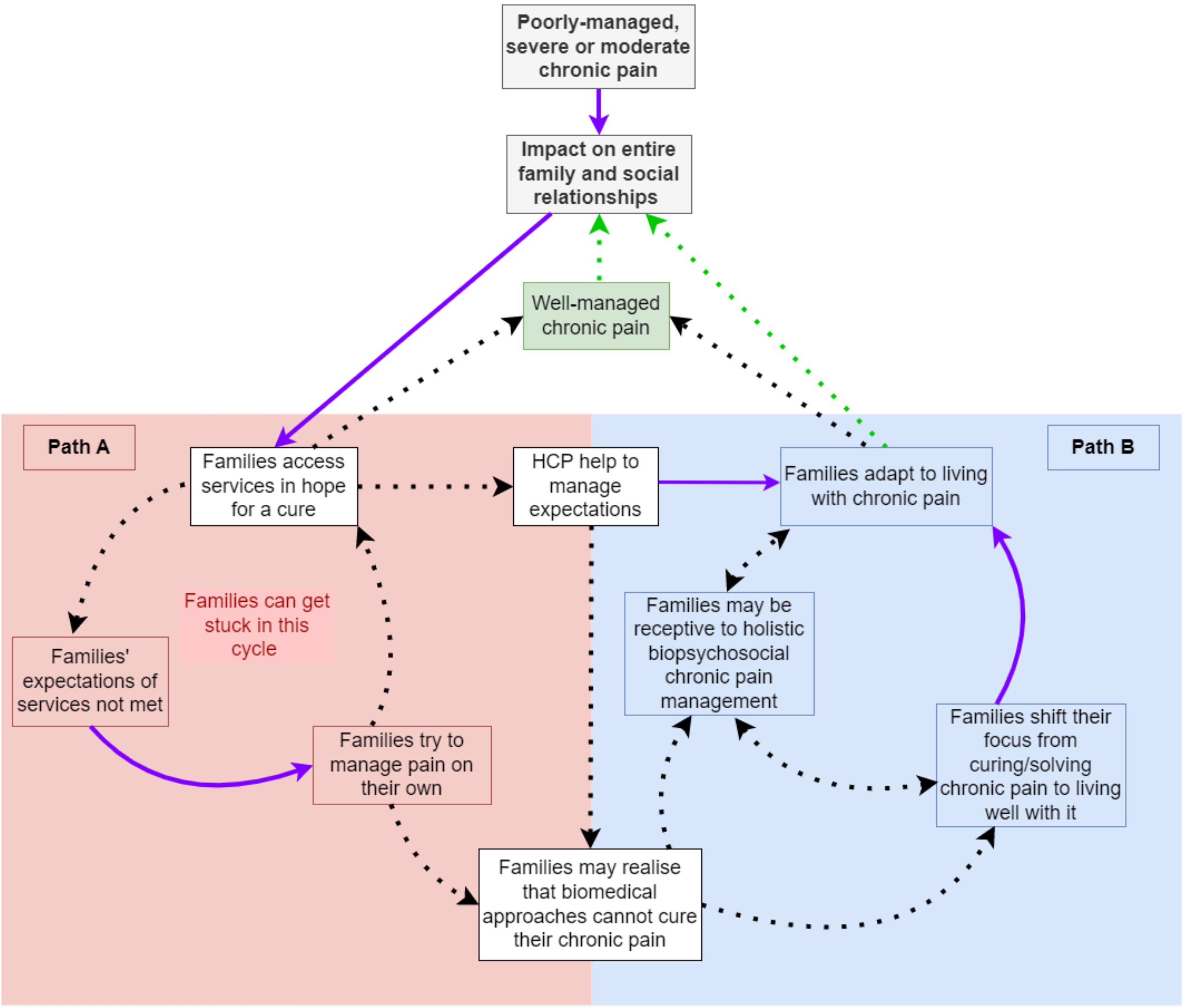
Poorly managed, moderate or severe pain deeply restricted and shaped family life and relationships. At the onset of chronic pain, families tried to hold on to a sense of normality and sought help from services with the aim of curing pain. Families believed a diagnosis could help to determine the treatment they should take to get rid of the pain. However, receiving help from health services was not straightforward and a cure was not always possible. Services were fragmented and difficult to navigate, and families found themselves being referred from one clinical speciality to another without a clear care pathway to indicate the steps in the process or what the result would be.

In addition, communication with healthcare professionals was difficult, families did not feel their experiences of pain were listened to and believed, and therefore a diagnosis was difficult to achieve. In the end, families' expectations of services (particularly services not specialising in pain) were not met - pain was not cured, healthcare professionals did not acknowledge the disruption on family life and families were left to deal with pain on their own. They dealt with pain on their own by employing self-management strategies and seeking complementary/alternative medicine, which sometimes increased the negative impact of pain and its management on the whole family. Some families moved on from searching for a cure as they realised they had no option but to 'get on with it,' so some started to prioritise living well with pain rather than 'curing' pain; others gave up hope and became depressed. As part of the process of moving on, families learnt as best they could how to manage the pain and how to plan their routine around it. We hypothesise that adopting a biopsychosocial perspective of chronic pain management and shifting the focus solely from curing pain to living well with pain could reduce the impact on the family life and improve how families experience pain management and experiences of navigating services. To facilitate this biopsychosocial perspective in families early on in their journey, it is important for healthcare professionals to set expectations regarding the unlikely probability of a cure, if appropriate, to help families in this process of adaptation and help them navigate their chronic pain journey.

Linking the lines of argument: Families navigating chronic pain management

The interpretation of all data and lines of argument helped us to understand families' journeys dealing with chronic pain and how these were affected by health services. The diagram depicted in Figure 5 illustrates a model of the non-linear nature of families' journeys with chronic pain while they navigated services seeking a resolution for the pain. The diagram describes families' journeys dealing with chronic pain and how health services can affect their journey. We hypothesise that there are two main paths families can follow during their journeys (A and B). Families navigating Path A can move on to Path B with time or help from healthcare professionals and interventions. Families can also move from Path B to A, e.g. when pain worsens or fluctuates in severity.

Figure 5. Families navigating chronic pain management (connects all lines of argument) Key: Dashed green lines – reduces impact on family life; black dashed line – possible direction (i.e. families may follow this path); Purple lines - direction (i.e. usual path families took)



On the left side of the diagram on Path A, families experiencing the impact of poorly managed, moderate or severe pain seek services in hope of a cure. When their expectations are not met due to fragmented services, referral fatigue, lack of diagnosis, poor communication with healthcare professionals, and so on, they try to adapt to pain on their own. To adapt they use many strategies, such as adapted parenting, adapting and changing the family routine according to pain levels, and so on, which can have a negative impact on their lives as the whole family focus is shifted towards dealing with the pain. Families also employ different strategies to manage pain on their own and seek help from alternative medicines, which are not always successful.

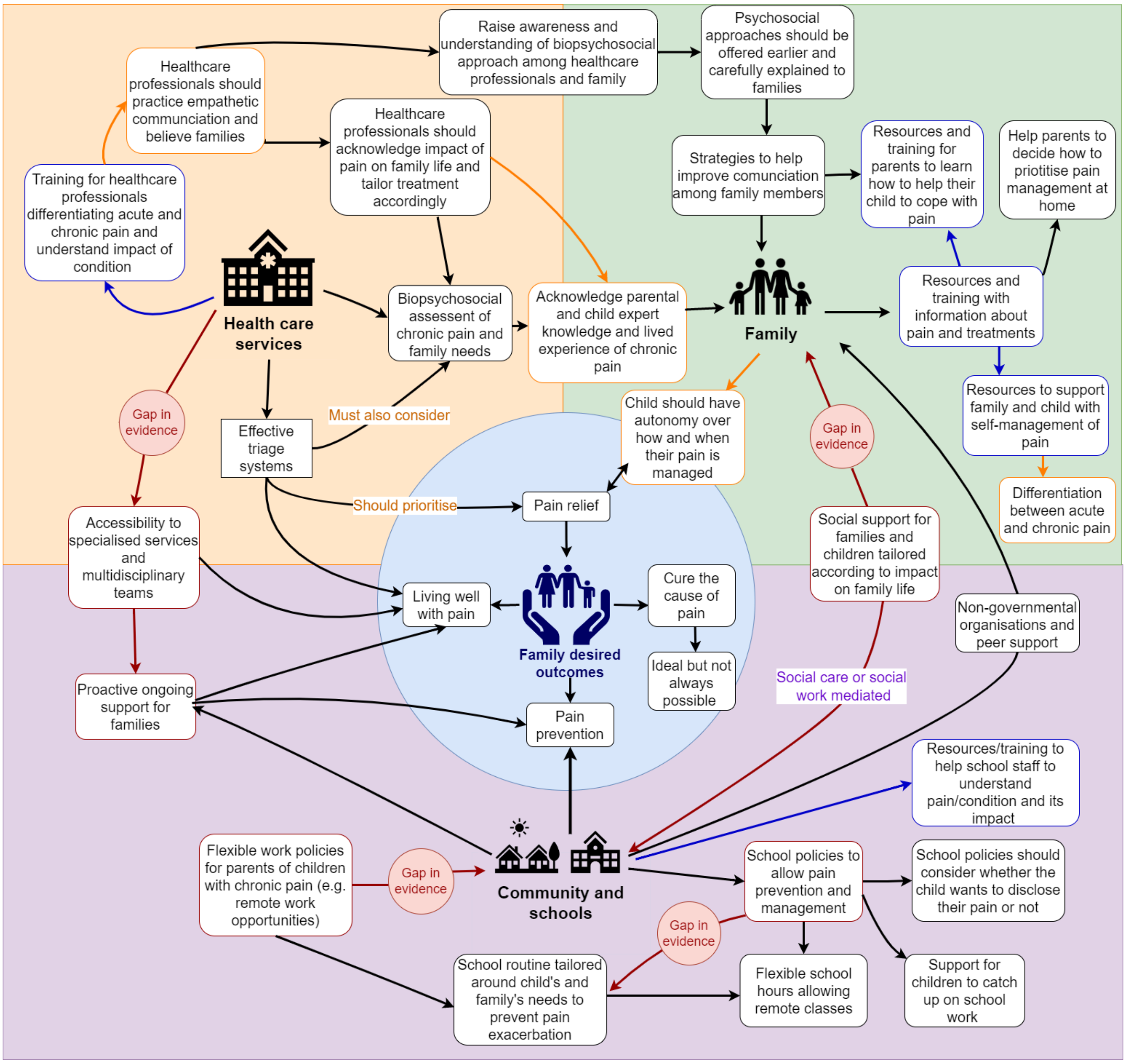
Because pain remains poorly managed families are stuck in a cycle of pain affecting their lives and seeking services in the hope for a cure but without any resolution for the pain. Families and healthcare professionals understand pain and its causes through a biomedical lens/perspective, which deeply affects their expectations of pain management and services. Psychological treatments are stigmatised and only used as a last option.

The right side of the diagram depicts when healthcare professionals are effective in helping set families' expectations of treatment, which requires them to listen to and believe the families and acknowledge their lived experiences. Realistic expectations can help families to adapt to living with pain as they shift their focus from trying to cure pain to trying to live well despite the pain. Families might also realise on their own that a biomedical cure is unlikely after following Path A for a long time without any resolution for the pain. Families on Path B tend to be more receptive to biopsychosocial approaches for pain management, due to lack of other options.

Family-centred theory of children and young people's chronic pain and its management

Based on interpretation of all evidence and PPI input we developed a theory of what would constitute 'good' children's chronic pain management interventions and services. This is described in Figure 6 and the detailed explanatory text below. Our family-centred theory of children and young people's chronic pain and its management is based on a biopsychosocial model and a 'whole systems' approach, i.e. based on the premise that everything is inter-related and interdependent. Because chronic pain affects all aspects of family life and their relationships with the community, pain management strategies should encompass the family (depicted in green), health care services (depicted in yellow) and the community, including schools (depicted in purple). The systems (e.g. community, school, health and social care services) in place should work together as enablers, either facilitating or delivering families' desired outcomes. Four key outcomes desired by families and children and young people (blue circle) are at the centre of this approach to chronic pain management and services. Families' most desired outcome is resolution of/a cure for their pain. This systems approach resolves service fragmentation by offering intuitive services and proactive ongoing support for families across all environments (family, healthcare services and community/schools) as they communicate and work together to achieve satisfactory outcomes for families.

Figure 6. Family-centred theory of children and young people's chronic pain and its management Key: Black and blue lines, boxes and arrows – review authors' hypothesis based on evidence. Blue lines, boxes and arrows – resources and training needs/interventions. Orange lines, boxes and arrows – based on evidence and corroborated by PPI. Red circles, lines, boxes and arrows: gaps in qualitative evidence.



Given that parents and children and young people had to constantly assess pain levels in order to plan family life and pain management, more support to facilitate pain assessment at home should be put in place via links with health services and resources/training. Families and children and young people carried out most of the pain management and prevention, particularly in the form of self-management, self-care and following prescribed treatment interventions (e.g. physiotherapy, injections/medications). Parents should receive resources and support on how they can help their child deal with pain and how to prioritise different pain management options at home. Children and young people should receive support on different types of pain management strategies, tailored to their needs and pain levels, and how to differentiate between acute and chronic pain. Further resources and training with information about pain and treatments tailored for families, which could be provided by health and social care services, non-government organisations and/or community organisations working together, could enable families to achieve their desired outcomes and support self-management of pain.

Psychosocial treatment approaches should be offered earlier, alongside medical treatments, as a way to address the physical, emotional and social impacts of pain holistically, and these should be carefully explained to families. For instance, psychosocial approaches that improve communication amongst family members and help children and young people to build autonomy over how and when their pain is managed can enable pain management and should be facilitated by health services and the community/schools.

The healthcare services environment is where triage and pain assessment by healthcare professionals occurs, which are fundamental steps for pain treatment and prevention. An effective triage system should be underpinned by a biopsychosocial assessment of chronic pain, mapping the family's psychosocial as well as medical needs; should prioritise pain relief and living well with pain; and should trigger appropriate action from different services. For instance, triage could trigger referral to appropriate specialised services and multidisciplinary teams, and/or the mobilisation of schools, social care and social services to evaluate the level of support the children and young people and family require. Empathetic communication by professionals is a core component of this approach, which is fundamental for building trust between families and services. Healthcare professionals should look holistically at the impact of pain on families' lives and listen to the expert knowledge of parents, seeing parents and children as true active agents in the decision-making processes, in order to tailor pain management strategies, while at the same time guiding and supporting parents in helping their child to manage pain. The impact of treatments on family life and relationships, and vice versa, should be considered.

When appropriate, services and healthcare professionals should help families set expectations regarding the possibility of a cure for the pain. The frontline staff, such as children's nurses, should be trained to use simple interventions when appropriate to avoid repeated returns to services and referral fatigue. Specifically, simple early interventions should be the first option when appropriate. Families who need them should have access to suitable multidisciplinary teams (including, for example, pain clinical specialists, nutritionists, physiotherapists, psychologists, occupational therapists, social workers and social care workers, etc.) according to their needs and underlying conditions. Accessibility of services should be considered as part of the pain management plan. The transition to adults' services should be done gradually and planned as part of the pain management strategy.

To enable healthcare services to work efficiently as part of the system, the provision of training and resources for healthcare professionals is needed. Training and resources should be aimed at differentiating chronic and acute pain and helping healthcare professionals to understand the impact of chronic pain and any associated condition, including an awareness and understanding of the importance of the biopsychosocial approach.

The community/school environment is where much self-management and pain prevention occurs, in addition to that which occurs in the home environment. Social support, which could include peer support, for families and children and young people should be tailored according to the impact on their lives and mediated by social care, social work or non-governmental organisations. School and work policies should be in place to allow adjustments to life in the community/schools allowing for pain prevention and management. For example, school policies should facilitate a routine for children and young people to prevent pain exacerbation, including flexible school hours and support for children to catch up on school-work. Work policies for parents of children and young people with chronic pain should allow flexible work hours and remote work opportunities. To enable schools/community to work efficiently as part of the system, it is fundamental that resources and training should be provided to help staff at school and work to understand chronic pain and how it can impact family life. The community/school environment can provide or facilitate social support and help to create a sense of belonging, which can help families to deal with the impacts of chronic pain on their family and social life. Social support interventions and policies should consider how families' and children and young people's social groups understand chronic pain and pain management, and whether children and young people want to disclose their pain condition.

Managing pain is essential to enable families to live well; it should be a priority and a combined effort involving multiple systems, such as health services, schools, social care and social services. Proactive support for families, e.g. via check-up phone calls or digital clinics, should be put in place to support families to manage pain across all the different environments (health services, schools/community and at home).

Assessing our confidence in the review findings

We have presented summaries of the findings and descriptions of our assessments of confidence in these findings in Summary of findings 1 and the Evidence Profile Tables in Summary of findings 2, which show the application of GRADE-CERQual to the key (descriptive) synthesis findings. The summary of findings tables are organised by topics, e.g. social support, experiences of health services and care. There are 36 CERQual findings: 21 assessed as high confidence, 12 as moderate, two as low and one as very low confidence.

Integration of meta-ethnography findings with Cochrane intervention effects reviews

We integrated our synthesised qualitative findings with 14 recent Cochrane Reviews of intervention effectiveness focusing on children's chronic pain, including those in preparation for publication (Abbott 2017; Anie 2015; Cooper 2017a; Cooper 2017b; Cooper 2017c; Cooper 2017d; de Bruijn 2021; Eccleston 2017; Fisher 2018; Fisher 2019Law 2019; Leite 2023; Martin 2017; Newlove-Delgado 2017). Given that our analytic synthesis identified several key impacts of a child's chronic pain of importance to families (i.e. pain impacts the whole family; pain has mainly negative psychosocial impacts on all family members; children and their families desire, at least initially, alleviation of the pain), we focused this integration on whether the interventions included in these reviews had:

- focused on interventions for the whole family;
- measured whole family outcomes, such as family functioning;
- measured parental outcomes;
- measured sibling outcomes;
- measured child psychological/emotional outcomes;
- measured child social outcomes;
- measured absence of pain as an outcome.

We also wanted to know if certain under-represented subgroups of children with chronic pain and parents were included:

- children under five years old;
- children with learning disabilities or autism;

- children or parents of minority/non-Caucasian ethnic origin.

As reflected in the synthesis findings, pain is a biopsychosocial issue, therefore we also examined the programme theories (specifically, how the interventions were thought to work) to verify whether they took a biopsychosocial approach.

Matrix analysis results

The results of the matrix analysis (see additional Table 7) show that, of the 14 reviews, no reviews focused on whole-family interventions. Only one review focused on interventions for parents of children with chronic illness, and measured family functioning (Law 2019). Only two reviews (14%) measured parental outcomes – one analysed parenting behaviours and parental mental health, including that of mothers and fathers, although they did not perform a subgroup analysis by parental sex (Law 2019), and the other planned to analyse caregiver distress but none of the included studies reported this (Leite 2023). None measured sibling outcomes.

All 14 Cochrane Reviews specified that their inclusion criteria included trial outcome measures of child psychological/wellbeing outcomes such as quality of life, depression, anxiety and psychological functioning, however in five (36%) reviews (Cooper 2017a; Cooper 2017b; Cooper 2017c; Cooper 2017d; Eccleston 2017), none of their included trials had analysed and reported these outcomes. The inclusion criteria of only four (29%) reviews included measures of child social outcomes including school attendance in three reviews (de Bruijn 2021; Martin 2017; Newlove-Delgado 2017), social functioning in three reviews (Abbott 2017; Martin 2017; Newlove-Delgado 2017) and social disruption in one review (Newlove-Delgado 2017).

The inclusion criteria of eight (57%) reviews included pain outcome measures that measured absence of pain, such as the numerical rating scale, the visual analogue scale, the Wong Baker FACES pain scale and/or other pain rating scales (Abbott 2017; de Bruijn 2021; Law 2019; Martin 2017; Newlove-Delgado 2017; Fisher 2018; Fisher 2019; Leite 2023). The inclusion criteria of six (43%) reviews did not include a measure for absence of pain (Anie 2015; Cooper 2017a; Cooper 2017b; Cooper 2017c; Cooper 2017d; Eccleston 2017), five of which were focused on the evaluation of pharmacological therapies (Cooper 2017a; Cooper 2017b; Cooper 2017c; Cooper 2017d; Eccleston 2017).

Regarding under-represented subgroups of children, specifically children with autism or learning disabilities and children under five years old, nine (64%) of the Cochrane Reviews specified in their inclusion criteria that all children up to the age of 18 years old with the pain diagnosis of interest were eligible to be included in analyses, however in all of those nine reviews, none of the eligible trials had included children with learning disabilities/autism or aged under five years in their samples. The inclusion criteria of five (36%) of the Cochrane Reviews, four on recurrent abdominal pain (Abbott 2017; de Bruijn 2021; Martin 2017; Newlove-Delgado 2017) and one on musculoskeletal pain (Leite 2023), focused only on school-aged children aged 4 or 5 to 18 years old and thus excluded younger children – for the abdominal pain reviews this was due to the use of diagnostic criteria that do not apply to younger children. The inclusion criteria of eight (57%) reviews included children under five but none of their included trials had participants under five, while the inclusion criteria of two (14%) reviews specified in the protocol that children under five were included but only the mean age was provided in the reviews (Fisher 2018; Law 2019). Only one review had planned to conduct subgroup analyses by ethnic origin of participants, although there were insufficient data to permit this (Anie 2015).

In summary, existing Cochrane intervention effects reviews on children's chronic pain focused on the psychological impact on children, but have not measured, or have been unable to measure, many of the outcomes of importance to children and their families (e.g. the psychosocial impact on whole family). Few have results relevant to children under five years old or children with learning disabilities or autism, either because of the inclusion criteria of the review or the trials it synthesised. None of the studies had data that inform outcomes for children or parents from different ethnic origins.

Analysis of evidence for the chosen intervention (programme theories)

Programme theories explain how an intervention is thought to work to achieve an outcome. However, in all reviews, their descriptions of how the interventions might work to manage pain (described in some reviews as the 'mechanisms of action') were brief and lacking in detail. None had a clearly discernible biopsychosocial explanation of how the intervention(s) might work. Eight (57%) reviews exploring either pharmacological interventions (Cooper 2017a; Cooper 2017b; Cooper 2017c; Cooper 2017d; de Bruijn 2021; Eccleston 2017; Martin 2017) or dietary interventions for recurrent abdominal pain (Newlove-Delgado 2017) described only the biomedical 'mechanisms of action' without consideration of the social and personal contexts/factors affecting, for example, medication adherence. Additional Table 8 gives the programme theories and our assessment of whether each was biopsychosocial.

In some reviews, it was difficult to discern how the interventions were thought to work and whether they adopted a biopsychosocial or another approach. Biological (e.g. act on physical mechanisms) and psychological (e.g. influence cognitions, coping) aspects were apparent in programme theories in two reviews – one focusing on psychological therapies for sickle cell disease and pain (Anie 2015) and one on physical activity and education for chronic musculoskeletal pain. Nevertheless, both lacked detail or precise mechanisms (Anie 2015; Leite 2023): Anie 2015 specified expected outcomes of interventions rather than mechanisms and Leite 2023 stated only that the interventions affect physical and psychological mechanisms (additional Table 8).

Four more reviews investigated psychological or psychosocial interventions only, and did not appear to consider any biological mechanisms (Abbott 2017; Fisher 2018; Fisher 2019; Law 2019). Two of these reviews, one focusing on psychological therapies (Law 2019) and one focusing on psychosocial interventions (Abbott 2017), covered multiple types of interventions, each with different programme theories. The Abbott 2017 review included very brief descriptions of how CBT, hypnotherapy, guided imagery, yoga and written self-disclosure are thought to work, all of which were described as mainly psychological in nature, except for family therapy, which was social (in contrast to the description of family therapy as psychosocial in Law 2019). The Law 2019 review also included separate programme theories for a variety of interventions including those that were described as both social and psychological: CBT, family therapy, multisystemic therapy, problem-solving therapy and motivational interviewing, which was described as having a psychological mechanism. One review investigating psychological therapies appeared to describe a psychosocial mechanism about which they gave little detail (Fisher 2019).

In summary, programme theories in Cochrane Reviews of intervention effects on children's chronic pain were brief and lacking detail making it challenging to ascertain whether explanations were biopsychosocial or not. Nor were there any considerations about feasibility, acceptability or implementation as additional context to the programme theories. Overall, our integration of findings has shown that outcomes measured in Cochrane Reviews and trials of interventions do not always match those of importance to children and families, possibly in some cases because of a lack of suitable measurement tools, and that a biopsychosocial approach has been largely neglected in programme theories.

DISCUSSION

Our synthesis findings reveal the profound and adverse impacts of children's chronic pain on the child or young person but, importantly, also on their wider family including relationships and dynamics. Findings also highlight how the impacts of pain on children and young people extend beyond the family (e.g. the impact on the child's education) and how families try to overcome these impacts. Our findings highlight the diverse nature of the difficulties that families face in seeking and obtaining help and support from health services to manage their child's pain and its impacts. We have reached new interpretations of the primary data resulting in several lines of argument, a model (Figure 5), and developed a new theory (Figure 6). To our knowledge, we have developed the first comprehensive family-centred theory of children's chronic non-cancer pain and its management, using a biopsychosocial perspective, which incorporates how children and families conceptualise pain, their experiences of living with pain and how this impacts their use of pain management and health services. The new theory, described in the Results and Figure 6, also defines what 'good' pain management and services should look like.

We set out to answer four questions in our meta-ethnography:

1. How do children with chronic non-cancer pain and their families conceptualise chronic pain?
2. How do children with chronic non-cancer pain and their families live with chronic pain?
3. What do children with chronic non-cancer pain and their families think of how health and social care services respond to and manage their own/their child's chronic pain?
4. What do children with chronic non-cancer pain and their families conceptualise as 'good' chronic pain management, and what do they want to achieve from chronic pain management interventions and services?

In this section, we summarise the key findings for each question (from the third-order constructs and lines of argument presented in the Results), relate these to the wider literature, and make recommendations for policy and practice backed up by GRADE-CERQual assessments of confidence in our synthesised findings. Recommendations for improving chronic pain management interventions and services draw upon our interpretative findings, review authors' expertise and recommendations identified by the authors of included studies – these are summarised in additional Table 9.

RQ1. How do children with chronic non-cancer pain and their families conceptualise chronic pain?

Our findings (presented in our line of argument 'dominance of biomedical perspective in how children and families conceptualised chronic pain and pain management') show that there is a difference in how children and families conceptualised the impacts of pain versus its causes and, therefore, the role of health services in managing the pain. Children and young people and their families expressed biopsychosocial (biological, psychological and social) *impacts* of chronic pain on their lives, for all kinds of chronic non-cancer pain. However, when there was no identifiable or known medical cause of the pain, families initially tended to reject the idea of psychosocial *causes* or *influences* (e.g. anxiety), because it challenged the legitimacy of the children and young people's pain or suggested that pain was caused by parental shortcomings. For children whose chronic pain was identified as being caused by an underlying health condition, such as SCD, JIA or cerebral palsy, families were less likely to consider psychosocial causes of, or influences on, pain. Most children and young people and parents tended to understand the *cause* of chronic pain as solely biomedical - having an underlying pathophysiological cause. This influenced their expectations of, and interactions with, health services. However, families' conceptualisations were dynamic and could change over time with experiences of treatments, services and interactions with healthcare professionals. Thus, healthcare professionals and targeted interventions could play an important role in managing family understandings of pain and expectations of services.

It is important to highlight that the above conceptualisation stems mainly from high-income countries and their ethnic populations. Nonetheless, our included studies did represent a fairly wide range of ethnic backgrounds. Families from other countries and ethnic and cultural backgrounds may have very different conceptualisations to that described above. Furthermore, menstrual pain may be conceptualised differently. Girls and young women, their families and healthcare professionals at times may not perceive pain as a pathological/pathophysiological issue, for example severe menstrual pain was perceived as 'normal' pain not requiring medical intervention.

RQ2. How do children with chronic non-cancer pain and their families live with chronic non-cancer pain?

The impacts of poorly managed, moderate and severe chronic non-cancer pain on the child, their whole family and their wider social connections and relationships were profound (described in the third-order construct 'pain organises the family system and social realm' in the Results). There were serious negative impacts of children's chronic pain on the whole family and family life. Pain affected family dynamics and relationships; family members' emotions, well-being, autonomy and sense of self-identity; parenting strategies; friendships and socialising; children's education and future employment prospects; and parental employment. Children and family members experienced adverse physical/biological, psychological and social impacts of chronic pain. We found that most chronic pain management happened at home and in the community, e.g. at school, and was supervised or implemented by parents, especially mothers who were often the main caregivers. Thus, the demands of caregiving disproportionately affected women (mothers).

Even though there were many serious negative psychosocial impacts on families, there was very little support provided by health and social care services or in the community (e.g. school health services) to address these. Families needed greater family-centred psychosocial support, including peer support. Children benefited from awareness about pain and its associated impact on children and young people within schools and school health services, e.g. some school policies and practices flexibly supported children and young people with chronic pain in self-care, while avoiding stigmatisation, and avoided negative impacts of disruption to their education.

RQ3. What do children with chronic non-cancer pain and their families think of how health and social care services respond to and manage their/their child's chronic pain?

A key challenge identified by children and young people and families concerned their experiences of health systems and individual health services as difficult to access and navigate, resulting in challenges to achieving satisfactory chronic pain management (as described in 'families struggling to navigate health services' and the line of argument 'the journey of living with chronic pain' in the Results). Families often entered a lengthy cycle, which could last many years, of attending then re-attending health services, and awaiting referral to secondary or tertiary services for tests and/or treatment. In the meantime, chronic pain was not usually well-managed, and families were left largely unsupported to find their own solutions. Being referred to a pain clinic could 'validate' the pain (i.e. confirm it was a real illness), be a source of hope, and emotional and practical support. One of the reasons for families' difficulties in navigating services was the lack of a clear care pathway for children and young people with chronic pain.

Interactions with healthcare professionals were frequently negative and stressful. Children and young people and their main caregivers, usually mothers, felt at times they were not being listened to and believed, and thus they felt unsupported. For instance, children and young people's experiences of living with pain were ignored or their pain was disbelieved, and mothers felt blamed for their child's pain. Parents of younger children and of children with communication difficulties perceived that healthcare professionals did not always recognise their expertise in assessing their child's pain. In contrast, open, empathetic healthcare professional communication helped children and young people and their families to develop a trusting relationship with professionals. Children and families wanted healthcare professionals to explore and understand their experiences of the impacts of chronic non-cancer pain and their priorities for pain management. Family and children's preferences, needs and lifestyle can have implications for pain management and pain management can affect family life.

Parents wanted healthcare professionals to recognise and make use of their parental expertise in assessing and responding to their child's pain, particularly for children who had communication difficulties. Tools to assess pain in children and young people did not seem to incorporate parental assessment and advice regarding children with special needs (e.g. non-verbal/unable to communicate), and there appeared to be no tools suitable for all children and young people, tailored for chronic as opposed to acute pain. Children and young people wanted healthcare professionals to use the child's expertise and knowledge of their pain, especially for those with underlying chronic conditions like SCD and JIA. Children and young people sometimes hid or minimised their pain to avoid causing their parents' distress, which is likely to pose challenges for pain assessment.

In the data, there was an apparent lack of use of shared decision-making frameworks by healthcare professionals, used alongside appropriate clinical pathways, that signposted to all the available and appropriate treatment options, which families could discuss with healthcare professionals and choose from. Our evidence suggests that a scattergun rather than a co-ordinated approach was common, with few children referred to specialist pain clinics when it was appropriate to do so. Many children and young people did not appear to be offered the full range of appropriate treatment options, hence parents tended to seek out one option after another in an uncoordinated way that was not based on evidence of potential appropriateness, benefits or potential harms.

Services were fragmented and some children who needed it waited a long time to be referred to or access tertiary specialist pain services, even for pain conditions like CRPS, which might benefit from early referral to such services. There was a lack of data regarding screening and assessment tools for children's chronic pain, which could have facilitated triage of children, e.g. to specialist services or use of primary care interventions, such as signposting families to educational pain management resources. In the UK and in other countries, there is currently no care pathway for children's chronic pain, including chronic pain of unknown cause, for children and families and healthcare professionals to follow.

Lastly, but importantly, children and young people and their families, particularly children and young people with SCD, experienced racism and discrimination in health services. Children with chronic pain and learning disabilities, such as Down syndrome, also encountered discrimination. Direct and indirect prejudice and discrimination towards patients adversely affected the care they received and their pain management.

RQ4. What do children with chronic non-cancer pain, their families conceptualise as 'good' chronic pain management, and what do they want to achieve from chronic pain management interventions and services?

Our findings indicate that because of the way families in mainly high-income countries initially conceptualised the cause of chronic pain as biomedical, they first approached health services looking for medical treatment and/or cure, and they usually rejected psychological treatments or approaches (as described in the third-order construct 'families struggling to navigate health services' and the line of argument 'how children and families conceptualised chronic pain and pain management' in the Results). Families of children with diagnosed underlying health conditions (such as JIA, SCD) that cause chronic pain also might not have seen the value of psychosocial pain treatments, given the cause of pain was a disease. Families did want help with the psychosocial consequences of pain, such as parental distress, but did not think health services could assist with that. This perceived medical focus for families and healthcare professionals could act as a possible barrier to biopsychosocial care.

Families' reluctance to accept there may be psychosocial influences on, or causes of, chronic pain (or them not seeing the role of psychosocial support in managing pain) means healthcare professionals need to carefully manage how and when they offer psychosocial support to avoid alienating them. Healthcare professionals could play a role in sensitively explaining biopsychosocial explanations of pain management to families – since these apply even when there is a biological cause - by building on the family's prior experiences of the biopsychosocial impacts and aspects of pain. However, when not approached sensitively, children and their families can feel healthcare professionals do not believe their pain is real and parents can feel they are being blamed for any social and psychological causes of pain. Biopsychosocial approaches are important for all children and young people and families managing chronic pain whatever the cause. Parents and children and young people highly value healthcare professionals who listen to and understand the impact chronic pain has on them and their family life.

An important role for healthcare professionals was in managing families' understanding of chronic pain and expectations of chronic pain management. Families needed clear communication about the purpose of any tests, examinations and treatments, and to have their expectations managed about the possibility of a cure (which will be condition-dependent) from the outset of their contact with health services. Children and young people needed to have their pain managed while awaiting test results and diagnosis.

Families ideally wanted interventions that reduced or removed the pain; if that is not possible, then strategies to help them live well with pain would be beneficial. Interventions that do not worsen the impact on the whole family and its well-being would be more acceptable to families. Consequently, it is important to tailor interventions to families' preferences and needs so that they are not boring or excessively time-consuming, not painful, and have minimal side effects.

Situation of the findings in relation to wider literature

Since we conducted our meta-ethnography, two new qualitative evidence syntheses on children's chronic pain have been published focusing on specific pain populations and topics: a thematic synthesis of adolescents' experiences of fluctuating pain in musculoskeletal disorders (Khanom 2020a), and an aggregative synthesis of the experiences of children and young adults (up to 21 years) and their parents of living with JIA (Min 2022). Khanom 2020a found that pain flares restricted adolescents' activities, leading to them feeling isolated and different from peers. The fluctuating nature of the pain was difficult for others to understand and adolescents tried strategies, including medical treatments, social support and concealing the pain, to try to regain a feeling of control over the unpredictable pain (Khanom 2020a). Min 2022 found adverse effects of JIA on young people's emotional and physical well-being and on their relationships with parents, teachers and healthcare professionals. Young people and parents needed more self-management knowledge and skills (Min 2022). A further mixed methods review synthesising three qualitative studies on the impact of pain on adolescents' schooling found mainly negative impacts of pain on school functioning with a need for better pain management in schools (Alsaggaf 2020). These syntheses had narrower focuses and populations and different aims from our meta-ethnography. Their findings confirm but do not substantively add to ours. Consequently, our meta-ethnography still adds valuable, key knowledge to the growing literature.

Our synthesis indicates serious negative impacts of children's chronic non-cancer pain on family systems. We have added to the scant knowledge of the impact of childhood chronic pain on the whole family system (Lewandowski 2007). Quantitative cross-sectional research (e.g. Lewandowski 2010) shows family dysfunction in children's chronic pain but cross-sectional research cannot indicate the direction of causal relationships. Notably, our synthesis shows that pain can cause family dysfunction and family-system-wide changes. Family systems interventions for children and young people with chronic pain could be beneficial for the whole family (Distelberg 2014). The demands of caregiving can have negative impacts on the whole family but also can contribute to sex inequalities between women (mothers) and men (fathers), therefore health and social care policies and interventions should take care not compound this inequality by increasing the burden on women (Cascella 2020). There is a clear need for greater family-centred psychosocial support as part of a biopsychosocial approach.

There is a need for biopsychosocial health and social care tailored for children and young people, which is family-centred, considering the needs of the entire family and the impact on the family system. Care should include support in the community (schools, home, primary care, social care, cultural and religious networks) and not just in tertiary services. The WHO 2020a guidelines on the management of chronic pain in children, for which three of our review authors (EF, JN, MSB) provided a supporting qualitative evidence synthesis, also reflected the need for a biopsychosocial approach to pain management that supports and is tailored to the child and their family in terms of their needs, values, preferences, culture and resources.

In our synthesis, we found that families in high-income countries mainly conceptualised pain as having a biomedical cause. This perceived medical focus could act as a possible barrier to biopsychosocial care. Shortcomings in healthcare professional education, training and experience about chronic pain could also contribute to the biomedical focus (Briggs 2015; Lee 2021; WHO 2020a). However, families from other countries and ethnic and cultural backgrounds may have very different conceptualisations. For example, some people in some African countries believe pain is caused by witchcraft or their ancestors (e.g. in Cameroon, Zambia) (Munkombwe 2020; Njifon 2019) or 'worms' (e.g. in Ghana) (Ajinkpang 2022). In Jordan, many families believed that pain is given by God and should not be treated (e.g. Forgeron 2006), while in Morocco pain was seen as a sign of weakness (McCarthy 2004). Furthermore, in our synthesis, severe menstrual pain was perceived as 'normal' pain not requiring medical intervention. This finding originated from a single study, conducted in Hong Kong, however it is also supported by global literature on dysmenorrhoea (e.g. Barrington 2021). Awareness and understanding of how families conceptualise chronic pain will facilitate treatment and care, for example pain management plans should be tailored to the family and child's preferences, needs and lifestyle.

In palliative end-of-life care the concept of 'total pain' is commonly used, i.e. pain is not just biological in cause but can be caused by emotional distress, existential concerns, and so on, and the physiological impacts cannot be separated out from the emotional and social impacts of the pain, therefore they need to be managed as connected (Clark 1999; Mehta 2008). This concept of total pain has not been applied to chronic pain that is not at end of life; it may be a useful concept to facilitate biopsychosocial management of children's chronic pain. Adopting a 'total pain' approach to service delivery would help to knit together the biopsychosocial influences on and consequences of pain (Clark 1999; Mehta 2008). A barrier to biopsychosocial approaches to managing pain is that health services largely still operate on a biomedical model of understanding, assessing and treating pain (Eccleston 2021).

It is accepted that healthcare professional chronic pain education urgently needs improving, e.g. by adapting medical education curricula for undergraduates, postgraduates and qualified healthcare professionals, and there is a known lack of healthcare professionals with the knowledge and expertise in chronic pain assessment and management (Briggs 2015; Eccleston 2021; Hurley-Wallace 2019; Lee 2021; Mackintosh-Franklin 2017; NSH Scotland 2014, Scottish Govt 2018; WHO 2020a). The WHO 2020a guidelines also identified that capacity of healthcare providers and health systems needs strengthening, especially in LMICs, including training of healthcare professionals in pain assessment and management and effective communication with families.

There may be a need for assessment tools specific to chronic as opposed to acute pain. Screening tools specifically for chronic pain exist, e.g. the Paediatric Pain Screening Tool (PPST) (Simons 2015), which can help identify those children at risk of adverse outcomes. In addition, there are some other chronic pain paediatric assessment tools for specific age groups, such as self-report questionnaires for adolescents and their parents (Eccleston 2005) and a measure of patient-reported pain behaviours for school-aged children (Cunningham 2017). However, it is not clear if and how these tools are used in practice; there were no data on this in our included studies, and few data that we can identify in the healthcare professional literature. However, one USA study of nurses working with paediatric inpatients with chronic pain reported that nurses had doubts about the truthfulness of the child's pain reports, frustration with self-report of pain and beliefs that patients might be seeking drugs. They also expressed concerns about the validity of pain assessment tools they were required to use stating that children did not appear to understand numeric rating scales. They perceived that children with chronic pain placed excessive demands on them in terms of the policies for providing pain medications and the regularity of pain assessment (Rodrigues 2018).

The recent Lancet commission identified the importance of healthcare professionals developing a more detailed understanding of pain, which provides an understanding of children's experience of living with chronic pain (Eccleston 2021). Denying a child's subjective experience of pain is likely to result in child and family distress. Healthcare professionals should believe the child's pain is real, regardless of the (possible or actual) cause; this synthesis finding supports a key recommendation in the Lancet commission (Eccleston 2021). Our findings suggest that healthcare professionals should recognise and make use of parental expertise in assessing and responding to their child's pain, particularly for children who have communication difficulties, and use children's expertise and knowledge of their pain, especially for those with underlying chronic conditions like SCD and JIA. Tools should incorporate parental assessment and advice for children with special needs (e.g. non-verbal/unable to communicate), there should be tools suitable for all children, and they should take into account that children may hide or minimise their pain to avoid causing their parents' distress. In LMICs, there is often a lack of healthcare professional access to, training in and knowledge of assessment tools and a lack of culturally appropriate tools (Forgeron 2009; Silva 2011). In addition, there may be cultural barriers to pain assessment, such as norms around it being unacceptable to express pain or use pain relief (Forgeron 2009; Jongudomkarn 2006; Nilsson 2016; Silva 2011).

Another important role for healthcare professionals is in managing families' understanding of chronic pain and expectations of pain management. Healthcare professionals could signpost families to appropriate existing high-quality information resources, such as leaflets, storybooks for children and young people, peer support groups, online modules, websites (e.g. 'Kids In Pain' (SKIP 2020, www.kidsinpain.ca); 'It Doesn't Have To Hurt' (itdoesnthavetohurt.ca)) (Chambers 2023; Eccleston 2021; Scottish Govt 2018).

Another current barrier to improving children's pain management includes the lack of specialist pain management services (Scottish Govt 2018; WHO 2020a). In LMICs there is often a lack of paediatric health services (e.g. Munkombwe 2020; Ngwenya 2019). Multidisciplinary care/treatment is currently recognised as the 'gold standard' (Eccleston 2021), but we need to increase availability and accessibility of specialist multidisciplinary pain management for children's complex pain problems rather than having a few isolated tertiary specialist pain services. There should be a greater focus on making chronic pain services accessible to all children and families who need them. The WHO 2020a guidelines for children's chronic pain management recommended interdisciplinary, multimodal care and shared decision-making with children and their families.

The current lack of a clear care pathway for children with chronic pain is one of the reasons for families' difficulties in navigating services. For instance, in the UK, only Scotland out of the four UK nations has a clinical guideline for children's chronic pain management (Scottish Govt 2018); the pathway it contains mainly describes how services are currently organised rather than a step-by-step guide to pain assessment and treatment with clear decision points for healthcare professionals and families. Children's needs may differ from adults' needs and younger children's needs may differ from those of older children. The global WHO guidelines on the management of chronic pain in children make recommendations on best practices for the clinical management of chronic pain and advice on their uptake and implementation; they do not describe care pathways, which may vary considerably depending on the country and its health systems (WHO 2020a).

In developing and implementing pathways, use of screening and assessment tools for children's chronic pain could help with triage to know whether to fast-track children to specialist services, where they exist, or to provide primary care interventions, such as signposting families to educational pain management resources. Some pain conditions, such as CRPS, which are difficult to diagnose especially for generalist healthcare professionals, might benefit from early referral to and diagnostic input from tertiary specialist pain services, where they exist (Neville 2021). Children need a clear clinical pathway with specialist condition-specific pathways where appropriate, e.g. for JIA, CRPS, headache.

We found that children and young people and their families, particularly children and young people with SCD, experienced racial prejudice and discrimination in health services. A possible alternative interpretation is that the inadequate care of children and young people of mainly African-Caribbean origin was related to the widespread suboptimal care of children with chronic pain in general rather than due to racism. However, in their recent comment in the Lancet commission, Inusa 2021 also identified inequalities in access to care for children and young people with SCD across various high- and low-income countries. Furthermore, an editorial literature review in the *Journal of Pain Research* concluded that there was systemic racism in chronic pain management, in the USA context (Ghoshal 2020). We found that children with chronic pain and learning disabilities, such as Down syndrome, also encountered discrimination, a finding that is supported by the wider literature on the poorer health care provided to people with learning disabilities (e.g. Heslop 2014). There is a need to address direct and indirect prejudice and discrimination towards patients in health systems, including through education of healthcare professionals and examining inequitable provision of services and impacts of policies. WHO 2020a highlighted equity of access to services as a key issue:

*"It is important that Member States' national policies and regulations ensure wide and equitable access to appropriate and high-quality services for children with chronic pain. Treatment costs and bureaucratic processes must not preclude or discourage equitable access to appropriate therapies. Health services for chronic pain are an essential part of universal health coverage (UHC) for children."(*WHO 2020a*, p26).*

In the longer term, we recommend a whole system change for children's chronic pain – a completely new approach to children's chronic non-cancer pain services. Existing health and social care service models are adult-orientated. Child-specific, child- and family-centred models need to be developed rather than focusing on improving only single aspects of systems, such as improved pain education for healthcare professionals. Furthermore, efforts should be made to liaise with schools and school health services to raise awareness about chronic pain and its associated impact on children and young people, to ensure that school policies and practices can flexibly support them in self-care, while avoiding stigmatisation, and avoid negative impacts of disruption to their education. Health providers, schools and families working together to achieve outcomes valued by children with chronic pain and their families is the basis of a 'whole systems' approach, which is based on strong connections and communication.

Our new theory goes beyond existing theories, which have either too wide a focus to derive clear testable hypotheses or a narrow focus, such as on the causes of pain, a developmental perspective concerning how children understand their chronic pain (Carter 2014), a biopsychosocial approach to clinical assessment and management of children's chronic pain (Bursch 1998), or the role of parent and family factors in children's chronic pain (Palermo 2014; Palermo 2005).

Integration with Cochrane Reviews

We integrated our synthesised findings with 14 relevant Cochrane intervention effects reviews. The outcomes measured in trials of intervention effectiveness and systematic reviews of effects did not always match those of importance to children and families; for instance, there is a need to measure impacts of interventions on the whole family and absence of pain. In addition, a biopsychosocial approach, which takes into account the full complexity of how interventions work, is required but has been mainly neglected in intervention programme theories.

Patient-reported outcome measures

One of our study objectives was to help inform the selection and design of patient-reported outcome measures for use in chronic pain studies. Since we started our meta-ethnography, a patient-reported outcome consensus study was published (Palermo 2021). Drawing on a much wider range of in-depth qualitative evidence from broader contexts than their study, our findings support and validate some of their final outcome domains including pain interference with daily living, pain severity, overall well-being, physical functioning and emotional functioning. Additional outcomes we have identified as important to children and families not found in their study are absence of pain; the impact on family life, relationships and functioning; and the psychosocial impacts on family members including parents/the main caregiver and siblings.

Equality, diversity and inclusion

Participant representation

Our sample of included studies specifically sought to represent diverse populations. However, we were restricted by the available primary qualitative study publications in terms of the study population characteristics and how inclusive the populations were. We identified and have already described evidence gaps and under-represented groups.

We have described our PPI recruitment strategy and engagement in Appendix 3. In short, for our core PPI group we successfully recruited children and young people with different kinds of chronic pain ranging in ages from eight years old upward and mothers of children with chronic pain, but we did not have any fathers directly involved despite recruitment attempts. Group members came from England, Scotland and Wales in the UK. We tried to recruit children and parents from a variety of ethnic backgrounds through third-sector organisations but were unsuccessful. We also used social media and online surveys for wider PPI engagement, which may have reached a more diverse group of children and families, but their feedback was anonymous.

Reflections on the research team and wider involvement

Our core research team is made up of adults (all female) some of whom have lived experience of chronic pain, which started in childhood or adulthood. Six review authors are parents, some of whom have children with long-term health and/or developmental conditions. Our meta-ethnography focused on children and young people with chronic pain and their families; they were not part of the core research team but were members of our PPI and advisory groups. Our core team has diversity in nationalities (Belgian, Brazilian, British, French) and professional backgrounds in nursing children with chronic pain (JN), psychology (EF), health psychology (AJ, LC), sociology (IU, RT), family therapy (LF) and physiotherapy with children with chronic pain (MSB), occupational therapy (KT), children's pain research (AJ, LC) and health services research (all).

As a result of our diverse backgrounds, there were some divergent views on aspects of the findings, which we record here for transparency. Two team members with extensive expertise in children's pain research were uncomfortable with use of the term 'cure' in relation to chronic pain because for most young people there is no cure for their chronic pain. Therefore, it might be more scientifically accurate to use terms like 'alleviate' or 'reduce' pain. However, we retained the term 'cure' because it was used by research participants in a large proportion of the included primary studies and refers to their focus on absence rather than reduction of pain. There was also a difference in team members' opinions about whether we should refer to '*potential* racism and prejudice' or 'racism and prejudice' in health services because of difficulties in knowing whether poor treatment of children and young people with chronic pain was related to their protected characteristics. We decided to refer to 'racism and prejudice,' given that included studies reported racism and that there is further supporting evidence in the wider literature, as reported above.

There was a range of experience and expertise amongst the review authors including a new post-doctoral researcher, early-career and mid-career researchers, as well as senior academics. In terms of development opportunities, the junior member of the team was mentored by more senior members; accessed institutional and external training, including writing workshops and a grant writing development group; Cochrane systematic review training seminars including use of GRADE-CERQual; and was supported to present at conferences and lead journal articles.

Our wider team included a project advisory group including clinicians with pain expertise, a general practitioner, physiotherapists, Scottish Government representatives, an academic expert in qualitative evidence synthesis, voluntary sector representatives from patient organisations, and a PPI group of children and young people with chronic pain and parents.

Patient and public involvement

We have described our approach to PPI and the impact it had in detail in Appendix 3 using the ACTIVE framework to guide our reporting (Pollock 2019). We believe ours is the first meta-ethnography to have actively included patients and the public in every stage of the project from its inception through to dissemination (Park 2020). Including PPI in systematic reviews of intervention effects is more common, but the extent of involvement has varied (Pollock 2018).

We engaged with our core PPI group using a variety of media and methods to engage them. The core group remained involved throughout the entire project duration. We used email, video calls, online workshops, short online surveys and social media including a project Facebook group and a Twitter page. The format of workshops and meetings was specifically designed to accommodate and engage children and young people with chronic pain, as described already in Appendix 3. We innovated in the methods used to involve children and young people with chronic pain and their parents in our analysis and synthesis using visual methods, such as cartoons and graphics, and used simple language to convey complex concepts. In our PPI materials we used plain English language suitable for children as young as eight years old, showed ethnic and gender diversity in our visual materials (e.g. cartoons of findings), and carried out video call briefings prior to any meetings or workshops to explain what would happen. For wider PPI engagement beyond the group, we used social media including online surveys and relevant charities. We believe that many of our approaches could be used as examples of good PPI practice for other researchers.

The impact of PPI is summarised briefly here. Our initial PPI engagement during grant development confirmed the importance of the topic and review questions and informed our dissemination plan. Our core PPI group agreed our final study inclusion criteria, contributed to study sampling decisions (described in the Methods) and furthered our understanding and interpretation of data, particularly in areas of ambiguity or low clarity, such as the reasons why children and young people might not communicate their pain verbally. They also helped fill gaps in the data, e.g. around disengagement with NHS health services, and brought experiences of pain conditions not represented in the included studies, such as Ehlers-Danlos syndrome. Our PPI group collaborated with us to design a short animation of findings for children and young people (CHAMPION 2023) and will help us disseminate via social media and support groups. In addition, a young person with chronic pain co-produced and co-presented an oral presentation with us at the RCN Annual Research Conference in Cardiff, UK, in 2022.

Strengths

The strengths of our meta-ethnography are that we conducted a rigorous, systematic analytic synthesis involving a team of eight core researchers from a range of disciplines including nursing, psychology, sociology, physiotherapy and family therapy, and a wider group of stakeholders including children and young people with chronic pain and their parents, healthcare professionals, academics and the third sector. We developed novel insights and a new family-centred theory of children's chronic pain and its management, which has improved our understanding of how children and young people with chronic pain and their families think about, live with and experience chronic pain and what they need and want from services. No other qualitative evidence synthesis on children and young people's chronic pain has looked at such wide-ranging data and ours is the first theory encompassing such diverse aspects and pain populations as well as having a family focus. The majority (21 out 36, 58%) of our findings are high confidence and a third (12 out of 36, 33%) were moderate confidence, as assessed using the GRADE-CERQual approach. We initially produced CERQual assessments of our findings for a UK funder and context. For this review, we revised and reassessed all findings for a global context by reassessing their relevance and rewording some findings to specify contexts. This is the first time that CERQual findings have been reassessed for context relevance. To our knowledge, this is also the first time that a qualitative evidence synthesis has been integrated with such a large number (n = 14) of Cochrane Reviews of intervention effects.

Limitations

Evidence syntheses are reliant on the available evidence and its quality. We identified gaps in the primary qualitative evidence base: there was a lack of qualitative studies overall, especially studies conducted in LMICs and studies focusing on common pain conditions like headache, recurrent abdominal pain, musculoskeletal pain, dysmenorrhoea and earache, and some rarer conditions like Ehlers-Danlos syndrome, osteogenesis imperfecta and others. There was a lack of conceptually rich UK and non-UK qualitative studies on the aforementioned common pain conditions. Certain populations of children and young people were poorly represented, such as those with learning disabilities; children under five years old with chronic pain, particularly babies and infants under two years old; and siblings of children and young people with chronic pain. There were few eligible studies focusing on the experiences of siblings and fathers. In included studies, the experiences of boys with chronic pain and fathers were under-represented. There was a lack of detailed data on family living arrangements in the included studies, so we do not know how well-represented different family configurations were. The data came mainly from studies conducted in high-income countries, which could limit their transferability to other populations and participant groups, e.g. health systems and cultures will differ in LMICs. The likely transferability of findings to the decision-maker's context could be assessed by using the TRANSFER approach (Munthe-Kaas 2020). There was a lack of studies focused on experiences and perceptions of treatments and services for chronic pain - most were about living with pain. However, through understanding the impact of pain on families' lives we have been able to make recommendations for improving services for pain management. In addition, there is a need for improved reporting of participant characteristics and methods in primary qualitative studies.

Three (out of 36, 8%) of our findings were low or very low confidence, as assessed using GRADE-CERQual. Additional evidence could increase our confidence in those findings. Low- or very low-confidence findings were focusing on the impact of chronic pain on siblings without chronic pain; bullying of children with chronic pain at school; and what children and parents valued in interventions and treatments.

There are some limitations of our review process. We chose to focus only on children and families' experiences and perceptions – we did not search for and synthesise data on healthcare professionals' perceptions and experiences of assessing and managing pain. However, a Master's dissertation (unpublished, conducted by Scott Gribbon in 2022 supervised by EF) that synthesised the healthcare professional literature and a qualitive evidence synthesis for WHO with a global focus conducted by authors JN, EF and MSB that also explored healthcare professional's views have informed our discussion section and conclusions. We excluded publications focusing on chronic cancer pain and end-of-life pain management and so some of our results may not apply to those populations. We were unable to screen 17 publications in full text because they were unavailable by our cut-off date due to libraries being closed when we carried out our original searches in 2020 during the COVID-19 pandemic. The closures particularly affected the availability of some books, book chapters, PhD theses and older journal articles (pre-2006); consequently we may have missed a few eligible publications.

We recommend that the meta-ethnography is updated in the near future, e.g. late 2024, given that there appeared to have been a recent increase in the volume of relevant studies being published (based on our update search in 2022), that there are under-represented populations, evidence gaps and that with GRADE-CERQual we assessed a few synthesised findings as being low or very low confidence.

AUTHORS' CONCLUSIONS

We synthesised a diverse body of qualitative evidence on children and young people's chronic pain, pulling together different types of chronic pain conditions from a range of family members and children of different ages from a range of mainly high-income countries, to develop new findings including a novel family-centred theory of children's chronic pain and its management.

Poorly managed, moderate or severe chronic pain has wide-ranging serious impacts on children and their families. Current services are fragmented and difficult to navigate. There is no clear care pathway for children's chronic pain. Children's chronic pain is frequently poorly managed and children and young people are suffering suboptimal care. Trials and reviews of intervention effects should incorporate outcomes of importance to children and families including impacts on the whole family and absence of pain.

Implications for practice

Health and social care systems for children and young people's chronic pain require modification to ensure that a more holistic approach to addressing pain in children and young people is adopted, which considers all biopsychosocial, family-centred health and social care systems. Below are a set of questions that may help health service providers or managers when implementing or planning for children's chronic pain management services. These questions were drawn from the findings.

1. In your service, how do healthcare professionals assess a child's chronic pain? In addition to using any formal assessment tools, do they make use of a child's knowledge of their pain? Do they include the main family caregiver's expertise in assessing their child's pain, particularly for children who have communication difficulties?
2. In your service, how do healthcare professionals explore the potential underlying cause or causes of a child's chronic pain? Do they explore any underlying physical/biological, psychological and social contexts?
3. In your service, how do healthcare professionals explore children and families' experiences of the physical/biological, psychological and social impacts of living with chronic pain on the whole family?
4. In your service, do healthcare professionals discuss priorities for chronic pain management with the child and main family caregiver before developing a pain management plan? How do healthcare professionals realistically and sensitively manage child and family expectations for treating or curing the child's pain? Consider that children and families might want and expect complete resolution of chronic pain.
5. In your service, how do healthcare professionals check that children with chronic pain and their families understand the purpose of each test, examination and/or treatment?
6. In your service, how do healthcare professionals explain chronic pain to children and their families? To what extent do they adopt a comprehensive view to understanding chronic pain and its management, which considers physical/biological, psychological and social contexts and impacts?
7. In your service, do healthcare professionals have knowledge of, and access to, appropriate existing chronic pain patient education resources? If so, do they direct children with chronic pain and their families to these resources?

8. How often do children with chronic pain and their families repeatedly return to your service seeking a diagnosis and/or better pain relief? How does your service deal with these children? What could be done to better support these children to avoid repeated return visits to your service and ineffectively managed pain?
9. In your service, do healthcare professionals have access to, and use, shared decision-making frameworks, decision aids or decision support tools with children with chronic pain and their families that indicate all the available and appropriate treatment options?
10. In your service, how confident are healthcare professionals in assessing, triaging and/or managing children's chronic pain? Consider what their training needs are to deal specifically with children with chronic pain, their parents/guardians and their other family members. How does your service provide staff with continuing professional development opportunities in chronic pain-specific education?
11. For organisations that provide healthcare professional education and training, how much of your curriculum focusses on children's chronic pain assessment and management? Does any such education and training address the biopsychosocial (biological, psychological and social) approach to treating chronic pain? Does it address how sex and ethnicity impact children's experience and reporting of chronic pain?
12. How does your service consider the impacts of chronic pain on the whole family and their needs? For example, through providing or signposting to family-centred psychosocial support such as family counselling or family systems interventions, where available, and/or tailoring pain management plans and interventions to the family and child's preferences, needs and lifestyle. Consider the impact on family life when planning chronic pain management strategies.
13. Has your service evaluated its provision of healthcare professional training about ensuring an inclusive approach to meeting the diverse needs of children and young people presenting with chronic pain and their families? How has reflection on equalities affected the personalised approach to families using your service?
14. Does your staff team reflect the ethnic make-up of the local population?
15. How does your service include fathers in the chronic pain management plan, even if they are not attending each clinical appointment?
16. How have children with chronic pain and their families been involved in shaping how your service is run?
17. How accessible is your service to children with chronic pain and their families? Consider geographical location, awareness of your service among referrers and families, child and family communication and language needs, and disabled access, for example.
18. For non-specialised health services, does your service have clear referral pathways to specialist chronic pain services, where these are available? Where specialist services are not available, how could your service support children with chronic pain and their families with current resources and by utilising community resources, e.g. peer support, community groups, charities?
19. Does your service have a clear referral pathway to psychosocial (psychological and social) support, such as family systems therapists or counselling, for children with chronic pain and their families? Where such services are not available, how could your service support children and their families with current resources and by utilising community resources, e.g. peer support, community groups, charities?

Implications for future research

There are qualitative evidence gaps, which need addressing to inform improvements to policy and practice. Future research should prioritise conducting further primary qualitative in-depth studies to produce conceptually rich findings to address gaps in understanding the experiences and perceptions of certain under-researched populations, including family experiences of children's chronic pain in low- and middle-income countries. Furthermore, research is needed to explore aspects of families' experiences of pain treatment, such as pain management plans and experiences of pain assessment, and experiences of social care services. There is a need for development and testing of a triage approach to make sure that children and young people get the right care, at the right time, from the right service. This could be on a spectrum from simple first-line interventions that can be recommended at first contact with healthcare professionals, to fast-track referral, to a holistic pain service if initial simple first-line interventions do not work. This would mean that front-line healthcare professionals need additional training and access to new tools, shared decision-making processes and child-centred care pathways, and so on. There is a need for the development and testing of family-centred interventions and services and to develop treatments that are less onerous for, and more acceptable to, families. Family-centred outcomes should be included in future in trials of chronic pain interventions. We found little evidence from families who mentioned use of opioids; opioid use in children and young people remains controversial and requires further research.

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Editorial and peer reviewer contributions

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The following people conducted the editorial process for this article:

- Sign-off Editor (final editorial decision): Neil O'Connell, Department of Health Sciences at Brunel University London
- Managing Editor (selected peer reviewers, provided editorial guidance to authors, edited the article): Helen Wakeford, Cochrane Central Editorial Service

- Editorial Assistant (conducted editorial policy checks, collated peer reviewer comments and supported editorial team): Leticia Rodrigues, Cochrane Central Editorial Service
- Copy Editor (copy editing and production): Jenny Bellorini, Cochrane Central Production Service; Mary Anna Rice, Senior Copy Editor, J&J Editorial
- Peer reviewers (provided comments and recommended an editorial decision): Jennifer Hilgart, Cochrane Central Editorial Service (methods), Steve McDonald, Cochrane Australia (search), Emma Fisher (PhD), Centre for Pain Research, University of Bath (clinical), Manasi Murthy Mittinty, University of Sydney (clinical) and Jessica D'Urbano (consumer).

REFERENCES

References to studies included in this review

Ahlqwist 2012 *{published data only}*

Ahlqwist A, Sällfors C. Experiences of low back pain in adolescents in relation to physiotherapy intervention. *International Journal of Qualitative Studies on Health and Well-being* 2012;**7**:15471.

Ahola 2018 *{published data only}*

Ahola Kohut S, Stinson J, Forgeron P, van Wyk M, Harris L, Luca S. A qualitative content analysis of peer mentoring video calls in adolescents with chronic illness. *Journal of Health Psychology* 2018;**23**(6):788-99.

Ajinkpang 2022 *{published data only}*

Ajinkpang S, Anim-Boamah O, Bimpong K, Kanton F, Pwavra J, Abdul-Mumin A. Sickle cell disease in children: knowledge and home-based management strategies among caregivers at a tertiary facility in Northern Ghana. *BioMed Research International* 2022;**2022**:1-6.

Ali 2017 *{published data only}*

Ali A, Weiss TR, Dutton A, McKee D, Jones KD, Kashikar-Zuck S, et al. Mindfulness-based stress reduction for adolescents with functional somatic syndromes: a pilot cohort study. *Journal of Pediatrics* 2017;**183**:184-90.

Allgood 2018 *{published data only}*

Allgood SJ, Kozachik S, Alexander KA, Thaxton A, Vera M, Lechtzin N. Descriptions of the pain experience in adults and adolescents with cystic fibrosis. *Pain Management Nursing* 2018;**19**(4):340-7.

Asmussen 1999 *{published data only}*

Asmussen L, Olson LM, Sullivan SA. 'You have to live it to understand it...' Family experiences with chronic otitis media in children. *Ambulatory Child Health* 1999;**5**(4):303-12.

Atkin 2000 *{published data only}*

Atkin K, Ahmad WI. Family care-giving and chronic illness: how parents cope with a child with a sickle cell disorder or thalassaemia. *Health & Social Care in the Community* 2000;**8**(1):57-69.

Atkin 2001 *{published data only}*

Atkin K, Ahmad WI. Living a 'normal' life: young people coping with thalassaemia major or sickle cell disorder. *Social Science and Medicine* 2001;**53**(5):615-26.

Atoui 2015 *{published data only}*

Atoui M, Badr LK, Brand TD, Khoury R, Shahine R, Abboud M. The daily experiences of adolescents in Lebanon with sickle cell disease. *Journal of Pediatric Healthcare* 2015;**29**(5):424-34.

Baert 2020 *{published data only}*

Baert F, McParland J, Miller MM, Hirsh AT, Wallace E, Dickson A, et al. Mothers' appraisals of injustice in the context of their child's chronic pain: an interpretative phenomenological analysis. *European Journal of Pain* 2020;**24**(10):1932-45.

Bagge-Petersen 2020 *{published data only}*

Bagge-Petersen CM, Skovdal M, Langstrup H. The socio-material self-care practices of children living with hemophilia or juvenile idiopathic arthritis in Denmark. *Social Science and Medicine* 2020;**255**:113022.

Barlow 1998 *{published data only}*

* Barlow J, Harrison K, Shaw K. The experience of parenting in the context of juvenile chronic arthritis. *Clinical Child Psychology and Psychiatry* 1998;**3**(3):445-63.

Barlow JH, Shaw KL, Harrison K. Consulting the 'experts': children's and parents' perceptions of psycho-educational interventions in the context of juvenile chronic arthritis. *Health Education Research* 1999;**14**(5):597-610.

Barlow 1999 *{published data only}*

Barlow JH, Shaw KL, Harrison K. Consulting the 'experts': children's and parents' perceptions of psycho-educational interventions in the context of juvenile chronic arthritis. *Health Education Research* 1999;**14**(5):597-610.

Beneitez 2020 *{published data only}*

Beneitez I, Nieto R, Hernandez E, Boixados M. Adolescents' social needs living with juvenile idiopathic arthritis and their views about digital resources. *Advances in Rheumatology* 2020;**60**(1):36.

Beyer 2004 *{published data only}*

Beyer JE, Simmons LE. Home treatment of pain for children and adolescents with sickle cell disease. *Pain Management Nursing* 2004;**5**(3):126-35.

Borghi 2014 *{published data only}*

Borghi CA, Rossato LM, Damião EB, Guedes DM, Silva EM, Barbosa SM, et al. Living with pain: the experience of children and adolescents in palliative care. *Revista da Escola de Enfermagem da USP* 2014;**48 Spec No**:67-73.

Bradshaw 2016 *{published data only}*

Bradshaw E, Barlas P. An outpatient paediatric pain management service lessens the impact of pain on the child: a service evaluation. *Pain and Rehabilitation* 2016;**2016**(40):4-9.

Brandelli 2021 *{published data only}*

Brandelli YN, Tutelman PR, Chambers CT, Parker JA, Stinson JN, Huber AM, et al. "Every Little Furrow of Her Brow Makes Me Want To Stop": An Interpretative Phenomenological Analysis of Mothers' Experiences With Juvenile Idiopathic Arthritis Treatments. *Arthritis Care & Research* 2021;**74**(11):1761-9. [ISSN: 2151-4658 2151-464X]

Brekke 2020 *{published data only}*

Brekke M, Brodwall A. Understanding parents' experiences of disease course and influencing factors: a 3-year follow-up qualitative study among parents of children with functional abdominal pain. *BMJ Open* 2020;**10**(8):e037288.

Britton 2002 *{published data only}*

Britton C, Moore A. Views from the inside, part 1: routes to diagnosis - families' experience of living with a child with arthritis. *British Journal of Occupational Therapy* 2002;**65**(8):374-80.

Britton 2002a *{published data only}*

Britton C, Moore A. Views from the inside, part 2: what the children with arthritis said, and the experiences of siblings, mothers, fathers and grandparents. *British Journal of Occupational Therapy* 2002;**65**(9):413-9.

Britton 2002b *{published data only}*

Britton C, Moore A. Views from the inside, part 3: how and why families undertake prescribed exercises and splinting programmes and a new model of the families' experience of living with juvenile arthritis. *British Journal of Occupational Therapy* 2002;**65**(10):453-60.

Brodwall 2018 *{published data only}*

Brodwall A, Glavin K, Lagerlov P. Parents' experience when their child has chronic abdominal pain: a qualitative study in Norway. *BMJ Open* 2018;**8**(5):e021066.

Bruce 2022 *{published data only}*

Bruce AA, Guilcher GM, Desai S, Truong TH, Leaker M, Alaazi DA, et al. ADaPTS "(AD)olescents (P)ath through (T)ransplant (S)ickle cell disease". *Health and Quality of Life Outcomes* 2022;**20**(1):118.

Burbage 2015 *{published data only}*

Burbage ML, Mason MB, Nabors LA, Kichler JC. An evaluation of a juvenile idiopathic arthritis retreat for families. *Pediatric Rheumatology Online Journal* 2015;**13**:12.

Carter 2002 *{published data only}*

Carter B. Chronic pain in childhood and the medical encounter: professional ventriloquism and hidden voices. *Qualitative Health Research* 2002;**12**(1):28-41.

Carter 2002a *{published data only}*

Carter B, Lambrenos K, Thursfield J. A pain workshop: an approach to eliciting the views of young people with chronic pain. *Journal of Clinical Nursing* 2002;**11**(6):753-62.

Carter 2002b *{published data only}*

Carter B, McArthur E, Cunliffe M. Dealing with uncertainty: parental assessment of pain in their children with profound special needs. *Journal of Advanced Nursing* 2002;**38**(5):449-57.

Carter 2017 *{published data only}*

Carter B, Arnott J, Simons J, Bray L. Developing a sense of knowing and acquiring the skills to manage pain in children with profound cognitive impairments: mothers' perspectives. *Pain Research & Management* 2017;**2017**:2514920.

Cartwright 2015 *{published data only}*

Cartwright T, Fraser E, Edmunds S, Wilkinson N, Jacobs K. Journeys of adjustment: the experiences of adolescents living with juvenile idiopathic arthritis. *Child: Care, Health & Development* 2015;**41**(5):734-43.

Castle 2007 *{published data only}*

Castle K, Imms C, Howie L. Being in pain: a phenomenological study of young people with cerebral palsy. *Developmental Medicine & Child Neurology* 2007;**49**(6):445-9.

Conboy 2008 *{published data only}*

Conboy L, Quilty MT, Kerr C, Shaw J, Wayne P. A qualitative analysis of adolescents' experiences of active and sham Japanese-style acupuncture protocols administered in a clinical trial. *Journal of Alternative & Complementary Medicine* 2008;**14**(6):699-705.

Constantinou 2021 *{published data only}*

Constantinou C, Payne N, van den Akker O, Inusa B. A qualitative exploration of health-related quality of life and health behaviours in children with sickle cell disease and healthy siblings. *Psychology & Health* 2023;**38**(1):125-46.

Corey 2021 *{published data only}*

Corey JR, Heathcote LC, Mahmud F, Kronman C, Mukerji C, McGinnis E, et al. Longitudinal narrative analysis of parent experiences during graded exposure treatment for children with chronic pain. *Clinical Journal of Pain* 2021;**37**(4):301-9.

Cotton 2012 *{published data only}*

Cotton S, Grossoehme D, McGrady ME. Religious coping and the use of prayer in children with sickle cell disease. *Pediatric Blood & Cancer* 2012;**58**(2):244-9.

Cox 2022 *{published data only}*

Cox D, McParland JL, Jordan A. Parenting an adolescent with complex regional pain syndrome: a dyadic qualitative investigation of resilience. *British Journal of Health Psychology* 2022;**27**(1):194-214.

Cunningham 2018 *{published data only}*

Cunningham NR, Nelson S, Jagpal A, Moorman E, Farrell M, Pentiuk S, et al. Development of the aim to decrease anxiety and pain treatment for pediatric functional abdominal pain disorders. *Journal of Pediatric Gastroenterology & Nutrition* 2018;**66**(1):16-20.

Cunningham 2019 *{published data only}*

Cunningham NR, Fussner LM, Moorman E, Avar Aydin PO, Brunner HI, Kashikar-Zuck S. Development and pilot testing of the treatment and education approach for childhood-onset lupus (TEACH): a cognitive behavioral treatment. *Pediatric Rheumatology Online Journal* 2019;**17**(1):9.

Curtis 2019 *{published data only}*

Curtis K, Lebedev A, Aguirre E, Lobitz S. A medication adherence app for children with sickle cell disease: qualitative study. *JMIR mHealth uHealth* 2019;**7**(6):e8130.

Dell'Api 2007 *{published data only}*

Dell'Api M, Rennick JE, Rosmus C. Childhood chronic pain and health care professional interactions: shaping the chronic pain experiences of children. *Journal of Child Health Care* 2007;**11**(4):269-86.

de Monte 2009 *{published data only}*

de Monte R, Rodger S, Jones F, Broderick S. Living with juvenile idiopathic arthritis: children's experiences of participating in home exercise programmes. *British Journal of Occupational Therapy* 2009;**72**(8):357-65.

de Moura 2021 *{published data only}*

de Moura LA, de Oliveira PR, Medeiros M, Rossato LM, Borges ND, Pereira LV. Chronic pain following inguinal herniorrhaphy: perceptions of children and adolescents. *Revista da Escola de Enfermagem da U S P* 2021;**55**:e20200490.

Dogan 2022 *{published data only}*

Dogan M, Hartenstein-Pinter A, Lopez Lumbi S, Blankenburg M, Frühwald MC, Ahnert R, et al. Exploring the mechanisms underlying the effectiveness of psychosocial aftercare in pediatric chronic pain treatment: a qualitative approach. *Children* 2022;**9**(3):407.

Donovan 2013 *{published data only}*

Donovan E, Mehringer S, Zeltzer LK. A qualitative analysis of adolescent, caregiver, and clinician perceptions of the impact of migraines on adolescents' social functioning. *Pain Management Nursing* 2013;**14**(4):e135-41.

Donovan 2019 *{published data only}*

Donovan E, Martin SR, Lung K, Evans S, Seidman LC, Cousineau TM, et al. Pediatric irritable bowel syndrome: perspectives on pain and adolescent social functioning. *Pain Medicine* 2019;**20**(2):213-22.

dos Santos 2022 *{published data only}*

dos Santos L, Neta T, Brito L, Passos S, Jenerette C, Carvalho E. Being an adolescent despite the restrictions and discrimination imposed by sickle cell disease. *Acta Paulista de Enfermagem* 2022;**35**:eAPE0243345.

Dyson 2011 *{published data only}*

Dyson SM, Atkin K, Culley LA, Dyson SE, Evans H. Sickle cell, habitual dys-positions and fragile dispositions: young people with sickle cell at school. *Sociology of Health and Illness* 2011;**33**(3):465-83. [DOI: 10.1111/j.1467-9566.2010.01301.x]

Evans 2010 *{published data only}*

Evans S, Meldrum M, Tsao JC, Fraynt R, Zeltzer LK. Associations between parent and child pain and functioning in a pediatric chronic pain sample: a mixed methods approach. *International Journal on Disability and Human Development* 2010;**9**(1):11-21.

Evans 2018 *{published data only}*

Evans S, Seidman LC, Lung K, Sternlieb B, Zeltzer LK. Yoga for teens with irritable bowel syndrome: results from a mixed-methods pilot study. *Holistic Nursing Practice* 2018;**32**(5):253-60.

Forgeron 2008 *{published data only}*

Forgeron P, McGrath PJ. Self-identified needs of youth with chronic pain. In: Pain in Children and Youth. Nova Science Publishers Inc, 2008:101-113.

Forgeron 2013 *{published data only}*

Forgeron PA, Evans J, McGrath PJ, Stevens B, Finley GA. Living with difference: exploring the social self of adolescents with chronic pain. *Pain Research & Management* 2013;**18**(6):e115-23.

Gaughan 2014 *{published data only}*

Gaughan V, Logan D, Sethna N, Mott S. Parents' perspective of their journey caring for a child with chronic neuropathic pain. *Pain Management Nursing* 2014;**15**(1):246-57.

Gernet 2011 *{published data only}*

Gernet S, Mestre C, Runel-Belliard C. Emotional representations of the illness among 22 sickle cell children. *Neuropsychiatrie de l'Enfance et de l'Adolescence* 2011;**59**:404-10.

Ghio 2018 *{published data only}*

Ghio D, Thomson W, Calam R, Ulph F, Baildam EM, Hyrich K, et al. The prioritization of symptom beliefs over illness beliefs: the development and validation of the Pain Perception Questionnaire for Young People. *British Journal of Health Psychology* 2018;**23**(1):68-87.

Ghio 2021 *{published data only}*

Ghio D, Calam R, Lee RR, Cordingley L, Ulph F, Childhood Arthritis Prospective Study (CAPS). "I just want to be normal": A qualitative investigation of adolescents' coping goals when dealing with pain related to arthritis and the underlying parent-adolescent personal models. *Paediatric and Neonatal Pain* 2021;**4**(3):1-14.

Gibler 2022 *{published data only}*

Gibler RC, Abelson E, Williams SE, Lynch-Jordan AM, Kashikar-Zuck S, Jastrowski Mano KE. Establishing the content validity of a modified bank of School Anxiety Inventory items for use among adolescents with chronic pain. *Journal of Pediatric Psychology* 2022;**47**(9):1044-56.

Goldenberg 2013 *{published data only}*

Goldenberg D, Payne LA, Hayes LP, Zeltzer LK, Tsao JC. Peer mentorship teaches social tools for pain self-management: a case study. *Journal of Pain Management* 2013;**6**(1):61-8.

Gomez-Ramirez 2016 *{published data only}*

Gómez-Ramírez O, Gibbon M, Berard R, Jurencak R, Green J, Tucker L, et al. A recurring rollercoaster ride: a qualitative study of the emotional experiences of parents of children with juvenile idiopathic arthritis. *Pediatric Rheumatology Online Journal* 2016;**14**(1):13.

Gordon 2013 *{published data only}*

Gordon M. Experiences of Children with Inflammatory Bowel Disease and their Families in General Education Classrooms [PhD thesis]. Ottawa (Canada): University of Ottawa, 2013.

Gorodzinsky 2012 *{published data only}*

Gorodzinsky AY, Tran ST, Medrano GR, Fleischman KM, Anderson-Khan KJ, Ladwig RJ, et al. Parents' initial perceptions of multidisciplinary care for pediatric chronic pain. *Pain Research and Treatment* 2012;**2012**:791061.

Gorodzinsky 2013 *{published data only}*

Gorodzinsky AY, Davies WH, Tran ST, Medrano GR, Bernacki JM, Burks LM, et al. Adolescents' perceptions of family dynamics when a sibling has chronic pain. *Children's Health Care* 2013;**42**(4):333-52.

Gremillion 2022 *{published data only}*

Gremillion M, Lang A, Everhart S, Davies H, Stolzman S, Weisman S, et al. Effects of weight and pain on physical activity: insights from the lived experiences of youth with co-occurring chronic pain and obesity. *Childhood Obesity* 2022;**18**(5):301-8.

Guell 2007 *{published data only}*

Guell C. Painful childhood: children living with juvenile arthritis. *Qualitative Health Research* 2007;**17**(7):884-92.

Hackett 2003 *{published data only}*

Hackett J. Perceptions of play and leisure in junior school aged children with juvenile idiopathic arthritis: what are the implications for occupational therapy? *British Journal of Occupational Therapy* 2003;**66**(7):303-10.

Haridasa 2019 *{published data only}*

Haridasa N, DeBaun MR, Sanger M, Mayo-Gamble TL. Student perspectives on managing sickle cell disease at school. *Pediatric Blood and Cancer* 2019;**66**(2):e27507.

Heffernan 2021 *{published data only}*

Heffernan M, Wilson C, Keating K, McCarthy K. "Why isn't it going away?": a qualitative exploration of worry and pain experiences in adolescents with chronic pain. *Pain Medicine* 2021;**22**(2):459-69.

Helvig 2013 *{published data only}*

Helvig AW, Minick P. Adolescents and headaches: maintaining control. *Pediatric Nursing* 2013;**39**(1):19-26.

Hendry 2012 *{published data only}*

Hendry GJ, Turner DE, Lorgelly PK, Woodburn J. Room for improvement: patient, parent, and practitioners' perceptions of foot problems and foot care in juvenile idiopathic arthritis. *Archives of Physical Medicine & Rehabilitation* 2012;**93**(11):2062-7.

Hilário 2022 *{published data only}*

Hilário AP. When pain never goes away: understanding the lived experiences of children with chronic pain and their parents in Portugal. *Children & Society* 2022;**36**(5):840-56.

Hollier 2018 *{published data only}*

Hollier JM, Vaughan AO, Liu Y, van Tilburg MA, Shulman RJ, Thompson DI. Maternal and child acceptability of a proposed guided imagery therapy mobile app designed to treat functional abdominal pain disorders in children: mixed-methods predevelopment formative research. *JMIR Pediatrics and Parenting* 2018;**1**(1):e6.

Hulgaard 2020 *{published data only}*

* Hulgaard DR, Rask CU, Risor MB, Dehlholm G. Illness perceptions of youths with functional disorders and their parents: an interpretative phenomenological analysis study. *Clinical Child Psychology and Psychiatry* 2020;**25**(1):45-61.

Hulgaard DR, Rask CU, Risør MB, Dehlholm G. 'I can hardly breathe': exploring the parental experience of having a child with a functional disorder. *Journal of Child Health Care* 2020;**24**(2):165-79.

Hulgaard 2020a *{published data only}*

Hulgaard DR, Rask CU, Risør MB, Dehlholm G. 'I can hardly breathe': exploring the parental experience of having a child with a functional disorder. *Journal of Child Health Care* 2020a;**24**(2):165-79.

Hunt 2003 *{published data only}*

Hunt A, Mastroyannopoulou K, Goldman A, Seers K. Not knowing—the problem of pain in children with severe neurological impairment. *International Journal of Nursing Studies* 2003;**40**(2):171-83.

Hurtubise 2021 *{published data only}*

Hurtubise K, Brousselle A, Noel M, Jordan A, White J, Rasic N, et al. Youth and parent perceptions on participating in specialized multidisciplinary pain rehabilitation options: a qualitative timeline effect analysis. *Canadian Journal of Pain* 2021;**5**(1):1-21.

Iliyasu 2021 *{published data only}*

Iliyasu Z, Borodo A, Jibir B, Nass N, Aliyu M. "A child with sickle cell disease can't live with just anyone." A mixed methods study of socio-behavioral influences and severity of sickle cell disease in northern Nigeria. *Health Science Reports* 2021;**4**(1):e222.

Jacobson 2013 *{published data only}*

Jacobson CJ, Farrell JE, Kashikar-Zuck S, Seid M, Verkamp E, Dewitt EM. Disclosure and self-report of emotional, social, and physical health in children and adolescents with chronic pain - a qualitative study of PROMIS pediatric measures. *Journal of Pediatric Psychology* 2013;**38**(1):82-93.

Jacobson 2015 *{published data only}*

Jacobson Jr CJ, Kashikar-Zuck S, Farrell J, Barnett K, Goldschneider K, Dampier C, et al. Qualitative evaluation of pediatric pain behavior, quality, and intensity item candidates and the PROMIS Pain Domain Framework in children with chronic pain. *The Journal of Pain* 2015;**16**(12):1243-55.

Jensen 2019 *{published data only}*

Jensen SE, Patel ZS, Listernick R, Charrow J, Lai JS. Lifespan development: symptoms experienced by individuals with neurofibromatosis type 1 associated plexiform neurofibromas from childhood into adulthood. *Journal of Clinical Psychology in Medical Settings* 2019;**26**(3):259-70.

Jones 2009 *{published data only}*

Jones F, Rodger S, Broderick S, De Monte R. Living with juvenile idiopathic arthritis: parents' experiences of treatment regimens and home exercise programmes. *British Journal of Occupational Therapy* 2009;**72**(6):249-58.

Jones 2020 *{published data only}*

Jones A, Caes L, Eccleston C, Noel M, Rugg T, Jordan A. Loss-adjusting: young people's constructions of a future living with complex regional pain syndrome. *Clinical Journal of Pain* 2020;**36**(12):932-9.

Jones 2022 *{published data only}*

Jones A, Caes L, Eccleston C, Noel M, Gauntlett-Gilbert J, Jordan A. The sands of time: adolescents' temporal perceptions of peer relationships and autonomy in the context of living with chronic pain. *Paediatric and Neonatal Pain* 2022;**4**:110-24.

Jordan 2007 *{published data only}*

Jordan AL, Eccleston C, Osborn M. Being a parent of the adolescent with complex chronic pain: an interpretative phenomenological analysis. *European Journal of Pain* 2007;**11**(1):49-56.

Jordan 2016 *{published data only}*

Jordan A, Crabtree A, Eccleston C. 'You have to be a jack of all trades': fathers parenting their adolescent with chronic pain. *Journal of Health Psychology* 2016;**21**(11):2466-76.

Jordan 2018 *{published data only}*

Jordan A, Noel M, Caes L, Connell H, Gauntlett-Gilbert J. A developmental arrest? Interruption and identity in adolescent chronic pain. *Pain Reports* 2018;**3**(Suppl 1):e678.

Joslin 2021 *{published data only}*

Joslin R, Donovan-Hall M, Roberts L. Exploring the outcomes that matter most to young people treated for chronic pain: a qualitative study. *Children* 2021;**8**(12):1170.

Kanstrup 2019 *{published data only}*

Kanstrup M, Jordan A, Kemani MK. Adolescent and parent experiences of acceptance and commitment therapy for pediatric chronic pain: an interpretative phenomenological analysis. *Children* 2019;**6**(9):101.

Kashikar-Zuck 2016 *{published data only}*

Kashikar-Zuck S, Tran ST, Barnett K, Bromberg MH, Strotman D, Sil S, et al. A qualitative examination of a new combined cognitive-behavioral and neuromuscular training intervention for juvenile fibromyalgia. *Clinical Journal of Pain* 2016;**32**(1):70-81.

Khair 2015 *{published data only}*

Khair K, Meerabeau L, Gibson F. Self-management and skills acquisition in boys with haemophilia. *Health expectations* 2015;**18**(5):1105-13.

Khanom 2020 *{published data only}*

Khanom S, McDonagh JE, Briggs M, McBeth J. Characterizing pain flares in adolescent inflammatory and non-inflammatory musculoskeletal disorders: a qualitative study using an interpretative phenomenological approach. *European Journal of Pain* 2020;**24**(9):1785-96.

Kroon 2018 *{published data only}*

Kroon Van Diest AM, Ernst MM, Vaughn L, Slater S, Powers SW. CBT for pediatric migraine: a qualitative study of patient and parent experience. *Headache* 2018;**58**(5):661-75.

Kulandaivelu 2018 *{published data only}*

Kulandaivelu Y, Lalloo C, Ward R, Zempsky WT, Kirby-Allen M, Breakey VR, et al. Exploring the needs of adolescents with sickle cell disease to inform a digital self-management and transitional care program: qualitative study. *JMIR Pediatrics and Parenting* 2018;**1**(2):e11058.

Lauridsen 2020 *{published data only}*

Lauridsen HH, Stolpe AB, Myburgh C, Hestbæk L. What are important consequences in children with non-specific spinal pain? A qualitative study of Danish children aged 9-12 years. *BMJ Open* 2020;**10**(10):e037315.

Law 2017 *{published data only}*

Law EF, Beals-Erickson SE, Fisher E, Lang EA, Palermo TM. Components of effective cognitive-behavioral therapy for pediatric headache: a mixed methods approach. *Clinical Practice in Pediatric Psychology* 2017;**5**(4):376-91.

Law 2017a *{published data only}*

Law EF, Fales JL, Beals-Erickson SE, Failo A, Logan D, Randall E, et al. A single-arm feasibility trial of problem-solving skills training for parents of children with idiopathic chronic pain conditions receiving intensive pain rehabilitation. *Journal of Pediatric Psychology* 2017a;**42**(4):422-33.

Le 2019 *{published data only}*

Le A, Dick BR, Spiers J, Reid K, Scott SD. Parents' experiences with pediatric chronic pain. *Canadian Journal of Pain* 2019;**3**(1):20-32.

Lee 2020 *{published data only}*

Lee RR, Shoop-Worrall S, Rashid A, Thomson W, Cordingley L. "Asking too much?": randomized N-of-1 trial exploring patient preferences and measurement reactivity to frequent use of remote multidimensional pain assessments in children and young people with juvenile idiopathic arthritis. *Journal of Medical Internet Research* 2020;**22**(1):e14503.

Leksell 2017 *{published data only}*

Leksell E, Hallberg U, Horne A, Ernberg M, Hedenberg-Magnusson B. Parenting a child with juvenile idiopathic arthritis, orofacial pain, and dysfunction: a qualitative study. *Journal of Oral & Facial Pain and Headache* 2017;**31**(4):353-61.

Lipstein 2016 *{published data only}*

Lipstein EA, Dodds CM, Lovell DJ, Denson LA, Britto MT. Making decisions about chronic disease treatment: a comparison of parents and their adolescent children. *Health Expectations* 2016;**19**(3):716-26.

Maciver 2005 *{published data only}*

Maciver D, Jones D, Nicol M. Parental experiences of pediatric chronic pain management services. *Journal of Pain Management* 2010;**4**(4):371-80.

Maciver D, Jones D, Nicol M. Parents' experiences of caring for a child with chronic pain. *Qualitative Health Research* 2010;**20**(9):1272-82.

* Maciver D. Caring for a Child With Chronic Pain: A Qualitative Study of Parents' Lived Experiences [thesis]. Edinburgh (Scotland): Queen Margaret University College, 2005.

Maciver 2010 *{published data only}*

Maciver D, Jones D, Nicol M. Parents' experiences of caring for a child with chronic pain. *Qualitative Health Research* 2010;**20**(9):1272-82.

Maciver 2011 *{published data only}*

Maciver D, Jones D, Nicol M. Parental experiences of pediatric chronic pain management services. *Journal of Pain Management* 2011;**4**(4):371-80.

McDonagh 2021 *{published data only}*

McDonagh K, McGuire BE, Durand H. Being a parent of a child with Down's arthritis: an interpretative phenomenological analysis. *Disability and Rehabilitation* 2021;**44**(23):1-9.

McKinnon 2020 *{published data only}*

McKinnon CT, White JH, Morgan PE, Antolovich GC, Clancy CH, Fahey MC, et al. The lived experience of chronic pain and dyskinesia in children and adolescents with cerebral palsy. *BMC Pediatrics* 2020;**20**(1):1-12.

McKinnon 2022 *{published data only}*

McKinnon C, White J, Harvey A, Antolovich G, Morgan P. Caregiver perspectives of managing chronic pain in children and adolescents with dyskinetic and mixed dyskinetic/spastic CP with communication limitations. *Journal of Pediatric Rehabilitation Medicine* 2022;**15**(1):69-81.

McNeill 2004 *{published data only}*

McNeill T. Fathers' experience of parenting a child with juvenile rheumatoid arthritis. *Qualitative Health Research* 2004;**14**(4):526-45.

Meldrum 2008 *{published data only}*

Meldrum ML, Tsao JC, Zeltzer LK. "I can't be what I want to be": children's narratives of chronic pain experiences and treatment outcomes. *Pain Medicine* 2009;**10**(6):1018-34.

* Meldrum ML, Tsao JC, Zeltzer LK. "Just be in pain and just move on": functioning limitations and strategies in the lives of children with chronic pain. *Journal of Pain Management* 2008;**1**(2):131-41.

Meldrum 2009 *{published data only}*

Meldrum ML, Tsao JC, Zeltzer LK. "I can't be what I want to be": children's narratives of chronic pain experiences and treatment outcomes. *Pain Medicine* 2009;**10**(6):1018-34.

Miles 2020 *{published data only}*

Miles S, Renedo A, Augustine C, Ojeer P, Willis N, Marston C. Obstacles to use of patient expertise to improve care: a co-produced longitudinal study of the experiences of young people with sickle cell disease in non-specialist hospital settings. *Critical Public Health* 30;**30**(5):544-54.

Mitchell 2007 *{published data only}*

Mitchell MJ, Lemanek K, Palermo TM, Crosby LE, Nichols A, Powers SW. Parent perspectives on pain management, coping, and family functioning in pediatric sickle cell disease. *Clinical Pediatrics* 2007;**46**(4):311-9.

Moulin 2015 *{published data only}*

* Moulin V, Akre C, Rodondi PY, Ambresin AE, Suris JC. A qualitative study of adolescents with medically unexplained symptoms and their parents. Part 1: experiences and impact on daily life. *Journal of Adolescence* 2015;**45**:307-16.

Moulin V, Akre C, Rodondi PY, Ambresin AE, Suris JC. A qualitative study of adolescents with medically unexplained symptoms and their parents. Part 2: how is healthcare perceived? *Journal of Adolescence* 2015;**45**:317-26.

Moulin 2015a *{published data only}*

Moulin V, Akre C, Rodondi PY, Ambresin AE, Suris JC. A qualitative study of adolescents with medically unexplained symptoms and their parents. Part 2: how is healthcare perceived? *Journal of Adolescence* 2015a;**45**:317-26.

Neto 2018 *{published data only}*

Neto M, Andias R, Silva AG. Pain neuroscience education and exercise for neck pain: a focus group study on adolescents' views. *Pediatric Physical Therapy* 2018;**30**(3):196-201.

Neville 2019 *{published data only}*

Neville A, Jordan A, Beveridge JK, Pincus T, Noel M. Diagnostic uncertainty in youth with chronic pain and their parents. *Journal of Pain* 2019;**20**(9):1080-90.

Newton 2019 *{published data only}*

Newton L, Randall JA, Hunter T, Keith S, Symonds T, Secrest RJ, et al. A qualitative study exploring the health-related quality of life and symptomatic experiences of adults and adolescents with ulcerative colitis. *Journal of Patient-Reported Outcomes* 2019;**3**(1):66.

Nguyen 2015 *{published data only}*

Nguyen AM, Humphrey L, Kitchen H, Rehman T, Norquist JM. A qualitative study to develop a patient-reported outcome for dysmenorrhea. *Quality of Life Research* 2015;**24**(1):181-91.

Nicholas 2007 *{published data only}*

Nicholas DB, Otley A, Smith C, Avolio J, Munk M, Griffiths AM. Challenges and strategies of children and adolescents with inflammatory bowel disease: a qualitative examination. *Health and Quality of Life Outcomes* 2007;**5**:28.

Nieto 2015 *{published data only}*

Nieto R, Hernández E, Boixadós M, Huguet A, Beneitez I, McGrath P. Testing the feasibility of DARWeb: an online intervention for children with functional abdominal pain and their parents. *Clinical Journal of Pain* 2015;**31**(6):493-503.

Nieto 2019 *{published data only}*

Nieto R, Boixadós M, Hernández E, Beneitez I, Huguet A, McGrath P. Quantitative and qualitative testing of DARWeb: an online self-guided intervention for children with functional abdominal pain and their parents. *Health Informatics Journal* 2019;**25**(4):1511-27.

Nieto 2019a *{published data only}*

Nieto R, Boixadós M, Ruiz G, Hernández E, Huguet A. Effects and experiences of families following a web-based psychosocial intervention for children with functional abdominal pain and their parents: a mixed-methods pilot randomized controlled trial. *Journal of Pain Research* 2019a;**12**:3395-412.

Nieto 2020 *{published data only}*

Nieto R, Sora B, Boixadós M, Ruiz G. Understanding the experience of functional abdominal pain through written narratives by families. *Pain Medicine* 2020;**21**(6):1093-105.

Nilsson 2011 *{published data only}*

Nilsson IM, List T, Willman A. Adolescents with temporomandibular disorder pain-the living with TMD pain phenomenon. *Journal of Oral & Facial Pain and Headache* 2011;**25**(2):107-16.

Nilsson 2016 *{published data only}*

Nilsson IM, Willman A. Treatment seeking and self-constructed explanations of pain and pain management strategies among adolescents with temporomandibular disorder pain. *Journal of Oral & Facial Pain and Headache* 2016;**30**(2):127-33.

Njifon 2019 *{published data only}*

Njifon Nsangou H, Scelles R. Sickle cell disease and siblings: a crossover look at the experiences of a sister and a brother of a sick child. *Journal de Pediatrie et de Puericulture* 2019;**32**(2):75-84.

Nkhoma 2021 *{published data only}*

Nkhoma K, Mwalabu G, Bristowe K, Lungu E, Harding R. "Pain Special Issue" "Stakeholders' perspectives and requirements on pain self-management for adolescents living with HIV/AIDS in Malawi: a cross-sectional qualitative study". *AIDS Care* 2021;**35**(8):1125-38.

Nsangou 2019 *{published data only}*

Nsangou HN, Falck J, Scelles R. Family culture of sickle cell disease and body image in affected children. *Annales Médico-Psychologiques* 2019;**178**(8):827-36.

Nutkiewicz 2008 *{published data only}*

Nutkiewicz M. Diagnosis versus dialogue: oral testimony and the study of pediatric pain. *Oral History Review* 2008;**35**(1):11-21.

O'Donnell 2013 *{published data only}*

O' Donnell SC, Marshman Z, Zaitoun H. 'Surviving the sting': the use of solicited diaries in children and young people with oral mucosal disease. *International Journal of Paediatric Dentistry* 2013;**23**(5):352-8.

O'Sullivan 2018 *{published data only}*

O'Sullivan G, O'Higgins S, Caes L, Saetes S, McGuire BE, Stinson J. Self-management needs of Irish adolescents with juvenile idiopathic arthritis (JIA): how can a Canadian web-based programme meet these needs? *Pediatric Rheumatology* 2018;**16**(1):68.

Ostojic 2022 *{published data only}*

Ostojic K, Sharp N, Paget S, Khut G, Morrow A. BrightHearts: a pilot study of biofeedback assisted relaxation training for the management of chronic pain in children with cerebral palsy. *Paediatric & Neonatal Pain* 2022;**4**(1):33-42.

Palmer 2008 *{published data only}*

Palmer K, Shepard B. An art inquiry into the experiences of a family of a child living with a chronic pain condition: a case study. *Canadian Journal of Counselling* 2008;**42**(1):7-23.

Panepinto 2012 *{published data only}*

Panepinto JA, Torres S, Varni JW. Development of the PedsQL™ Sickle Cell Disease Module items: qualitative methods. *Quality of Life Research* 2012;**21**(2):341-57.

Pate 2019 *{published data only}*

Pate JW, Noblet T, Hush JM, Hancock MJ, Sandells R, Pounder M, et al. Exploring the concept of pain of Australian children with and without pain: qualitative study. *BMJ Open* 2019;**9**(10):e033199.

Peláez-Ballestas 2013 *{published data only}*

Peláez-Ballestas I, Pérez-Taylor R, Aceves-Avila JF, Burgos-Vargas R. 'Not-belonging': illness narratives of Mexican patients with ankylosing spondylitis. *Medical Anthropology* 2013;**32**(5):487-500.

Race 2016 *{published data only}*

Race DL, Sims-Gould J, Tucker LB, Duffy CM, Feldman DE, Gibbon M, et al. 'It might hurt, but you have to push through the pain': perspectives on physical activity from children with juvenile idiopathic arthritis and their parents. *Journal of Child Health Care* 2016;**20**(4):428-36.

Randall 2020 *{published data only}*

Randall JA, Guobyte A, Delbecque L, Newton L, Symonds T, Hunter T. Qualitative research to explore the symptoms and impacts experienced by children with ulcerative colitis. *Journal of Patient Reported Outcomes* 2020;**4**(1):75.

Renedo 2019 *{published data only}*

Renedo A, Miles S, Chakravorty S, Leigh A, Telfer P, Warner JO, et al. Not being heard: barriers to high quality unplanned hospital care during young people's transition to adult services - evidence from 'this sickle cell life' research. *BMC Health Services Research* 2019;**19**(1):1-11.

Renedo 2020 *{published data only}*

Renedo A, Miles S, Chakravorty S, Leigh A, Telfer P, Warner JO, et al. Not being heard: barriers to high quality unplanned hospital care during young people's transition to adult services - evidence from 'this sickle cell life' research. *BMC Health Services Research* 2019;**19**(1):876.

* Renedo A, Miles S, Chakravorty S, Leigh A, Warner JO, Marston C. Understanding the health-care experiences of people with sickle cell disorder transitioning from paediatric to adult services: This Sickle Cell Life, a longitudinal qualitative study. Health Services and Delivery Research 2020;**8**(44):1-93. [ISSN: 2050-4349, 20504357]

Risko 2018a *{published data only}*

Risko JL. Adolescent Experiences in an Intensive Interdisciplinary Pediatric Chronic Pain Rehabilitation Program [Doctor of Philosophy thesis]. Kent (OH): Kent State University, 2018.

Rossato 2007 *{published data only}*

Rossato LM, Angelo M, Silva CA. Care delivery for the child to grow up despite the pain: the family's experience. *Revista Latino-Americana de Enfermagem* 2007;**15**(4):556-62.

Ruskin 2017 *{published data only}*

Ruskin D, Harris L, Stinson J, Kohut SA, Walker K, McCarthy E. "I learned to let go of my pain". The effects of mindfulness meditation on adolescents with chronic pain: an analysis of participants' treatment experience. *Children* 2017;**4**(12):110.

Sällfors 2001 *{published data only}*

Sällfors C, Fasth A, Hallberg LR. Oscillating between hope and despair - a qualitative study. *Child: Care, Health and Development* 2002;**28**(6):495-505.

* Sällfors C, Hallberg LR, Fasth A. Coping with chronic pain: in-depth interviews with children suffering from juvenile chronic arthritis. *Scandinavian Journal of Disability Research* 2001;**3**(1):3-20.

Sällfors C, Hallberg LR. A parental perspective on living with a chronically ill child: a qualitative study. *Families, Systems, & Health* 2003;**21**(2):193-204.

Sällfors 2002 *{published data only}*

Sällfors C, Fasth A, Hallberg LR. Oscillating between hope and despair - a qualitative study. *Child: Care, Health & Development* 2002;**28**(6):495-505.

Sällfors 2003 *{published data only}*

Sällfors C, Hallberg LR. A parental perspective on living with a chronically ill child: a qualitative study. *Families, Systems, & Health* 2003;**21**(2):193-204.

Sällfors 2009 *{published data only}*

Sällfors C, Hallberg LR. Fitting into the prevailing teenage culture: a grounded theory on female adolescents with chronic arthritis. *International Journal of Qualitative Studies on Health and Well-being* 2009;**4**(2):106-14.

Santos 2018 *{published data only}*

Santos MCD, Pires AF, Soares K, Barros L. Family experience with osteogenesis imperfecta type 1: the most distressing situations. *Disability and Rehabilitation* 2018;**40**(19):2281-7.

Secor-Turner 2011 *{published data only}*

Secor-Turner M, Scal P, Garwick A, Horvath K, Wells CK. Living with juvenile arthritis: adolescents' challenges and experiences. *Journal of Pediatric Health Care* 2011;**25**(5):302-7.

Serafimova 2022 *{published data only}*

Serafimova T, Ascough C, Parslow RM, Crawley E. Experiences of pain in paediatric chronic fatigue syndrome/myalgic encephalomyelitis: a single-centre qualitative study. *BMJ Pediatrics Open* 2022;**6**(1):e001201.

Shaygan 2021 *{published data only}*

* Shaygan M, Jaberi A. The effect of a smartphone-based pain management application on pain intensity and quality of life in adolescents with chronic pain. *Scientific Reports* 2021;**11**(1):6588.

Shaygan M, Jaberi A. The experience of chronic pain among adolescents: suffering and attempt to overcome pain? *BMC Pediatrics* 2022;**22**(1):554.

Shaygan 2022 *{published data only}*

Shaygan M, Jaberi A. The experience of chronic pain among adolescents: suffering and attempt to overcome pain? *BMC Pediatrics* 2022;**22**(1):554.

Skarstein 2016 *{published data only}*

* Skarstein S, Lagerløv P, Kvarme LG, Helseth S. High use of over-the-counter analgesic; possible warnings of reduced quality of life in adolescents - a qualitative study. *BMC Nursing* 2016;**15**:16.

Skarstein S, Lagerløv P, Kvarme LG, Helseth S. Pain and development of identity in adolescents who frequently use over-the-counter analgesics: a qualitative study. *Journal of Clinical Nursing* 2018;**27**(19-20):3583-91.

Skarstein 2018 *{published data only}*

Skarstein S, Lagerløv P, Kvarme LG, Helseth S. Pain and development of identity in adolescents who frequently use over-the-counter analgesics: a qualitative study. *Journal of Clinical Nursing* 2018;**27**(19-20):3583-91.

Skogvold 2019 *{published data only}*

Skogvold L, Magnussen LH. Chronic tension-type headache and coping strategies in adolescents: a qualitative interview study. *Physiotherapy Research International* 2019;**24**(3):e1778.

Slotter 2021 *{published data only}*

Slotter C. Adolescents with Chronic Pain and Their Peer Relationships: A Preliminary Study [PhD dissertation]. Hartford (CT): University of Hartford, 2021.

Smart 2005 *{published data only}*

Smart S, Cottrell D. Going to the doctors: the views of mothers of children with recurrent abdominal pain. *Child: Care, Health and Development* 2005;**31**(3):265-73.

Soni-Jaiswal 2016 *{published data only}*

Soni-Jaiswal A, Mercer J, Jones SA, Bruce IA, Callery P. Mucopolysaccharidosis I; parental beliefs about the impact of disease on the quality of life of their children. *Orphanet Journal of Rare Diseases* 2016;**11**:96.

Sorensen 2017 *{published data only}*

Sørensen K, Christiansen B. Adolescents' experience of complex persistent pain. *Scandinavian Journal of Pain* 2017;**15**:106-12.

Sorensen 2021 *{published data only}*

Sørensen K, Skirbekk H, Kvarstein G, Wøien H. I don't want to think about it: a qualitative study of children (6-18 years) with rheumatic diseases and parents' experiences with regular needle injections at home. *Pediatric Rheumatology Online Journal* 2021;**19**(1):8.

Ståhle-Öberg 2009 *{published data only}*

Ståhle-Öberg L, Fjellman-Wiklund A. Parents' experience of pain in children with cerebral palsy and multiple disabilities – an interview study. *Advances in Physiotherapy* 2009;**11**(3):137-44.

Stiles-Shields 2022 *{published data only}*

Stiles-Shields C, Osos S, Sunnquist M, Mak G, Skelly C, Drossos T. Patient-reported experiences with median arcuate ligament syndrome: resilience and resources required. *Clinical Practice in Pediatric Psychology* 2022;**10**(1):44-53.

Stinson 2008 *{published data only}*

Stinson JN, Toomey PC, Stevens BJ, Kagan S, Duffy CM, Huber A, et al. Asking the experts: exploring the self-management needs of adolescents with arthritis. *Arthritis and Rheumatism* 2008;**59**(1):65-72.

Stinson 2012 *{published data only}*

Stinson JN, Feldman BM, Duffy CM, Huber AM, Tucker LB, McGrath PJ, et al. Jointly managing arthritis: information needs of children with juvenile idiopathic arthritis (JIA) and their parents. *Journal of Child Health Care* 2012;**16**(2):124-40.

Stinson 2014 *{published data only}*

Stinson JN, Lalloo C, Harris L, Isaac L, Campbell F, Brown S, et al. iCanCope with Pain^{TM}: User-centred design of a web- and mobile-based self-management program for youth with chronic pain based on identified health care needs. *Pain Research and Management* 2014;**19**(5):257-65.

Stinson 2017 *{published data only}*

Stinson J, Harris L, Garofalo E, Lalloo C, Isaac L, Brown S, et al. Understanding the use of over-the-counter pain treatments in adolescents with chronic pain. *Canadian Journal of Pain* 2017;**1**(1):84-93.

Suder 2016 *{published data only}*

Suder RC. The Lived Experience of Adolescents with Chronic Pain: A Phenomenological Study [thesis]. Davie (FL): Nova Southeastern University, 2016.

Szwimer 2020 *{published data only}*

Szwimer R, Widjaja M, Ingelmo P, Hovey RB. A phenomenological exploration of the personal implications of female adolescents living with chronic pain. *Journal of Pediatric Healthcare* 2020;**34**(5):470-7.

Tong 2013 *{published data only}*

Tong A, Jones J, Speerin R, Filocamo K, Chaitow J, Singh-Grewal D. Consumer perspectives on pediatric rheumatology care and service delivery: a qualitative study. *Journal of Clinical Rheumatology* 2013;**19**(5):234-40.

Valenzuela 2013 *{published data only}*

Valenzuela JM, Vaughn LM, Crosby LE, Strong H, Kissling A, Mitchell MJ. Understanding the experiences of youth living with sickle cell disease: a photovoice pilot. *Family & Community Health* 2013;**36**(2):97-108.

Van Gulik 2020 *{published data only}*

Van Gulik EC, Verkuil F, Barendregt AM, Schonenberg-Meinema D, Rashid ANS, Kuijpers TW, et al. Experiences, perspectives and expectations of adolescents with juvenile idiopathic arthritis regarding future work participation; a qualitative study. *Pediatric Rheumatology* 2020;**18**(1):33.

van Scheppingen 2008 *{published data only}*

van Scheppingen C, Lettinga AT, Duipmans JC, Maathuis KG, Jonkman MF. The main problems of parents of a child with epidermolysis bullosa. *Qualitative Health Research* 2008;**18**(4):545-56.

van Tilburg 2006 *{published data only}*

van Tilburg MA, Venepalli N, Ulshen M, Freeman KL, Levy R, Whitehead WE. Parents' worries about recurrent abdominal pain in children. *Gastroenterology Nursing* 2006;**29**(1):50-5; quiz 56-7.

Voigtman 2002 *{published data only}*

Voigtman JL. Learning to suffer: pain response in a community of Saudi Arab children with sickle cell disease [Doctor of Philosophy thesis]. Tucson (AZ): The University of Arizona, 2002.

Waite-Jones 2008 *{published data only}*

Waite-Jones JM, Madill A. Amplified ambivalence: having a sibling with juvenile idiopathic arthritis. *Psychology and Health* 2008;**23**(4):477-92.

Wakefield 2018 *{published data only}*

Wakefield EO, Zempsky WT, Puhl RM, Litt MD. Conceptualizing pain-related stigma in adolescent chronic pain: a literature review and preliminary focus group findings. *Pain Reports* 2018;**3**(Suppl 1):e679.

Wakefield 2021 *{published data only}*

Wakefield EO, Belamkar V, Litt MD, Puhl RM, Zempsky WT. "There's nothing wrong with you": pain-related stigma in adolescents with chronic pain. *Journal of Pediatric Psychology* 2022;**47**(4):456-68.

* Wakefield EO, Puhl RM, Litt MD, Zempsky WT. "If it ever really hurts, I try not to let them know:" the use of concealment as a coping strategy among adolescents with chronic pain. *Frontiers in Psychology* 2021;**12**:666275.

Wakefield EO, Zempsky WT, Puhl RM, Litt MD. Conceptualizing pain-related stigma in adolescent chronic pain: a literature review and preliminary focus group findings. *Pain Reports* 2018;**3**(1):679.

Wakefield 2022 *{published data only}*

Wakefield E, Belamkar V, Litt M, Puhl R, Zempsky W. "There's nothing wrong with you": pain-related stigma in adolescents with chronic pain. *Journal of Pediatric Psychology* 2022;**47**(4):456-68.

Walter 2017 *{published data only}*

Walter SM. The experience of adolescents living with headache. *Holistic Nursing Practice* 2017;**31**(5):280-9.

While 2004 *{published data only}*

While AE, Mullen J. Living with sickle cell disease: the perspective of young people. *British Journal of Nursing* 2004;**13**(6):320-5.

Williams 2008 *{published data only}*

Williams F. A qualitative study of the experiences of children and young people with Epidermolysis Bullosa [thesis]. London (UK): University of East London, 2008.

Wong 2016 *{published data only}*

Wong CL, Ip WY, Lam LW. Self-care strategies among Chinese adolescent girls with dysmenorrhea: a qualitative study. *Pain Management Nursing* 2016;**17**(4):262-71.

Woodgate 1998 *{published data only}*

Woodgate RL. Adolescents' perspectives of chronic illness: 'it's hard'. *Journal of Pediatric Nursing* 1998;**13**(4):210-23.

Yeung 2017 *{published data only}*

Yeung KK, Engle L, Rabel A, Adamson K, Schwellnus H, Evans C. It just feels weird!: a qualitative study of how children aged 10-18 years describe neuropathic pain. *Disability and Rehabilitation* 2017;**39**(17):1695-702.

Yuwen 2017 *{published data only}*

Yuwen W, Lewis FM, Walker AJ, Ward TM. Struggling in the dark to help my child: parents' experience in caring for a young child with juvenile idiopathic arthritis. *Journal of Pediatric Nursing* 2017;**37**:e23-9.

References to studies excluded from this review

Abadesso 2020 *{published data only}*

Abadesso C, Pacheco S, Machado MC, Finley GA. Pain in children and adolescents with sickle cell disease: multidimensional assessment. *Journal of Pediatric Hematology/Oncology* 2020;**42**(8):455-46. [DOI: doi: 10.1097/MPH.0000000000001941]

Ahola Kohut 2016 *{published data only}*

Ahola Kohut S, Stinson J, Forgeron P, Luca S, Harris L. (490) Being a peer mentor to youth with painful chronic conditions: perceived benefits and challenges. *Journal of Pain* 2016;**17**(4 Suppl):S97. [DOI: https://doi.org/10.1016/j.jpain.2016.01.297]

Ahola Kohut 2017 *{published data only}*

Ahola Kohut S, Stinson J, Forgeron P, Luca S, Harris L. Been there, done that: the experience of acting as a young adult mentor to adolescents living with chronic illness. *Journal of Pediatric Psychology* 2017;**42**(9):962-9. [DOI: DOI: 10.1093/jpepsy/jsx062] [PMCID: PMC5896590] [PMID: 28340203]

Alavi 2012 *{published data only}*

Alavi Y, Jumbe V, Hartley S, Smith S, Lamping D, Muhit M, et al. Indignity, exclusion, pain and hunger: the impact of musculoskeletal impairments in the lives of children in Malawi. *Disability and Rehabilitation* 2012;**34**(20):1736-46. [DOI: 10.3109/09638288.2012.662260] [PMID: 22409227]

Albasri 2022 *{published data only}*

Albasri R, Metcalfe P, Ghio D. Using art workshops to facilitate research priority settings: identifying research questions with primary school children with juvenile idiopathic arthritis. *Rheumatology* 2022;**61**(Suppl 1):keac133.172. [DOI: https://doi.org/10.1093/rheumatology/keac133.172]

Alhowimel 2022 *{published data only}*

Alhowimel A, Alotaibi M, Coulson N, Radford K. Psychosocial consequences of diagnosing nonspecific low-back pain radiologically: a qualitative study. *Physiotherapy Theory and Practice* 2022;**38**:890-6. [DOI: https://doi.org/10.1080/09593985.2020.1802799]

Allgood 2015 *{published data only}*

Allgood S, Thaxton A, Vera M, Kozachik S, Mogayzel P, Lechtzin N. 651 A phenomenological study of pain in individuals with cystic fibrosis. *Pediatric Pulmonology* 2015;**50**(12):1175. [DOI: http://dx.doi.org/10.1002/ppul.23297]

Allyn 2020 *{published data only}*

Allyn K, Evans S, Seidman LC, Payne LA. "Tomorrow, I'll be fine": impacts and coping mechanisms in adolescents and young adults with primary dysmenorrhoea. *Journal of Advanced Nursing* 2020;**76**(10):2637-47. [DOI: 10.1111/jan.14460] [PMCID: PMC8567463] [PMID: 32761654]

Alongi 2018 *{published data only}*

Alongi A, Calandra S, Thornhill S, Stinson J, Luca S, Horonjeff J, et al. Differences in the perception of disease impact between US and Italian children with juvenile idiopathic arthritis: a network analysis of virtual focus groups. *Pediatric Rheumatology* 2018;**16**(Suppl 2):P071. [DOI: http://dx.doi.org/10.1186/s12969-018-0265-6]

Arbabisarjou 2014 *{published data only}*

Arbabisarjou A, Karimzaei T, Jamalzaei A. The perception of biological experience in patients with major thalassemia: a qualitative research. *Global Journal of Health Science* 2014;**7**(1):79-87. [DOI: 10.5539/gjhs.v7n1p79] [PMCID: PMC4796504] [PMID: 25560333]

Arbabisarjou 2015 *{published data only}*

Arbabisarjou A, Karimzaei T, Jamalzaei A. The perception of biological experience in patients with major thalassemia: a qualitative research. *Global Journal of Health Science* 2015;**7**(1):79-87. [DOI: 10.5539/gjhs.v7n1p79] [PMCID: PMC4796504] [PMID: 25560333]

Arbitre 2019 *{published data only}*

Arbitre C, Gaucher N, Trottier E, Bourque CJ, Robitaille N, Pastore Y. Poster 737. Patients' and caregivers' experiences with pain management in children with sickle cell disease. *Pediatric Blood and Cancer. Supplement: American Society of Pediatric*

Hematology/Oncology 2019;**66**(Suppl 2):e27713. [DOI: http://dx.doi.org/10.1002/pbc.27713]

Arbitre 2019a *{published data only}*

Arbitre C, Gaucher N, Trottier ED, Bourque C, Robitaille N, Pastore Y. LO31: Patients' and caregivers' experiences with pain management in children and teenagers with sickle cell disease requiring admission for vaso-occlusive crisis. *Canadian Journal of Emergency Medicine* 2019;**21**(Suppl 1):S18. [DOI: http://dx.doi.org/10.1017/cem.2019.74]

Arbuckle 2010 *{published data only}*

Arbuckle R, Lewis BE, Carson R, Abetz L, Johnston JM. Child and parent reports of symptoms of irritable bowel syndrome with constipation (IBS-C): results of qualitative interviews. In: Value in Health. Vol. 13(7). 2010:A373.

Arruda 2017 *{published data only}*

Arruda J, Bogetz A, Wren A, Vellanki S, Yeh AM. 77. Yoga for youth with inflammatory bowel disease: a pilot feasibility study. *Journal of Pediatric Gastroenterology and Nutrition* 2017;**65**(Suppl 2):S35. [DOI: http://dx.doi.org/10.1097/MPG.0000000000001805]

Arruda 2018 *{published data only}*

Arruda JM, Bogetz AL, Vellanki S, Wren A, Yeh AM. Yoga as adjunct therapy for adolescents with inflammatory bowel disease: a pilot clinical trial. *Complementary Therapies in Medicine* 2018;**41**:99-104. [DOI: http://dx.doi.org/10.1097/MPG.0000000000001805]

Atkin 1998 *{published data only}*

Atkin K, Ahmad WI, Anionwu EN. Screening and counselling for sickle cell disorders and thalassaemia: the experience of parents and health professionals. *Social Science & Medicine* 1998;**47**(11):1639-51. [DOI: 10.1016/s0277-9536(98)00261-5]

Aziato 2015 *{published data only}*

Aziato L, Dedey F, Clegg-Lamptey JNA. Dysmenorrhea management and coping among students in Ghana: a qualitative exploration. *Journal of Pediatric & Adolescent Gynecology* 2015;**28**(3):163-9. [DOI: https://dx.doi.org/10.1016/j.jpag.2014.07.002]

Baert 2020a *{published data only}*

Baert F, McParland J, Miller MM, Hirsh AT, Wallace E, Dickson A, et al. Mothers' appraisals of injustice in the context of their child's chronic pain: an interpretative phenomenological analysis. *European Journal of Pain* 2020;**24**(10):1932-45. [DOI: https://dx.doi.org/10.1002/ejp.1642]

Bailey 2018 *{published data only}*

Bailey M, Stebbins P, D'Alessio D, Raymond K, White MK. Content validation of the sickle cell pain diary-self report. *Blood* 2018;**132**(Suppl 1):2277. [DOI: http://dx.doi.org/10.1182/blood-2018-99-119205]

Bailey 2018a *{published data only}*

Bailey M, Stebbins P, D'Alessio D, Mitchell A, Saucier C, White MK. Content validation of sickle cell pain diaries for caregivers: results from interviews with caregivers. *Blood* 2018;**132**(Suppl 1):3572. [DOI: http://dx.doi.org/10.1182/blood-2018-99-119410]

Bakshi 2015 *{published data only}*

Bakshi N, Stinson JN, Ross D, Lukombo I, Mittal N, Joshi SV, et al. Development, content validity, and user review of a web-based multidimensional pain diary for adolescent and young adults with sickle cell disease. *Clinical Journal of Pain* 2015;**31**(6):580-90. [DOI: 10.1097/AJP.0000000000000195]

Barlow 1998a *{published data only}*

Barlow J, Harrison K, Shaw K. The experience of parenting in the context of juvenile arthritis. *Clinical Child Psychology and Psychiatry* 1998;**3**(3):445-63. [DOI: 10.1177/1359104598033008]

Barned 2022 *{published data only}*

Barned C, Fabricius A, Stintzi A, Mack DR, O'Doherty KC. "The rest of my childhood was lost": Canadian children and adolescents' experiences navigating inflammatory bowel disease. *Qualitative Health Research* 2022;**32**(1):95-107. [DOI: 10.1177/10497323211046577]

Beales 1983 *{published data only}*

Beales JG, Keen JH, Holt PJ. The child's perception of the disease and the experience of pain in juvenile chronic arthritis. *Journal of Rheumatology* 1983;**10**(1):61-5.

Becker 2019 *{published data only}*

Becker EM, Wilson Jr B, Chen-Lim ML, Ely E. The experience of pain and pain tool preferences of hospitalized youth. *Pain Management Nursing* 2019;**20**(3):245-52. [DOI: 10.1016/j.pmn.2018.12.003]

Bennett 2000 *{published data only}*

Bennett SM, Chambers CT, Bellows D, Court CA, Huntsman E, Montgomery C, et al. Evaluating treatment outcome in an interdisciplinary pediatric pain service. *Pain Research and Management* 2000;**5**:767058. [DOI: 10.1155/2000/767058]

Bennett 2000a *{published data only}*

Bennett SM, Huntsman E, Lilley CM. Parent perceptions of the impact of chronic pain in children and adolescents. *Children's Health Care* 2000;**29**(3):147-59.

Beresford 2003 *{published data only}*

Beresford BA, Sloper P. Chronically ill adolescents' experiences of communicating with doctors: a qualitative study. *Journal of Adolescent Health* 2003;**33**(3):172-9.

Beyer 1999 *{published data only}*

Beyer JE, Platt AF, Kinney TR, Treadwell M. Practice guidelines for the assessment of children with sickle cell pain. *Journal of the Society of Pediatric Nurses* 1999;**4**(2):61-73.

Bieniak 2022 *{published data only}*

Bieniak KH, Koven ML, Bedree H, Tinkle BT, Tran ST. Hypermobile Ehlers-Danlos syndrome: caregiver–child concordance across challenges, readiness to change, and coping. *Clinical Practice in Pediatric Psychology* 2022;**10**(2):139-49.

Birks 2008 *{published data only}*

Birks Y. Adolescents learned self-management of arthritis by acquiring knowledge and skills and experiencing understanding from social support. *Evidence-Based Nursing* 2008;**11**(3):92.

Borghi 2014a *{published data only}*

Borghi CA, Rossato LM, Damiao EBC, Guedes DMB, da Silva EMR, Barbosa SMD, et al. Living with pain: the experience of children and adolescents in palliative care. *Revista da Escola de Enfermagem da USP* 2014;**48**:67-73.

Borghi 2016 *{published data only}*

Borghi CA, Rossato LM, Bousso RS, Damiao EB, Cintra G. PO11 "Living with pain-the life from childrens and adolescents in palliative care". *Palliative Medicine* 2016;**30**(6):NP250-1. [DOI: 10.1177/0269216316646056]

Borini 2021 *{published data only}*

Borini CH, Carlos DM, Avila LA, Saltareli S, Hortense P. Suffered life, hard life: adverse experiences in childhood of people with chronic musculoskeletal pain. *Revista Gaúcha de Enfermagem* 2021;**42**:e20200385.

Bousso 2014 *{published data only}*

Bousso RS, Santos MR, Borghi CA, Frizzo HCF. PO84. Expressions of a teenager under palliative care on Facebook. *Palliative Medicine* 2014;**28**(6):850.

Bousso 2015 *{published data only}*

Bousso R, Camara UTJ, Rodrigues M, Borghi C, Baliza M. Expressions of teenagers under palliative care on Facebook: a fresh approach for healthcare professionals. *Journal of Pain and Symptom Management* 2015;**49**(2):414.

Branson 2011 *{published data only}*

Branson JA, Kozlowska K, Kaczynski KJ, Roesler TA. Managing chronic pain in a young adolescent girl with Ehlers-Danlos syndrome. *Harvard Review of Psychiatry* 2011;**19**(5):259-70.

Britton 1999 *{published data only}*

Britton C. A pilot study exploring families' experience of caring for children with chronic arthritis: views from the inside. *British Journal of Occupational Therapy* 1999;**62**(12):534-42.

Brown 2021 *{published data only}*

Brown C, Moshkovich O, Lipman K, Murphy R, Beaubrun A, Agodoa I. PB1769. Pediatric patient reported outcomes in patients receiving voxelotor for sickle cell disease. *HemaSphere* 2021;**5**(Suppl 2):834. [DOI: 10.1097/ HS9.0000000000000566]

Buchannan 2018 *{published data only}*

Buchannan K, Banez GA, Benore E, Senders P, Coker C. An initial examination of parent satisfaction following intensive rehabilitation for pediatric chronic pain. *Clinical Practice in Pediatric Psychology* 2018;**6**(3):238-47.

Buchbinder 2011 *{published data only}*

Buchbinder MH. Children's Pain and the Ethics of Care. Los Angeles (CA): University of California, 2010.

Buesa-Estéllez 2022 *{published data only}*

Buesa-Estéllez A, Calvo S, Jiménez-Sánchez C, Giménez-Piedrafita O, Lafuente-Ureta R, Francín-Gallego M. Uso de la balneoterapia y el ejercicio terapéutico en la mejora física y psicosocial en adolescentes con lupus y artritis juvenil: un estudio de método mixto. *Fisioterapia* 2022;**44**(3):145-53.

Burke 2016 *{published data only}*

Burke L, Hobart JC, Fox K, Lehrer-Graiwer J, Bridges K, Kraus M, et al. The 10-item Sickle Cell Disease Severity Measure (SCDSM-10): a novel measure of daily SCD symptom severity developed to assess benefit of GBT440, an experimental HbS polymerization inhibitor. *Blood* 2016;**128**(22):4760.

Byczkowski 2016 *{published data only}*

Byczkowski TL, Gillespie GL, Kennebeck SS, Fitzgerald MR, Downing KA, Alessandrini EA. Family-centered pediatric emergency care: a framework for measuring what parents want and value. *Academic Pediatrics* 2016;**16**(4):327-35.

Caes 2019 *{published data only}*

Caes L, Chambers CT, Otley A, Stinson J. Pain and quality of life in youth with inflammatory bowel disease: the role of parent and youth perspectives on family functioning. *Pain Reports* 2019;**4**(2):e715.

Cai 2017 *{published data only}*

Cai RA, Beste D, Chaplin H, Varakliotis S, Suffield L, Josephs F, et al. Developing and evaluating JIApp: acceptability and usability of a smartphone app system to improve self-management in young people with juvenile idiopathic arthritis. *JMIR mHealth and uHealth* 2017;**5**(8):e121.

Calhoun 2022 *{published data only}*

Calhoun C, Luo L, Baumann AA, Bauer A, Shen E, McKay V, et al. Transition for adolescents and young adults with sickle cell disease in a US Midwest urban center: a multilevel perspective on barriers, facilitators, and future directions. *Journal of Pediatric Hematology/Oncology* 2022;**44**(5):e872-80.

Candel 2021 *{published data only}*

Candel MIJ, Salvador Pinto T, García Peris M, Crehuá Gaudiza E, Jovaní Casano C, Moreno Ruiz MA, et al. Usefulness of complementary test in the study of patients with chronic abdominal pain. *Anales de Pediatría* 2021;**95**(1):26-32. [DOI: https://doi.org/10.1016/j.anpede.2020.04.021]

Cappon 2020 *{published data only}*

Cappon J, Van Rossum M, Littooij E, Van Der Leeden M. Feasibility of the back and forth school booklet, a shared self management instrument for young children with juvenile idiopathic arthritis (JIA) at school. *Annals of the Rheumatic Diseases* 2020;**79**(Suppl 1):1958-9.

Cappon 2021 *{published data only}*

Cappon J, Van Rossum M, Littooij E, Van Der Leeden M. Applicability and effectiveness of the back and forth schoolbooklet, a shared self management instrument for young children with juvenile idiopathic arthritis (JIA) at school. *Pediatric Rheumatology* 2021;**19**(Suppl 1):P332.

Carlson 2012 *{published data only}*

Carlson MJ, Moore CE, Tsai CM, Shulman RJ, Chumpitazi BP. Focus group assessment of reported food intolerances (RFIs) and quality of life (QOL) in children with abdominal pain-related functional gastrointestinal disorders (APFGIDs). *Gastroenterology* 2012;**142**(5 Suppl 1):S382-3.

Carlson 2014 *{published data only}*

Carlson MJ, Moore CE, Tsai CM, Shulman RJ, Chumpitazi BP. Child and parent perceived food-induced gastrointestinal symptoms and quality of life in children with functional gastrointestinal disorders. *Journal of the Academy of Nutrition and Dietetics* 2014;**114**(3):403-13.

Carter 1998 *{published data only}*

Carter B. Perspectives on Pain: Mapping the Territory. 1st edition. London (UK): Arnold, 1998.

Carter 2016 *{published data only}*

Carter B, Bray L, Simons J, Arnott J. 'Left to get on with it': the experiences of parents of children with profound cognitive impairment managing their child's pain. *Archives of Disease in Childhood* 2016;**101**(Suppl 1):A366-67.

Carter 2017a *{published data only}*

Carter B. Being Me (with IBD): growing up and getting on with my life. crohnsandcolitis.org.uk 2017.

Carter 2020 *{published data only}*

Carter B, Rouncefield-Swales A, Bray L, Blake L, Allen S, Probert C, et al. "I don't like to make a big thing out of it": a qualitative interview-based study exploring factors affecting whether young people tell or do not tell their friends about their IBD. *International Journal of Chronic Diseases* 2020;**2020**:1059025.

Castro 2020 *{published data only}*

Castro AR, Marinello J, Chougui K, Morand M, Bilodeau C, Tsimicalis A. The day-to-day experiences of caring for children with osteogenesis imperfecta: a qualitative descriptive study. *Journal of Clinical Nursing* 2020;**29**(15-16):2999-3011.

Chadi 2018 *{published data only}*

Chadi N, Kaufman M, Weisbaum E, Malboeuf-Hurtubise C, Ahola Kohut S, Locke J, et al. Comparison of an in-person vs. ehealth mindfulness meditation-based intervention for adolescents with chronic medical conditions: a mixed methods study. *Journal of Adolescent Health* 2018;**62**(2 Suppl):S12.

Chakravorty 2017 *{published data only}*

Chakravorty S, Tallett A, John W. OR2-009. Using a new patient feedback survey to explore experiences of living with sickle cell disease in the UK. *British Journal of Haematology* 2017;**176**(Suppl 1):15. [DOI: 10.1111/bjh.14613]

Chaplin 2018 *{published data only}*

Chaplin H, Barnett R, Ioannou Y, Sen D, Lempp H, Cai RA, et al. 299 The impact of juvenile idiopathic arthritis on adolescents and young adults: a qualitative study. *Rheumatology* 2018;**57**(Suppl 3):key075.523. [DOI: 10.1093/rheumatology/key075.523]

Chaplin 2018a *{published data only}*

Chaplin H, Ioannou Y, Sen D, Lempp H, Norton S. OP0101 Exploring pain and the impact of JIA on adolescents and young adults: a mixed-methods study. *Annals of the Rheumatic Diseases* 2018;**77**(Suppl 2):101.

Chaplin 2019 *{published data only}*

Chaplin H, Verhey I, Ng N, Galloway J, Scott I, Sen D, et al. AB0372 Exploring refractory disease & persistent symptoms in RA/polyJIA despite bDMARDs: patient & professional experiences. *Annals of the Rheumatic Diseases* 2019;**78**(Suppl 2):1646.

Childs 1998 *{published data only}*

Childs S. Expressed emotion, pain describing and family response behaviours in individuals with chronic pain [Doctoral thesis]. Guildford (UK): University of Surrey, 1998. [99514320202346]

Christian 1997 *{published data only}*

Christian BJ, D'Auria JP. The child's eye: memories of growing up with cystic fibrosis. *Journal of Pediatric Nursing* 1997;**12**(1):3-12.

Claar 2007 *{published data only}*

Claar RL, Scharff L. Parent and child perceptions of chronic pain treatments. *Children's Health Care* 2007;**36**(3):285-301.

Clery 2021 *{published data only}*

Clery P, Starbuck J, Laffan A, Parslow RM, Linney C, Leveret J, et al. Qualitative study of the acceptability and feasibility of acceptance and commitment therapy for adolescents with chronic fatigue syndrome. *BMJ Paediatrics Open* 2021;**5**(1):e001139.

Coleman 2016 *{published data only}*

Coleman B, Ellis-Caird H, McGowan J, Benjamin MJ. How sickle cell disease patients experience, understand and explain their pain: an interpretative phenomenological analysis study. *British Journal of Health Psychology* 2016;**21**(1):190-203.

Colver 2018 *{published data only}*

Colver A, Pearse R, McConachie H, Parr JR, Le Couteur A, Mann KD, et al, on behalf of the Transition Collaborative Group. How well do services for young people with long term conditions deliver features proposed to improve transition? *BMC Health Services Research* 2018;**18**(1):337.

Cooke 2021 *{published data only}*

Cooke M, Richards J, Tjondronegoro D, Raj Chakraborty P, Jauncey-Cooke J, Andresen E, et al. myPainPal: co-creation of a mHealth app for the management of chronic pain in young people. *Informatics for Health and Social Care* 2021;**46**(3):291-305.

Cotton 2009 *{published data only}*

Cotton S, Grossoehme D, Rosenthal SL, McGrady ME, Roberts YH, Hines J, et al. Religious/spiritual coping in adolescents with sickle cell disease: a pilot study. *Journal of Pediatric Hematology/Oncology* 2009;**31**(5):313-8.

Crego 2021 *{published data only}*

Crego N, Masese R, Bonnabeau E, Douglas C, Rains G, Shah N, et al. Patient perspectives of sickle cell management in the emergency department. *Critical Care Nursing Quarterly* 2021;**44**(2):160-74.

Crosby 2022 *{published data only}*

Crosby LE, Joffe NE, Kidwell KM, Harry O, McTate EA, Nwankwo C, et al. Perceptions of a self-management intervention for adolescents with sickle cell disease. *Clinical Practice in Pediatric Psychology* 2022;**10**(1):79-90.

Cunningham 2019a *{published data only}*

Cunningham N, Fussner L, Danguecan A, Le C, Chapson A, Nguyen E, et al. A25. A patient-engaged approach to refining a psychological therapy for individuals with childhood-onset lupus. *Pediatric Rheumatology* 2019;**17**(Suppl 2):73. [DOI: 10.1186/s12969-019-0373-y]

Cunningham 2019b *{published data only}*

Cunningham N, Fussner L, Danguecan A, Le C, Chapson A, Nguyen E, et al. A patient-engaged approach to refining a psychological therapy for individuals with childhood-onset lupus. *Paediatric Rheumatology* 2019;**17**(Suppl 2):73. [DOI: 10.1186/s12969-019-0373-y]

Dahal 2018 *{published data only}*

Dahal P, Geetha K, Judie A. A study to extrapolate the lived in experience of parents of children with chronic illness in SRM general hospital, Kattankulathur. *International Journal of Pharmaceutical and Clinical Research* 2018;**10**(6):169-75.

Davis 2016 *{published data only}*

Davis SE. Making connections: exploring social and relational influences for young people experiencing and coping with chronic pain. *Physiotherapy* 2016;**102**(Suppl 1):e153.

de Graaf 2017 *{published data only}*

de Graaf H, Sukhtankar P, Arch B, Ahmad N, Lees A, Bennett A, et al. Duration of intravenous antibiotic therapy for children with acute osteomyelitis or septic arthritis: a feasibility study. *Health Technology Assessment* 2017;**21**(48):1-164.

Dekker 2020 *{published data only}*

Dekker C, van Haastregt JCM, Verbunt J, de Jong JR, van Meulenbroek T, Pernot HFM, et al. Pain-related fear in adolescents with chronic musculoskeletal pain: process evaluation of an interdisciplinary graded exposure program. *BMC Health Services Research* 2020;**20**(1):213.

de Lucca 2016 *{published data only}*

de Lucca SA, Petean EBL. Fatherhood: experiences of fathers of boys diagnosed with Duchenne muscular dystrophy. *Ciência & Saúde Coletiva* 2016;**21**(10):3080-8.

de Souza 2011 *{published data only}*

de Souza AA, Ribeiro CA, de Borba RI. [Sickle-cell disease: short communication on how children express through games what it means for them to have the disease]. *Revista gaucha de enfermagem/EENFUFRGS* 2011;**32**(1):194-6.

Dickson 2002 *{published data only}*

Dickson C. Quality of life in children with headache [Doctoral thesis]. Southampton (UK): University of Southampton, 2002.

Diehl 1991 *{published data only}*

Diehl SF, Moffitt KA, Wade SM. Focus group interview with parents of children with medically complex needs: an intimate look at their perceptions and feelings. *Children's Health Care* 1991;**20**(3):170-8.

Donovan 2022 *{published data only}*

Donovan E, Tanson K, Martin SR, Weston G, Griffin A, Zeltzer LK. The acceptability of photovoice as a method for incorporating resilience-enhancing factors into pediatric pain research. *PLoS One* 2022;**17**(9):e0272504.

Dunford 2014 *{published data only}*

Dunford E, Thompson M, Gauntlett-Gilbert J. Parental behaviour in paediatric chronic pain: a qualitative observational study. *Clinical Child Psychology and Psychiatry* 2014;**19**(4):561-75.

Easterlin 2020 *{published data only}*

Easterlin MC, Berdahl CT, Rabizadeh S, Spiegel B, Agoratus L, Hoover C, et al. Child and family perspectives on adjustment to and coping with pediatric inflammatory bowel disease. *Journal of Pediatric Gastroenterology and Nutrition* 2020;**71**(1):e16-e27.

Eaves 2014 *{published data only}*

Eaves ER, Ritenbaugh C, Nichter M, Hopkins AL, Sherman KJ. Modes of hoping: understanding hope and expectation in the context of a clinical trial of complementary and alternative medicine for chronic pain. *Explore: The Journal of Science & Healing* 2014;**10**(4):225-32.

Eaves 2015 *{published data only}*

Eaves ER, Nichter M, Ritenbaugh C, Sutherland E, Dworkin SF. Works of illness and the challenges of social risk and the specter of pain in the lived experience of TMD. *Medical Anthropology Quarterly* 2015;**29**(2):157-77.

Eaves 2016 *{published data only}*

Eaves ER, Nichter M, Ritenbaugh C. Ways of hoping: navigating the paradox of hope and despair in chronic pain. *Culture, Medicine, and Psychiatry* 2016;**40**(1):35-58.

Ebrahimpour 2019 *{published data only}*

Ebrahimpour F, Pashaeypoor S, Salisu WJ, Cheraghi MA, Hosseini ASS. Children's description of pain through drawings and dialogs: a concept analysis. *Nursing Open* 2019;**6**(2):301-12.

Elander 2019 *{published data only}*

Elander J, Bij D, Kapadi R, Schofield MB, Osias A, Khalid N, et al. Development and validation of the Satisfaction with Treatment for Pain Questionnaire (STPQ) among patients with sickle cell disease. *British Journal of Haematology* 2019;**187**(1):105-16.

Elliott 1997 *{published data only}*

Elliott BE, Luker K. The experiences of mothers caring for a child with severe atopic eczema. *Journal of Clinical Nursing* 1997;**6**(3):241-7.

El Miedany 2018 *{published data only}*

El Miedany Y, Lotfy H, El Aroussy N, Mekkawy D, Nasef SI, Hassan W, et al. THU0604 Juvenile inflammatory arthritis: the development and validation of an illustrated questionnaire to measure children's motivation. *Annals of the Rheumatic Diseases* 2018;**77**(Supplement 2):501-2. [DOI: 10.1136/annrheumdis-2018-eular.2791]

Ely 1992 *{published data only}*

Ely EA. The experience of pain for school-age children: blood, Band-Aids, and feelings. *Children's Health Care* 1992;**21**(3):168-76.

Ely 2016 *{published data only}*

Ely B, Chen Lim M, Becker E, Wilson Jr B. (108) The pain experience of hospitalized youth: assessment and management preferences. *Journal of Pain* 2016;**17**(4 Suppl):S3. [DOI: 10.1016/j.jpain.2016.01.011]

Engel 1991 *{published data only}*

Engel JM. Behavioral assessment of chronic headaches in children. *Issues in Comprehensive Pediatric Nursing* 1991;**14**(4):267-76.

Esteve 2012 *{published data only}*

Esteve R, Marquina-Aponte V. Children's pain perspectives. *Child: care, health and development* 2012;**38**(3):441-52.

Evans 2010a *{published data only}*

Evans S, Meldrum M, Tsao J, Allen L, Zeltzer L. Sex-specific associations between parent and child pain and functioning in a pediatric chronic pain sample: a mixed methods approach. *Journal of Pain* 2010;**11**(4 Suppl):S61.

Eyckmans 2011 *{published data only}*

Eyckmans L, Hilderson D, Westhovens R, Wouters C, Moons P. What does it mean to grow up with juvenile idiopathic arthritis? A qualitative study on the perspectives of patients. *Clinical Rheumatology* 2011;**30**(4):459-65.

Fairhurst 2013 *{published data only}*

Fairhurst CBR, Cheung Y. Poster W034 Functional deterioration in severe adolescent hemidystonia. *Developmental Medicine and Child Neurology* 2013;**55**(Suppl 1):30. [DOI: 10.1111/dmcn.12068]

Farrell 2012 *{published data only}*

Farrell J, Kashikar-Zuck S, Jacobson C, Correia H, Verkamp E, Segerman J, et al. The role of cognitive interviews in the development of pain behavior and pain quality item banks for pediatrics: a Patient Reported Outcomes Measurement Information System (PROMIS) study. *The Journal of Pain* 2012;**13**(4 Suppl):S7.

Farrugia 2018 *{published data only}*

Farrugia E, Raimondo V, Kelly I, Davidson J. Long-term art therapy intervention for a teenage girl with chronic pain and enthesitis-related JIA. *Rheumatology* 2018;**57**(Suppl 8):key273.031.

fe Souza 2011 *{published data only}*

de Souza Ana AM, Ribeiro Circea A, de Borba Regina IH. [Having sickle-cell disease: short communication on the meaning for children as expressed through games what it means for them to have the disease]. *Revista Gaucha de Enfermagem* 2011;**32**(1):194-96. [DOI: 10.1590/S1983-14472011000100026]

Fidanci 2013 *{published data only}*

Fidanci B, Ozen S, Acikel C, Fidanci K, Yildiz D, Basbozkurt G, et al. Living with childhood vasculitis; a qualitative study. *Annals of the Rheumatic Diseases* 2013;**71**(Suppl 3):738.

Fleitas 2000 *{published data only}*

Fleitas J. When Jack fell down … Jill came tumbling after. Siblings in the web of illness and disability. *MCN: American Journal of Maternal/Child Nursing* 2000;**25**(5):267-73.

Flores 2017 *{published data only}*

Flores MT, Rose J, Toral P, Mendez L, Pichardo DM, Horton R, et al. The Charla de Lupus (Lupus Chat) program: assessing the needs of teens and young adults with lupus and their caregivers to develop a family model nutrition and fitness intervention. *Arthritis and Rheumatology* 2017;**69**(Suppl 10):232.

Forgeron 2008a *{published data only}*

Forgeron P, McGrath PJ. Self-identified needs of youth with chronic pain. In: Schofield P, Merrick J, editors(s). Pain in Children and Youth. Hauppauge (NY): Nova Science Publishers, 2008:101-113.

Forgeron 2011 *{published data only}*

Forgeron P, McGrath P, Stevens B, Finley A, Evans J. Social interactions of adolescents with chronic pain: are they different? *Journal of Pain* 2011;**12**(4 Suppl):P82.

Forgeron 2019 *{published data only}*

Forgeron PA, McKenzie E, O'Reilly J, Rudnicki E, Caes L. Support for my video is support for me: a YouTube scoping review of videos including adolescents with chronic pain. *Clinical Journal of Pain* 2019;**35**(5):443-50.

Forgeron 2019a *{published data only}*

Forgeron PA, McKenzie E, O'Reilly J, Rudnicki E, Caes L. Support for my video is support for me: a YouTube scoping review of videos including adolescents with chronic pain. *Clinical Journal of Pain* 2019;**35**(5):443-50. [DOI: 10.1097/AJP.0000000000000693]

Forrest 2020 *{published data only}*

Forrest CB, Forrest KD, Clegg JL, de la Motte A, Amaral S, Grossman AB, et al. Establishing the content validity of PROMIS Pediatric pain interference, fatigue, sleep disturbance, and sleep-related impairment measures in children with chronic kidney disease and Crohn's disease. *Journal of Patient-Reported Outcomes* 2020;**4**(1):11.

Forrester 2015 *{published data only}*

Forrester AB, Barton-Gooden A, Pitter C, Lindo JLM. The lived experiences of adolescents with sickle cell disease in Kingston, Jamaica. *International Journal of Qualitative Studies on Health and Well-Being* 2015;**10**(1):28104.

Fosdal 2015 *{published data only}*

Fosdal MB. Perception of Pain Among Pediatric Patients With Sickle Cell Pain Crisis. *Journal of Pediatric Oncology Nursing* 2015;**32**(1):5-20.

Garrett 2015 *{published data only}*

Garrett KC. Sickle cell disease and the family: a phenomenological study [Doctoral thesis]. Manhattan (KS): Kansas State University, 2015.

Gesteira 2017 *{published data only}*

Gesteira ER, Bousso RS, de Faria Ichikawa CR, Misko MD, de Oliveira PP, Silveira EAA. Evaluation of family management of an adolescent with sickle cell disease [Avaliação do manejo familiar de uma adolescente com doença falciforme, evaluación del manejo familiar de una adolescente con enfermedad falciforme]. *Journal of Nursing UFPE/Revista de Enfermagem UFPE* 2017;**11**(9):3439-45.

Ghio 2011 *{published data only}*

Ghio D, Thomson W, Baildam EM, Hyrich K, Beresford MW, Lydon C, et al, Childhood Arthritis Prospective Study. 290. Investigating children's beliefs about juvenile arthritis: a study using cognitive interviewing. *Arthritis and Rheumatism* 2011;**63**(10 Suppl 1):S108.

Ghio 2015 *{published data only}*

Ghio D, Calam R, Hyrich KL, Thomson W, Cordingly L, Childhood Arthritis Prospective Study. 268. Validating a pain perception questionnaire for young people with juvenile arthritis. *Rheumatology* 2015;**54**(Suppl 1):i154.

Gordon 2021 *{published data only}*

Gordon BBE, Jones K, Stewart K, Bitoungui VN, Wonkam A, Asnani M, et al. Examining experiences of acute and chronic pain among individuals with sickle cell disease (SCD) in Jamaica and Cameroon. *Blood* 2021;**138**(Suppl 1):5000.

Graff 2012 *{published data only}*

Graff JC, Hankins J, Graves RJ, Robitaille KY, Roberts R, Cejda K, et al. Exploring family communication about sickle cell disease in adolescence. *Journal of Pediatric Hematology/Oncology Nursing* 2012;**29**(6):323-36.

Grant 2019 *{published data only}*

Grant L, Seiding Larsen L, Trennery C, Silverberg JI, Abramovits W, Simpson EL, et al. Conceptual model to illustrate the symptom experience and humanistic burden associated with atopic dermatitis in adults and adolescents. *Dermatitis* 2019;**30**(4):247-54.

Gravelle 1997 *{published data only}*

Gravelle AM. Caring for a child with a progressive illness during the complex chronic phase: parents' experience of facing adversity. *Journal of Advanced Nursing* 1997;**25**(4):738-45.

Gray 2013 *{published data only}*

Gray N, McDonagh J, Harvey K, Prescott J, Shaw K, Smith F, et al. 0100 Context is everything: supporting young people taking medication for arthritis. *International Journal of Pharmacy Practice* 2013;**21**(Suppl 2):88-9. [DOI: 10.1111/ijpp.12064]

Gray 2014 *{published data only}*

Gray NJ, Harvey K, Prescott J, Roberts R, Shaw KL, Smith FJ, et al. Context is everything: supporting young people taking medication for arthritis. *Rheumatology* 2014;**53**(Suppl 3):iii10.

Gray 2014a *{published data only}*

Gray NJ, McDonagh JE, Prescott J, Smith FJ, Harvey K, Shaw KL, et al. Arthriting-insights about the links between identity, arthritis and medication in the blogs of young people living with juvenile arthritis. *Journal of Adolescent Health* 2014;**54**(2 Suppl):S18.

Green 2018 *{published data only}*

Green A, Abbott P, Davidson PM, Delaney P, Delaney J, Patradoon-Ho P, et al. Interacting with providers: an intersectional exploration of the experiences of carers of aboriginal children with a disability. *Qualitative Health Research* 2018;**28**(12):1923-32.

Griffiths 2017 *{published data only}*

Griffiths C, Guest E, Harcourt D. Collaborating with burn patients and their families to develop the CARe Burn Scales: portfolio of burn-specific quality of life PROMs for use in paediatric and adult burn care. *Health and Quality of Life Outcomes* 2017;**15**(Suppl 1):A75. [DOI: 10.1186/s12955-017-0757-y]

Gross 2017 *{published data only}*

Gross T. Pain management for children in emergency departments - primum non nocere. *Clinical Pediatric Emergency Medicine* 2017;**18**(4):233-4.

Gulhati 1998 *{published data only}*

Gulhati A, Minty B. Parental health attitudes, illnesses and supports and the referral of children to medical specialists. *Child: care, health and development* 1998;**24**(4):295-315.

Gupta 2018 *{published data only}*

Gupta J, Cardoso LF, Harris CS, Dance AD, Seckin T, Baker N, et al. How do adolescent girls and boys perceive symptoms suggestive of endometriosis among their peers? Findings from focus group discussions in New York City. *BMJ Open* 2018;**8**(6):e020657.

Guzman 2013 *{published data only}*

Guzman J, Benseler S, Berard R, Rollin B, Duffy C, Jurencak R, et al. 121 What matters the most for parents, patients and clinicians in predicting the course of juvenile idiopathic arthritis (JIA)? *Journal of Rheumatology* 2013;**40**(6):997. [DOI: 10.3899/jrheum.130301]

Guzman 2013a *{published data only}*

Guzman J, Gomez-Ramirez O, Benseler SM, Berard RA, Brant R, Duffy CM, et al. 284 What is the relative priority of the ACR pediatric core set measures for youth with juvenile idiopathic arthritis and their parents? *Arthritis and Rheumatology* 2013;**65**(Suppl 10):S119-20.

Guzman 2014 *{published data only}*

Guzman J, Gomez-Ramirez O, Jurencak R, Shiff NJ, Berard RA, Duffy CM, et al. What matters most for patients, parents, and clinicians in the course of juvenile idiopathic arthritis? A qualitative study. *Journal of Rheumatology* 2014;**41**(11):2260-9.

Hall 2019 *{published data only}*

Hall AL, Karvounides D, Gelfand AA, Mankin H, Kessel S, Corroo J, et al. Improving the patient experience with Migraine Camp, a one-day group intervention for adolescents with chronic headache and their parents. *Headache* 2019;**59**(8):1392-1400.

Hallberg 2009 *{published data only}*

Hallberg L, Sällfors C. PB50 Fitting into the prevailing teenage culture: a grounded theory on female adolescents with chronic arthritis. *Pain Practice* 2009;**9**(Suppl 1):107. [DOI: 10.1111/j.1533-2500.2009.00267.x]

Hanson 2018 *{published data only}*

Hanson H, Hart RI, Thompson B, McDonagh JE, Tattersall R, Jordan A, et al. Experiences of employment among young people with juvenile idiopathic arthritis: a qualitative study. *Disability and Rehabilitation* 2018;**40**(16):1921-8.

Harris 2017 *{published data only}*

Harris S, Gilbert M, Beasant L, Linney C, Broughton J, Crawley E. A qualitative investigation of eating difficulties in adolescents with chronic fatigue syndrome/myalgic encephalomyelitis. *Clinical Child Psychology and Psychiatry* 2017;**22**(1):128-39.

Harry 2018 *{published data only}*

Harry O, Combs AC, Hater B, Roemisch E, Favier LA, Aljaberi N, et al. Adolescents' perspectives on living with childhood-onset systemic lupus erythematosus. *Arthritis and Rheumatology* 2018;**70**(Suppl 9):475. [DOI: 10.1002/art.40700]

Harry 2018a *{published data only}*

Harry O, Combs AC, Hater B, Roemisch E, Smith AW, Fussner LM, et al. Living with childhood-onset systemic lupus erythematosus: a focus group with caregivers. *Pediatric Rheumatology* 2018;**16**(Suppl 1):P55. [DOI: 10.1186/s12969-018-0252-y]

Harry 2019 *{published data only}*

Harry G, Huggins J, Crosby L, Modi A. 40 Adolescents' perspectives on living with childhood-onset systemic lupus erythematosus. *Lupus Science and Medicine* 2019;**6**(Suppl 1):A29-A30. [DOI: 10.1136/lupus-2019-lsm.40]

Harry 2019a *{published data only}*

Harry O, Crosby LE, Smith AW, Favier L, Aljaberi N, Ting TV, et al. Self-management and adherence in childhood-onset systemic lupus erythematosus: what are we missing? *Lupus* 2019;**28**(5):642-50.

Hart 2014 *{published data only}*

Hart R, Foster H, Kay L, McDonagh J, Thompson B, Rapley T. Being as normal as possible: how young people value the risks and benefits of treatment. *Rheumatology* 2014;**53**(Suppl 1):i168.

Hatchette 2005 *{published data only}*

Hatchette JE. Pain self-management in adolescents: a psychosocial approach to understanding the acquisition of knowledge, attitudes and behaviors [Doctoral thesis]. St. John's (Canada): Memorial University of Newfoundland, 2005.

Hatchette 2006 *{published data only}*

Hatchette JE, McGrath P, Murray M, Allen Finley G. Maternal influences in adolescents' pain self-management: a qualitative investigation. *Vulnerable Children and Youth Studies* 2006;**1**(2):159-69.

Hatchette 2008 *{published data only}*

Hatchette JE, McGrath PJ, Murray M, Finley GA. The role of peer communication in the socialization of adolescents' pain experiences: a qualitative investigation. *BMC Pediatrics* 2008;**8**:2.

Haukeland 2015 *{published data only}*

Haukeland YB, Fjermestad KW, Mossige S, Vatne TM. Emotional experiences among siblings of children with rare disorders. *Journal of Pediatric Psychology* 2015;**40**(7):712-20.

Hawkins 2019 *{published data only}*

Hawkins L, Sinha C, Ross D, Yee M, Quarmyne MO, Krishnamurti L, et al. Poster # 729 Experience of chronic transfusion therapy in sickle cell disease: a qualitative study. *Pediatric Blood and Cancer* 2019;**66**(Suppl 2, e27713):S252. [DOI: 10.1002/pbc.27713]

Hawkins 2020 *{published data only}*

Hawkins L, Sinha C, Ross D, Yee M, Quarmyne MO, Krishnamurti L, et al. Patient and family experience with chronic transfusion therapy for sickle cell disease: a qualitative study. *BMC Pediatrics* 2020;**20**:172. [DOI: 10.1186/s12887-020-02078-w]

Hayes 2008 *{published data only}*

Hayes CC, Savage E. Fathers' perspectives on the emotional impact of managing the care of their children with cystic fibrosis. *Journal of Pediatric Nursing* 2008;**23**(4):250-6.

Helms 2008 *{published data only}*

Helms JE, Barone CP. Physiology and treatment of pain. *Critical Care Nurse* 2008;**28**(6):38-50.

Henderson 2014 *{published data only}*

Henderson EM, Keogh E, Eccleston C. Why go online when you have pain? A qualitative analysis of teenagers' use of the Internet for pain management advice. *Child: care, health and development* 2014;**40**(4):572-9.

Hexem 2013 *{published data only}*

Hexem KR, Miller VA, Carroll KW, Faerber JA, Feudtner C. Putting on a happy face: emotional expression in parents of children with serious illness. *Journal of Pain and Symptom Management* 2013;**45**(3):542-51.

Higginson 2019 *{published data only}*

Higginson A, Forgeron P, Harrison D, Finley GA, Dick BD. Moving on: transition experiences of young adults with chronic pain. *Canadian Journal of Pain* 2019;**3**(1):85-97.

Hildenbrand 2015 *{published data only}*

Hildenbrand AK, Barakat LP, Alderfer MA, Marsac ML. Coping and coping assistance among children with sickle cell disease and their parents. *Journal of Pediatric Hematology/Oncology* 2015;**37**(1):25-34.

Hill 2022 *{published data only}*

Hill M, Hammond J, Sharmin M, Lewis C, Heathfield M, Crowe B, et al. Living with osteogenesis imperfecta: a qualitative study exploring experiences and psychosocial impact from the perspective of patients, parents and professionals. *Disability and Health Journal* 2022;**15**(1):101168.

Hind 2017 *{published data only}*

Hind D, Parkin J, Whitworth V, Rex S, Young T, Hampson L, et al. Aquatic therapy for children with Duchenne muscular dystrophy: a pilot feasibility randomised controlled trial and mixed-methods process evaluation. *Health Technology Assessment* 2017;**21**(27):1-120.

Horne 2017 *{published data only}*

Horne T, Leonard H, Stannage K, Downs J. A qualitative investigation of recovery after femoral fracture in Rett syndrome. *Child: care, health and development* 2017;**43**(2):232-9.

Horonjeff 2016 *{published data only}*

Horonjeff JR, Thornhill S, Horton DB, Stinson JN, Fortna A, Luca S, et al. Reconsidering the juvenile idiopathic arthritis core set: how patients and caregivers define disease activity. *Arthritis and Rheumatology* 2016;**68**(Suppl 10):3115.

Hulgaard 2019 *{published data only}*

Hulgaard DR, Rask CU, Risor MB, Dehlholm G. Illness perceptions of youths with functional disorders and their parents: an interpretative phenomenological analysis study. *Clinical Child Psychology and Psychiatry* 2019;**25**(1):45-61.

Hummelinck 2006 *{published data only}*

Hummelinck A, Pollock K. Parents' information needs about the treatment of their chronically ill child: a qualitative study. *Patient Education and Counseling* 2006;**62**(2):228-34.

Humphrey 2018 *{published data only}*

Humphrey L, Randall JA, Hunter T, Keith S, Symonds T, Abetz-Webb L, et al. P007 A qualitative study of the experience of adults and adolescents with ulcerative colitis. *Gastroenterology* 2018;**154**(1 Suppl):S5.

Hunfeld 2001 *{published data only}*

Hunfeld JA, Perquin CW, Duivenvoorden HJ, Hazebroek-Kampschreur AA, Passchier J, van Suijlekom-Smit LW, et al. Chronic pain and its impact on quality of life in adolescents and their families. *Journal of Pediatric Psychology* 2001;**26**(3):145-53.

Hunfeld 2002 *{published data only}*

Hunfeld JAM, Perquin CW, Bertina W, Hazebroek-Kampschreur AAJM, Van Suijlekom-Smit LWA, Koes BW, et al. Stability of pain parameters and pain-related quality of life in adolescents with persistent pain: a three-year follow-up. *Clinical Journal of Pain* 2002;**18**(2):99-106.

Hurley-Wallace 2021 *{published data only}*

Hurley-Wallace A, Schoth DE, Lilley S, Williams G, Liossi C. Online paediatric chronic pain management: assessing the needs of UK adolescents and parents, using a cross-sectional survey. *British Journal of Pain* 2021;**15**(3):312-25. [DOI: 10.1177/2049463720940341]

Hurley-Wallace 2021a *{published data only}*

Hurley-Wallace A, Schoth DE, Lilley S, Williams G, Liossi C. Online paediatric chronic pain management: assessing the needs of UK adolescents and parents, using a crosssectional survey. *British Journal of Pain* 2021;**3**(15):312-25. [DOI: 10.1177/2049463720940341]

Hurley-Wallace 2022 *{published data only}*

Hurley-Wallace A. Exploring Internet needs for the management of adolescent chronic pain: developing digital interventions in context [Doctoral thesis]. Southampton (UK): University of Southampton, 2022.

Hurtubise 2020 *{published data only}*

Hurtubise K, Brousselle A, Camden C. Using collaborative logic analysis evaluation to test the program theory of an intensive interdisciplinary pain treatment for youth with pain-related disability. *Paediatric & Neonatal Pain* 2020;**2**(4):113-30.

Hutchinson 2007 *{published data only}*

Hutchinson E, Hall C. A phenomenological exploration of the patient learning J experiences of 16—19 year-old women accessing a young people's rheumatology service in the UK. *Journal of Research in Nursing* 2007;**12**(5):521-33.

Ingeman 2022 *{published data only}*

Ingeman K, Hulgaard DR, Rask CU. Health anxiety by proxy - through the eyes of the parents. Journal of Child Health Care 2022 May 5 [Epub ahead of print]. [DOI: 10.1177/13674935221095648]

Inusa 2013 *{published data only}*

Inusa B, Bristow F, Appleby H, Jones H. P1095 What do preliminary analyses highlight as the key fears and worries of children and young people with sickle cell disease and what can we do to support them? *Haematologica* 2013;**98**(Suppl 1):449-50.

Inusa 2015 *{published data only}*

Inusa B, Wakeford SA, Kirkham F. Overnight respiratory support for prevention of morbidity in sickle cell disease (POMS 2A)-parent and child preferences. *Blood* 2015;**126**(23):4457.

Jacob 2005 *{published data only}*

Jacob E, Beyer JE, Miaskowski C, Savedra M, Treadwell M, Styles L. Are there phases to the vaso-occlusive painful episode in sickle cell disease? *Journal of Pain and Symptom Management* 2005;**29**(4):392-400.

Jacobs 2021 *{published data only}*

Jacobs K, Smith A, Heathcote L, Caes L. Which passengers are on your bus? A taxonomy of the barriers adolescents with chronic pain face in achieving functional recovery. *European Journal of Pain* 2021;**25**(2):348-58.

Jacobson 2011 *{published data only}*

Jacobson CJ, Farrell J, Kashikar-Zuck S, Verkamp E, Seid M, DeWitt EM. Accounts of chronic pain and emotional distress in children and youth with juvenile idiopathic arthritis or chronic pain: qualitative analysis of interviews to assess content validity of the patient reported outcome measurement information system. *Arthritis and Rheumatology* 2011;**63**(Suppl 10):2492.

Jacoby 2020 *{published data only}*

Benveniste S, Goldzweig G, Jacoby R. Illness narratives through the eyes of parents of children with end-stage renal disease. *Qualitative Health Research* 2020;**30**(12):1798-1806.

Jansaithong 2002 *{published data only}*

Jansaithong J. Northern Thai school-aged children pain experience: pain descriptions and pain management strategies [Doctoral thesis]. Seattle (OR): University of Washington, 2002.

Jerrett 1994 *{published data only}*

Jerrett MD. Parents' experience of coming to know the care of a chronically ill child. *Journal of Advanced Nursing* 1994;**19**(6):1050-6.

Johansen 2022 *{published data only}*

Johansen SK, Holden S, Pourbordbari N, Jensen MB, Thomsen JL, Rathleff MS. PAINSTORIES - exploring the temporal developments in the challenges, barriers, and self-management needs of adolescents with longstanding knee pain: a qualitative, retrospective interview study with young adults experiencing knee pain since adolescence. *Journal of Pain* 2022;**23**(4):577-94.

Johnson 2000 *{published data only}*

Johnson BS. Mothers' perceptions of parenting children with disabilities. *MCN: American Journal of Maternal/Child Nursing* 2000;**25**(3):127-32.

Johnson 2015 *{published data only}*

Johnson C, Arbuckle R, Bonner N, Connett G, Dominguez-Munoz E, Haeusler JM, et al. Development of a patient-reported outcome measure in pancreatic exocrine insufficiency (PEI). *Pancreatology* 2015;**15**(3 Suppl):S11.

Jones 2019 *{published data only}*

Jones A, Caes L, Jordan A. My future: using story completion methods to examine how adolescents with complex regional pain syndrome think about their future. *British Journal of Pain* 2019;**13**(Suppl 2):61. [DOI: 10.1177/20494637198365]

Jongudomkarn 2006 *{published data only}*

Jongudomkarn D, Aungsupakorn N, Camfield L. The meanings of pain: a qualitative study of the perspectives of children living with pain in north-eastern Thailand. *Nursing & Health Sciences* 2006;**8**(3):156-63.

Jongudomkarn 2008 *{published data only}*

Jongudomkarn D, Aungsupakorn N, Camfield L. Families in northeast Thailand - living with a child in pain. *Asian Journal of Nursing* 2008;**11**(1):11-20.

Joslin 2022 *{published data only}*

Joslin R, Roberts L, Donovan-Hall M. Communication preferences of young people experiencing persistent musculoskeletal pain. *Physiotherapy* 2022;**114**(Suppl 1):e81.

Josset-Raffet 2016 *{published data only}*

Josset-Raffet E, Yi MK, Benkerrou M. Bodily and psychic trajectory of pain in children with sickle cell disease [La trajectoire corporelle et psychique de la douleur chez l'enfant atteint de drépanocytose]. *Neuropsychiatrie de l'Enfance et de l'Adolescence* 2016;**64**(2):131-8. [DOI: 10.1016/j.neurenf.2016.01.003]

Kennedy 2012 *{published data only}*

Kennedy AP. Systematic ethnography of school-age children with bleeding disorders and other chronic illnesses: exploring children's perceptions of partnership roles in family-centred care of their chronic illness. *Child: care, health and development* 2012;**38**(6):863-9.

Kenyon 2012 *{published data only}*

Kenyon CC, Kavanagh PL, Fiechtner LG, Textor TE, Wang CJ. Setting the agenda for quality improvement in pediatric sickle cell disease. *Journal of the National Medical Association* 2012;**104**(7-8):337-41.

Khanom 2019 *{published data only}*

Khanom S, McBeth J, Briggs M, McDonagh J. P37 Exploring the experience of pain flares in adolescent inflammatory and non-inflammatory musculoskeletal disorders: a phenomenological study. *Rheumatology* 2019;**58**(Suppl 4):kez416.004. [DOI: 10.1093/rheumatology/kez416.004]

Khanom 2020a *{published data only}*

Khanom S, McDonagh JE, Briggs M, McBeth J. Characterizing pain flares in adolescent inflammatory and non-inflammatory musculoskeletal disorders: a qualitative study using an interpretative phenomenological approach. *European Journal of Pain* 2020;**24**(9):1785-96.

Khazendar 2021 *{published data only}*

Khazendar Z, Harrison L, Wicksell R, Simons L. User-centered development of a digital exposure treatment for youth with chronic pain. *Journal of Pain* 2021;**22**(5):607.

Khemani 2016 *{published data only}*

Khemani K, Ross D, Haight A, Sinha C, Bakshi N, Krishnamurti L. Experiences and decision making for bone marrow transplant in sickle cell disease: patients and caregivers perspective. *Blood* 2016;**128**(22):2393. [DOI: 10.1182/blood.V128.22.2393.2393]

Khemani 2018 *{published data only}*

Khemani K, Ross D, Sinha C, Haight A, Bakshi N, Krishnamurti L. Experiences and decision making in hematopoietic stem cell transplant in sickle cell disease: patients' and caregivers' perspectives. *Biology of Blood and Marrow Transplantation* 2018;**24**(5):1041-8.

Kim 2011 *{published data only}*

Kim HK. Lived experience of women with severe dysmenorrhea. *Korean Journal of Women Health Nursing* 2011;**17**(3):304-15. [DOI: 10.4069/kjwhn.2011.17.3.304]

Kirk 2012 *{published data only}*

Kirk S, Beatty S, Callery P, Milnes L, Pryjmachuk S. Perceptions of effective self-care support for children and young people with long-term conditions. *Journal of Clinical Nursing* 2012;**21**(13-14):1974-87.

Kirschbaum 1996 *{published data only}*

Kirschbaum MS. Life support decisions for children: what do parents value? *Advances in Nursing Science* 1996;**19**(1):51-71.

Knafl 1992 *{published data only}*

Knafl K, Breitmayer B, Gallo A, Zoeller L. Parents' views of health care providers: an exploration of the components of a positive working relationship. *Children's Health Care* 1992;**21**(2):90-5.

Kohut 2018 *{published data only}*

Ahola Kohut S, LeBlanc C, O'Leary K, McPherson AC, McCarthy E, Nguyen C, et al. The internet as a source of support for youth with chronic conditions: a qualitative study. *Child: care, health and development* 2018;**44**(2):212-20.

Kohut 2020 *{published data only}*

Ahola Kohut S, Stinson J, Jelen A, Ruskin D. Feasibility and acceptability of a mindfulness-based group intervention for adolescents with inflammatory bowel disease. *Journal of Clinical Psychology in Medical Settings* 2020;**27**(1):68-78.

Kohut 2021 *{published data only}*

Ahola Kohut S, Forgeron P, McMurtry M, Weiser N, Iuliano A, Stinson J. Resilience factors in paediatric inflammatory bowel disease: health care provider, parent and youth perspectives. *Journal of Child and Family Studies* 2021;**30**:2250-63.

Kortesluoma 2004 *{published data only}*

Kortesluoma RL, Nikkonen M. 'I had this horrible pain': the sources and causes of pain experiences in 4- to 11-year-old hospitalized children. *Journal of Child Health Care* 2004;**8**(3):210-31.

Kortesluoma 2006 *{published data only}*

Kortesluoma RL, Nikkonen M. 'The most disgusting ever': children's pain descriptions and views of the purpose of pain. *Journal of Child Health Care* 2006;**10**(3):213-27.

Kortesluoma 2008 *{published data only}*

Kortesluoma RL, Nikkonen M, Serlo W. "You just have to make the pain go away"--children's experiences of pain management. *Pain Management Nursing* 2008;**9**(4):143-9, 149.e1-5.

Kortesluoma 2008a *{published data only}*

Kortesluoma RL, Punamäki RL, Nikkonen M. Hospitalized children drawing their pain: the contents and cognitive and emotional characteristics of pain drawings. *Journal of Child Health Care* 2008;**12**(4):284-300.

Korus 2011 *{published data only}*

Korus M, Stinson JN, Pool R, Williams A, Kagan S. Exploring the information needs of adolescents and their parents throughout the kidney transplant continuum. *Progress in Transplantation* 2011;**21**(1):53-60.

Korving 2021 *{published data only}*

Korving H, Sterkenburg PS, Menke LA, Huisman S. Pain recognition in children and adults with rare genetic syndromes and intellectual disability. *Journal of Intellectual Disability Research* 2021;**65**(8):710.

Kosakowski 2022 *{published data only}*

Kosakowski S, Benintendi A, Lagisetty P, Larochelle MR, Bohnert ASB, Bazzi AR. Patient perspectives on improving patient-provider relationships and provider communication during opioid tapering. *Journal of General Internal Medicine* 2022;**37**(7):1722-8.

Kristjansdottir 2000 *{published data only}*

Kristjansdottir G. Familial aggregation and pain theory relating to recurrent pain experiences in children. *Acta Paediatrica* 2000;**89**(12):1403-5.

Kvarnström 2012 *{published data only}*

Kvarnström S, Willumsen E, Andersson-Gäre B, Hedberg B. How service users perceive the concept of participation, specifically in interprofessional practice. *British Journal of Social Work* 2012;**42**(1):129-46.

Kwarteng-Siaw 2017 *{published data only}*

Kwarteng-Siaw M, Paintsil V, Catherine KT, Owusu-Ansah A, Green NS. Transition readiness assessment of adolescents with sickle cell disease and their caretakers at the sickle cell clinic in Kumasi, Ghana. *Blood* 2017;**130**(Suppl 1):4663.

Lagerløv 2016 *{published data only}*

Lagerløv P, Rosvold EO, Holager T, Helseth S. How adolescents experience and cope with pain in daily life: a qualitative study on ways to cope and the use of over-the-counter analgesics. *BMJ Open* 2016;**6**(3):e010184.

Lai 2012 *{published data only}*

Lai J-S, Nowinski C, Victorson D, Bode R, Podrabsky T, McKinney N, et al. Quality-of-life measures in children with neurological conditions: pediatric Neuro-QOL. *Neurorehabilitation and Neural Repair* 2012;**26**(1):36-47.

Lai 2017 *{published data only}*

Lai JS, Jensen SE, Patel ZS, Listernick R, Charrow J. Using a qualitative approach to conceptualize concerns of patients with neurofibromatosis type 1 associated plexiform neurofibromas (pNF) across the lifespan. *American Journal of Medical Genetics* 2017;**173**(1):79-87.

Lalla 2010 *{published data only}*

Lalla A, Boer R, Pocoski J, Dean B. Using patient focus groups to inform economic modeling: experience from a hemophilia patient focus group. *Value in Health* 2010;**13**(3):A216-7. [DOI: http://dx.doi.org/10.1016/S1098-3015%2810%2973060-6]

Lalloo 2013 *{published data only}*

Lalloo C. "There's a pain app for that": promoting pain self-management among adolescents and young adults. *Pain Research and Management* 2013;**18**(2):e9-e10.

Lalloo 2013a *{published data only}*

Lalloo C, Stinson JN, Brown SC, Campbell F, Isaac L, Henry JL. Clinical feasibility of the iconic pain assessment tool from the perspective of adolescents with chronic pain and their multi-disciplinary team of healthcare providers. *Pain Research and Management* 2013;**18**(2):e28.

Lalloo 2014 *{published data only}*

Lalloo C, Stinson JN, Brown SC, Campbell F, Isaac L, Henry JL. Pain-QuILT: assessing clinical feasibility of a web-based tool for the visual self-report of pain in an interdisciplinary pediatric chronic pain clinic. *Clinical Journal of Pain* 2014;**30**(11):934-43.

Lanis 2021 *{published data only}*

Lanis A, Tu E, Peskin M, Melendez M, Tarshish G, Akinsete A, et al. Storytelling of young adults with chronic rheumatologic illnesses: a pilot study. *Arthritis and Rheumatology* 2021;**73**(Suppl 9):3431-2.

Latimer 2014 *{published data only}*

Latimer M, Finley GA, Rudderham S, Inglis S, Francis J, Young S, et al. Expression of pain among Mi'kmaq children in one Atlantic Canadian community: a qualitative study. *CMAJ Open* 2014;**2**(3):E133-8.

Latimer 2018 *{published data only}*

Latimer M, Sylliboy JR, MacLeod E, Rudderham S, Francis J, Hutt-MacLeod D, et al. Creating a safe space for First Nations youth to share their pain. *Pain Reports* 2018;**3**(7):e682.

Latimer 2020 *{published data only}*

Latimer M, Sylliboy JR, Francis J, Amey S, Rudderham S, Finley GA, et al. Co-creating better healthcare experiences for First Nations children and youth: the FIRST approach emerges from Two-Eyed seeing. *Paediatric and Neonatal Pain* 2020;**2**(4):104-12.

Lauderdale 2003 *{published data only}*

Lauderdale G. The lived experience of African American adolescents with sickle cell disease [Doctoral thesis]. Charlottesville (VA): University of Virginia, 2003.

Laursen 2019 *{published data only}*

Laursen SS, Dehlholnn-Lannbertsen B, Stenager E, Johannessen H. Morality in clinical space: treatment of youngsters with functional somatic symptoms in a Western clinical context. *Anthropology & Medicine* 2019;**26**(2):228-43.

Law 2016 *{published data only}*

Law E, Fales J, Beals-Erikson S, Logan D, Weiss K, Randall E, et al. Problem-solving therapy for parents of children receiving intensive pain rehabilitation. *Journal of Pain* 2016;**17**(4 Suppl):S98-9. [DOI: 10.1016/j.jpain.2016.01.303]

Law 2021 *{published data only}*

Law EF, Zhou C, Seung F, Perry F, Palermo TM. Longitudinal study of early adaptation to the coronavirus disease pandemic among youth with chronic pain and their parents: effects of direct exposures and economic stress. *Pain* 2021;**162**(7):2132-44.

Lee 2022 *{published data only}*

Lee R, Mountain D, McDonagh J, Connelly M, Peters S, Cordingley L. 'Because that's their job, isn't it?': exploring children and young peoples' experiences of and perspectives about pain communication in paediatric rheumatology in the UK. *Annals of the Rheumatic Diseases* 2022;**81**(Suppl 1):37.

Lerner 2018 *{published data only}*

Lerner A, Picard H, May A, Gajdos V, Malou-Dhaussy L, Maroja-Cox F, et al. Implications of a paediatrician-psychologist tandem for sickle cell disease care and impact on cognitive functioning. *European Journal of Pediatrics* 2018;**177**(2):193-203.

Lesane-Brown 2012 *{published data only}*

Lesane-Brown CL, Brown A, Ofori M, Sarpolis A. Parent-child communication about sickle cell disease. *American Journal of Hematology* 2012;**87**(7):E48. [DOI: https://doi.org/10.1002/ajh.23331]

Lewandowski 2005 *{published data only}*

Lewandowski LA, Kobayashi H, Bevier P, Harold JM, Morraset L, Vallerand A. Exploring family resiliency: adolescents with multiple neurosurgeries and chronic pain. In: 16th International Nursing Research Congress. 2005.

Lewis 2007 *{published data only}*

Lewis DB. The princess and the pain: an exploration of the therapeutic efficacy of personalised story telling for children in chronic pain [Doctoral thesis]. Colchester (UK): University of Essex, 2007.

Lewis 2010 *{published data only}*

Lewis BE, Arbuckle R, Abetz LN, Carson RT, Pomplius F, Johnston JM, et al. Development of pediatric irritable bowel syndrome with constipation measures: results of qualitative interviews with children and their parents. *Journal of Pediatric Gastroenterology and Nutrition* 2010;**51**(Suppl 2):E56.

Lewis 2018 *{published data only}*

Lewis KA, Mabry A, Nielson L. Does the role of food in the self management of pain in teens with juvenile arthritis vary based on gender or ethnicity? *Obesity Facts* 2018;**11**(Suppl 1):206. [KARGER: https://karger.com/ofa/article/11/Suppl.%201/1/239451/25th-European-Congress-on-Obesity-Vienna-Austria]

Lewis 2018a *{published data only}*

Lewis KA, Mabry-Flynn A, Carrasco R, Nielson L. P65 The role of food in the self-management of pain in teens with juvenile arthritis: gender and ethnic differences. *Pediatric Rheumatology* 2018;**16**(Suppl 1):42.

Lim 2011 *{published data only}*

Lim PJ, Goodison-Farnsworth M, Glogauer M, Anderson D, Champion D. Why parental education is needed in a paediatric chronic pain clinic. *Anaesthesia and Intensive Care* 2011;**39**(4):745-6. [DOI: 10.1177/0310057X1103900428]

Lindsay 2013 *{published data only}*

Lindsay S, McDougall C, Sanford R. Disclosure, accommodations and self-care at work among adolescents with disabilities. *Disability and Rehabilitation* 2013;**35**(26):2227-36.

Liossi 2012 *{published data only}*

Liossi C, Noble G, Franck LS. How parents make sense of their young children's expressions of everyday pain: a qualitative analysis. *European Journal of Pain* 2012;**16**(8):1166-75.

Lipstein 2013 *{published data only}*

Lipstein EA, Muething KA, Dodds CM, Britto MT. "I'm the one taking it": adolescent participation in chronic disease treatment decisions. *Journal of Adolescent Health* 2013;**53**(2):253-9.

Livermore 2016 *{published data only}*

Livermore P, Eleftheriou D, Wedderburn LR. The lived experience of juvenile idiopathic arthritis in young people receiving etanercept. *Pediatric Rheumatology* 2016;**14**(1):21.

Lloyd 2014 *{published data only}*

Lloyd O, Tume L, Beresford M. From symptom onset to diagnosis: a critical exploration into the experiences of young people with juvenile systemic lupus erythematosus (JSLE). *Pediatric Rheumatology* 2014;**12**(Suppl 1):P317.

Lundberg 2021 *{published data only}*

Lundberg V, Eriksson C, Lind T, Coyne I, Fjellman Wiklund A. How children with juvenile idiopathic arthritis view participation and communication in healthcare encounters: a qualitative study. *Pediatric Rheumatology* 2021;**19**(1):156.

MacGregor 2018 *{published data only}*

MacGregor D, Marlowe S, Olivieri H, Gunn G, Mulligan J, Bozinis K, et al. The value of education workshops for patients and families in the management of pediatric headache. *Annals of Neurology* 2018;**84**(Suppl 22):S361-2.

Maciver 2011a *{published data only}*

Maciver D, Jones D, Nicol M. Parental experiences of pediatric chronic pain management services. *Journal of Pain Management* 2011;**4**(4):371-80.

Maciver 2013 *{published data only}*

Maciver D, Jones D, Nicol M. Parental experiences of pediatric chronic pain management services. *Journal of Pain Management* 2011;**4**:371-80.

Maciver 2014 *{published data only}*

Maciver D, Jones D, Nicol M. Parental experiences of pediatric chronic pain management services. *Journal of Pain Management* 2011;**4**(4):371-80.

Mackner 2014 *{published data only}*

Mackner LM, Ruff JM, Vannatta K. Focus groups for developing a peer mentoring program to improve self-management in pediatric inflammatory bowel disease. *Journal of Pediatric Gastroenterology and Nutrition* 2014;**59**(4):487-92.

Maikler 2001 *{published data only}*

Maikler VE, Broome ME, Bailey P, Lea G. Childrens' and adolescents' use of diaries for sickle cell pain. *Journal of the Society of Pediatric Nurses* 2001;**6**(4):161.

Malcolm 2014 *{published data only}*

Malcolm C, Gibson F, Adams S, Anderson G, Forbat L. A relational understanding of sibling experiences of children with rare life-limiting conditions: findings from a qualitative study. *Journal of child health care: for professionals working with children in the hospital and community* 2014;**18**(3):230-40.

Marcar 2020 *{published data only}*

Marcar CS, Keller M, Hillewerth K, van Holten K. Everyday life of adolescents with sickle cell disease – a qualitative, explorative and participative photovoice study [Der alltag von jugendlichen mit einer sichelzellerkrankung – eine qualitative, explorative und partizipative photovoice-studie]. *Pflege* 2020;**33**(6):347-56. [DOI: 10.1024/1012-5302/a000767]

Mather 2008 *{published data only}*

Mather CV. An Investigation of Childhood Trauma, Dissociation and Body-Focused Attention in Medically Unexplained Symptoms [Doctoral thesis]. Manchester (UK): University of Manchester, 2008.

Maxwell 1998 *{published data only}*

Maxwell K, Streetly A. Sickle Cell Society. London (UK): Guy's, King's St Thomas' School of Medicine, Department of Public Health Sciences, 1998. [ISBN: 9781869942038]

McDonagh 2016 *{published data only}*

McDonagh JE, Shaw KL, Prescott J, Smith FJ, Roberts R, Gray NJ. “Sometimes I feel like a pharmacist”: identity and medication use among adolescents with juvenile arthritis. *Pediatric Rheumatology* 2016;**14**(1):57.

McGurgan 2021 *{published data only}*

McGurgan A, Wilson C, McGuire S. Parental experiences of psychological interventions for recurrent abdominal pain in childhood. *Journal of Health Psychology* 2021;**27**(12):2834-46.

McKinnon 2020a *{published data only}*

McKinnon C, White J, Harvey A, Antolovich G, Morgan P. The lived experience of chronic pain in children with dyskinetic cerebral palsy from the perspective of carers. *Developmental Medicine and Child Neurology* 2020a;**62**(Suppl 2):46-7.

McLeod-Fletcher 1996 *{published data only}*

McLeod-Fletcher C. Appraisal and Coping with Vaso-occlusive Crisis in Adolescents with Sickle Cell Disease [Doctoral thesis]. Miami (FL): University of Miami, 1996.

McLeod-Fletcher 1997 *{published data only}*

McLeod-Fletcher C. Appraisal and Coping with Vaso-occlusive Crisis in Adolescents with Sickle Cell Disease [Doctoral thesis]. Miami (FL): University of Miami, 1996.

Meldrum 2009a *{published data only}*

Meldrum Marcia L, Tsao Jennie CI, Zeltzer Lonnie K. 'Just be in pain and just move on': functioning limitations and strategies in the lives of children with chronic pain. *Journal of Pain Management* 2009a;**1**(2):131-41.

Melville 2014 *{published data only}*

Melville L, Buerkle K, Mulligan K, Wedderburn LR, Newman S. Development of a comprehensive support website for parents of children with juvenile idiopathic arthritis. *Rheumatology (United Kingdom)* 2014;**53**(Suppl 3):iii8-9.

Merlijn 2005 *{published data only}*

Merlijn VPBM, Hunfeld JAM, van der Wouden JC, Hazebroek-Kampschreur AAJM, van Suijlekom-Smit LWA, Koes BW, et al. A cognitive-behavioural program for adolescents with chronic pain--a pilot study. *Patient Education and Counseling* 2005;**59**(2):126-34.

Merolli 2014 *{published data only}*

Merolli M, Gray K, Martin-Sanchez F. Therapeutic affordances of social media: emergent themes from a global online survey of people with chronic pain. *Journal of Medical Internet Research* 2014;**16**(12):e284.

Miettunen 2017 *{published data only}*

Miettunen P, Lang M, Laing C, Benseler S, Gerschman T, Luca N, et al. Giving children a voice through art: To understand and educate about the impact of juvenile idiopathic arthritis by creating art and telling digital stories. *Pediatric Rheumatology* 2017;**15**(Suppl 1):P336.

Mihelicova 2016 *{published data only}*

Mihelicova M, Siegel Z, Evans M, Brown A, Jason L. Caring for people with severe myalgic encephalomyelitis: an interpretative phenomenological analysis of parents' experiences. *Journal of Health Psychology* 2016;**21**(12):2824-37.

Miller 2016 *{published data only}*

Miller M, Scott E, Trost Z, Hirsh A. Injustice perceptions predict future functioning in children with chronic pain. *Journal of Pain* 2016;**17**(4 Suppl 1):S99-100.

Miller 2021 *{published data only}*

Miller AK, Ely SL, Garcia BNB, Richardson P, Cunningham NR. Engagement during a mixed in-person and remotely delivered psychological intervention for youth with functional abdominal pain disorders and anxiety. *Children* 2021;**8**(9):775.

Missen 2012 *{published data only}*

Missen A, Hollingworth W, Eaton N, Crawley E. The financial and psychological impacts on mothers of children with chronic fatigue syndrome (CFS/ME). *Child Care Health and Development* 2012;**38**(4):505-12.

Mitchell 2002 *{published data only}*

Mitchell W, Sloper P. Information that informs rather than alienates families with disabled children: developing a model of good practice. *Health and Social Care in the Community* 2002;**10**(2):74-81.

Mittinty 2022 *{published data only}*

Mittinty MM, Hedges J, Jamieson L. Building evidence to reduce inequities in management of pain for Indigenous Australian people. *Scandinavian Journal of Pain* 2022;**22**(2):356-64.

Modi 2009 *{published data only}*

Modi A, Crosby L, Guilfoyle S, Lemanek K, Witherspoon D, Mitchell M. Barriers to treatment adherence for pediatric patients with sickle cell disease and their families. *Children's Health Care* 2009;**38**(2):107-22.

Modica 2016 *{published data only}*

Modica RF, Lomax KG, Batzel P, Cassanas A, Elder M. Impact of systemic juvenile idiopathic arthritis/Still's disease on adolescents as evidenced through social media posting. *Annals of the Rheumatic Diseases* 2016;**75**(Suppl 2):272.

Modica 2017 *{published data only}*

Modica RF, Lomax KG, Batzel P, Cassanas A, Elder ME. Impact of systemic juvenile idiopathic arthritis/Still's disease on adolescents as evidenced through social media posting. *Pediatric Rheumatology* 2017;**15**(Suppl 1):P424.

Modica 2018 *{published data only}*

Modica RF, Lomax KG, Batzel P, Cassanas A, Elder ME. Impact of systemic juvenile idiopathic arthritis/Still's disease on adolescents as evidenced through social media posts. *Open Access Rheumatology* 2018;**10**:73-81.

Moghadam 2021 *{published data only}*

Moghadam ZB, Faezi ST, Zareian A, Rezaei E. Experiences of Iranian female patients with systemic lupus erythematosus: a qualitative study. *Archives of Rheumatology* 2021;**36**(1):120-8.

Molloy 2017 *{published data only}*

Molloy H, Beesley V, Ghosh D, Elliot M. NIV in duchenne muscular dystrophy: a qualitative study. *European Respiratory Journal* 2017;**50**(Suppl 61):PA1890.

Monsen 1999 *{published data only}*

Monsen RB. Mothers' experiences of living worried when parenting children with spina bifida. *Journal of Pediatric Nursing* 1999;**14**(3):157-63.

Monterosso 2007 *{published data only}*

Monterosso L, Kristjanson LJ, Aoun S, Phillips MB. Supportive and palliative care needs of families of children with life-threatening illnesses in Western Australia: evidence to guide the development of a palliative care service. *Palliative Medicine* 2007;**21**(8):689-96.

Mora 2017 *{published data only}*

Mora E, Llombart MPI, Albertin P. The gender vulnerability contexts of chronic pain. *Revista Internacional De Sociologia* 2017;**75**(2):e058.

Morgan 2018 *{published data only}*

Morgan E, Consolaro A, Munro J, Horonjeff J, Feldman BM, Clairman H, et al. New consensus on an updated core domain set for clinical trials in juvenile idiopathic arthritis. *Arthritis and Rheumatology* 2018;**70**(Suppl 9):1099-100.

Mosor 2019 *{published data only}*

Mosor E, Studenic P, Alunno A, Padjen I, Olsder W, Ramiro S, et al. "When you read this, you really feel old!" perspectives of young people with inflammatory arthritis on patient reported outcome measures from a European qualitative study. *Arthritis and Rheumatology* 2019;**71**(Suppl 10):1521-3.

Mufti 2014 *{published data only}*

Mufti G-ER, Towell T, Cartwright T. Pakistani children's experiences of growing up with beta-thalassemia major. *Qualitative Health Research* 2014;**25**(3):386-96.

Mufti 2015 *{published data only}*

Mufti G-ER, Towell T, Cartwright T. Pakistani children's experiences of growing up with beta-thalassemia major. *Qualitative Health Research* 2015;**25**(3):386-96.

Mulchan 2016 *{published data only}*

Mulchan SS, Valenzuela JM, Crosby LE, Diaz Pow Sang C. Applicability of the SMART model of transition readiness for sickle-cell disease. *Journal of Pediatric Psychology* 2016;**41**(5):543-554.

Mulvogue 2009 *{published data only}*

Mulvogue JLB, Joy LJ, Barbara MM, Tamsin. Relief-oriented use of marijuana by teens. *Substance Abuse Treatment, Prevention, and Policy* 2009;**4**(1):1-10.

Murray 2022 *{published data only}*

Murray CB, Murphy LK, Jordan A, Owens MT, McLeod D, Palermo TM. Healthcare transition among young adults with childhood-onset chronic pain: a mixed methods study and proposed framework. *Journal of Pain* 2022;**23**(8):1358-1370.

Nabors 2017 *{published data only}*

Nabors L, Liddle M. Perceptions of hospitalization by children with chronic illnesses and siblings. *Journal of Child and Family Studies* 2017;**26**(6):1681-1691.

Namisango 2020 *{published data only}*

Namisango E, Bristowe K, Murtagh FEM, Downing J, Powell RA, Abas M, et al. Towards person-centred quality care for children with life-limiting and life-threatening illness: self-reported symptoms, concerns and priority outcomes from a multi-country qualitative study. *Palliative Medicine* 2020;**34**(3):319-335.

Navarro 2018 *{published data only}*

Navarro K, Wainwright E, Rodham K, Jordan A. Parenting young people with complex regional pain syndrome: an analysis of the process of parental online communication. *Pain Reports* 2018;**3**(Suppl 1):e681.

Ndengeyingoma 2021 *{published data only}*

Ndengeyingoma A, Lebel V, Bigras M, Jacob MH, Lacelle M. Youngsters' perceptions of the experience of pain and utilisation of over-the-counter pain medication as needed in community: a qualitative study. *Journal for Specialists in Pediatric Nursing* 2021;**26**(2):1-9.

Neville 2021 *{published data only}*

Neville A, Lund T, Soltani S, Jordan A, Stinson J, Killackey T. Pediatric Chronic Pain in the Midst of the COVID-19 Pandemic: Lived Experiences of Youth and Parents. *The Journal of Pain* 2021;**23**:841-851.

Newton 2018 *{published data only}*

Newton L, Delbecque L, Coskun U, Symonds T, Clegg J, Hunter T. A qualitative study into the experience of adolescents and adults with ulcerative colitis. *Journal of Pediatric Gastroenterology and Nutrition* 2018;**67**(Supplement 1):S345.

Newton 2021 *{published data only}*

Newton L, Randall J, Hunter T, Keith S, Symonds T, Komocsar W, et al. A qualitative study to explore symptoms and impacts of pediatric and adolescent Crohn's disease from patient and caregiver perspective. *Journal of Patient-Reported Outcomes* 2021;**5**(1):49.

Nicholas 2011 *{published data only}*

Nicholas DB, Picone G, Selkirk EK. The lived experiences of children and adolescents with end-stage renal disease. *Qualitative Health Research* 2011;**21**(2):162-73.

Nichols 2015 *{published data only}*

Nichols VP, Griffiths FE, Patel S, Lamb SE. Patterns of interaction between factors that enhance or inhibit recovery from chronic low back pain. *Disability and Rehabilitation* 2015;**37**(3):194-206.

Niekerk 2020 *{published data only}*

Van Niekerk A, Jacobs R, Hornsby N, Singh-Adriaanse R, Sengoelge M, Laflamme L. Enablers of psychosocial recovery in pediatric burns: perspectives from the children, parents and burn recovery support staff. *BMC Pediatrics* 2020;**20**(1):289.

Nkhoma 2021a *{published data only}*

Nkhoma K, Mwalabu G, Bristowe K, Lungu E, Harding R. Modelling an appropriate pain self-management intervention for adolescents with HIV/AIDS in Malawi. *Palliative Medicine* 2021a;**35**(1 SUPPL):144.

Nkoy 2019 *{published data only}*

Nkoy FL, Hofmann MG, Stone BL, Poll J, Clark L, Fassl BA, et al. Information needs for designing a home monitoring system for children with medical complexity. *International Journal of Medical Informatics* 2019;**122**:7-12.

Noel 2016 *{published data only}*

Noel M, Beals-Erickson SE, Law EF, Alberts NM, Palermo TM. Characterizing the pain narratives of parents of youth with chronic pain. *Clinical Journal of Pain* 2016;**32**(10):849-858.

Nsangou 2020 *{published data only}*

Nsangou HN, Scelles R. Sickle cell anemia and projection into the future: a comprehensive approach to the experiences of a sick child's sister in Cameroon [Drépanocytose et projection vers l'avenir: Une approche compréhensive du vécu d'une sœur d'un enfant atteint au Cameroun]. *Neuropsychiatrie de l'Enfance et de l'Adolescence* 2020;**68**(8):410-420.

Nyante 2019 *{published data only}*

Nyante GG, Carpenter C. The experience of carers of children with cerebral palsy living in rural areas of Ghana who have received no rehabilitation services: a qualitative study. *Child: Care, Health and Development* 2019;**45**(6):815-822.

Oddy 2000 *{published data only}*

Oddy P. The development of a social psychological chronic pain scale through utilisation of a qualitative-quantitative facilitation paradigm. Doctoral Thesis, University of Surrey 2000.

Ojo 2018 *{published data only}*

Ojo F, Litcher-Kelly L, Mazar I, Klooster B, Ollis S, Chaston E, Roeder A, Treadwell MJ, Reasner D. Measurement of sickle cell disease symptoms from the patient perspective: considerations for clinical trials. In: Blood. Vol. 132. 2018.

Ojo 2018a *{published data only}*

Ojo O, Litcher-Kelly L, Mazar I, Klooster B, Ollis S, Chaston E, Roeder A, Reasner D. What maters to individuals with sickle cell disease? Patient input on the relevant and improtant symptoms and impacts of the condition. *Value in Health* 2018a;**21**(Supplement 3):S472-S473.

Oreper 2022 *{published data only}*

Oreper J, Khalid A, Sheffe S, Mustafa N, Vader K, Bosma R. Defining success in transitions from pediatric to adult chronic pain care: a descriptive qualitative study of perspectives of young adults living with chronic pain. *Pain medicine (Malden, Mass.)* 2022;**23**(7):1217-1224.

Ortiz 2014 *{published data only}*

Ortiz CMV, Valencia VD, Daniel O, Paez P, Paez PFJF. The health of caregivers of children with chronic disability and the rehabilitation impact on them. *PM and R* 2014;**6**(8 SUPPL. 2):S148-S149.

Ostojic 2019 *{published data only}*

Ostojic K, Morrow A, Paget S. Biofeedback assisted relaxation training for the management of chronic pain in children and adolescents with cerebral palsy. *Developmental Medicine and Child Neurology* 2019;**61**(Supplement 3):138-139.

Ostojic 2020 *{published data only}*

Ostojic K, Sharp N, Paget S, Khut G, Morrow A. BrightHearts: a pilot study of biofeedback assisted relaxation training for the management of chronic pain in children and adolescents with cerebral palsy. *Developmental Medicine and Child Neurology* 2020;**62**(SUPPL 4):38-39.

Ostojic 2020a *{published data only}*

Ostojic K, Sharp N, Paget S, Morrow A. Biofeedback assisted relaxation training for the management of chronic pain in children and adolescents with cerebral palsy. *Developmental Medicine and Child Neurology* 2020a;**62**(Supplement 2):62.

Packham 2014 *{published data only}*

Packham TL, Macdermid J. Content validity of the patient-report Hamilton Inventory for Complex Regional Pain Syndrome. *Journal of Hand Therapy* 2014;**27**(3):e3-e3.

Packham 2020 *{published data only}*

Packham TL, Wainio K, Wong MK. Persons with complex regional pain syndrome renegotiate social roles and intimacy: a qualitative study. *Pain Medicine (Malden, Mass.)* 2020;**21**(2):239-246.

Palermo 2014 *{published data only}*

Palermo TM, Law EF, Essner B, Jessen-Fiddick T, Eccleston C. Adaptation of problem-solving skills training (PSST) for parent caregivers of youth with chronic pain. *Clinical Practice in Pediatric Psychology* 2014;**2**(3):212-223.

Palsgrove 2014 *{published data only}*

Palsgrove AC, Guay-Woodford LM, Cheng R, Oberdhan D, Blais J, Cole JC, et al. Burden of autosomal dominant polycystic kidney disease (ADPKD): effects on the daily lives of patients and their caregivers. *American Journal of Kidney Diseases* 2014;**63**(5):A86.

Panepinto 2011 *{published data only}*

Panepinto JA, Torres S, Varni JW. The development of the PedsQLTM sickle cell disease module items: qualitative methods. *American Journal of Hematology* 2011;**86**(10):E36.

Pantaleao 2019 *{published data only}*

Pantaleao A, DiPlacido J, Guite JW, Zempsky WT. Caregiver factors related to emergency department utilization for youth with sickle cell disease. *Childrens Health Care* 2019;**48**(1):59-74.

Park 2000 *{published data only}*

Park J. "The worst hassle is you can't play rugby": haemophilia and masculinity in New Zealand. *Current Anthropology* 2000;**41**(3):443-453.

Peck 2018 *{published data only}*

Peck J, Viswanath O. A perspective on adolescent chronic pain dismissal. *Psychopharmacology Bulletin* 2018;**48**(4):10-12.

Pelaez-Ballestas 2013 *{published data only}*

Pelaez-Ballestas I, Perez-Taylor R, Aceves-Avila JF, Burgos-Vargas R. 'Not-belonging': illness narratives of Mexican patients with ankylosing spondylitis. *Medical Anthropology* 2013;**32**(5):487-500.

Pendleton 2002 *{published data only}*

Pendleton SM, Cavalli KS, Pargament KI, Nasr SZ. Religious/spiritual coping in childhood cystic fibrosis: a qualitative study. *Pediatrics* 2002;**109**(1):E8.

Peters 2017 *{published data only}*

Peters J. What is the role of the clinical nurse specialist in a multi-disciplinary, chronic pain management service for young people, in a tertiary hospital in London? *British Journal of Pain* 2017;**11**(2 Supplement 1):84-85.

Polkki 1997 *{published data only}*

Polkki T, Rissanen L, Pietila A. It feels like a hedgehog sticks in my foot... school-aged children's experiences of pain in hospital. *Hoitotiede* 1997;**9**(4):159-168.

Polkki 1997a *{published data only}*

Pölkki T, Rissanen L, Pietila AM. "It feels like a hedgehog quill sticking in my foot...". School-aged children's experience of pain in the hospital ["Tuntuu kuin siili nippais jalakaan...". Kouluikaisten lasten kipukokemuksia sairaalassa.]. *Hoitotiede* 1997;**9**(4):159-68.

Pölkki 1999 *{published data only}*

Pölkki T, Pietilä AM, Rissanen L. Pain in children: qualitative research of Finnish school-aged children's experiences of pain in hospital. *International Journal of Nursing Practice* 1999;**5**(1):21-8.

Pousette 2019 *{published data only}*

Pousette Lundgren G, Hasselblad T, Johansson AS, Johansson A, Dahllof G. Experiences of being a parent to a child with amelogenesis imperfecta. *Dentistry Journal* 2019;**7**(1):17.

Preston 2016 *{published data only}*

Preston J, Ainsworth S, Smith E, Wilson E. Living with an invisible illness. *Archives of Disease in Childhood* 2016;**101**(Suppl 1):A73.

Qualter 2020 *{published data only}*

Qualter P, Rouncefield-Swales A, Bray L, Blake L, Allen S, Probert C, et al. Depression, anxiety, and loneliness among adolescents and young adults with IBD in the UK: the role of disease severity, age of onset, and embarrassment of the condition. *Quality of Life Research* 2021;**30**(2):497–506. [DOI: 10.1007/s11136-020-02653-9]

Quintanar-Solares 2013 *{published data only}*

Quintanar-Solares M, Martin ML, Bryant AJ, Ascoytia CM, Asmus F, Geister TL. Using questionnaire design to explore reporting differences for spasticity related pain in children and adolescents with cerebral palsy. *Value in Health* 2013;**16**(3):PA41. [DOI: 10.1016/j.jval.2013.03.232]

Rabbitts 2017 *{published data only}*

Rabbitts JA, Aaron RV, Fisher E, Lang EA, Bridgwater C, Tai GG, et al. Long-term pain and recovery after major pediatric surgery: a qualitative study with teens, parents, and perioperative care providers. *Journal of Pain* 2017;**18**(7):778-86. [DOI: 10.1016/j.jpain.2017.02.423. Epub 2017 Feb 21]

Ramlee 2017 *{published data only}*

Ramlee F. Sleep and physical activity: a mixed method study in people with chronic pain [Doctoral thesis]. Coventry (UK): University of Warwick, 2017.

Randall 2019 *{published data only}*

Randall J, Guobyte A, Delbecque L, Newton L, Symonds T, Hunter T. Ulcerative colitis experiences among a paediatric population: a qualitative study reviewing the agreement of symptoms discussed by children and their parents. *The American Journal of Gastroenterology* 2019;**114**:S475-6. [DOI: 10.14309/01.ajg.0000592836.52334.ce]

Reid 2017 *{published data only}*

Reid K, Hartling L, Ali S, Le A, Norris A, Scott SD. Development and usability evaluation of an art and narrative-based knowledge translation tool for parents with a child with pediatric chronic pain: multi-method study. *Journal of Medical Internet Research* 2017;**19**(12):e412.

Rich 2000 *{published data only}*

Rich M, Lamola S, Gordon J, Chalfen R. Video intervention/prevention assessment: a patient-centered methodology for understanding the adolescent illness experience. *Journal of Adolescent Health* 2000;**27**(3):155-65. [DOI: 10.1016/s1054-139x(00)00114-2]

Risko 2018b *{published data only}*

Risko JL. Adolescent experiences in an intensive interdisciplinary pediatric chronic pain rehabilitation program [Doctoral thesis]. Kent, OH: Kent State University, 2018.

Roberts 2021 *{published data only}*

Roberts S. Reflexions beyond words: using auto-driven photo-elicitation to explore the pain management programme journey [Doctoral thesis]. Wolverhampton (UK): University of Wolverhampton, 2021.

Roper 2018 *{published data only}*

Roper L, Sherratt F, Baildam EM, McErlane F, Beresford MW, Foster H, et al. Children's and parents' perspectives on outcomes for JIA trials comparing different corticosteroid delivery routes: a qualitative study. *Pediatric Rheumatology* 2018;**16**(Suppl 2):P250.

Ross 1984 *{published data only}*

Ross DM, Ross SA. Childhood pain: the school-aged child's viewpoint. *Pain* 1984;**20**(2):179-91.

Rossato 2011 *{published data only}*

Rossato LM, Morete M, Borghi C, Lindenberg M, Pereira CA, Bousso RS, et al. The experience of child in pain with juvenile idiopathic arthritis. *European Journal of Pain Supplements* 2011;**5**(1):245.

Rossato 2014 *{published data only}*

Rossato LM, Silva EMR, Bousso RS, Dias CG, Borghi CA, Santos MR, et al. Assessment of pain in children and adolescents in palliative care. *Palliative Medicine* 2014;**28**(6):842.

Roth 2018 *{published data only}*

Roth IJS. Ethnography of integrative pain management at a large urban pediatric hospital [Doctorate dissertation]. Houston (TX): The University of Texas School of Public Health, 2017.

Roth 2019 *{published data only}*

Roth I, Highfield L, Cuccaro P, Wells R, Misra S, Engebretson J. Employing evidence in evaluating complementary therapies: findings from an ethnography of integrative pain management at a large urban pediatric hospital. *Journal of Alternative and Complementary Medicine* 2019;**25**(Suppl 1):S95-105.

Roth 2020 *{published data only}*

Roth I, Engebretson J. Implementation strategies used in a pediatric integrative pain management pilot consult service: findings from an ethnography. *Global Advances in Health and Medicine* 2020;**9**:22.

Rouse 2011 *{published data only}*

Rouse CM. Informing choice or teaching submission to medical authority: a case study of adolescent transitioning for sickle cell patients. *Ethnicity & Health* 2011;**16**(4-5):313-25.

Rousseau 2007 *{published data only}*

Rousseau K. Children as young as 4 years of age with type 1 diabetes showed understanding and competence in managing their condition. *Evidence Based Nursing* 2007;**10**(1):28. [DOI: 10.1136/ebn.10.1.28]

Ruddy 2019 *{published data only}*

Rennick JE, St-Sauveur I, Knox AM, Ruddy M. Exploring the experiences of parent caregivers of children with chronic medical complexity during pediatric intensive care unit hospitalization: an interpretive descriptive study. *BMC Pediatrics* 2019;**19**(1):272. [DOI: 10.1186/s12887-019-1634-0]

Rullander 2013 *{published data only}*

Rullander AC, Jonsson H, Lundström M, Lindh V. Young people's experiences with scoliosis surgery: a survey of pain, nausea, and global satisfaction. *Orthopaedic Nursing* 2013;**32**(6):327-35. [DOI: 10.1097/NOR.0000000000000007]

Ruskin 2014 *{published data only}*

Ruskin D, Kohut SA, Stinson J. The development of a mindfulness-based stress reduction group for adolescents with chronic pain. *Journal of Pain Management* 2014;**7**(4):301-12.

Sällfors 1999 *{published data only}*

Sällfors C, Dahlberg K. Children and adolescents' experiences of living with juvenile idiopathic arthritis [Barn och ungdomars upplevelser av att leva med juvenil idiopatiskartrit]. *Nordisk Fysioterapi* 1999;**3**:20-30.

Sällfors 2003 *{published data only}*

Sällfors C. Pain coping and well-being in children with chronic arthritis [Doctoral thesis]. Göteborg (Sweden): Nordic School of Public Health, 2003.

Salvo 2022 *{published data only}*

Salvo T, Davison-Jenkins A, Hitchcock M, Daniilidi X, Lambert D. The journey of 'living with pain': a feasibility study of the development and running of a collective narrative group. *Clinical Child Psychology and Psychiatry* 2023;**28**(1):35-55. [DOI: 10.1177/13591045221112719]

Sangha 2021 *{published data only}*

Sangha N, MacLellan AN, Pope E. Psychosocial impact of epidermolysis bullosa on patients: a qualitative study. *Pediatric Dermatology* 2021;**38**(4):819-24. [DOI: 10.1111/pde.14656]

Santos 2013 *{published data only}*

Santos M, Barros L. The impact of chronic health conditions: learning from osteogenesis imperfecta (OI) patients and their families. *Atención Primaria* 2013;**45**(Suppl 2):52.

Santos 2017 *{published data only}*

Santos M, Zempsky W. Parental beliefs on the impact of obesity in pediatric pain. *Journal of Pain* 2017;**18**(4 Suppl 1):S39-40. [DOI: 10.1016/j.jpain.2017.02.148]

Savedra 1981 *{published data only}*

Savedra M, Tesler M, Ward J, Wegner C, Gibbons P. Description of the pain experience: a study of school-age children. *Issues in Comprehensive Pediatric Nursing* 1981;**5**(5-6):373-80. [DOI: 10.3109/01460868109106352]

Schultz 2010 *{published data only}*

Schultz LF, Sabates AL. Family living through sickness and child's hospitalization: qualitative study. *Online Brazilian Journal of Nursing* 2010;**9**(2). [DOI: 10.5935/1676-4285.20103054]

Schulz 2014 *{published data only}*

Schulz C, Leininger B, Evans R, Vavrek D, Peterson D, Haas M, et al. Spinal manipulation and exercise for low back pain in adolescents: study protocol for a randomized controlled trial. *Chiropractic & Manual Therapies* 2014;**22**:21. [DOI: 10.1186/2045-709X-22-21]

Scorgie 1996 *{published data only}*

Scorgie K, Wilgosh L, McDonald L. A qualitative study of managing life when a child has a disability. *Developmental Disabilities Bulletin* 1996;**24**(2):68-90.

Seangrung 2021 *{published data only}*

Seangrung R, Tempeetikul T, Pannarunothai S, Sakdanuwatwong S. Perspectives of pain specialists, patients, and family members on long-term opioid use for chronic non-cancer pain: a qualitative study. *BMC Anesthesiology* 2021;**21**(1):275. [DOI: 10.1186/s12871-021-01501-8]

Shaw 2004 *{published data only}*

Shaw KL, Southwood TR, McDonagh JE, on behalf of the British Paediatric Rheumatology Group. User perspectives of transitional care for adolescents with juvenile idiopathic arthritis. *Rheumatology (Oxford)* 2004;**43**(6):770-8. [DOI: 10.1093/rheumatology/keh175]

Sil 2021 *{published data only}*

Sil S, Lee JL, Klosky J, Vaz A, Mee L, Cochran S, et al. The comfort ability program for adolescents with sickle cell pain: evaluating feasibility and acceptability of an inpatient group-based clinical implementation. *Pediatric Blood & Cancer* 2021;**68**(6):e29013. [DOI: 10.1002/pbc.29013]

Simon 1992 *{published data only}*

Simon NB, Smith D. Living with chronic pediatric liver disease: the parents' experience. *Pediatric Nursing* 1992;**18**(5):453-9, 489.

Simons 2020 *{published data only}*

Simons J, Carter B, Craske J. Developing a framework to support the delivery of effective pain management for children: an exploratory qualitative study. *Pain Research and Management* 2020;**2020**:5476425. [DOI: 10.1155/2020/5476425]

Skarstein 2020 *{published data only}*

Skarstein S, Bergem AK, Helseth S. How do mothers of adolescents with chronic pain experience their own quality of life? *BMC Psychology* 2020;**8**(1):64. [DOI: 10.1186/s40359-020-00430-4]

Slater 2016 *{published data only}*

Slater H, Jordan JE, Chua J, Schutze R, Wark JD, Briggs AM. Young people's experiences of persistent musculoskeletal pain, needs, gaps and perceptions about the role of digital technologies to support their co-care: a qualitative study. *BMJ Open* 2016;**6**(12):e014007. [DOI: 10.1136/bmjopen-2016-014007]

Smeland 2019 *{published data only}*

Smeland AH, Rustøen T, Naess T, Nybro L, Lundeberg S, Reinertsen H, et al. Children's views on postsurgical pain in recovery units in Norway: a qualitative study. *Journal of Clinical Nursing* 2019;**28**(11-12):2157-70. [DOI: 10.1111/jocn.14788]

Smith 2018 *{published data only}*

Smith K, Reinman L, Schatz J, Roberts CW. Parent perspectives on pain management in preschool-age children with sickle cell disease. *Journal of Pediatric Oncology Nursing* 2018;**35**(1):16-24. [DOI: 10.1177/1043454217735829]

Smith 2022 *{published data only}*

Smith J. A qualitative exploration of the impact of persistent pain [Doctoral thesis]. Lancaster (UK): Lancaster University, 2022.

Snelgrove 2015 *{published data only}*

Snelgrove R. Youth with chronic illness forming identities through leisure. *Journal of Leisure Research* 2015;**47**(1):154-73.

Snyder 2001 *{published data only}*

Snyder BS. An exploration of treatment interference in children hospitalized in a pediatric intensive care unit [Doctoral thesis]. Philadelphia (PA): University of Pennsylvania, 2001.

Solodiuk 2020 *{published data only}*

Solodiuk JC, Jantz B, Fuller M, Osterling D, Foxman H, Grafft N, et al. The use of music by adolescents and young adults with sickle cell disease. *Creative Nursing* 2020;**26**(3):189-96. [DOI: 10.1891/CRNR-D-19-00069]

Solomon 2016 *{published data only}*

Solomon O, Heritage J, Yin L, Maynard DW, Bauman ML. 'What brings him here today?': medical problem presentation involving children with autism spectrum disorders and typically developing children. *Journal of Autism and Developmental Disorders* 2016;**46**(2):378-93. [DOI: 10.1007/s10803-015-2550-2]

Solyom 2017 *{published data only}*

Solyom A, Johnson B, Ehlert K, Tetzl D, Coyne K. Defining the clinical impact of symptoms in a diverse population of patients with a rare disease: a qualitative research study in acid ceramidase deficiency (Farber disease). *Pediatric Rheumatology* 2017;**15**(Suppl 2):66-7.

Sparapani 2015 *{published data only}*

Sparapani VdC, Jacob E, Nascimento LC. What is it like to be a child with type 1 diabetes mellitus? *Pediatric Nursing* 2015;**41**(1):17-22.

Spiers 2016 *{published data only}*

Spiers G, Allgar V, Richardson G, Thurland K, Hinde S, Birks Y, et al. Transforming community health services for children and young people who are ill: a quasi-experimental evaluation. Health Services and Delivery Research 2016;**4**(25):219.

Stebbins 2018 *{published data only}*

Stebbins P, Bailey M, D'Alessio D, Saucier C, Raymond K, White M. Barriers to treatment for patients with sickle cell disease: results from in-depth interviews with patients and caregivers. *HemaSphere* 2018;**2**(Supplement 2):1065.

Stebbins 2018a *{published data only}*

Stebbins P, Saucier C, Bailey M, D'Alessio D, Mitchell A, White M, Raymond K. Impact of sickle cell disease on work, school, relation ships, and social life: results from in-depth interviews with patients. *HemaSphere* 2018a;**2**(Supplement 2):1064-1065.

Stefanatou 1997 *{published data only}*

Stefanatou A, Bowler D. Depiction of pain in the self-drawings of children with sickle cell disease. *Child: Care, Health and Development* 1997;**23**(2):135-55.

Stegenga 2004 *{published data only}*

Stegenga KA, Ward-Smith P, Hinds PS, Routhieaux JA, Woods GM. Quality of life among children with sickle cell disease receiving chronic transfusion therapy. *Journal of Pediatric Oncology Nursing* 2004;**21**(4):207-213.

Stenekes 2009 *{published data only}*

Stenekes SJ, Hughes A, Gregoire M-C, Frager G, Robinson WM, McGrath PJ. Frequency and self-management of pain, dyspnea, and cough in cystic fibrosis. *Journal of Pain and Symptom Management* 2009;**38**(6):837-48.

Stenner 2016 *{published data only}*

Stenner R, Swinkels A, Mitchell T, Palmer S. Exercise prescription for non-specific chronic low back pain (NSCLBP): a qualitative study of patients' experiences of involvement in decision making. *Physiotherapy* 2016;**102**(4):339-344.

Stewart 2011 *{published data only}*

Stewart M, Barnfather A, Magill-Evans J, Ray L, Letourneau N. Brief report: An online support intervention: Perceptions of adolescents with physical disabilities. *Journal of Adolescence* 2011;**34**(4):795-800.

Stinson 2006 *{published data only}*

Stinson JN, Petroz GC, Tait G, Feldman BM, Streiner D, McGrath PJ, et al. e-Ouch: usability testing of an electronic chronic pain diary for adolescents with arthritis. *Clinical Journal of Pain* 2006;**22**(3):295-305.

Stinson 2015 *{published data only}*

Stinson JN, Huber AM, Connelly M, Luca N, Spiegel LR, Tsimicalis A, et al. Development and usability testing of an iPad-based psycho-educational game for children with juvenile idiopathic arthritis and their parents. In: Arthritis and Rheumatology. Vol. 67. 2015.

Stinson 2016 *{published data only}*

Stinson J, Connelly M, Huber A, Luca N, Spiegel L, Tsimicalis A, et al. Development and usability testing of an iPad and desktop psycho-educational game for children with Juvenile Idiopathic Arthritis and their parents. *Journal of Pain* 2016;**17**(4 SUPPL. 1):S106.

Stinson 2016a *{published data only}*

Stinson J, Lalloo C, Harris L, Cafazzo J, Campbell F, Chorney J, et al. iCanCope with pain: user-centered design of an integrated smartphone and web-based pain self-management program for youth and young adults with chronic pain. *Journal of Pain* 2016a;**17**(4 SUPPL. 1):S109.

Stratton 2011 *{published data only}*

Stratton KK, Hartshorne TS. Experiencing stress. In: CHARGE syndrome. San Diego, CA: Plural Publishing Inc., 2011:353-359.

Strauss 2019 *{published data only}*

Strauss S, Kit-Lewis EA, Amory M. “I don’t feel like I have any control of my life at all... Everything overwhelms me. Everything”: analyzing caregiver uncertainty and control through stance marking. *Qualitative Health Research* 2019;**29**(12):1794-1809.

Suder 2017 *{published data only}*

Suder R, Peirce C, Winston K, Bazyk S. The lived experience of adolescents with chronic pain: a phenomenological study. *American Journal of Occupational Therapy* 2017;**71**:256-256.

Svedberg 2010 *{published data only}*

Svedberg LE, Englund E, Malker H, Stener-Victorin E. Comparison of impact on mood, health, and daily living experiences of primary caregivers of walking and non-walking children with cerebral palsy and provided community services support. *European Journal of Paediatric Neurology* 2010;**14**(3):239-46.

Swallow 2011 *{published data only}*

Swallow V, Lambert H, Santacroce S, Macfadyen A. Fathers and mothers developing skills in managing children's long-term medical conditions: how do their qualitative accounts compare? *Child: Care, Health and Development* 2011;**37**(4):512-23.

Swallow 2013 *{published data only}*

Swallow V, Nightingale R, Williams J. Multidisciplinary teams, and parents, negotiating common ground in shared-care of children with long-term conditions: a mixed methods study. *BMC Health Services Research* 2013;**13**(1):264.

Swift 2014 *{published data only}*

Swift CM, Reed K, Hocking C. A new perspective on family involvement in chronic pain management programmes. *Musculoskeletal Care* 2014;**12**(1):47-55.

Szentagotai 2005 *{published data only}*

Szentagotai A, Crăciun C. Reprezentarea durerii la copii = Children's representation of pain. *Cogniţie Creier Comportament* 2005;**9**(1):85-96.

Tanabe 2013 *{published data only}*

Tanabe P, Dias N, Gorman L. Care of children with sickle cell disease in the emergency department: parent and provider perspectives inform quality improvement efforts. *Journal of Pediatric Oncology Nursing* 2013;**30**(4):205-217.

Tapping 2015 *{published data only}*

Tapping P, Rashid A, Ghio D, Chieng A, Jimmieson P, Calam R, et al. Development and feasibility testing of a new iPad application, this feeling, to aid communication of pain in children with juvenile idiopathic arthritis. In: Rheumatology (Oxford). Vol. 54. 2015.

Tapping 2015a *{published data only}*

Tapping P, Rashid A, Thomson W, Ghio D, Cordingley L, Calam R, Jimmieson P, Chieng A. "This feeling!": Can a new IPAD app help children with juvenile idiopathic arthritis communicate their pain experiences? feasibility, usability and acceptability. *Annals of the Rheumatic Diseases* 2015a;**74**(SUPPL. 2):128.

Taub 2000 *{published data only}*

Taub Diane E, Greer Kimberly R. Physical activity as a normalizing experience for school-age children with physical disabilities: implications for legitimation of social identity and enhancement of social ties. *Journal of Sport and Social Issues* 2000;**24**(4):395-414.

Tekano 2014 *{published data only}*

Tekano J, Tucker LB, Chen A. Children and parent satisfaction in the pediatric rheumatology clinic: patient orientated quality service measures. *Arthritis and Rheumatology* 2014;**66**(SUPPL. 10):S823.

Tetzl 2017 *{published data only}*

Tetzl D, Coyne K, Johnson B, Solyom A, Ehlert K. A qualitative research study documenting the clinical impact of symptoms in a diverse population of patients and caregivers with acid ceramidase deficiency (farber disease). *Journal of Inborn Errors of Metabolism and Screening* 2017;**5**:324.

Timko 1992 *{published data only}*

Timko C, Stovel KW, Moos RH. Functioning among mothers and fathers of children with juvenile rheumatic disease: a longitudinal study. *Journal of Pediatric Psychology* 1992;**17**(6):705-24.

Toupin 2020 *{published data only}*

Toupin April K, Huber A, Duffy C, Couchman D, Proulx L, Morgan E, et al. Acceptability and usability testing of a preliminary version of the JIA option map, an electronic decision aid for pain management options in juvenile idiopathic arthritis. *Arthritis and Rheumatology* 2020;**72**(Suppl 4):93-4. [DOI: http://dx.doi.org/10.1002/art.41304]

Toupin-April 2018 *{published data only}*

Toupin-April K, Stinson J, Huber A, Duffy C, Morgan E, Brinkman W, et al. First steps in developing a novel decision support intervention for pain management options in juvenile idiopathic arthritis. *Journal of Rheumatology* 2018;**45**(7):981-982.

Toupin-April 2018a *{published data only}*

Toupin-April K, Stinson JN, Huber A, Duffy CM, Gaboury I, Morgan E, et al. Exploring decision making needs about pain management among adolescents with juvenile idiopathic arthritis and their families: preliminary results from interviews. *Arthritis and Rheumatology* 2018a;**70**(Supplement 9):2590-2591.

Toupin-April 2020 *{published data only}*

Toupin-April K, Huber AM, Duffy CM, Proulx L, Morgan EM, Cohen JS, et al, on behalf of JIA Option Map Group. Development and acceptability of a patient decision aid for pain management in juvenile idiopathic arthritis: The JIA Option Map. *The Patient–Patient Centered Outcomes Research* 2020;**13**(6):719-28.

Trennery 2019 *{published data only}*

Trennery C, Larsen LS, Silverberg J, Abramovits W, Simpson E, Stalder JF, et al. Qualitative patient research to support the development of a conceptual model to illustrate the experience of atopic dermatitis in adolescents. *Journal of the American Academy of Dermatology* 2019;**81**(4 Supplement 1):AB112.

Treves 1999 *{published data only}*

Treves Katharine F. The management of insomnia on a residential pain management programme: a single case series and qualitative analysis. Doctoral Thesis, The Open University 1999.

Trope 2018 *{published data only}*

Trope S, Belot A, Fahy W, Maire PQD, Sordet C, Cohen JD. Referential skills participatory in JIA for children, adolescents and parents. In: Pediatric Rheumatology. Vol. 16. 2018.

Tuchman 2008 *{published data only}*

Tuchman LK, Slap GB, Britto MT. Transition to adult care: experiences and expectations of adolescents with a chronic illness. *Child: Care, Health and Development* 2008;**34**(5):557-63.

Unruh 1983 *{published data only}*

Unruh A, McGrath P, Cunningham SJ, Humphreys P. Children's drawings of their pain. *Pain* 1983;**17**(4):385-92.

Vaienzuela 2010 *{published data only}*

Vaienzuela JM, Crosby LE, Vaughn L, Robinson VM, Ross M, Mitchell MJ. Empowering youth with sickle cell disease: a photovoice pilot. *American Journal of Hematology* 2010;**85**(8):E20.

Vaira-Joyce 2022 *{published data only}*

Vaira-Joyce Courtney J. What are the experiences of identity development in young adult women who had chronic pain in adolescence? Doctoral Thesis, Capella University 2022;**83**.

van Staa 2011 *{published data only}*

van Staa A, Jedeloo S, van der Stege H, on behalf of On Your Own Feet Research Group. "What we want": chronically ill adolescents' preferences and priorities for improving health care. *Patient Preference and Adherence* 2011;**5**:291-305.

Varni 2012 *{published data only}*

Varni JW, Kay MT, Limbers CA, Franciosi JP, Pohl JF. PedsQL gastrointestinal symptoms module item development: Qualitative methods. *Journal of Pediatric Gastroenterology and Nutrition* 2012;**54**(5):664-71.

Varni 2012a *{published data only}*

Varni JW, Kay MT, Limbers CA, Franciosi JP, Pohl JF. PedsQL^{TM} gastrointestinal symptoms module item development: Qualitative methods. *Journal of Pediatric Gastroenterology and Nutrition* 2012;**54**:664–71.

Vendetti 2016 *{published data only}*

Vendetti NJ, Benjamin K, Moshkovich O, Lipman K, Sivamurthy KM, Pleil AM. A new measure assessing recovery from a sickle cell crisis. In: Blood. Vol. 128. 2016.

Venner 2014 *{published data only}*

Venner GP, Zakus D, Soka D, Makani J. Health education for sickle cell disease: strategies to support families and health care workers in Tanzania. *Annals of Global Health* 2014;**80**(3):180-181.

Vera 2015 *{published data only}*

Vera M, Allgood S, Kozachik S, Riekert K, Haythornthwaite J, Lechtzin N. The lived experience of pain in adolescents diagnosed with cystic fibrosis. *Journal of Pain* 2015;**16**(4 SUPPL. 1):S30.

Vervoort 2008 *{published data only}*

Vervoort T, Craig KD, Goubert L, Dehoorne J, Joos R, Matthys D, et al. Expressive dimensions of pain catastrophizing: a comparative analysis of school children and children with clinical pain. *Pain* 2008;**134**(1-2):59-68.

Vine 2020 *{published data only}*

Curran JA, Breneol S, Vine J. Improving transitions in care for children with complex and medically fragile needs: a mixed methods study. *BMC Pediatrics* 2020;**20**(1):1-14.

Visram 2013 *{published data only}*

Visram F. Development of conceptual and process models of growing pains: a mixed-method research design. Doctoral Thesis, The University of Saskatchewan 2013;**74**.

Visram 2017 *{published data only}*

Visram S. Impact and acceptability of lay health trainer-led lifestyle interventions delivered in primary care: a mixed method study. *Primary Health Care Research & Development* 2017;**18**(4):333-343.

von Scheven 2021 *{published data only}*

von Scheven E, Nahal BK, Cohen IC, Kelekian R, Franck LS. Research questions that matter to us: priorities of young people with chronic illnesses and their caregivers. *Pediatric Research* 2021;**89**(7):1659-1663.

Vuorimaa 2013 *{published data only}*

Vuorimaa H, Stinson J. Cultural adaptation of the "Teens taking charge: managing arthritis online" program to Finland. In: Annals of the Rheumatic Diseases. Vol. 72. 2013:A362.

Wainwright 2022 *{published data only}*

Wainwright E, Jordan A, Fisher E, Wilson C, Mullen D, Madhavakkannan H. Beliefs about worry and pain amongst adolescents with and without chronic pain. *Journal of Pediatric Psychology* 2022;**47**(4):432-445.

Waite-Jones 2008a *{published data only}*

Waite-Jones JM, Madill A. Concealed concern: fathers' experiences of having a child with juvenile idiopathic arthritis. *Psychology & Health* 2008;**23**(5):585-601.

Wakefield 2020 *{published data only}*

Wakefield E, Zempsky W, Puhl R, Litt M. "It'll go away. There's nothing wrong with you:" the experience of pain-related stigma among adolescents with pain amplification syndrome. *Arthritis and Rheumatology* 2020;**72**(SUPPL 10):1454-1455.

Ware 2014 *{published data only}*

Ware H, Madan-Swain A, Howard TH, Bemrich-Stolz CJ, Hilliard L, Lebensburger JD. Coping and adjustment among adolescents with sickle cell disease. *Blood* 2014;**124**(21):440. [DOI: 10.1182/blood.V124.21.440.440]

Warnink-Kavelaars 2019 *{published data only}*

Warnink-Kavelaars J, Beelen A, Dekker S, Nollet F, Menke LA, Engelbert RHH. Marfan syndrome in childhood: parents' perspectives of the impact on daily functioning of children, parents and family; a qualitative study. *BMC Pediatrics* 2019;**19**(1):262.

Warnink-Kavelaars 2019a *{published data only}*

Warnink-Kavelaars J, Beelen A, Goedhart TMHJ, de Koning LE, Nollet F, Alsem MW, et al. Marfan syndrome in adolescence: adolescents' perspectives on (physical) functioning, disability, contextual factors and support needs. *European Journal of Pediatrics* 2019a;**178**(12):1883-1892.

Webb 2011 *{published data only}*

Webb Carly M, Collin Simon M, Deave Toity. What stops children with a chronic illness accessing health care: a mixed methods study in children with chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME). *BMC Health Services Research* 2011;**11**:308.

Wells 2013 *{published data only}*

Wells F, Ritchie D, McPherson AC. 'It is life threatening but I don't mind'. A qualitative study using photo elicitation interviews to explore adolescents' experiences of renal replacement therapies. *Child: Care, Health and Development* 2013;**39**(4):602-12.

Westesson 2018 *{published data only}*

Westesson LM, Wallengren C, Baghaei F, Sparud-Lundin C. Reaching independence through forced learning: learning processes and illness management in parents of children affected by hemophilia. *Qualitative Health Research* 2018;**28**(14):2142-54. [DOI: 10.1177/1049732318789631]

Wihak 2020 *{published data only}*

Wihak T, Burns M, Miranda J, Windmueller G, Oakley C, Coakley R. Development and feasibility testing of the Comfort Ability Program for sickle cell pain: a patient-informed, video-based pain management intervention for adolescents with sickle cell disease. *Clinical Practice in Pediatric Psychology* 2020;**8**(2):150-63.

Williams 2001 *{published data only}*

Williams C. Alert assistants in managing chronic illness: the case of mothers and teenage sons. *Sociology of Health and illness* 2001;**22**(2):254-72.

Williams 2011 *{published data only}*

Williams EF, Gannon K, Soon K. The experiences of young people with epidermolysis bullosa simplex: a qualitative study. *Journal of Health Psychology* 2011;**16**(5):701-10. [DOI: 10.1177/1359105310387954]

Witwicki 2015 *{published data only}*

Witwicki C, Hay H, Tallett A. Piloting a new patient reported experience measure for sickle cell disease: a report of the findings. Oxford (UK): Sickle Cell Society, Picker Institute, 2015.

Wong 2019 *{published data only}*

Wong H, Wheeler M, Nisbet J, McDonagh J, Cuthbert V. Feasibility of the learning and exercise to avert pain (LEAP) programme: an evaluation of a group therapy intervention for young people with chronic musculoskeletal pain. *Rheumatology (Oxford)* 2019;**58**(Suppl 4):IV14.

Wren 2021 *{published data only}*

Wren AA, Neiman N, Caruso TJ, Rodriguez S, Taylor K, Madill M, et al. Mindfulness-based virtual reality intervention for children and young adults with inflammatory bowel disease: a pilot feasibility and acceptability study. *Children (Basel, Switzerland)* 2021;**8**(5):368. [DOI: 10.3390/children8050368]

Wren 2022 *{published data only}*

Wren G, Mercer J. Dismissal, distrust, and dismay: a phenomenological exploration of young women's diagnostic experiences with endometriosis and subsequent support. *Journal of Health Psychology* 2022;**27**(11):2549-65. [DOI: 10.1177/13591053211059387]

Wright 2015 *{published data only}*

Wright J, Elwell L, McDonagh JE, Kelly DA, Wray J. ‘It’s hard but you've just gotta get on with it’—the experiences of growing-up with a liver transplant. *Psychology & Health* 2015;**30**(10):1129-45. [DOI: 10.1080/08870446.2015.1024245]

Yeh 2018 *{published data only}*

Yeh EA, Chiang N, Darshan B, Nejati N, Grover SA, Schwartz CE, et al, for the Pediatric MS Adherence Study Group. Adherence in youth with multiple sclerosis: a qualitative assessment of habit formation, barriers, and facilitators. *Qualitative Health Research* 2018;**29**(5):645-57.

Young 2020 *{published data only}*

Young AJ, Richardson F, Fitzgerald D, Heavrin BS, Tweddell B, Gettings L, et al. Let their voices be seen. *Annals of Emergency Medicine* 2020;**76**(3S):S73-7. [DOI: 10.1016/j.annemergmed.2020.08.015]

Zabalia 2013 *{published data only}*

Zabalia M, Jacquet D, Grasménil C, Wood C. Pediatric pain assessment: a pragmatic analysis of dialogues in the interactions of healthcare providers, children and their parents. *Journal of Pain Management* 2013;**6**(2):159-65.

Zeevenhooven 2020 *{published data only}*

Zeevenhooven J, Rexwinkel R, Van Berge Henegouwen VWA, Krishnan U, Vandenplas Y, Strisciuglio C, et al. A core outcome set for clinical trials in pediatric functional abdominal pain disorders. *Journal of Pediatrics* 2020;**221**:115-22. [DOI: 10.1016/j.jpeds.2020.02.032]

Zengin 2017 *{published data only}*

Zengin H, Fidanci BE, Kaymakamgil C, Konukbay D, Simsek D, Batu ED, et al. Evaluation of biopsychosocial aspects of patients with juvenile Behcet's disease: a qualitative study. *Pediatric Rheumatology* 2017;**15**(Suppl 1: 37):P26. [DOI: 10.1186/s12969-017-0141-9]

Additional references

Abbott 2017

Abbott RA, Martin AE, Newlove-Delgado TV, Bethel A, Thompson-Coon J, Whear R, et al. Psychosocial interventions for recurrent abdominal pain in childhood. *Cochrane Database of Systematic Reviews* 2017, Issue 1. Art. No: CD010971. [DOI: 10.1002/14651858.CD010971.pub2]

Alsaggaf 2020

Alsaggaf F, Coyne I. A systematic review of the impact of chronic pain on adolescents' school functioning and school personnel responses to managing pain in the schools. *Journal of Advanced Nursing* 2020;**76**(8):2005-22. [DOI: 10.1111/jan.14404]

Ames 2017

Ames HM. Mapping, exploring and understanding communication interventions for childhood vaccination [Doctoral dissertation]. Oslo (Norway): University of Oslo, 2017.

Ames 2019

Ames H, Glenton C, Lewin S. Purposive sampling in a qualitative evidence synthesis: a worked example from a synthesis on parental perceptions of vaccination communication. *BMC Medical Research Methodology* 2019;**19**(1):26. [DOI: 10.1186/s12874-019-0665-4]

Anie 2015

Anie KA, Green J. Psychological therapies for sickle cell disease and pain. *Cochrane Database of Systematic Reviews* 2015, Issue 5. Art. No: CD001916. [DOI: 10.1002/14651858.CD001916.pub3]

Barrington 2021

Barrington DJ, Robinson HJ, Wilson E, Hennegan J. Experiences of menstruation in high income countries: a systematic review, qualitative evidence synthesis and comparison to low- and middle-income countries. *PLOS One* 2021;**16**(7):e0255001. [DOI: 10.1371/journal.pone.0255001]

Benoot 2016

Benoot C, Hannes K, Bilsen J. The use of purposeful sampling in a qualitative evidence synthesis: a worked example on sexual adjustment to a cancer trajectory. *BMC Medical Research Methodology* 2016;**16**:21. [DOI: 10.1186/s12874-016-0114-6]

Booth 2013a

Booth A, Carroll C, Ilott I, Low LL, Cooper K. Desperately seeking dissonance: identifying the disconfirming case in qualitative evidence synthesis. *Qualitative Health Research* 2013;**23**(1):126-41. [DOI: 10.1177/1049732312466295]

Booth 2013b

Booth A, Harris J, Croot E, Springett J, Campbell F, Wilkins E. Towards a methodology for cluster searching to provide conceptual and contextual "richness" for systematic reviews of complex interventions: case study (CLUSTER). *BMC Medical Research Methodology* 2013;**13**:118. [DOI: 10.1186/1471-2288-13-118]

Briggs 2015

Briggs EV, Battelli D, Gordon D, Kopf A, Ribeiro S, Puig MM, et al. Current pain education within undergraduate medical studies across Europe: Advancing the Provision of Pain Education and Learning (APPEAL) study. *BMJ Open* 2015;**5**(8):e006984. [DOI: 10.1136/bmjopen-2014-006984]

Britten 2002

Britten N, Campbell R, Pope C, Donovan J, Morgan M, Pill R. Using meta ethnography to synthesise qualitative research: a worked example. *Journal of Health Services Research & Policy* 2002;**7**(4):209-15. [DOI: 10.1258/135581902320432732]

Bursch 1998

Bursch B, Walco GA, Zeltzer L. Clinical assessment and management of chronic pain and pain-associated disability syndrome. *Journal of Developmental Behavioral Pediatrics* 1998;**19**(1):45–53. [DOI: 10.1097/00004703-199802000-00008]

Campbell 2011

Campbell R, Pound P, Morgan M, Daker-White G, Britten N, Pill R, et al. Evaluating meta-ethnography: systematic analysis and synthesis of qualitative research. *Health Technology Assessment* 2011;**15**(43):1-164. [DOI: 10.3310/hta15430]

Campbell 2020

Campbell IH, Rudan I. Effective approaches to public engagement with global health topics. *Journal of Global Health* 2020;**10**(1):01040901. [DOI: 10.7189/jogh.10.010901]

Carter 2012

Carter BD, Threlkeld BM. Psychosocial perspectives in the treatment of pediatric chronic pain. *Pediatric Rheumatology Online Journal* 2012;**10**(1):15. [DOI: 10.1186/1546-0096-10-15]

Carter 2014

Carter B, Simons J. Stories of Children's Pain: Linking Evidence to Practice. London (UK): Sage Publications Ltd, 2014.

Cascella 2020

Cascella Carbó GF, García-Orellán R. Burden and gender inequalities around informal care [Sobrecarga e desigualdades de gênero nos cuidados informais]. *Investigación y educación en enfermería* 2020;**38**(1):e10. [DOI: 10.17533/udea.iee.v38n1e10]

CASP 2018

CASP UK. Critical appraisal skills programme (CASP): qualitative studies checklist. casp-uk.net/casp-tools-checklists/ (accessed 30 March 2021).

Chambers 2023

Chambers C. It doesn't have to hurt. itdoesnthavetohurt.ca/ (accessed 1 September 2023).

CHAMPION 2023

CHAMPION study team. The chronic pain rollercoaster. youtu.be/Oz5I7xKYf5o (accessed 1 September 2023).

Clark 1999

Clark D. 'Total pain', disciplinary power and the body in the work of Cicely Saunders, 1958-1967. *Social Science & Medicine* 1999;**49**(6):727-36. [DOI: 10.1016/s0277-9536(99)00098-2]

CMO 2009

Chief Medical Officer of Department of Health and Social Care (UK). Pain: breaking through the barrier. www.britishpainsociety.org/static/uploads/resources/files/members_articles_putting_pain_agenda.pdf (accessed 30 March 2021).

Cochrane PaPaS 2018

Cochrane Pain, Palliative and Supportive Care (PaPaS) Group. Addressing the gap in knowledge on chronic pain in childhood. www.cochrane.org/news/addressing-gap-knowledge-chronic-pain-childhood (accessed 30 March 2021).

Colvin 2018

Colvin CJ, Garside R, Wainwright M, Munthe-Kaas H, Glenton C, Bohren MA, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 4: how to assess coherence. *Implementation Science* 2018;**13**(Suppl 1):13. [DOI: 10.1186/s13012-017-0691-8]

Cooper 2017a

Cooper TE, Fisher E, Anderson B, Wilkinson NMR, Williams DG, Eccleston C. Paracetamol (acetaminophen) for chronic non-cancer pain in children and adolescents. *Cochrane Database of Systematic Reviews* 2017, Issue 8. Art. No: CD012539. [DOI: 10.1002/14651858.CD012539.pub2]

Cooper 2017b

Cooper TE, Fisher E, Gray AL, Krane E, Sethna N, van Tilburg MAL, et al. Opioids for chronic non-cancer pain in children and adolescents. *Cochrane Database of Systematic Reviews* 2017, Issue 7. Art. No: CD012538. [DOI: 10.1002/14651858.CD012538.pub2]

Cooper 2017c

Cooper TE, Heathcote LC, Clinch J, Gold JI, Howard R, Lord SM, et al. Antidepressants for chronic non-cancer pain in children and adolescents. *Cochrane Database of Systematic Reviews* 2017, Issue 8. Art. No: CD012535. [DOI: 10.1002/14651858.CD012535.pub2]

Cooper 2017d

Cooper TE, Wiffen PJ, Heathcote LC, Clinch J, Howard R, Krane E, et al. Antiepileptic drugs for chronic non-cancer pain in children and adolescents. *Cochrane Database of Systematic Reviews* 2017, Issue 8. Art. No: CD012536. [DOI: 10.1002/14651858.CD012536.pub2]

Covidence [Computer program]

Covidence. Version accessed 2 June 2022. Melbourne, Australia: Veritas Health Innovation. Available at covidence.org.

Cunningham 2017

Cunningham NR, Kashikar-Zuck S, Mara C, Goldschneider KR, Revicki DA, Dampier C, et al. Development and validation of the self-reported PROMIS pediatric pain behavior item bank and short form scale. *Pain* 2017;**158**(7):1323-31. [DOI: 10.1097/j.pain.0000000000000914]

Cunningham 2019

Cunningham M, France EF, Ring N, Uny I, Duncan EAS, Roberts RJ, et al. Developing a reporting guideline to improve meta-ethnography in health research: the eMERGe mixed-methods study. 7.4 edition. Southampton (UK): Health Services and Delivery Research, 2019.

de Bruijn 2021

de Bruijn CMA, Rexwinkel R, Gordon M, Benninga M, Tabbers MM. Antidepressants for functional abdominal pain disorders in children and adolescents. *Cochrane Database of Systematic Reviews* 2021, Issue 2. Art. No: CD008013. [DOI: 10.1002/14651858.CD008013.pub3]

Distelberg 2014

Distelberg B, Williams-Reade J, Tapanes D, Montgomery S, Pandit M. Evaluation of a family systems intervention for managing pediatric chronic illness: Mastering Each New Direction (MEND). *Family Process* 2014;**53**(2):194-213. [DOI: 10.1111/famp.12066]

Donnelly 2020

Donnelly TJ, Palermo TM, Newton-John TRO. Parent cognitive, behavioural, and affective factors and their relation to child pain and functioning in pediatric chronic pain: a systematic review and meta-analysis. *Pain* 2020;**161**(7):1401-19. [DOI: 10.1097/j.pain.0000000000001833]

Eccleston 2005

Eccleston C, Jordan A, McCracken LM, Sleed M, Connell H, Clinch J. The Bath Adolescent Pain Questionnaire (BAPQ): development and preliminary psychometric evaluation of an instrument to assess the impact of chronic pain on adolescents. *Pain* 2005;**118**(1-2):263-70. [DOI: 10.1016/j.pain.2005.08.025]

Eccleston 2008

Eccleston C, Wastell S, Crombez G, Jordan A. Adolescent social development and chronic pain. *European Journal of Pain* 2008;**12**(6):765-74. [DOI: 10.1016/j.ejpain.2007.11.002]

Eccleston 2017

Eccleston C, Cooper TE, Fisher E, Anderson B, Wilkinson NMR. Non-steroidal anti-inflammatory drugs (NSAIDs) for chronic non-cancer pain in children and adolescents. *Cochrane Database of Systematic Reviews* 2017, Issue 8. Art. No: CD012537. [DOI: 10.1002/14651858.CD012537.pub2]

Eccleston 2021

Eccleston C, Fisher E, Howard RF, Slater R, Forgeron P, Palermo TM, et al. Delivering transformative action in paediatric pain: a Lancet Child & Adolescent Health Commission. *Lancet Child Adolescent Health* 2021;**5**(1):47-87. [DOI: 10.1016/S2352-4642(20)30277-7]

Faculty 2015

Faculty of Pain Medicine of the Royal College of Anaesthetists. CSPMS core standards for pain management services. Available at fpm.ac.uk/standards-guidelines/core-standards (accessed 30 March 2021).

Fisher 2018

Fisher E, Law E, Dudeney J, Palermo TM, Stewart G, Eccleston C. Psychological therapies for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database of Systematic Reviews* 2018, Issue 9. Art. No: CD003968. [DOI: 10.1002/14651858.CD003968.pub5]

Fisher 2019

Fisher E, Law E, Dudeney J, Eccleston C, Palermo TM. Psychological therapies (remotely delivered) for the management of chronic and recurrent pain in children and adolescents. *Cochrane Database of Systematic Reviews* 2019, Issue 4. Art. No: CD011118. [DOI: 10.1002/14651858.CD011118.pub3]

Fisher 2022

Fisher E, Villanueva G, Henschke N, Nevitt SJ, Zempsky W, Probyn K, et al. Efficacy and safety of pharmacological, physical, and psychological interventions for the management of chronic pain in children: a WHO systematic review and meta-analysis. *Pain* 2022;**163**(1):e1-19. [DOI: 10.1097/j.pain.0000000000002297]

Forgeron 2006

Forgeron PA, Finley GA, Arnaout M. Pediatric pain prevalence and parents' attitudes at a cancer hospital in Jordan. *Journal of Pain and Symptom Management* 2006;**31**(5):440-8. [DOI: 10.1016/j.jpainsymman.2005.09.003]

Forgeron 2009

Forgeron PA, Jongudomkarn D, Evans J, Finley GA, Thienthong S, Siripul P, et al. Children's pain assessment in northeastern Thailand: perspectives of health professionals. *Qualitative Health Research* 2009;**19**(1):71-81. [DOI: 10.1177/1049732308327242]

France 2019a

France EF, Cunningham M, Ring N, Uny I, Duncan EAS, Jepson RG, et al. Improving reporting of meta-ethnography: the eMERGe reporting guidance. *Review of Education* 2019;**7**(2):430-51.

France 2019b

France EF, Cunningham M, Ring N, Uny I, Duncan EAS, Jepson RG, et al. Improving reporting of meta-ethnography: the eMERGe reporting guidance. *Psycho-oncology* 2019;**28**(3):447-58. [DOI: 10.1002/pon.4915]

France 2019c

France F, Cunningham M, Ring N, Uny I, Duncan EAS, Jepson RG, et al. Improving reporting of meta-ethnography: the eMERGe reporting guidance. *Journal of Advanced Nursing* 2019;**75**(5):1126-39. [DOI: 10.1111/jan.13809]

France 2019d

France EF, Cunningham M, Ring N, Uny I, Duncan EAS, Jepson RG, et al. Improving reporting of meta-ethnography: the eMERGe reporting guidance. *BMC Medical Research Methodology* 2019;**19**(1):1-13. [DOI: 10.1186/s12874-018-0600-0]

France 2019e

France EF, Uny I, Ring N, Turley RL, Maxwell M, Duncan EAS, et al. A methodological systematic review of meta-ethnography conduct to articulate the complex analytical phases. *BMC Medical Research Methodology* 2019;**19**(1):35. [DOI: 10.1186/s12874-019-0670-7]

Gauntlett-Gilbert 2007

Gauntlett-Gilbert J, Eccleston C. Disability in adolescents with chronic pain: patterns and predictors across different domains of functioning. *Pain* 2007;**131**(1-2):132-41. [DOI: 10.1016/j.pain.2006.12.021]

Ghoshal 2020

Ghoshal M, Shapiro H, Todd K, Schatman ME. Chronic noncancer pain management and systemic racism: time to move toward equal care standards. *Journal of Pain Research* 2020;**13**:2825-36. [DOI: 10.2147/JPR.S287314]

Glenton 2018

Glenton C, Carlsen B, Lewin S, Munthe-Kaas H, Colvin CJ, Tunçalp Ö, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings-paper 5: how to assess adequacy of data. *Implementation Science* 2018;**13**(Suppl 1):14. [DOI: 10.1186/s13012-017-0692-7]

Gobina 2019

Gobina I, Villberg J, Välimaa R, Tynjälä J, Whitehead R, Cosma A, et al. Prevalence of self-reported chronic pain among adolescents: evidence from 42 countries and regions. *European Journal of Pain* 2019;**23**(2):316-26. [DOI: 10.1002/ejp.1306]

Google Translate

Google. Google Translate. Available at translate.google.com (accessed 2 June 2022).

Groenewald 2014

Groenewald CB, Essner BS, Wright D, Fesinmeyer MD, Palermo TM. The economic costs of chronic pain among a cohort of treatment-seeking adolescents in the United States. *Journal of Pain* 2014;**15**(9):925-33. [DOI: 10.1016/j.jpain.2014.06.002]

Harden 2018

Harden A, Thomas J, Cargo M, Harris J, Pantoja T, Flemming K, et al. Cochrane qualitative and implementation methods group guidance series – paper 5: methods for integrating qualitative and implementation evidence within intervention effectiveness reviews. *Journal of Clinical Epidemiology* 2018;**97**:70-8. [DOI: 10.1016/j.jclinepi.2017.11.029]

Harris 2018

Harris JL, Booth A, Cargo M, Hannes K, Harden A, Flemming K, et al. Cochrane qualitative and implementation methods group guidance series – paper 2: methods for question formulation, searching, and protocol development for qualitative evidence synthesis. *Journal of Clinical Epidemiology* 2018;**97**:39-48. [DOI: 10.1016/j.jclinepi.2017.10.023]

Haslam 2021

Haslam SA, Haslam C, Jetten J, Cruwys T, Bentley SV. Rethinking the nature of the person at the heart of the biopsychosocial model: exploring social changeways not just personal pathways. *Social Science & Medicine* 2021;**272**:113566. [DOI: 10.1016/j.socscimed.2020.113566]

Heslop 2014

Heslop P, Blair PS, Fleming P, Hoghton M, Marriott A, Russ L. The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *Lancet* 2014;**383**(9920):889-95. [DOI: 10.1016/S0140-6736(13)62026-7]

Huguet 2008

Huguet A, Miró J. The severity of chronic pediatric pain: an epidemiological study. *Journal of Pain* 2008;**9**(3):226-36. [DOI: 10.1016/j.jpain.2007.10.015]

Hurley-Wallace 2019

Hurley-Wallace A, Wood C, Franck LS, Howard RF, Liossi C. Paediatric pain education for health care professionals. *Pain Reports* 2019;**4**(1):e701. [DOI: 10.1097/PR9.0000000000000701]

IASP 2018

International Association for the Study of Pain (IASP). 2019 Global year against pain in the most vulnerable. Available at www.iasp-pain.org/GlobalYear/MostVulnerable (accessed 30 March 2021).

Inusa 2021

Inusa BPD, Jacob E, Dogara L, Anie KA. Racial inequalities in access to care for young people living with pain due to sickle cell disease. *Lancet Child & Adolescent Health* 2021;**5**(1):7-9. [DOI: 10.1016/S2352-4642(20)30318-7]

INVOLVE 2012

Research National Institute for Health (NIHR) INVOLVE Group. INVOLVE strategy 2012 – 2015 putting people first in research; March 2012. Available at www.invo.org.uk/wp-content/uploads/2012/04/INVOLVEStrategy2012-15.pdf (accessed 1 September 2023).

iSoQ 2022 [Computer program]

GRADE-CERQual Interactive Summary of Qualitative Findings (iSoQ). Health Norwegian Institute of Public, Version (accessed 2022). Oslo (Norway): Norwegian Institute of Public Health (developed by the Epistemonikos Foundation, Megan Wainwright Consulting, and the Norwegian Institute of Public Health for the GRADE-CERQual Project Group), 2022. Available at isoq.epistemonikos.org.

Jongudomkarn 2006

Jongudomkarn D, Aungsupakorn N, Camfield L. The meanings of pain: a qualitative study of the perspectives of children living with pain in north-eastern Thailand. *Nursing & Health Sciences* 2006;**8**(3):156-63. [DOI: 10.1111/j.1442-2018.2006.00273.x]

Jordan 2007

Jordan AL, Eccleston C, Osborn M. Being a parent of the adolescent with complex chronic pain: an interpretative phenomenological analysis. *European Journal of Pain* 2007;**11**(1):49-56. [DOI: 10.1016/j.ejpain.2005.12.012]

Jordan 2016

Jordan A, Crabtree A, Eccleston C. 'You have to be a jack of all trades': fathers parenting their adolescent with chronic pain. *Journal of Health Psychology* 2016;**21**(11):2466-76. [DOI: 10.1177/1359105315580461]

Jordan 2017

Jordan A, Family H, Forgeron P. Interpersonal relationships in adolescent chronic pain: a qualitative synthesis. *Clinical Practice in Pediatric Psychology* 2017;**5**(4):303.

Keogh 2021

Keogh E. The gender context of pain. *Health Psychology Review* 2021;**15**(3):454-81. [DOI: 10.1080/17437199.2020.1813602]

Khanom 2020a

Khanom S, McDonagh JE, Briggs M, Bakir E, McBeth J. Adolescents' experiences of fluctuating pain in musculoskeletal disorders: a qualitative systematic review and thematic synthesis. *BMC Musculoskeletal Disorders* 2020;**21**(1):645. [DOI: 10.1186/s12891-020-03627-1]

King 2011

King S, Chambers CT, Huguet A, MacNevin RC, McGrath PJ, Parker L, et al. The epidemiology of chronic pain in children and adolescents revisited: a systematic review. *Pain* 2011;**152**(12):2729-38. [DOI: 10.1016/j.pain.2011.07.016]

Law 2019

Law E, Fisher E, Eccleston C, Palermo TM. Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database of Systematic*

Reviews 2019, Issue 3. Art. No: CD009660. [DOI: 10.1002/14651858.CD009660.pub4]

Lee 2021

Lee RR, McDonagh JE, Connelly M, Peters S, Cordingley L. Identifying the content and context of pain within paediatric rheumatology healthcare professional curricula in the UK: a summative content analysis. *Pediatric Rheumatology Online Journal* 2021;**19**(1):129. [DOI: 10.1186/s12969-021-00614-1]

Leite 2023

Leite MN, Kamper SJ, O'Connell NE, Michaleff ZA, Fisher E, Silva PV, et al. Physical activity and education about physical activity for chronic musculoskeletal pain in children and adolescents. *Cochrane Database of Systematic Reviews* 2023, Issue 7. Art. No: CD013527. [DOI: 10.1002/14651858.CD013527.pub2]

Lewandowski 2007

Lewandowski W, Morris R, Draucker CB, Risko J. Chronic pain and the family: theory-driven treatment approaches. *Issues in Mental Health Nursing* 2007;**28**(9):1019-44. [DOI: 10.1080/01612840701522200]

Lewandowski 2010

Lewandowski AS, Palermo TM, Stinson J, Handley S, Chambers CT. Systematic review of family functioning in families of children and adolescents with chronic pain. *Journal of Pain* 2010;**11**(11):1027-38. [DOI: 10.1016/j.jpain.2010.04.005]

Lewin 2018

Lewin S, Booth A, Glenton C, Munthe-Kaas H, Rashidian A, Wainwright M, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings: introduction to the series. *Implementation Science* 2018;**13**(Suppl 1):2. [DOI: 10.1186/s13012-017-0688-3]

Liossi 2016

Liossi C, Howard RF. Pediatric chronic pain: biopsychosocial assessment and formulation. *Pediatrics* 2016;**138**(5):e20160331. [DOI: 10.1542/peds.2016-0331]

Logan 2008

Logan DE, Simons LE, Stein MJ, Chastain L. School impairment in adolescents with chronic pain. *Journal of Pain* 2008;**9**(5):407-16. [DOI: 10.1016/j.jpain.2007.12.003]

Maciver 2010

Maciver D, Jones D, Nicol M. Parents' experiences of caring for a child with chronic pain. *Qualitative Health Research* 2010;**20**(9):1272-82. [DOI: 10.1177/1049732310367499]

Mackintosh-Franklin 2017

Mackintosh-Franklin C. Pain: a content review of undergraduate pre-registration nurse education in the United Kingdom. *Nurse Education Today* 2017;**48**:84-9. [DOI: 10.1016/j.nedt.2016.08.035]

Martin 2017

Martin AE, Newlove-Delgado TV, Abbott RA, Bethel A, Thompson-Coon J, Whear R, et al. Pharmacological interventions for recurrent abdominal pain in childhood. *Cochrane Database of Systematic Reviews* 2017, Issue 3. Art. No: CD010973. [DOI: 10.1002/14651858.CD010973.pub2]

McCarthy 2004

McCarthy P, Chammas G, Wilimas J, Alaoui FM, Harif M. Managing children's cancer pain in Morocco. *Journal of Nursing Scholarship* 2004;**36**(1):11-5. [DOI: 10.1111/j.1547-5069.2004.04005.x]

Mehta 2008

Mehta A, Chan LS. Understanding of the concept of total pain: a prerequisite for pain control. *Journal of Hospice & Palliative Nursing* 2008;**10**(1):26-34.

Merlijn 2006

Merlijn VPBM, Hunfeld JAM, van der Wouden JC, Hazebroek-Kampschreur AAJM, Passchier J, Koes BW. Factors related to the quality of life in adolescents with chronic pain. *Clinical Journal of Pain* 2006;**22**(3):306-15. [DOI: 10.1097/01.ajp.0000177509.93523.68]

Microsoft Corporation 2018a [Computer program]

Microsoft Excel. Version Microsoft 365. Redmond (WA): Microsoft Corporation, 2018. Available at office.microsoft.com/excel.

Microsoft Corporation 2018b [Computer program]

Microsoft Word. Version Microsoft 365. Redmond (WA): Microsoft Corporation, 2018. Available at office.microsoft.com/excel.

Microsoft Corporation 2018c [Computer program]

Microsoft Teams. Version Microsoft 365. Redmond (WA): Microsoft Corporation, 2018. Available at office.microsoft.com.

Min 2022

Min M, Hancock DG, Aromataris E, Crotti T, Boros C. Experiences of living with juvenile idiopathic arthritis: a qualitative systematic review. *JBI Evidence Synthesis* 2022;**20**(1):60-120. [DOI: 10.11124/JBIES-21-00139]

Moher 2009

Moher D, Liberati A, Tetzlaff J, Altman DG, PRISMA Group. Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *PLOS Medicine* 2009;**6**(7):e1000097. [DOI: 10.1371/journal.pmed.1000097]

Munabi-Babigumira 2017

Munabi-Babigumira S, Glenton C, Lewin S, Fretheim A, Nabudere H. Factors that influence the provision of intrapartum and postnatal care by skilled birth attendants in low-and middle-income countries: a qualitative evidence synthesis. *Cochrane Database of Systematic Reviews* 2017, Issue 11. Art. No: CD011558. [DOI: 10.1002/14651858.CD011558.pub2]

Munkombwe 2020

Munkombwe WM, Petersson K, Elgán C. Nurses' experiences of providing nonpharmacological pain management in palliative care: a qualitative study. *Journal of Clinical Nursing* 2020;**29**(9-10):1643-52. [DOI: 10.1111/jocn.15232]

Munthe-Kaas 2018

Munthe-Kaas H, Bohren MA, Glenton C, Lewin S, Noyes J, Tunçalp Ö, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings – paper 3: how to assess methodological limitations. *Implementation Science* 2018;**13**(Suppl 1):9. [DOI: 10.1186/s13012-017-0690-9]

Munthe-Kaas 2020

Munthe-Kaas H, Nøkleby H, Lewin S, Glenton C. The TRANSFER approach for assessing the transferability of systematic review findings. *BMC Medical Research Methodology* 2020;**20**(1):11. [DOI: 10.1186/s12874-019-0834-5]

Neville 2019

Neville A, Jordan A, Beveridge J, Pincus T, Noel M. Diagnostic uncertainty in youth with chronic pain and their parents. *Journal of Pain* 2019;**20**(9):1080-90. [DOI: 10.1016/j.jpain.2019.03.004]

Neville 2021

Neville A, Noel M, Clinch J, Pincus T, Jordan A. 'Drawing a line in the sand': physician diagnostic uncertainty in paediatric chronic pain. *European Journal of Pain* 2021;**25**(2):430-41. [DOI: 10.1002/ejp.1682]

Newlove-Delgado 2017

Newlove-Delgado TV, Martin AE, Abbott RA, Bethel A, Thompson-Coon J, Whear R, et al. Dietary interventions for recurrent abdominal pain in childhood. *Cochrane Database of Systematic Reviews* 2017, Issue 3. Art. No: CD010972. [DOI: 10.1002/14651858.CD010972.pub2]

Ngwenya 2019

Ngwenya N, Ambler J, Archary M. Qualitative situational analysis of palliative care for adolescents with cancer and HIV in South Africa: healthcare worker perceptions. *BMJ Open* 2019;**9**(1):e023225. [DOI: 10.1136/bmjopen-2018-023225]

NICE 2012

National Institute for Health and Care Excellence (NICE). Sickle cell acute painful episode: management of an acute painful sickle cell episode in hospital; June 2012. Available at www.nice.org.uk/guidance/cg143/evidence/full-guideline-pdf-186634333 (accessed 1 September 2023).

NICE 2018

National Institute for Health and Care Excellence. Guideline scope: chronic pain: assessment and management; January 2018. Available at www.nice.org.uk/guidance/ng193/documents/final-scope (accessed 30 March 2021).

Nilsson 2016

Nilsson S, Johnson E, Adolfsson M. Professionals' perceptions about the need for pain management interventions for children with cerebral palsy in South African school settings. *Pain Management Nursing* 2016;**17**(4):249-61. [DOI: 10.1016/j.pmn.2016.03.002]

Noblit 1988

Noblit GW, Hare RD. Meta-Ethnography: Synthesizing Qualitative Studies. 11th edition. Thousand Oaks (CA): Sage Publications, 1988.

Noyes 2016a

Noyes J, Hendry M, Booth A, Chandler J, Lewin S, Glenton C, et al. Current use was established and Cochrane guidance on selection of social theories for systematic reviews of complex interventions was developed. *Journal of Clinical Epidemiology* 2016;**75**:78-92. [DOI: 10.1016/j.jclinepi.2015.12.009]

Noyes 2016b

Noyes J, Hendry M, Lewin S, Glenton C, Chandler J, Rashidian A. Qualitative "trial-sibling" studies and "unrelated" qualitative studies contributed to complex intervention reviews. *Journal of Clinical Epidemiology* 2016;**74**:133-43. [DOI: 10.1016/j.jclinepi.2016.01.009]

Noyes 2018a

Noyes J, Booth A, Cargo M, Flemming K, Garside R, Hannes K, et al. Cochrane qualitative and implementation methods group guidance series – paper 1: introduction. *Journal of Clinical Epidemiology* 2018;**97**:35-8. [DOI: 10.1016/j.jclinepi.2017.09.025]

Noyes 2018b

Noyes J, Booth A, Flemming K, Garside R, Harden A, Lewin S, et al. Cochrane qualitative and implementation methods group guidance series – paper 3: methods for assessing methodological limitations, data extraction and synthesis, and confidence in synthesized qualitative findings. *Journal of Clinical Epidemiology* 2018;**97**:49-58. [DOI: 10.1016/j.jclinepi.2017.06.020]

Noyes 2018c

Noyes J, Booth A, Lewin S, Carlsen B, Glenton C, Colvin CJ, et al. Applying GRADE-CERQual to qualitative evidence synthesis findings – paper 6: how to assess relevance of the data. *Implementation Science* 2018;**13**(Suppl 1):4. [DOI: 10.1186/s13012-017-0693-6]

Noyes 2019

Noyes J, Booth A, Moore G, Flemming K, Tunçalp Ö, Shakibazadeh E. Synthesising quantitative and qualitative evidence to inform guidelines on complex interventions: clarifying the purposes, designs and outlining some methods. *BMJ Global Health* 2019;**4**(Suppl 1):e000893. [DOI: 10.1136/bmjgh-2018-000893]

Noyes 2022

Noyes J, Booth A, Cargo M, Flemming K, Harden A, Garside R, et al. Chapter 21: Qualitative evidence. In: Higgins JPT, Thomas J, Chandler J, Cumpston M, Li T, Page MJ, Welch VA, editors. Cochrane Handbook for Systematic Reviews of Interventions Version 6.3 (updated February 2022). Cochrane, 2022. Available from training.cochrane.org/handbook.

NSH Scotland 2014

NSH Healthcare Improvement Scotland. Chronic pain services in Scotland: where are we now? Pain services for children; April 2014. Available at www.healthcareimprovementscotland.org/

our_work/long_term_conditions/chronic_pain/where_are_we_now.aspx (accessed 1 September 2023).

O'Neill 2014

O'Neill J, Tabish H, Welch V, Petticrew M, Pottie K, Clarke M, et al. Applying an equity lens to interventions: using PROGRESS ensures consideration of socially stratifying factors to illuminate inequities in health. *Journal of Clinical Epidemiology* 2014;**67**(1):56-64. [DOI: 10.1016/j.jclinepi.2013.08.005]

Padlet 2022 [Computer program]

Padlet: a real-time collaborative web platform used to share and organise content. Padlet. Padlet, 2022. Available at padlet.com.

Pain Summit 2012

Pain Summit. Putting pain on the agenda: the report of the first English pain summit. Available at www.britishpainsociety.org/static/uploads/resources/files/members_articles_putting_pain_agenda.pdf (accessed 30 March 2021).

Palermo 2005

Palermo TM, Chambers CT. Parent and family factors in pediatric chronic pain and disability: an integrative approach. *Pain* 2005;**119**(1-3):1-4. [EMBASE: 10.1016/j.pain.2005.10.027]

Palermo 2012

Palermo TM. Cognitive-Behavioral Therapy for Chronic Pain in Children and Adolescents. Oxford (UK): Oxford University Press, 2012.

Palermo 2014

Palermo TM, Valrie CR, Karlson CW. Family and parent influences on pediatric chronic pain: a developmental perspective. *American Psychologist* 2014;**69**(2):142-52. [DOI: 10.1037/a0035216]

Palermo 2019

Palermo TM, Slack M, Zhou C, Aaron R, Fisher E, Rodriguez S. Waiting for a pediatric chronic pain clinic evaluation: a prospective study characterizing waiting times and symptom trajectories. *Journal of Pain* 2019;**20**(3):339-47. [DOI: 10.1016/j.jpain.2018.09.009]

Palermo 2021

Palermo TM, Walco GA, Paladhi UR, Birnie KA, Crombez G, de la Vega R, et al. Core outcome set for pediatric chronic pain clinical trials: results from a Delphi poll and consensus meeting. *Pain* 2021;**162**(10):2539-47. [DOI: 10.1097/j.pain.0000000000002241]

Park 2020

Park S, Khan N, Stevenson F, Malpass A. Patient and public involvement (PPI) in evidence synthesis: how the PatMed study approached embedding audience responses into the expression of a meta-ethnography. *BMC Medical Research Methodology* 2020;**20**(1):29. [DOI: 10.1186/s12874-020-0918-2]

Perquin 2000

Perquin CW, Hazebroek-Kampschreur AAJM, Hunfeld JAM, Bohnen AM, van Suijlekom-Smit LWA, Passchier J, et al. Pain in children and adolescents: a common experience. *Pain* 2000;**87**(1):51-8. [DOI: 10.1016/S0304-3959(00)00269-4]

Pollock 2018

Pollock A, Campbell P, Struthers C, Synnot A, Nunn J, Hill S, et al. Stakeholder involvement in systematic reviews: a scoping review. *Systematic Reviews* 2018;**7**(1):208. [DOI: 10.1186/s13643-018-0852-0]

Pollock 2019

Pollock A, Campbell P, Struthers C, Synnot A, Nunn J, Hill S, et al. Development of the ACTIVE framework to describe stakeholder involvement in systematic reviews. *Journal of Health Services Research & Policy* 2019;**24**(4):245-55. [DOI: 10.1177/1355819619841647]

Popay 1998

Popay J, Rogers A, Williams G. Rationale and standards for the systematic review of qualitative literature in health services research. *Qualitative Health Research* 1998;**8**(3):341-51. [DOI: 10.1177/104973239800800305]

Pope 2006

Pope C, Mays N. Synthesising qualitative research. In: Pope C, Mays N, editors(s). Qualitative Research in Health Care. 3rd edition. Oxford, UK: Blackwell Publishing; BMJ Books, 2006:142-52.

QSR International 2018 [Computer program]

NVivo. Version 12. QSR International Pty Ltd, 2018. Available at www.qsrinternational.com/nvivo-qualitative-data-analysis-software/home.

Rodrigues 2018

Rodrigues NP, Cohen LL, Swartout KM, Trotochaud K, Murray E. Burnout in nurses working with youth with chronic pain: a mixed-methods analysis. *Journal of Pediatric Psychology* 2018;**43**(4):369-81. [DOI: 10.1093/jpepsy/jsx105]

Roth-Isigkeit 2005

Roth-Isigkeit A, Thyen U, Stöven H, Schwarzenberger J, Schmucker P. Pain among children and adolescents: restrictions in daily living and triggering factors. *Pediatrics* 2005;**115**(2):e152-62. [DOI: 10.1542/peds.2004-0682]

Schutz 1962

Schutz A. The Problem of Social Reality: Collected Papers . Leiden (The Netherlands): Martinus Nijhoff, The Hague, 1962.

Scottish Govt 2018

Scottish Government. Management of chronic pain in children and young people: summary. Available at www.gov.scot/publications/management-chronic-pain-children-young-people/ (accessed 30 March 2021).

Silva 2011

Silva MS, Pinto MA, Gomes LM, Barbosa TL. Pain in hospitalized children: nursing team perception [Dor na criança internada: a percepção da equipe de enfermagem]. *Revista Dor* 2011;**12**(4):314-20.

Simons 2015

Simons LE, Smith A, Ibagon C, Coakley R, Logan DE, Schechter N, et al. Pediatric pain screening tool: rapid identification of risk in youth with pain complaints. *Pain* 2015;**156**(8):1511-8. [DOI: 10.1097/j.pain.0000000000000199]

SKIP 2020

Solutions for Kids in Pain (SKIP). Solutions for Kids in Pain (SKIP). https://kidsinpain.ca/ (accessed 1 September 2023).

Skivington 2021

Skivington K, Matthews L, Simpson S A, Craig P, Baird J, Blazeby J M et al. A new framework for developing and evaluating complex interventions: update of Medical Research Council guidance. *BMJ* 2021;**374**:n2061. [DOI: 10.1136/bmj.n2061]

Sleed 2005

Sleed M, Eccleston C, Beecham J, Knapp M, Jordan A. The economic impact of chronic pain in adolescence: methodological considerations and a preliminary costs-of-illness study. *Pain* 2005;**119**(1-3):183-90. [DOI: 10.1016/j.pain.2005.09.028]

Tong 2012

Tong A, Jones J, Craig JC, Singh-Grewal D. Children's experiences of living with juvenile idiopathic arthritis: a thematic synthesis of qualitative studies. *Arthritis Care & Research* 2012;**64**(9):1392-404. [DOI: 10.1002/acr.21695]

Treede 2019

Treede RD, Rief W, Barke A, Aziz Q, Bennett MI, Benoliel R, et al. Chronic pain as a symptom or a disease: the IASP classification of chronic pain for the International Classification of Diseases (ICD-11). *Pain* 2019;**160**(1):19-27. [DOI: 10.1097/j.pain.0000000000001384]

UK 2019

UK Public Involvement Standards Development Partnership Group. UK standards for public involvement. Available at sites.google.com/nihr.ac.uk/pi-standards/standards (accessed 30 March 2021).

Walker 2010

Walker LS, Dengler-Crish CM, Rippel S, Bruehl S. Functional abdominal pain in childhood and adolescence increases risk for chronic pain in adulthood. *Pain* 2010;**150**(3):568-72. [DOI: 10.1016/j.pain.2010.06.018]

WHO 2019

World Health Organization (WHO). International Classification of Diseases, Eleventh Revision (ICD-11). Geneva (Switzerland): WHO, 2019.

WHO 2020a

World Health Organization (WHO). Guidelines on the management of chronic pain in children. Available at apps.who.int/iris/bitstream/handle/10665/337999/9789240017870-eng.pdf (accessed 30 March 2021).

WHO 2020b

World Health Organization (WHO). Guidelines on the management of chronic pain in children: web annexes A to K. Available at www.who.int/publications/i/item/9789240017894 (accessed 30 March 2021).

WHO 2020c

World Health Organization (WHO). WHO definition of palliative care. Available at www.who.int/cancer/palliative/definition/en/ (accessed 30 March 2021).

Workspace 2022 [Computer program]

Jamboard: a digital interactive whiteboard. Google Workspace. Google LLC, 2022. Available at edu.google.com/intl/ALL_us/jamboard/.

World Bank 2023

The World Bank. World Bank country and lending groups: country classification. Available at datahelpdesk.worldbank.org/knowledgebase/articles/906519-world-bank-country-and-lending-groups; 2023 (accessed 8 September 2023).

References to other published versions of this review

France 2019

France EF, Forbat L, Uny I, Caes L, Noyes J, Turley R, et al. A meta-ethnography of how children and young people with chronic non-cancer pain and their families experience and understand their condition, pain services and treatments; 2019. Available at www.crd.york.ac.uk/prospero/display_record.php?ID=CRD42019161455 (accessed 7 June 2022).

France 2020

France EF, Turley R, Uny I, Forbat L, Caes L, Jordan A, et al. Award ID NIHR128671: a meta-ethnography of how children and young people with chronic non-cancer pain and their families experience and understand their condition, pain services and treatments. Available at fundingawards.nihr.ac.uk/award/NIHR128671 (accessed 7 June 2022).

* Indicates the major publication for the study

CHARACTERISTICS OF STUDIES

Characteristics of included studies *[ordered by study ID]*

Ahlqwist 2012

Study characteristics

Ahlqwist 2012 *(Continued)*

Funding Source	Swedish Association of Registered Physiotherapists and Renee Eanders Foundation
Country	Sweden
Recruitment setting	Unclear
Aim	Generate a substantive theory, based on interviews with adolescents with low back pain, explaining how they succeed in managing their main concerns in daily life
Participant details	n = 14, 8 female participants, 6 male participants, 12 to 18 years
Chronic pain condition	Musculoskeletal pain
Data collection	Interview
Data analysis	Grounded theory
Notes	Sampling status: sampled for inclusion in the analysis

Ahola 2018

Study characteristics	
Funding Source	Canadian Institutes of Health Research Catalyst Grant, Pain in Child Health, Early Research Award
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the topics of discussion during open-ended peer mentoring sessions between adolescents and mentors living with chronic illness
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Ajinkpang 2022

Study characteristics	
Funding Source	Not reported
Country	Ghana

Ajinkpang 2022 *(Continued)*

Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the knowledge of caregivers
Participant details	2 to 14 years No further information extracted from unsampled studies
Chronic pain condition	Sickle cell disease
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Ali 2017

Study characteristics	
Funding Source	National Center for Complementary and Integrative Health and National Center for Advancing Translational Sciences
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Assess the feasibility of a mindfulness-based stress reduction programme
Participant details	10 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Allgood 2018

Study characteristics	
Funding Source	Unfunded
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore participant-reported descriptions of the pain experience among adolescents and adults living with cystic fibrosis
Participant details	10 to 19 years

Allgood 2018 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	Cystic fibrosis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Asmussen 1999

Study characteristics	
Funding Source	SmithKline Beecham, Henry J. Kaiser Family Foundation, American Academy of Pediatrics Friends of Children Fund
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Investigated how otitis media impacts the day-to-day lives and experiences of children and their families
Participant details	Infant to 9 years No further information extracted from unsampled studies
Chronic pain condition	Otitis media
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Atkin 2000

Study characteristics	
Funding Source	NHS Executive
Country	UK
Recruitment setting	Health professional records
Aim	Examines how parents cope with their caring responsibilities
Participant details	n = 25; 25 parents of child with sickle cell disease from 17 families
Chronic pain condition	Sickle cell disease and thalassaemia

Atkin 2000 *(Continued)*

Data collection	Interview
Data analysis	Not reported
Notes	Sampling status: sampled for inclusion in the analysis

Atkin 2001

Study characteristics	
Funding Source	National Lottery
Country	UK
Recruitment setting	Health professional records
Aim	Provide a detailed understanding of young people's experience of living with these conditions
Participant details	n = 26, 14 female participants, 12 male participants, average age = 14.2 years
Chronic pain condition	Sickle cell disease
Data collection	Interview
Data analysis	Case comparative
Notes	Sampling status: sampled for inclusion in the analysis

Atoui 2015

Study characteristics	
Funding Source	Not reported
Country	Lebanon
Recruitment setting	Paediatric clinics
Aim	Explore adolescents' lived experience and daily life with sickle cell disease in Lebanon
Participant details	n = 12, 12 to 17 years
Chronic pain condition	Sickle cell disease
Data collection	Interview
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Baert 2020

Study characteristics	
Funding Source	International Association for the Study of Pain Grant
Country	USA, UK and Belgium
Recruitment setting	Paediatric hospitals
Aim	Explore parents' views of the meaning of injustice
Participant details	n = 21 mothers of 14 female participants and 7 male participants aged 9 to 20 years
Chronic pain condition	Mixed conditions
Data collection	Interview
Data analysis	IPA
Notes	Sampling status: sampled for inclusion in the analysis

Bagge-Petersen 2020

Study characteristics	
Funding Source	Center of Telemedicine, Copenhagen Center for Health Technology (CACHET)
Country	Denmark
Recruitment setting	Information not extracted from unsampled studies
Aim	Explores ethnographically the self-care practices of children affected by haemophilia or JIA in Denmark
Participant details	7 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Barlow 1998

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Information not extracted from unsampled studies

Barlow 1998 *(Continued)*

Aim	Gain greater insight and understanding into the experience of parents in terms of the stressors encountered and the resultant impact on parental well-being
Participant details	8 to 15 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Barlow 1999

Study characteristics	
Funding Source	National Health Service Executive
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Gain insight and understanding of the needs and preferences of children with juvenile chronic arthritis and their parents
Participant details	8 to 15 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Beneitez 2020

Study characteristics	
Funding Source	Open University of Catalonia PhD Doctoral Fellowship
Country	Spain
Recruitment setting	Information not extracted from unsampled studies
Aim	Gain knowledge about adolescents' social needs living with JIA, particularly focused on their friendships
Participant details	11 to 18 years

Beneitez 2020 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Beyer 2004

Study characteristics	
Funding Source	National Institute of Nursing Research
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Examine caregivers' views of the effectiveness of home comfort for children with vaso-occlusive episodes
Participant details	5 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Sickle cell disease
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Borghi 2014

Study characteristics	
Funding Source	Not reported
Country	Brazil
Recruitment setting	Paediatric hospital
Aim	Understanding the experience of children and adolescents under palliative care when managing pain daily
Participant details	n = 6, 4 female participants, 2 male participants, 6 to 17 years
Chronic pain condition	Mixed conditions
Data collection	Interview

Borghi 2014 *(Continued)*

Data analysis	Thematic oral history
Notes	Sampling status: sampled for inclusion in the analysis

Bradshaw 2016

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Evaluate the effectiveness of the service in reducing the impact of pain in the lives of the young participants
Participant details	10 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Unspecified
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Brandelli 2021

Study characteristics	
Funding Source	IWK Health Centre, Arthritis Society, Maritime SPOR Support Unit, Nova Scotia Graduate Scholarship, Nova Scotia Health Research Foundation, Dalhousie Medical Research Foundation, Canada Foundation for Innovation, Canadian Institutes of Health Research
Country	Canada
Recruitment setting	Recruited from a larger study
Aim	Explore the lived experiences of parents with self-identified challenges with their child’s pharmacologic and nonpharmacologic juvenile idiopathic arthritis treatments
Participant details	n = 10, 10 mothers
Chronic pain condition	JIA
Data collection	Interview
Data analysis	IPA
Notes	Sampling status: sampled for inclusion in the analysis

Brekke 2020

Study characteristics	
Funding Source	Norwegian Committee on Research in General Practice
Country	Norway
Recruitment setting	Information not extracted from unsampled studies
Aim	Investigate the course of the child's abdominal pain, what may have helped, how the family's situation had been influenced and whether they had any unmet needs
Participant details	8 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Abdominal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Britton 2002

Study characteristics	
Funding Source	Arthritis Research Campaign
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Investigate families' experiences and perspectives of what it is like to live with and care for a child with JIA
Participant details	7 to 8 years or 11 to 13 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Britton 2002a

Study characteristics

Britton 2002a *(Continued)*

Funding Source	Arthritis Research Campaign
Country	UK
Recruitment setting	Juvenile arthritis clinic
Aim	To investigate the experiences of families who currently live with a child with juvenile idiopathic arthritis
Participant details	n = 27, 9 children, 14 parents, 4 siblings, children 7 to 8 years or 11 to 13 years
Chronic pain condition	Arthritis
Data collection	Questionnaire, diary and interview
Data analysis	Ethnographic processes
Notes	Sampling status: sampled for inclusion in the analysis

Britton 2002b

Study characteristics	
Funding Source	Arthritis Research Campaign
Country	UK
Recruitment setting	Juvenile arthritis clinic
Aim	Explore and describe the experiences of families of children with JIA
Participant details	7 to 8 years or 11 to 13 years, n = 27, 9 children, 14 parents, 4 siblings
Chronic pain condition	Arthritis
Data collection	Interview and video diaries
Data analysis	Grounded theory
Notes	Sampling status: sampled for inclusion in the analysis

Brodwall 2018

Study characteristics	
Funding Source	Norwegian Committee on Research in General Practice
Country	Norway
Recruitment setting	Hospital

Brodwall 2018 *(Continued)*

Aim	Explore the experiences of parents of children with chronic abdominal pain discharged from hospital without a somatic explanation
Participant details	n = 14, parents, children aged 5 to 15 years
Chronic pain condition	Abdominal pain
Data collection	Interview
Data analysis	Content analysis
Notes	Sampling status: sampled for inclusion in the analysis

Bruce 2022

Study characteristics	
Funding Source	Stollery Children's Hospital Foundation, Women and Children's Health Research Institute
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Understand the changes in quality of life for adolescent patients with sickle cell disease a year after transplant
Participant details	13 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Sickle cell disease
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Burbage 2015

Study characteristics	
Funding Source	Not reported
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Educate and provide support for families with a child who has JIA as well as assess parent perceptions
Participant details	7 to 18 years No further information extracted from unsampled studies

Burbage 2015 *(Continued)*

Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Carter 2002

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Paediatric hospital
Aim	Explore the way in which the experience of chronic pain impacts the lives of young people
Participant details	n = 5, 13 to 19 years
Chronic pain condition	Mixed conditions
Data collection	Focus groups
Data analysis	Theoretical coding technique
Notes	Sampling status: sampled for inclusion in the analysis

Carter 2002a

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Paediatric hospital
Aim	Explore the ways in which parents of children with profound special needs assess and manage their children’s pain
Participant details	n = 15, 15 parents/carers (12 families)
Chronic pain condition	Neurological conditions
Data collection	Interview
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Carter 2002b

Study characteristics	
Funding Source	Nestlé Charitable Scholarship
Country	UK
Recruitment setting	Unclear
Aim	Explore, from the children's and families' perspectives, the impact of living with chronic pain
Participant details	n = 11, 3 children, 7 parents, 1 sibling, children aged 12 to 13 years
Chronic pain condition	Mixed conditions
Data collection	Interview and journal
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Carter 2017

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Paediatric hospital
Aim	Explore the frequency, regularity and intensity of parent-reported pain episodes experienced by children with profound cognitive impairments and their parents' knowledge and skills in assessing their child's pain
Participant details	n = 8, 8 mothers, children aged 2 to 16 years
Chronic pain condition	Neurological conditions
Data collection	Interview and survey
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Cartwright 2015

Study characteristics	
Funding Source	Not reported

Cartwright 2015 *(Continued)*

Country	UK
Recruitment setting	Adolescent arthritis clinic
Aim	Explore adolescents' experiences of living with JIA, with particular focus on the process of adjustment
Participant details	n = 10, 7 female participants, 3 male participants, 13 to 17 years
Chronic pain condition	Arthritis
Data collection	Interview
Data analysis	IPA
Notes	Sampling status: sampled for inclusion in the analysis

Castle 2007

Study characteristics	
Funding Source	Not reported
Country	Australia
Recruitment setting	Paediatric hospital
Aim	Explore the experience and impact of chronic pain on the lives of adolescents and young adults with cerebral palsy
Participant details	n = 6, 2 female participants, 4 male participants, 14 to 24 years
Chronic pain condition	Cerebral palsy
Data collection	Interview
Data analysis	Phenomenology
Notes	Sampling status: sampled for inclusion in the analysis

Conboy 2008

Study characteristics	
Funding Source	Not reported
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Understand the experiences of adolescents involved in acupuncture treatment
Participant details	13 to 22 years

Conboy 2008 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	Endometriosis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Constantinou 2021

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the health-related quality of life and health behaviours of children with sickle cell disease and healthy siblings
Participant details	5 to 12 years No further information extracted from unsampled studies
Chronic pain condition	Sickle cell disease
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Corey 2021

Study characteristics	
Funding Source	American Pain Society/Sharon S. Keller Chronic Pain Research Grant, Deborah Munroe Noonan Memorial Research Fund
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	To characterise parent experiences during a multidisciplinary exposure-based treatment for children with chronic pain who express high fear of pain and pain-related disability
Participant details	8 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions

Corey 2021 *(Continued)*

Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Cotton 2012

Study characteristics	
Funding Source	National Institute of Child Health and Human Development
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Examine use of religious coping in children with sickle cell disease
Participant details	5 to 12 years No further information extracted from unsampled studies
Chronic pain condition	Sickle cell disease
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Cox 2022

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore how parental dyads experience and demonstrate resilience in response to parenting an adolescent with complex regional pain syndrome
Participant details	11 to 25 years No further information extracted from unsampled studies
Chronic pain condition	Complex regional pain syndrome
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Cunningham 2018

Study characteristics	
Funding Source	National Institutes of Health grants
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Evaluate the feasibility and acceptability of the Aim to Decrease Anxiety and Pain Treatment (ADAPT)
Participant details	10 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Abdominal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Cunningham 2019

Study characteristics	
Funding Source	National Institutes of Arthritis and Musculoskeletal and Skin Diseases, Cincinnati Children’s Research Foundation Academic Research Centers award
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Develop and refine the Treatment and Education Approach for Childhood-onset Lupus (TEACH) protocol
Participant details	10 to 19 years No further information extracted from unsampled studies
Chronic pain condition	CSLE
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Curtis 2019

Study characteristics

Curtis 2019 *(Continued)*

Funding Source	Charité
Country	Germany
Recruitment setting	Information not extracted from unsampled studies
Aim	Develop a theory-and-evidence-based medication adherence app to support children and adolescents with SCD
Participant details	10 to 19 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

de Monte 2009

Study characteristics	
Funding Source	Not reported
Country	Australia
Recruitment setting	Information not extracted from unsampled studies
Aim	Understand the children’s perspective of living with JIA
Participant details	8 to 16 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

de Moura 2021

Study characteristics	
Funding Source	Not reported
Country	Brazil

de Moura 2021 *(Continued)*

Recruitment setting	Information not extracted from unsampled studies
Aim	Analyse the perceptions of children and adolescents about chronic postsurgical pain
Participant details	8 to 15 years No further information extracted from unsampled studies
Chronic pain condition	Inguinal herniorrhaphy
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Dell'Api 2007

Study characteristics	
Funding Source	Not reported
Country	Canada
Recruitment setting	Paediatric hospital
Aim	Develop an understanding of the way in which children with chronic pain experienced, assigned meaning and described their interactions with healthcare professionals
Participant details	n = 5, 10 to 17 years
Chronic pain condition	Mixed conditions
Data collection	Interview
Data analysis	Interpretive description
Notes	Sampling status: sampled for inclusion in the analysis

Dogan 2022

Study characteristics	
Funding Source	German Innovation Fund of The Federal Joint Committee
Country	Germany
Recruitment setting	Information not extracted from unsampled studies
Aim	Gain further insight into the mechanisms and prerequisites for the effectiveness of this specialised aftercare programme
Participant details	9 to 16 years

Dogan 2022 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Donovan 2013

Study characteristics	
Funding Source	Eunice Kennedy Shriver National Institute of Child Health and Human Development
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Understand the impact of migraines on adolescents' social functioning from multiple informants
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Headache
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Donovan 2019

Study characteristics	
Funding Source	National Institute of Diabetes and Digestive and Kidney Diseases
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Describe the experiences of adolescents with IBS
Participant details	13 to 17 years No further information extracted from unsampled studies
Chronic pain condition	IBS
Data collection	Information not extracted from unsampled studies

Donovan 2019 *(Continued)*

Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

dos Santos 2022

Study characteristics	
Funding Source	National Council for Scientific and Technological Development
Country	Brazil
Recruitment setting	Information not extracted from unsampled studies
Aim	Understand the experiences of being a teenager with SCD
Participant details	Adolescents No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Dyson 2011

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Support groups, counselling centres and clinics
Aim	Examines the experiences of young people living with SCD in schools in England
Participant details	n = 32, 5 to 25 years
Chronic pain condition	Sickle cell disease
Data collection	Interview
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Evans 2010

Study characteristics	
Funding Source	National Institute of Mental Health Grant and Mayday Fund
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Examine sex-specific parent-child relationships in the development of chronic pain in preadolescent and adolescent children
Participant details	11 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Evans 2018

Study characteristics	
Funding Source	National Center for Complementary and Alternative Medicine grant; Oppenheimer Seed Grant for Complementary, Alternative, and Integrative Medicine; University of California, Los Angeles (UCLA) Clinical and Translational Science Institute Grant; UCLA Children's Discovery and Innovation Institute
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the full range of teens' experiences with the yoga programme
Participant details	14 to 17 years No further information extracted from unsampled studies
Chronic pain condition	IBS
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Forgeron 2008

Study characteristics	
Funding Source	Rising Researcher Support Award

Forgeron 2008 *(Continued)*

Country	Canada
Recruitment setting	Paediatric pain clinic
Aim	Explore the self-identified needs of adolescents living with chronic pain
Participant details	n = 6, 13 to 17 years
Chronic pain condition	Musculoskeletal pain
Data collection	Focus groups and interviews
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Forgeron 2013

Study characteristics	
Funding Source	Canadian Institute of Health Research Doctoral Fellowship, IWK Ruby Blois Scholarship and IWK Grant
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore peer relationships and, particularly, close friendships of adolescents with chronic pain to understand and identify factors that affect these relationships
Participant details	14 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Gaughan 2014

Study characteristics	
Funding Source	Ian Katz Fund
Country	USA
Recruitment setting	Paediatric hospital
Aim	Describe the parents' journey with their child from initial incidence of pain through the labyrinth of treatment options

Gaughan 2014 *(Continued)*

Participant details	n = 13, 8 mothers, 5 fathers, children aged 11 to 17 years
Chronic pain condition	Chronic regional pain syndrome
Data collection	Interview
Data analysis	Content analysis
Notes	Sampling status: sampled for inclusion in the analysis

Gernet 2011

Study characteristics	
Funding Source	Not reported
Country	France
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the emotional representations of children with SCD
Participant details	7 to 15 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Ghio 2018

Study characteristics	
Funding Source	Arthritis Research UK
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Investigate the extent to which adolescents’ illness beliefs could be assessed using the IPQ-R
Participant details	11 to 16 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies

Ghio 2018 *(Continued)*

Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Ghio 2021

Study characteristics	
Funding Source	Arthritis Research UK National Institute for Health Research Manchester Musculoskeletal Biomedical Research Unit Funding Scheme
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the coping goals and related personal models (cognitive and emotional profiles) of juvenile idiopathic arthritis of both the adolescents and their parent
Participant details	11 to 16 years No further information extracted from unsampled studies
Chronic pain condition	JIA
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Gibler 2022

Study characteristics	
Funding Source	University of Cincinnati Department of Psychology Seeman-Frakes Graduate Student Research grant
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Refine the School Anxiety Inventory
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Goldenberg 2013

Study characteristics	
Funding Source	National Institute of Child Health and Human Development
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Utilise peers who have learned to self-manage their own chronic pain to assist participants with social coping skills to reduce isolation
Participant details	17 years No further information extracted from unsampled studies
Chronic pain condition	Diffuse chronic body pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Gomez-Ramirez 2016

Study characteristics	
Funding Source	Canadian Rheumatology Association
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Describes the predominant emotional experiences reported by parents of children with JIA in 2 Canadian cities
Participant details	2 to 16 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Gordon 2013

Study characteristics

Gordon 2013 *(Continued)*

Funding Source	Not reported
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Investigate how children with IBS and their families perceived their school experiences in Quebec
Participant details	10 to 18 years No further information extracted from unsampled studies
Chronic pain condition	IBS
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Gorodzinsky 2012

Study characteristics	
Funding Source	Not reported
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Assesses treatment provided at a multidisciplinary chronic pain clinic
Participant details	Not reported for age. No further information extracted from unsampled studies
Chronic pain condition	Unspecified
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Gorodzinsky 2013

Study characteristics	
Funding Source	Not reported
Country	USA
Recruitment setting	Information not extracted from unsampled studies

Gorodzinsky 2013 *(Continued)*

Aim	The experiences of youth with chronic pain and their siblings and their perspectives on how pain experiences influence family dynamics
Participant details	12 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Gremillion 2022

Study characteristics	
Funding Source	Unfunded
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	To better understand the challenges experienced by adolescents with chronic pain and obesity, with a specific focus on physical activity
Participant details	13 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Obesity
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Guell 2007

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Self-help organisation and hospital
Aim	Explores the everyday life and coping of children living with juvenile arthritis
Participant details	n = 4, families, 7 to 16 years

Guell 2007 *(Continued)*

Chronic pain condition	Arthritis
Data collection	Observation
Data analysis	Ethnography
Notes	Sampling status: sampled for inclusion in the analysis

Hackett 2003

Study characteristics	
Funding Source	Arthritis Research Campaign
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Gather in-depth qualitative information on play and leisure experiences from junior school-aged children with JIA
Participant details	7 to 11 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Haridasa 2019

Study characteristics	
Funding Source	Not reported
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Identify the perceptions of children with SCD in the school environment
Participant details	6 to 10 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies

Haridasa 2019 *(Continued)*

Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Heffernan 2021

Study characteristics	
Funding Source	Not reported
Country	Ireland
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore beliefs about and experiences of worry and pain among a purposeful sample of adolescents with chronic pain
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Helvig 2013

Study characteristics	
Funding Source	Not reported
Country	USA
Recruitment setting	Unclear
Aim	Explored the experience of living with migraines in 6 adolescents
Participant details	n = 6, 4 female participants, 12 to 17 years, average age = 14 years
Chronic pain condition	Headache
Data collection	Interview
Data analysis	Not reported
Notes	Sampling status: sampled for inclusion in the analysis

Hendry 2012

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the perceived impact of disease-related foot problems and foot care in JIA from the perspectives of children with JIA, parents, paediatric rheumatologists and health professionals
Participant details	7 years old and 9 years old No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Hilário 2022

Study characteristics	
Funding Source	Fundação para a Ciência e a Tecnologia, I.P. (Foundation of Science and Technology)
Country	Portugal
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore children's and parents’ experience of uncertainty and perceptions of risk resulting from chronic pain in childhood
Participant details	7 to 17 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Hollier 2018

Study characteristics

Hollier 2018 *(Continued)*

Funding Source	US National Institutes of Health, Texas Medical Center Digestive Diseases Center, US Department of Agriculture
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Assess acceptability of a proposed guided imagery therapy app designed to treat functional abdominal pain disorders
Participant details	7 to 12 years No further information extracted from unsampled studies
Chronic pain condition	Abdominal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Hulgaard 2020

Study characteristics	
Funding Source	Helsefonden, Psychiatric Research Fund
Country	Denmark
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore illness perceptions of youths with functional disorders and their parents
Participant details	11 to 15 years No further information extracted from unsampled studies
Chronic pain condition	Functional disorders
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Hulgaard 2020a

Study characteristics	
Funding Source	Helsefonden, Psychiatric Research Fund
Country	Denmark

Hulgaard 2020a *(Continued)*

Recruitment setting	Information not extracted from unsampled studies
Aim	Explore parents' experiences of challenges related to their care for a child receiving treatment for functional disorders
Participant details	11 to 16 years No further information extracted from unsampled studies
Chronic pain condition	Functional disorders
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Hunt 2003

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Neuro-disability centre, charitable trust and paediatric hospices
Aim	Gain an understanding of the context in which pain occurs and of issues that could affect pain assessment and management in this group
Participant details	n = 20, parents, children aged 2 to 18 years, average age = 11 years
Chronic pain condition	Neurological impairment
Data collection	Interview
Data analysis	Grounded theory
Notes	Sampling status: sampled for inclusion in the analysis

Hurtubise 2021

Study characteristics	
Funding Source	Vanier Scholarship, Canadian Child Health Clinical Scientist, Pain in Child Health programs
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Describe and compare the treatment effects and outcomes as perceived by youth and their parents enrolled in intensive interdisciplinary pain treatment or multimodal treatment
Participant details	12 to 18 years

Hurtubise 2021 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Iliyasu 2021

Study characteristics	
Funding Source	Unfunded
Country	Nigeria
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore caregivers' perceptions on sociobehavioural and environmental influences on hospitalisation for pain and blood transfusion of children with SCD
Participant details	3 to 11 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Jacobson 2013

Study characteristics	
Funding Source	American Institutes for Research and a range of university funding
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Examine the content validity of the Patient-Reported Outcomes Measurement Information System paediatric measures
Participant details	8 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions

Jacobson 2013 *(Continued)*

Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Jacobson 2015

Study characteristics	
Funding Source	American Institutes for Research and a range of university funding
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Evaluate the overall conceptual scope and content validity, or fit, of the PROMIS pain domain framework
Participant details	8 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Jensen 2019

Study characteristics	
Funding Source	Neurofibromatosis Therapeutic Acceleration Program (NTAP)
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Identify commonalities and differences in symptom experiences across age groups to better assist individuals to adjust to symptoms across the lifespan
Participant details	5 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Neurofibromatosis type 1
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies

Jensen 2019 *(Continued)*

Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Jones 2009

Study characteristics	
Funding Source	Not reported
Country	Australia
Recruitment setting	Information not extracted from unsampled studies
Aim	To assist occupational therapists and other healthcare professionals to facilitate children's ability to live with JIA and participate optimally in home exercise programmes
Participant details	8 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Jones 2020

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Social media and newsletters
Aim	Explore the relative frequencies of hoped-for and feared-for future selves and how these are expressed in the future narratives of adolescents with chronic regional pain syndrome
Participant details	n = 50, 44 female participants, 5 male participants, 1 not declared, 14 to 25 years, average age = 19 years
Chronic pain condition	Chronic regional pain syndrome
Data collection	Interview
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Jones 2022

Study characteristics	
Funding Source	Pain Relief Foundation
Country	UK
Recruitment setting	NHS tertiary pain service
Aim	Explore how adolescents make sense of their experience of chronic pain in the context of development
Participant details	n = 9, 8 female participants, 1 male participant, 12 to 22 years, average age = 15.7 years
Chronic pain condition	Mixed conditions
Data collection	Interview
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Jordan 2007

Study characteristics	
Funding Source	BUPA Foundation
Country	UK
Recruitment setting	Paediatric rheumatology and pain management clinic
Aim	Investigate parental experiences of caring for an adolescent with chronic pain
Participant details	n = 17, 11 mothers, 5 fathers, 1 grandmother, children aged 13 to 18 years
Chronic pain condition	Mixed conditions
Data collection	Focus group
Data analysis	Interpretive phenomenological analysis
Notes	Sampling status: sampled for inclusion in the analysis

Jordan 2016

Study characteristics	
Funding Source	Unfunded
Country	UK
Recruitment setting	Pain management centre

Jordan 2016 *(Continued)*

Aim	Examine the specific experiences of what it is like to be a father of an adolescent with chronic pain
Participant details	n = 6, fathers, children were 3 female participants and 3 male participants aged 11 to 18 years
Chronic pain condition	Mixed conditions
Data collection	Interview
Data analysis	Interpretive phenomenological analysis
Notes	Sampling status: sampled for inclusion in the analysis

Jordan 2018

Study characteristics	
Funding Source	Royal United Hospitals Bath NHS Foundation Trust
Country	UK
Recruitment setting	Pain management centre
Aim	Examine how adolescents make sense of their own development in the context of living with chronic pain
Participant details	n = 10, 7 female participants, 3 male participants, 12 to 17 years
Chronic pain condition	Mixed conditions
Data collection	Interview
Data analysis	Interpretive phenomenological analysis
Notes	Sampling status: sampled for inclusion in the analysis

Joslin 2021

Study characteristics	
Funding Source	Unfunded
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Gain the opinions of young people during their multidisciplinary treatment for chronic pain
Participant details	11 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Chronic musculoskeletal pain

Joslin 2021 *(Continued)*

Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Kanstrup 2019

Study characteristics	
Funding Source	Mayflower Charity Foundation for Children, Sven Jerring Foundation, Claes Groschinskys Memorial Foundation
Country	Sweden
Recruitment setting	Hospital pain service
Aim	Explore the lived experiences of young people and parents with regard to participating in acceptance and commitment therapy for paediatric chronic pain
Participant details	n = 8, 4 adolescents (female), 4 parents, children aged 12 to 18 years, average age = 16 years
Chronic pain condition	Unspecified chronic pain
Data collection	Interview
Data analysis	IPA
Notes	Sampling status: sampled for inclusion in the analysis

Kashikar-Zuck 2016

Study characteristics	
Funding Source	National Institute of Arthritis and Musculoskeletal and Skin Diseases, Cincinnati Children's Hospital Medical Center
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Obtain information about the feasibility, safety and tolerability of the 8-week (16 session) group-based FIT Teens intervention for adolescents with JFM and gather impressions of acceptability, format and content
Participant details	12 to 18 years No further information extracted from unsampled studies
Chronic pain condition	JFM
Data collection	Information not extracted from unsampled studies

Kashikar-Zuck 2016 *(Continued)*

Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Khair 2015

Study characteristics	
Funding Source	Bayer HealthCare Pharmaceuticals
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Understanding self-management of haemophilia, from a child's perspective, in the 21st century in the UK where intensive prophylactic therapy is given from early childhood
Participant details	4 to 16 years No further information extracted from unsampled studies
Chronic pain condition	Haemophilia
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Khanom 2020

Study characteristics	
Funding Source	Versus Arthritis Grant
Country	UK
Recruitment setting	Paediatric hospital
Aim	Explore adolescents' lived experience of pain flares, including what pain flares are, why they occur, how they are managed and what lasting effects they have on adolescents
Participant details	n = 10, 8 female participants, 2 male participants, 13 to 17 years
Chronic pain condition	Musculoskeletal pain
Data collection	Interview
Data analysis	IPA
Notes	Sampling status: sampled for inclusion in the analysis

Kroon 2018

Study characteristics	
Funding Source	U.S. Department of Health and Human Services, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Determine which CBT-HA treatment components of paediatric headache patient stakeholders would report to be most helpful and essential to reducing headache frequency and related disability
Participant details	13 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Headache
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Kulandaivelu 2018

Study characteristics	
Funding Source	Not reported
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Examine the perspectives of adolescents with SCD, their parents and healthcare providers
Participant details	12 to 19 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Lauridsen 2020

Study characteristics	
Funding Source	Foundation of Chiropractic Research and Postgraduate Education

Lauridsen 2020 *(Continued)*

Country	Denmark
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the physical, psychological and social consequences of a life with nonspecific spinal pain among Danish children
Participant details	9 to 12 years No further information extracted from unsampled studies
Chronic pain condition	Musculoskeletal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Law 2017

Study characteristics	
Funding Source	Seattle Children's Research Institute Center for Child Health Behavior and Development, National Institute of Neurological Disorders and Stroke
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Inform adaptation of Web-MAP for youth with headache
Participant details	10 to 16 years No further information extracted from unsampled studies
Chronic pain condition	Headache
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Law 2017a

Study characteristics	
Funding Source	The Center for Child Health, Behavior and Development of Seattle Children's Research Eunice Kennedy Shriver National Institute of Child Health and Human Development Institute
Country	USA
Recruitment setting	Information not extracted from unsampled studies

Law 2017a *(Continued)*

Aim	Adapt PSST for parents of children receiving intensive pain rehabilitation and evaluate treatment feasibility, acceptability and satisfaction
Participant details	14 years (mean) No further information extracted from unsampled studies
Chronic pain condition	Idiopathic chronic pain conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Le 2019

Study characteristics	
Funding Source	Women and Children's Hospital Research Institute
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Describe parents’ experiences with paediatric chronic pain
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Lee 2020

Study characteristics	
Funding Source	National Institute for Health Research Biomedical Research Centre Funding Scheme, National Institute for Health Research Manchester Biomedical Research Centre
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Investigate patient preferences, feasibility and influence of several time sampling strategies in remote multidimensional pain reporting
Participant details	7 to 16 years

Lee 2020 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Leksell 2017

Study characteristics	
Funding Source	Swedish Rheumatism Association
Country	Sweden
Recruitment setting	Information not extracted from unsampled studies
Aim	Deepen knowledge of how parents of children diagnosed with JIA perceive the orofacial manifestations of the disease, its treatments and their encounters with dental care providers
Participant details	3 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Lipstein 2016

Study characteristics	
Funding Source	Academic Paediatric Association Young Investigator Award
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Compare factors considered by parents to those considered by adolescents making decisions about chronic disease treatments
Participant details	12 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions

Lipstein 2016 *(Continued)*

Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Maciver 2005

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Paediatric hospital
Aim	Examine parents’ experiences prediagnosis and their experiences of accessing specialist pain management services for the child
Participant details	n = 12, 10 mothers, 2 fathers, children aged 10 to 16 years
Chronic pain condition	Mixed conditions
Data collection	Interview
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Maciver 2010

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Paediatric hospital
Aim	Examining parents' experiences of paediatric chronic pain management services in the UK
Participant details	n = 12, 10 mothers, 2 fathers, 10 to 16 years
Chronic pain condition	Mixed conditions
Data collection	Interview
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Maciver 2011

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Paediatric hospital
Aim	Examining parents‘ experiences of paediatric chronic pain management services in the UK
Participant details	n = 12, 10 mothers, 2 fathers, 10 to 16 years
Chronic pain condition	Mixed conditions
Data collection	Interview
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

McDonagh 2021

Study characteristics	
Funding Source	Unfunded
Country	Ireland
Recruitment setting	Social media platforms
Aim	Exploring the impacts and experiences of parents caring for a child with Down arthritis
Participant details	n = 12, 10 mothers, 2 fathers
Chronic pain condition	Down arthritis
Data collection	Interview
Data analysis	IPA
Notes	Sampling status: sampled for inclusion in the analysis

McKinnon 2020

Study characteristics	
Funding Source	Australian Government Research Training Program Scholarship, Centre for Research Excellence in Cerebral Palsy, Murdoch Children’s Research Institute, Top-Up Scholarship
Country	Australia

McKinnon 2020 *(Continued)*

Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the lived experiences of chronic pain and dyskinesia through the unbiased lens of children and adolescents with cerebral palsy able to communicate experiences by either verbalising or using augmentative and alternative communication
Participant details	9 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Cerebral palsy
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

McKinnon 2022

Study characteristics	
Funding Source	The Research Foundation, Murdoch Children's Research Institute, Victorian Governments Operational Infrastructure Support Program
Country	Australia
Recruitment setting	Paediatric hospital
Aim	Explore the personal perspectives of caregivers regarding challenges faced within everyday pain management of their children
Participant details	n = 10, 10 mothers
Chronic pain condition	Cerebral palsy
Data collection	Interview
Data analysis	IPA
Notes	Sampling status: sampled for inclusion in the analysis

McNeill 2004

Study characteristics	
Funding Source	Not reported
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Examine the experience of fathers who have a child with juvenile rheumatoid arthritis

McNeill 2004 *(Continued)*

Participant details	8.7 years average No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Meldrum 2008

Study characteristics	
Funding Source	National Institute of Mental Health grant: Mayday Fund
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	To examine the impact of pain-associated functioning limitations on children's lives and the strategies they develop to try to continue functioning
Participant details	8 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Meldrum 2009

Study characteristics	
Funding Source	National Institute of Mental Health grant: Mayday Fund
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Understand the impact of chronic or recurrent pain on children within the context of their own lives and experiences
Participant details	10 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions

Meldrum 2009 *(Continued)*

Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Miles 2020

Study characteristics	
Funding Source	National Institute for Health Research Health Services and Delivery Research Programme
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore how participant expertise and participant involvement in their own care works in practice for young people with SCD
Participant details	13 to 21 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Mitchell 2007

Study characteristics	
Funding Source	Not reported
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Assess how healthcare service delivery and other intervention strategies can be improved and optimised
Participant details	7 to 13 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies

Mitchell 2007 *(Continued)*

Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Moulin 2015

Study characteristics	
Funding Source	Academic Society of the Canton de Vaud (Societe Academique Vaudoise) Country Switzerland
Country	Switzerland
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore how these adolescents and their parents experience the condition and its impact on their daily lives
Participant details	12 to 20 years No further information extracted from unsampled studies
Chronic pain condition	Medically unexplained symptoms
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Moulin 2015a

Study characteristics	
Funding Source	Academic Society of the Canton de Vaud (Societe Academique Vaudoise)
Country	Switzerland
Recruitment setting	Information not extracted from unsampled studies
Aim	Understand the experiences with and perceptions of the health care of adolescents
Participant details	14 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Medically unexplained symptoms
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Neto 2018

Study characteristics	
Funding Source	Not reported
Country	Portugal
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the views of adolescents with chronic idiopathic neck pain towards an intervention consisting of pain neuroscience education and exercise administered in the school setting
Participant details	10 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Musculoskeletal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Neville 2019

Study characteristics	
Funding Source	Not reported
Country	Canada
Recruitment setting	Paediatric Pain Clinic
Aim	Investigate how diagnostic uncertainty is experienced by both youth with chronic pain and their parents
Participant details	n = 37, 20 children, 17 mothers, 10 to 18 years
Chronic pain condition	Mixed conditions
Data collection	Interview
Data analysis	Thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Newton 2019

Study characteristics	
Funding Source	Eli Lilly and Company
Country	USA

Newton 2019 *(Continued)*

Recruitment setting	Information not extracted from unsampled studies
Aim	Understand the health-related quality of life and symptomatic experience of ulcerative colitis
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Ulcerative colitis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Nguyen 2015

Study characteristics	
Funding Source	Not reported
Country	Switzerland
Recruitment setting	Information not extracted from unsampled studies
Aim	Develop a new patient-reported outcome that meets scientific and regulatory standards for instrument development and can be used as a primary end point to assess change in dysmenorrhoea severity over-time in clinical trials
Participant details	14 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Dysmenorrhoea
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Nicholas 2007

Study characteristics	
Funding Source	Not reported
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Develop an evaluative disease-specific measure of quality of life in paediatric IBS
Participant details	7 to 19 years

Nicholas 2007 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	IBS
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Nieto 2015

Study characteristics	
Funding Source	Fundación la Caixa, Ministerio de Economía y Competitivad
Country	Spain
Recruitment setting	Information not extracted from unsampled studies
Aim	Test the feasibility of an online intervention (DARWeb) for children with functional abdominal pain and their families
Participant details	9 to 15 years No further information extracted from unsampled studies
Chronic pain condition	Abdominal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Nieto 2019

Study characteristics	
Funding Source	Fundación la Caixa (Recercaixa, 2012–2013), Ministerio de Economía y Competitivad (Spanish Government)
Country	Spain
Recruitment setting	Information not extracted from unsampled studies
Aim	Exploration of the effects of DARWeb (online intervention) on different outcomes (i.e. abdominal pain severity, disability and quality of life) from the point of view of the different actors involved (parents and children)
Participant details	9 to 15 years No further information extracted from unsampled studies
Chronic pain condition	Abdominal pain

Nieto 2019 *(Continued)*

Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Nieto 2019a

Study characteristics	
Funding Source	Fundación la Caixa Ministerio de Economía y Competitividad (Spanish Government)
Country	Spain
Recruitment setting	Information not extracted from unsampled studies
Aim	Evaluate post-treatment efficacy of DARWeb (online psychosocial intervention for children with functional abdominal pain)
Participant details	9 to 15 years No further information extracted from unsampled studies
Chronic pain condition	Abdominal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Nieto 2020

Study characteristics	
Funding Source	Fundación La Caixa Ministerio de Economía y Competitividad (Spanish Government)
Country	Spain
Recruitment setting	Information not extracted from unsampled studies
Aim	Learn about the specific experiences of families (parents and children) with a child with functional abdominal pain from their point of view
Participant details	9 to 15 years No further information extracted from unsampled studies
Chronic pain condition	Abdominal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies

Nieto 2020 *(Continued)*

Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Nilsson 2011

Study characteristics	
Funding Source	Public Dental Service of Östergötland, Swedish dental societies, Malmö University
Country	Sweden
Recruitment setting	Information not extracted from unsampled studies
Aim	Deepen our understanding of adolescents’ experiences of living with temporomandibular disorder pain
Participant details	16 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Temporomandibular disorder
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Nilsson 2016

Study characteristics	
Funding Source	Swedish dental societies, Malmö University
Country	Sweden
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore adolescents' explanations of temporomandibular disorder pain, their pain management strategies and treatment-seeking behaviour
Participant details	10 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Musculoskeletal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Njifon 2019

Study characteristics	
Funding Source	Not reported
Country	Cameroon
Recruitment setting	Research presentation
Aim	Focusses on how a brother and sister without SCD experience their brother's illness on a daily basis and the influence of this disease on family dynamics
Participant details	n = 2, siblings, 9 to 16 years
Chronic pain condition	SCD
Data collection	Interview, drawings
Data analysis	Thematic analysis and analysis of drawings
Notes	Sampling status: sampled for inclusion in the analysis

Nkhoma 2021

Study characteristics	
Funding Source	King’s College London Faculty Challenge Fund
Country	Malawi
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore stakeholders’ perspectives and experiences on pain self-management for adolescents living with HIV and chronic pain in Malawi
Participant details	10 to 17 years No further information extracted from unsampled studies
Chronic pain condition	HIV/AIDS
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Nsangou 2019

Study characteristics	
Funding Source	Not reported
Country	France

Nsangou 2019 *(Continued)*

Recruitment setting	Information not extracted from unsampled studies
Aim	Better understand the impact of the disease on body image by linking the illness with what the child says and knows about it
Participant details	9 to 12 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Nutkiewicz 2008

Study characteristics	
Funding Source	National Institute of Mental Health
Country	USA
Recruitment setting	Paediatric pain clinic
Aim	Examines the communication between people with paediatric pain and their doctor
Participant details	n = 32, 24 female participants, 8 male participants, 10 to 18 years
Chronic pain condition	Unspecified chronic pain
Data collection	Interview
Data analysis	Grounded theory
Notes	Sampling status: sampled for inclusion in the analysis

O'Donnell 2013

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the experiences of young people with chronic oral ulcers attending the paediatric oral medicine clinic in a UK dental hospital
Participant details	1 to 9 years and 10 to 19 years

O'Donnell 2013 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	Chronic oral ulcers
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

O'Sullivan 2018

Study characteristics	
Funding Source	Wellcome Trust Humanities and Social Sciences, The James Flaherty Research Scholarship
Country	Ireland
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the self-management needs of Irish adolescents living with JIA from their own perspective and from those of their parents and healthcare professionals
Participant details	12 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Ostojic 2022

Study characteristics	
Funding Source	Cerebral Palsy Alliance Research Foundation, NHRMC Centre of Research Excellence in Cerebral Palsy
Country	Australia
Recruitment setting	Information not extracted from unsampled studies
Aim	Investigate the acceptability and feasibility of biofeedback-assisted relaxation training for chronic pain management in children with cerebral palsy
Participant details	9 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Cerebral palsy

Ostojic 2022 *(Continued)*

Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Palmer 2008

Study characteristics	
Funding Source	Social Sciences and Humanities Research Council
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Gaining a rich description and a contextual understanding of the experiences of a young chronic pain sufferer, aged 6 years, and her family members
Participant details	6 to 10 years No further information extracted from unsampled studies
Chronic pain condition	Musculoskeletal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Panepinto 2012

Study characteristics	
Funding Source	National Institutes of Health
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Develop the new PedsQL Sickle Cell Disease Module for paediatric participants with SCD and support its content validity
Participant details	2 to 18 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies

Panepinto 2012 *(Continued)*

Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Pate 2019

Study characteristics	
Funding Source	Macquarie University Research Training Program (RTP) full-time scholarship
Country	Australia
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the concept of pain in children with and without persistent pain
Participant details	8 to 12 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Peláez-Ballestas 2013

Study characteristics	
Funding Source	Not reported
Country	Mexico
Recruitment setting	Information not extracted from unsampled studies
Aim	Explain the phenomenon of experiencing JIA within a specific cultural context
Participant details	17 to 66 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Race 2016

Study characteristics	
Funding Source	Canadian Institutes of Health Research
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Examine perspectives of children who have JIA and their parents
Participant details	8.3 to 16.3 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Randall 2020

Study characteristics	
Funding Source	Eli Lilly and Company
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Understand the health-related quality of life and symptomatic experience of children (2 to 11 years) living with ulcerative colitis
Participant details	2 to 11 years No further information extracted from unsampled studies
Chronic pain condition	Abdominal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Renedo 2019

Study characteristics	
Funding Source	National Institute for Health Research Health Services and Delivery Research Programme
Country	UK

Renedo 2019 *(Continued)*

Recruitment setting	Hospital and community network
Aim	Explore how young people with SCD experience health care during a period of transition
Participant details	n = 21, 13 to 18 years
Chronic pain condition	SCD
Data collection	Interview
Data analysis	Grounded theory, thematic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Renedo 2020

Study characteristics	
Funding Source	National Institute for Health Research Health Services and Delivery Research Programme
Country	UK
Recruitment setting	Specialist healthcare services, networks with patient advocates
Aim	Understand healthcare transitions of young people with SCD
Participant details	n = 48, 30 female participants, 18 male participants, 13 to 21 years
Chronic pain condition	SCD
Data collection	Interview
Data analysis	Grounded theory
Notes	Sampling status: sampled for inclusion in the analysis

Risko 2018a

Study characteristics	
Funding Source	Unfunded
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the lived experiences of adolescents engaged in an intensive interdisciplinary pain treatment programme
Participant details	10 to 19 years No further information extracted from unsampled studies

Risko 2018a *(Continued)*

Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Rossato 2007

Study characteristics	
Funding Source	Not reported
Country	Brazil
Recruitment setting	Paediatric clinic
Aim	Understand the meaning of the experience of families of children living in pain situations due to JIA
Participant details	n = 12 families, 12 mothers, 2 fathers, 12 children with JIA (11 female, 1 male), 2 siblings, 6 to 17 years
Chronic pain condition	Arthritis
Data collection	Interview
Data analysis	Grounded theory
Notes	Sampling status: sampled for inclusion in the analysis

Ruskin 2017

Study characteristics	
Funding Source	Pain Centre Seed Grant (Hospital for Sick Children)
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the experience of adolescents who participated in an 8-week mindfulness group adapted for adolescents with chronic pain (MBI-A)
Participant details	12 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies

Ruskin 2017 *(Continued)*

Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Santos 2018

Study characteristics	
Funding Source	Not reported
Country	Portugal
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the situations perceived by child participants, their parents and siblings as the most distressing and stressful when living with osteogenesis imperfecta
Participant details	4 to 16 years No further information extracted from unsampled studies
Chronic pain condition	Osteogenesis imperfecta type 1
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Secor-Turner 2011

Study characteristics	
Funding Source	Agency for Healthcare Research and Quality, University of Minnesota-Academic Health Center
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Identify challenges that teens experience as a result of living with juvenile arthritis
Participant details	14 to 29 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Serafimova 2022

Study characteristics	
Funding Source	Unfunded
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Describe the experience of pain, its impact and treatments in children with chronic fatigue syndrome/myalgic encephalomyelitis
Participant details	11 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Chronic fatigue syndrome/myalgic encephalomyelitis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Shaygan 2021

Study characteristics	
Funding Source	Research Affairs of Shiraz University of Medical Sciences
Country	Iran
Recruitment setting	Information not extracted from unsampled studies
Aim	To assess a smartphone-based pain management application
Participant details	12 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Unspecified
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Shaygan 2022

Study characteristics	
Funding Source	Research Affairs of Shiraz University of Medical Sciences
Country	Iran

Shaygan 2022 *(Continued)*

Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the experience of chronic pain among adolescents
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Unspecified
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Skarstein 2016

Study characteristics	
Funding Source	Department of Nursing and Akershus University College of Applied Sciences
Country	Norway
Recruitment setting	Information not extracted from unsampled studies
Aim	Gain a deeper understanding and increase our knowledge about adolescents who suffer from frequent pain and have a high consumption of over-the-counter analgesics
Participant details	14 to 16 years No further information extracted from unsampled studies
Chronic pain condition	Unspecified
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Skarstein 2018

Study characteristics	
Funding Source	Department of Nursing and Akershus University College of Applied Sciences
Country	Norway
Recruitment setting	Information not extracted from unsampled studies
Aim	Describe pain management and conditions that may influence the development of identity in adolescents frequently using analgesics
Participant details	10 to 19 years

Skarstein 2018 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	Unspecified
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Skogvold 2019

Study characteristics	
Funding Source	Norwegian Fund for Postgraduate Training in Physiotherapy
Country	Norway
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore which strategies adolescents use to cope with chronic tension-type headache in everyday life
Participant details	14 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Headache
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Slotter 2021

Study characteristics	
Funding Source	Not reported
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Gain further insight into how adolescents with chronic pain perceive their peer relationships
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies

Slotter 2021 *(Continued)*

Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Smart 2005

Study characteristics	
Funding Source	NHS Executive Northern and Yorkshire Region
Country	UK
Recruitment setting	Paediatric clinics and schools
Aim	Exploring the way in which mothers understand and cope with their children's recurrent abdominal pain and how this might be related to beliefs and values held about their relationship with their children
Participant details	n = 28, mothers, 6 to 14 years
Chronic pain condition	Abdominal pain
Data collection	Interview
Data analysis	Grounded theory
Notes	Sampling status: sampled for inclusion in the analysis

Soni-Jaiswal 2016

Study characteristics	
Funding Source	Unfunded
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore in-depth concerns of children with mucopolysaccharidosis and their parents, with an emphasis on the impact of head and neck disease on their lives
Participant details	6 months to 16 years
Chronic pain condition	Mucopolysaccharidosis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Sorensen 2017

Study characteristics	
Funding Source	Unfunded
Country	Norway
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore adolescents’ experiences of complex persistent pain
Participant details	n = 6, 4 female participants, 2 male participants, 12 to 19 years
Chronic pain condition	Complex persistent pain
Data collection	Interview
Data analysis	Hermeneutic analysis
Notes	Sampling status: sampled for inclusion in the analysis

Sorensen 2021

Study characteristics	
Funding Source	Extra Foundation for Health and Rehabilitation, Norwegian League Against Rheumatism
Country	Norway
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore how regular needle injections affect children with rheumatic diseases and their parents in their daily living
Participant details	6 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Stiles-Shields 2022

Study characteristics	
Funding Source	Comer Development Board and Cohn Family Foundation
Country	USA

Stiles-Shields 2022 *(Continued)*

Recruitment setting	Information not extracted from unsampled studies
Aim	Assess the paediatric participant- and parent-reported experience of (a) coping with and managing symptoms associated with MALS and (b) the diagnostic, treatment and recovery process for paediatric MALS
Participant details	15 to 28 years No further information extracted from unsampled studies
Chronic pain condition	Median arcuate ligament syndrome
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Stinson 2008

Study characteristics	
Funding Source	Canadian Arthritis Network
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the self-management needs of adolescents with JIA
Participant details	12 to 20 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Stinson 2012

Study characteristics	
Funding Source	Canadian Arthritis Network
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the information needs of parents and school-age children with JIA
Participant details	8 to 11 years

Stinson 2012 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Stinson 2014

Study characteristics	
Funding Source	Canadian Pain Society Small Grant Award
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Conduct a user-centred needs assessment to inform the development of an integrated web- and smartphone-based self-management program for adolescents with chronic pain called iCanCope with Pain
Participant details	10 to 19 years No further information extracted from unsampled studies Chronic
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Stinson 2017

Study characteristics	
Funding Source	Church and Dwight
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the use, decision-making process and communication about the use of OTC medication with HCPs in a multidisciplinary chronic pain team setting in adolescents living with chronic pain and their primary caregiver
Participant details	12 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions

Stinson 2017 *(Continued)*

Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Ståhle-Öberg 2009

Study characteristics	
Funding Source	Swedish Association of Registered Physiotherapists, Jerringfonden and County Council of Vasterbotten
Country	Sweden
Recruitment setting	Information not extracted from unsampled studies
Aim	Illuminate pain in children with cerebral palsy from the parents' experience
Participant details	10 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Cerebral palsy
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Suder 2016

Study characteristics	
Funding Source	Not reported
Country	Canada
Recruitment setting	Physician offices and paediatric hospital
Aim	Understand the lived experience of adolescents who live with chronic pain
Participant details	n = 10, 8 female participants, 2 male participants, average age = 16 years
Chronic pain condition	Mixed conditions
Data collection	Interview
Data analysis	Phenomenology
Notes	Sampling status: sampled for inclusion in the analysis

Szwimer 2020

Study characteristics	
Funding Source	Not reported
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Enquire into the experiences of female adolescents living with cerebral palsy
Participant details	14 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Sällfors 2001

Study characteristics	
Funding Source	Swedish Rheumatism Association, Norrbacka-Eugenia Foundation, Renee Enander Foundation
Country	Sweden
Recruitment setting	Information not extracted from unsampled studies
Aim	Gain a deeper understanding of how children cope with their chronic pain condition
Participant details	6 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Sällfors 2002

Study characteristics	
Funding Source	Swedish Social Insurance Agency, Spenshult Hospital for Rheumatic Diseases, Norrbacka-Eugenia Foundation

Sällfors 2002 *(Continued)*

Country	Sweden
Recruitment setting	Information not extracted from unsampled studies
Aim	Obtain a deeper understanding of children's experiences of living with chronic pain in daily life
Participant details	6 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Sällfors 2003

Study characteristics	
Funding Source	Not reported
Country	Sweden
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore parents' experience of living with a child with chronic pain related to juvenile chronic arthritis
Participant details	7 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Sällfors 2009

Study characteristics	
Funding Source	Swedish Social Insurance Agency, Spenshult Hospital for Rheumatic Diseases, Norrbacka-Eugenia Foundation
Country	Sweden
Recruitment setting	Information not extracted from unsampled studies
Aim	Deepen the understanding of female adolescents' daily living with chronic arthritis

Sällfors 2009 *(Continued)*

Participant details	14 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Tong 2013

Study characteristics	
Funding Source	George Weston Fund
Country	Australia
Recruitment setting	Information not extracted from unsampled studies
Aim	Elicit parental and adolescent perspectives on paediatric rheumatology care and service delivery
Participant details	14 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Valenzuela 2013

Study characteristics	
Funding Source	National Institutes of Health National Heart, Lung, and Blood Institute
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	To understand how children and adolescents with SCD perceive their lives and disease using Photovoice
Participant details	8 to 17 years No further information extracted from unsampled studies
Chronic pain condition	SCD

Valenzuela 2013 *(Continued)*

Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Van Gulik 2020

Study characteristics	
Funding Source	Unfunded
Country	The Netherlands
Recruitment setting	Information not extracted from unsampled studies
Aim	Elicit the experiences during school life and the perspectives and expectations regarding future work participation of adolescents with JIA
Participant details	14 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

van Scheppingen 2008

Study characteristics	
Funding Source	Johanna Kinderfonds, the Stichting BIO Kinderrevalidatie Kinderrevalidatie Fonds Adriaanstichting
Country	The Netherlands
Recruitment setting	Information not extracted from unsampled studies
Aim	Gain a more in-depth understanding of the wide-ranging and complex problems parents of children with epidermolysis bullosa have to deal with
Participant details	2 to 19 years No further information extracted from unsampled studies
Chronic pain condition	Epidermolysis bullosa
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies

van Scheppingen 2008 *(Continued)*

Notes	Sampling status: eligible but not sampled for inclusion in the analysis

van Tilburg 2006

Study characteristics	
Funding Source	National Institute of Diabetes and Digestive and Kidney Diseases
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Investigate the most common parental fears, worries and cognitions about recurrent abdominal pain
Participant details	5 to 13 years No further information extracted from unsampled studies
Chronic pain condition	Abdominal pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Voigtman 2002

Study characteristics	
Funding Source	Not reported
Country	Saudi Arabia
Recruitment setting	Information not extracted from unsampled studies
Aim	Describe the Qatif sociocultural response to children with SCD and pain
Participant details	7 to 14 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Waite-Jones 2008

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Support group
Aim	To address the research question 'What is it like to have a sibling with juvenile idiopathic arthritis?'
Participant details	n = 32, 8 children, 16 parents, 8 siblings, 12 to 18 years
Chronic pain condition	Arthritis
Data collection	Interview
Data analysis	Grounded theory
Notes	Sampling status: sampled for inclusion in the analysis

Wakefield 2018

Study characteristics	
Funding Source	Goldfarb Pain and Palliative Medicine Fund
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Examine pain-related stigma in the literature documenting paediatric and adult health-related stigma
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Unspecified
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Wakefield 2021

Study characteristics	
Funding Source	National Institute of Arthritis, Musculoskeletal and Skin Diseases of the National Institutes of Health, Goldfarb Pain and Palliative Medicine Fund
Country	USA

Wakefield 2021 *(Continued)*

Recruitment setting	Information not extracted from unsampled studies
Aim	Examine adolescent motivations for using concealment and the possible benefits and harmful consequences of this form of coping
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Wakefield 2022

Study characteristics	
Funding Source	National Institute of Arthritis, Musculoskeletal and Skin Diseases of the National Institutes of Health, Goldfarb Pain and Palliative Medicine Fund
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Identify and describe pain-related stigma among adolescents with chronic pain and their parents
Participant details	12 to 17 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Walter 2017

Study characteristics	
Funding Source	Neuroscience Nursing Foundation
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Determine the dimensions of the health challenge of adolescent headache
Participant details	14 to 18 years

Walter 2017 *(Continued)*

	No further information extracted from unsampled studies
Chronic pain condition	Headache
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

While 2004

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Information not extracted from unsampled studies
Aim	Explore the lived experience of young people with SCD as they transferred to adult services
Participant details	12 to 16 years No further information extracted from unsampled studies
Chronic pain condition	SCD
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Williams 2008

Study characteristics	
Funding Source	Not reported
Country	UK
Recruitment setting	Unclear
Aim	Investigate the experiences of young people with epidermolysis bullosa
Participant details	n = 11, 5 female participants, 6 male participants, 10 to 14 years
Chronic pain condition	Epidermolysis bullosa
Data collection	Interview
Data analysis	IPA

Williams 2008 *(Continued)*

Notes	Sampling status: sampled for inclusion in the analysis

Wong 2016

Study characteristics	
Funding Source	Association of Hong Kong Nursing Staff Professional Development Fund
Country	Hong Kong
Recruitment setting	Secondary school
Aim	Explore the self-care strategies among Hong Kong Chinese adolescent girls with dysmenorrhoea
Participant details	n = 28, average age = 15 years
Chronic pain condition	Dysmenorrhoea
Data collection	Interview
Data analysis	Content analysis
Notes	Sampling status: sampled for inclusion in the analysis

Woodgate 1998

Study characteristics	
Funding Source	Health Sciences Centre Foundation Nursing Research Award
Country	Canada
Recruitment setting	Information not extracted from unsampled studies
Aim	Elicit detailed descriptions of adolescents' chronic illness experiences
Participant details	13 to 16 years No further information extracted from unsampled studies
Chronic pain condition	Mixed conditions
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Yeung 2017

Study characteristics

Yeung 2017 *(Continued)*

Funding Source	Physiotherapy Practice Council
Country	Information not extracted from unsampled studies
Recruitment setting	Canada
Aim	Explore how children aged 10 to 18 years describe their neuropathic pain
Participant details	10 to 18 years No further information extracted from unsampled studies
Chronic pain condition	Neuropathic pain
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Yuwen 2017

Study characteristics	
Funding Source	National Institute of Nursing Research, with additional scholarships and small grant
Country	USA
Recruitment setting	Information not extracted from unsampled studies
Aim	Describe parents' experiences in caring for 2- to 5-year-old children with JIA
Participant details	2 to 5 years No further information extracted from unsampled studies
Chronic pain condition	Arthritis
Data collection	Information not extracted from unsampled studies
Data analysis	Information not extracted from unsampled studies
Notes	Sampling status: eligible but not sampled for inclusion in the analysis

Abbreviations: CBT-HA: cognitive behavioural therapy for health anxiety; CSLE: childhood-onset systemic lupus erythematosus; FIT: fibromyalgia integrative training; HCP: healthcare provider; IBS: irritable bowel syndrome; IPA: interpretative phenomenological analysis; IPQ-R: Illness Perception Questionnaire revised version; JFM: juvenile fibromyalgia; JIA: juvenile idiopathic arthritis; MALS: median arcuate ligament syndrome; OTC: over-the-counter; PROMIS: Patient-Reported Outcomes Measurement Information System; PSST: problem-solving skills training; SCD: sickle cell disease; Web-MAP: Web-based Management of Adolescent Pain intervention

Characteristics of excluded studies *[ordered by study ID]*

Study	Reason for exclusion
Abadesso 2020	Ineligible publication type

Study	Reason for exclusion
Ahola Kohut 2016	Ineligible publication type
Ahola Kohut 2017	Ineligible population
Alavi 2012	Ineligible population
Albasri 2022	Ineligible publication type
Alhowimel 2022	Ineligible population
Allgood 2015	Ineligible publication type
Allyn 2020	Ineligible population
Alongi 2018	Ineligible publication type
Arbabisarjou 2014	Duplicate
Arbabisarjou 2015	Ineligible population
Arbitre 2019	Ineligible publication type
Arbitre 2019a	Ineligible publication type
Arbuckle 2010	Ineligible publication type
Arruda 2017	Ineligible publication type
Arruda 2018	Ineligible population
Atkin 1998	Unavailable by deadline
Aziato 2015	Ineligible population
Baert 2020a	Duplicate
Bailey 2018	Ineligible publication type
Bailey 2018a	Ineligible publication type
Bakshi 2015	Ineligible publication type
Barlow 1998a	Duplicate
Barned 2022	Ineligible population
Beales 1983	Unavailable by deadline
Becker 2019	Ineligible population
Bennett 2000	Ineligible publication type
Bennett 2000a	Ineligible publication type
Beresford 2003	Ineligible population

Study	Reason for exclusion
Beyer 1999	Ineligible publication type
Bieniak 2022	Ineligible publication type
Birks 2008	Ineligible publication type
Borghi 2014a	Ineligible population
Borghi 2016	Ineligible publication type
Borini 2021	Ineligible population
Bousso 2014	Ineligible publication type
Bousso 2015	Ineligible publication type
Branson 2011	Ineligible publication type
Britton 1999	Ineligible population
Brown 2021	Ineligible publication type
Buchannan 2018	Ineligible publication type
Buchbinder 2011	Unavailable by deadline
Buesa-Estéllez 2022	Ineligible publication type
Burke 2016	Ineligible publication type
Byczkowski 2016	Ineligible population
Caes 2019	Ineligible publication type
Cai 2017	Ineligible population
Calhoun 2022	Ineligible population
Candel 2021	Ineligible population
Cappon 2020	Ineligible publication type
Cappon 2021	Ineligible publication type
Carlson 2012	Ineligible publication type
Carlson 2014	Ineligible publication type
Carter 1998	Unavailable by deadline
Carter 2016	Ineligible publication type
Carter 2017a	Ineligible publication type
Carter 2020	Ineligible population

Study	Reason for exclusion
Castro 2020	Ineligible population
Chadi 2018	Ineligible publication type
Chakravorty 2017	Ineligible publication type
Chaplin 2018	Ineligible publication type
Chaplin 2018a	Ineligible publication type
Chaplin 2019	Ineligible publication type
Childs 1998	Ineligible population
Christian 1997	Ineligible population
Claar 2007	Ineligible publication type
Clery 2021	Ineligible population
Coleman 2016	Ineligible population
Colver 2018	Ineligible population
Cooke 2021	Ineligible population
Cotton 2009	Ineligible population
Crego 2021	Ineligible population
Crosby 2022	Ineligible population
Cunningham 2019a	Ineligible publication type
Cunningham 2019b	Duplicate
Dahal 2018	Ineligible population
Davis 2016	Ineligible publication type
de Graaf 2017	Ineligible population
de Lucca 2016	Ineligible publication type
de Souza 2011	Ineligible publication type
Dekker 2020	Ineligible publication type
Dickson 2002	Unavailable by deadline
Diehl 1991	Ineligible population
Donovan 2022	Ineligible population
Dunford 2014	Ineligible publication type

Study	Reason for exclusion
Easterlin 2020	Ineligible population
Eaves 2014	Ineligible population
Eaves 2015	Ineligible population
Eaves 2016	Ineligible population
Ebrahimpour 2019	Ineligible publication type
El Miedany 2018	Ineligible publication type
Elander 2019	Ineligible publication type
Elliott 1997	Ineligible population
Ely 1992	Ineligible population
Ely 2016	Ineligible publication type
Engel 1991	Ineligible publication type
Esteve 2012	Ineligible publication type
Evans 2010a	Ineligible publication type
Eyckmans 2011	Ineligible population
Fairhurst 2013	Ineligible publication type
Farrell 2012	Ineligible publication type
Farrugia 2018	Ineligible publication type
fe Souza 2011	Ineligible publication type
Fidanci 2013	Ineligible publication type
Fleitas 2000	Ineligible population
Flores 2017	Ineligible publication type
Forgeron 2008a	Unavailable by deadline
Forgeron 2011	Ineligible publication type
Forgeron 2019	Duplicate
Forgeron 2019a	Duplicate
Forrest 2020	Ineligible publication type
Forrester 2015	Ineligible population
Fosdal 2015	Ineligible publication type

Study	Reason for exclusion
Garrett 2015	Ineligible population
Gesteira 2017	Ineligible population
Ghio 2011	Ineligible publication type
Ghio 2015	Ineligible publication type
Gordon 2021	Ineligible publication type
Graff 2012	Ineligible population
Grant 2019	Ineligible population
Gravelle 1997	Ineligible population
Gray 2013	Ineligible publication type
Gray 2014	Ineligible publication type
Gray 2014a	Ineligible publication type
Green 2018	Ineligible population
Griffiths 2017	Ineligible publication type
Gross 2017	Ineligible publication type
Gulhati 1998	Ineligible publication type
Gupta 2018	Ineligible population
Guzman 2013	Ineligible publication type
Guzman 2013a	Ineligible publication type
Guzman 2014	Ineligible publication type
Hall 2019	Ineligible publication type
Hallberg 2009	Ineligible publication type
Hanson 2018	Ineligible population
Harris 2017	Ineligible population
Harry 2018	Ineligible publication type
Harry 2018a	Ineligible publication type
Harry 2019	Ineligible publication type
Harry 2019a	Ineligible population
Hart 2014	Ineligible publication type

Study	Reason for exclusion
Hatchette 2005	Ineligible population
Hatchette 2006	Ineligible population
Hatchette 2008	Ineligible population
Haukeland 2015	Ineligible population
Hawkins 2019	Ineligible population
Hawkins 2020	Duplicate
Hayes 2008	Ineligible population
Helms 2008	Unavailable by deadline
Henderson 2014	Ineligible population
Hexem 2013	Ineligible publication type
Higginson 2019	Ineligible population
Hildenbrand 2015	Ineligible publication type
Hill 2022	Ineligible population
Hind 2017	Ineligible population
Horne 2017	Ineligible population
Horonjeff 2016	Ineligible publication type
Hulgaard 2019	Ineligible population
Hummelinck 2006	Ineligible population
Humphrey 2018	Ineligible publication type
Hunfeld 2001	Ineligible publication type
Hunfeld 2002	Ineligible publication type
Hurley-Wallace 2021	Ineligible publication type
Hurley-Wallace 2021a	Duplicate
Hurley-Wallace 2022	Ineligible publication type
Hurtubise 2020	Ineligible publication type
Hutchinson 2007	Ineligible population
Ingeman 2022	Ineligible population
Inusa 2013	Ineligible publication type

Study	Reason for exclusion
Inusa 2015	Ineligible publication type
Jacob 2005	Ineligible publication type
Jacobs 2021	Ineligible population
Jacobson 2011	Ineligible publication type
Jacoby 2020	Ineligible population
Jansaithong 2002	Unavailable by deadline
Jerrett 1994	Ineligible population
Johansen 2022	Ineligible population
Johnson 2000	Ineligible population
Johnson 2015	Ineligible publication type
Jones 2019	Ineligible publication type
Jongudomkarn 2006	Ineligible population
Jongudomkarn 2008	Ineligible population
Joslin 2022	Ineligible publication type
Josset-Raffet 2016	Ineligible publication type
Kennedy 2012	Ineligible population
Kenyon 2012	Ineligible population
Khanom 2019	Ineligible publication type
Khanom 2020a	Duplicate
Khazendar 2021	Ineligible publication type
Khemani 2016	Ineligible publication type
Khemani 2018	Ineligible population
Kim 2011	Ineligible population
Kirk 2012	Ineligible population
Kirschbaum 1996	Ineligible population
Knafl 1992	Ineligible population
Kohut 2018	Ineligible population
Kohut 2020	Not chronic pain

Study	Reason for exclusion
Kohut 2021	Ineligible population
Kortesluoma 2004	Ineligible population
Kortesluoma 2006	Ineligible population
Kortesluoma 2008	Ineligible population
Kortesluoma 2008a	Ineligible publication type
Korus 2011	Ineligible population
Korving 2021	Ineligible population
Kosakowski 2022	Ineligible population
Kristjansdottir 2000	Ineligible publication type
Kvarnström 2012	Ineligible population
Kwarteng-Siaw 2017	Ineligible publication type
Lagerløv 2016	Ineligible population
Lai 2012	Ineligible publication type
Lai 2017	Ineligible publication type
Lalla 2010	Ineligible publication type
Lalloo 2013	Ineligible population
Lalloo 2013a	Ineligible publication type
Lalloo 2014	Ineligible population
Lanis 2021	Ineligible publication type
Latimer 2014	Ineligible population
Latimer 2018	Ineligible population
Latimer 2020	Ineligible population
Lauderdale 2003	Unavailable by deadline
Laursen 2019	Ineligible population
Law 2016	Ineligible publication type
Law 2021	Ineligible population
Lee 2022	Ineligible publication type
Lerner 2018	Ineligible publication type

Study	Reason for exclusion
Lesane-Brown 2012	Ineligible publication type
Lewandowski 2005	Ineligible publication type
Lewis 2007	Unavailable by deadline
Lewis 2010	Ineligible publication type
Lewis 2018	Ineligible publication type
Lewis 2018a	Ineligible publication type
Lim 2011	Ineligible publication type
Lindsay 2013	Ineligible population
Liossi 2012	Ineligible population
Lipstein 2013	Ineligible population
Livermore 2016	Ineligible population
Lloyd 2014	Ineligible publication type
Lundberg 2021	Ineligible population
MacGregor 2018	Ineligible publication type
Maciver 2011a	Duplicate
Maciver 2013	Duplicate
Maciver 2014	Duplicate
Mackner 2014	Ineligible population
Maikler 2001	Ineligible publication type
Malcolm 2014	Ineligible population
Marcar 2020	Ineligible population
Mather 2008	Ineligible publication type
Maxwell 1998	Unavailable by deadline
McDonagh 2016	Ineligible population
McGurgan 2021	Ineligible population
McKinnon 2020a	Ineligible publication type
McLeod-Fletcher 1996	Unavailable by deadline
McLeod-Fletcher 1997	Duplicate

Study	Reason for exclusion
Meldrum 2009a	Ineligible population
Melville 2014	Ineligible publication type
Merlijn 2005	Ineligible publication type
Merolli 2014	Ineligible population
Miettunen 2017	Ineligible publication type
Mihelicova 2016	Ineligible population
Miller 2016	Ineligible publication type
Miller 2021	Ineligible publication type
Missen 2012	Ineligible population
Mitchell 2002	Ineligible population
Mittinty 2022	Ineligible population
Modi 2009	Ineligible publication type
Modica 2016	Ineligible publication type
Modica 2017	Ineligible publication type
Modica 2018	Ineligible population
Moghadam 2021	Ineligible population
Molloy 2017	Ineligible publication type
Monsen 1999	Ineligible population
Monterosso 2007	Ineligible population
Mora 2017	Ineligible population
Morgan 2018	Ineligible population
Mosor 2019	Ineligible publication type
Mufti 2014	Ineligible population
Mufti 2015	Ineligible population
Mulchan 2016	Ineligible population
Mulvogue 2009	Ineligible population
Murray 2022	Ineligible population
Nabors 2017	Ineligible population

Study	Reason for exclusion
Namisango 2020	Ineligible population
Navarro 2018	Ineligible population
Ndengeyingoma 2021	Ineligible population
Neville 2021	Ineligible population
Newton 2018	Ineligible publication type
Newton 2021	Ineligible population
Nicholas 2011	Ineligible population
Nichols 2015	Ineligible population
Niekerk 2020	Ineligible population
Nkhoma 2021a	Ineligible publication type
Nkoy 2019	Ineligible population
Noel 2016	Ineligible publication type
Nsangou 2020	Ineligible publication type
Nyante 2019	Ineligible population
Oddy 2000	Ineligible publication type
Ojo 2018	Ineligible publication type
Ojo 2018a	Ineligible publication type
Oreper 2022	Ineligible population
Ortiz 2014	Ineligible publication type
Ostojic 2019	Ineligible publication type
Ostojic 2020	Ineligible publication type
Ostojic 2020a	Ineligible publication type
Packham 2014	Ineligible publication type
Packham 2020	Ineligible population
Palermo 2014	Ineligible publication type
Palsgrove 2014	Ineligible publication type
Panepinto 2011	Ineligible publication type
Pantaleao 2019	Ineligible population

Study	Reason for exclusion
Park 2000	Ineligible population
Peck 2018	Ineligible publication type
Pelaez-Ballestas 2013	Ineligible population
Pendleton 2002	Ineligible population
Peters 2017	Ineligible publication type
Polkki 1997	Unavailable by deadline
Polkki 1997a	Duplicate
Pousette 2019	Ineligible population
Preston 2016	Ineligible publication type
Pölkki 1999	Ineligible population
Qualter 2020	Ineligible publication type
Quintanar-Solares 2013	Ineligible publication type
Rabbitts 2017	Ineligible population
Ramlee 2017	Ineligible population
Randall 2019	Ineligible publication type
Reid 2017	Ineligible publication type
Rich 2000	Ineligible population
Risko 2018b	Duplicate
Roberts 2021	Ineligible population
Roper 2018	Ineligible publication type
Ross 1984	Ineligible population
Rossato 2011	Ineligible publication type
Rossato 2014	Ineligible publication type
Roth 2018	Ineligible population
Roth 2019	Ineligible population
Roth 2020	Ineligible publication type
Rouse 2011	Ineligible population
Rousseau 2007	Ineligible population

Study	Reason for exclusion
Ruddy 2019	Ineligible population
Rullander 2013	Ineligible population
Ruskin 2014	Ineligible publication type
Salvo 2022	Ineligible publication type
Sangha 2021	Ineligible population
Santos 2013	Ineligible population
Santos 2017	Ineligible publication type
Savedra 1981	Ineligible publication type
Schultz 2010	Ineligible population
Schulz 2014	Ineligible publication type
Scorgie 1996	Ineligible population
Seangrung 2021	Ineligible population
Shaw 2004	Ineligible population
Sil 2021	Ineligible publication type
Simon 1992	Ineligible population
Simons 2020	Ineligible population
Skarstein 2020	Ineligible population
Slater 2016	Ineligible population
Smeland 2019	Ineligible population
Smith 2018	Ineligible publication type
Smith 2022	Ineligible population
Snelgrove 2015	Ineligible population
Snyder 2001	Ineligible population
Solodiuk 2020	Unavailable by deadline
Solomon 2016	Ineligible population
Solyom 2017	Ineligible publication type
Sparapani 2015	Ineligible population
Spiers 2016	Ineligible population

Study	Reason for exclusion
Stebbins 2018	Ineligible publication type
Stebbins 2018a	Ineligible publication type
Stefanatou 1997	Ineligible publication type
Stegenga 2004	Ineligible population
Stenekes 2009	Ineligible publication type
Stenner 2016	Ineligible population
Stewart 2011	Ineligible population
Stinson 2006	Ineligible population
Stinson 2015	Ineligible publication type
Stinson 2016	Ineligible publication type
Stinson 2016a	Ineligible publication type
Stratton 2011	Ineligible population
Strauss 2019	Ineligible population
Suder 2017	Ineligible publication type
Svedberg 2010	Ineligible publication type
Swallow 2011	Ineligible population
Swallow 2013	Ineligible population
Swift 2014	Ineligible population
Szentagotai 2005	Unavailable by deadline
Sällfors 1999	Unavailable by deadline
Sällfors 2003	Unavailable by deadline
Tanabe 2013	Ineligible population
Tapping 2015	Ineligible publication type
Tapping 2015a	Ineligible publication type
Taub 2000	Ineligible population
Tekano 2014	Ineligible publication type
Tetzl 2017	Ineligible publication type
Timko 1992	Ineligible publication type

Study	Reason for exclusion
Toupin 2020	Ineligible publication type
Toupin-April 2018	Ineligible publication type
Toupin-April 2018a	Ineligible publication type
Toupin-April 2020	Ineligible publication type
Trennery 2019	Ineligible publication type
Treves 1999	Ineligible population
Trope 2018	Ineligible publication type
Tuchman 2008	Ineligible population
Unruh 1983	Ineligible publication type
Vaienzuela 2010	Ineligible publication type
Vaira-Joyce 2022	Ineligible population
van Staa 2011	Ineligible population
Varni 2012	Ineligible population
Varni 2012a	Duplicate
Vendetti 2016	Ineligible publication type
Venner 2014	Ineligible publication type
Vera 2015	Ineligible publication type
Vervoort 2008	Ineligible publication type
Vine 2020	Ineligible population
Visram 2013	Ineligible population
Visram 2017	Ineligible population
von Scheven 2021	Ineligible population
Vuorimaa 2013	Ineligible publication type
Wainwright 2022	Ineligible population
Waite-Jones 2008a	Ineligible population
Wakefield 2020	Ineligible publication type
Ware 2014	Ineligible publication type
Warnink-Kavelaars 2019	Ineligible population

Study	Reason for exclusion
Warnink-Kavelaars 2019a	Ineligible population
Webb 2011	Ineligible population
Wells 2013	Ineligible population
Westesson 2018	Ineligible population
Wihak 2020	Ineligible publication type
Williams 2001	Ineligible population
Williams 2011	Ineligible population
Witwicki 2015	Ineligible publication type
Wong 2019	Ineligible publication type
Wren 2021	Ineligible population
Wren 2022	Ineligible population
Wright 2015	Ineligible population
Yeh 2018	Ineligible population
Young 2020	Ineligible population
Zabalia 2013	Ineligible publication type
Zeevenhooven 2020	Ineligible publication type
Zengin 2017	Ineligible publication type

ADDITIONAL TABLES

Table 1. Findings of included studies

Pain condition grouping	Authors' first-order constructs (e.g. descriptive themes) or second-order constructs (e.g. concepts) from included primary studies	Review authors' second-order constructs from our initial interpretation of the study (created if author findings were descriptive)

Sickle cell disease	Atkin 2000
	• Coping with a haemoglobinopathy
	  ◦ Family relationships and coping
	• Service provision, coping and racism
	  ◦ Competence of health professionals
	  ◦ Information
	• The vulnerability of coping strategies
		• Balance
		• Embrace medical model
		• Engulfment
		• Mastery
		• Positive framing and normalisation
		• Racism
		• Religion

Table 1. **Findings of included studies** *(Continued)*

	Atkin 2001 • Coping with a chronic Illness ◦ Coping with uncertainty ◦ Religion and coping ◦ The importance of medical information ◦ Social and emotional factors • Coping with the response of others	• Maintaining sense of normalcy • Ambivalent relationship with parents • Disabling attitudes and discrimination • Dynamic nature of coping • Guilt and coping • Healthcare professionals lack of knowledge and ignorance • Maintaining a positive framing • Medical model and coping • Peer relationships • Relationships with healthcare professionals • Religion and coping • Social support • Why me? Sense of difference
	Atoui 2015 • Pain • Divine intervention • Family as a source of support and a source of guilt • Psychosocial and physical limitations • School issues	• Defined and limited by pain • Downplaying pain and acceptance (These 2 concepts were analysed in addition to the descriptive themes on the left)
	Dyson 2011 • Capital gained capital lost • Habitus and fragile dispositions • The field of the school-habitual ‘dyspositions’	• Capital: being excluded from school and peers • Capital: the impact of social class • Field of clinic: school routines undermines self-care • Field of school: pain and condition undermines learning • Field of school: school lacks support structure • Habitus: lack of understanding • Habitus: pressure to account for themselves or to explain condition • Habitus: the dilemma of disclosure • Habitus: transforming fragile dispositions through school policies
	Renedo 2019 • Barriers to receiving good, personalised and responsive care not being heard ◦ Being denied timely and adequate pain relief ◦ Body management and basic care needs ignored • Feeling out of place, unwelcoming adult wards • Trying hard to stay out of hospital	Not applicable (i.e. study authors’ reached level of second-order constructs)
	Njifon 2019	Not applicable

Table 1. Findings of included studies *(Continued)*

	• The adults' behaviour (Comportement des adultes) • The way in which the illness affects the family unit (Du «on» à l'impact de la maladie sur le groupe familial) • Guilt (La Culpabilité) ◦ Aggression directed at the ill child (Agressivité dirigée contre le malade) ◦ Painful feeling of powerlessness (Douloureux sentiment d'impuissance) ◦ The children's guilt (La culpabilité des enfants) • The meaning of sickle cell disease (La drépanocytose, son sens) • The question of death (La question de la mort) ◦ Death of the ill child and survival of the illness (Mort Du Malade et Survie De La Maladie) ◦ A fear that never ends (Une peur qui ne cesse jamais) • Loneliness and adults lack of interest (La solitude et le manque d'intérêt des adultes) • Is the sick child a brother? (Le malade est-il un frère?)	
Unspecified type of chronic pain	Nutkiewicz 2008 • Separate orientations/separate vocabularies • What oral testimonies teach us about the world of children in pain	• What makes a good doctor • The social and private world of children in pain • Search for a diagnosis is frustrating • Patients seek more than pain relief • Children are frustrated with treatment • Children and their doctors have 2 separate orientations
	Kanstrup 2019 • 'Warning system' ◦ Buying into a psychological approach ◦ Reframing the experience of pain • Change and challenges ◦ Values: doing what matters to you ◦ 'Getting the idea': the need for adaptation • 'A common language' ◦ Thinking outside the bubble • A new dialogue	Not applicable
Neurological conditions	Carter 2002b • Making decisions: managing pain and dealing with professionals • Dealing with uncertainty • Expression of pain • Learning to live with pain	• Dealing with professionals • Making decisions managing pain
	Hunt 2003 • Identifying pain ◦ A process of elimination: hypothesis testing ◦ Comparing with normal: knowing the child ◦ Inferring pain ◦ Intuition	Not applicable

Table 1. Findings of included studies *(Continued)*

	◦ Paying attention to parents and child • Management of pain ◦ Clinical and ethical decision-making • Types of pain	
	Castle 2007 • Being in pain • Doing anything to get rid of the pain • Enlisting help • Fighting the pain • Looking ahead • Making sense of the pain • The experience of chronic pain	Not applicable
	Carter 2017 • Developing a sense of knowing ◦ Learning to be a convincing advocate ◦ Learning to endure and finding a balance ◦ Learning to know without a rule book or guide	Not applicable
	McKinnon 2022 • The continual challenge of problem-solving pain and dyskinesia • The pursuit of a solution • Unfulfilled preferences within pain management • All-encompassing effects on families • The ongoing impacts of pain and dyskinesia with age	Not applicable
Musculoskeletal chronic pain	Khanom 2020 • Daily life with pain • Preflare period • Pain flare period • Postflare period	• Pain affects young people's relationship with family members • Persistent/constant background pain becomes 'normal' to children and young people • Uncertainty and anxiety: fluctuating nature of (complex regional pain syndrome/juvenile idiopathic arthritis) pain with pain 'flares,' which are difficult-to-manage pain and lead to uncertainty in regard to consequences on children and young people's future, anxiety and psychological impact of the pain
	Forgeron 2008 • Dealing with the pain • Healthy is being normal • Management strategies • Relating to friends • Relating to peers and society interferes with being normal • Struggling to be normal • Transitioning: not yet • Trying to be normal at school	• The challenges of transitioning to adult clinic: not ready for adult care, still dependent on parental involvement • Strategies to help young people to do well in school • Frustration of young people trying to succeed in school despite missed schooling • (Young people) support from another peer with chronic pain

Table 1. Findings of included studies *(Continued)*

		• Use of analgesics • Young people see restrictions caused by pain as unhealthy (pain is not 'normal' and healthy) • Trade-off: children and young people trade off fun activity (e.g. they 'pack it in' when feeling well) for the necessary consequence of increased pain • Stigma: feel stigmatised by acquaintances/strangers reactions to and treatment of them • Paradox of children and young people viewing themselves as different/abnormal but not wanting to be seen by others as different
	Ahlqwist 2012 • Compliance with physiotherapy • Gaining energy from pain-free moments • Mobilising their own resources • Coaching from the physiotherapist • Seeking for information	• Children and young people developing awareness of their bodies and pain (and being aware of inherent capabilities) • (Children and young people) seeking information • Children and young people's trust in physiotherapist and hope of cure/pain relief • Adherence/compliance (children and young people) • Positive aspects of treatment/physio programme (control) (children and young people) • Children and young people empowerment through physio programme/empowerment of children and young people through successful outcomes from physio • Contextual understanding of low back pain from physio (such information was not found through children and young people searching Internet sources) helps with finding a solution to pain
Abdominal pain	Brodwall 2018 • Desire for a specific diagnosis and discussion with a professional • How the pain rules the family • Interpreting and handling the child's pain	Not applicable
	Smart 2005 • Beliefs about doctors • Beliefs about mothers • Beliefs about the pain • Interactions with doctors	• Child health is a mother's responsibility
Complex regional pain syndrome	Gaughan 2014	• Readmission

Table 1. Findings of included studies *(Continued)*

	• Suffering and disempowerment
	  ○ Parent distress
	    ■ Disabled parenting
	    ■ Schism in parenting
	    ■ Searching
	    ■ Lack of control
	    ■ Family: community
	    ■ Fear
	• Empowerment
		(analysed in addition to the themes on the left)

	Jones 2020 • Adjusting to loss • Centrality of loss	Not applicable
Dysmenorrhoea	Wong 2016 • Lifestyle changes • Careful selection of diet • Reduced physical activity • Symptom management • Heat therapy • Self-medication • Communicating dysmenorrhoea with others • Family • Friends • Seeking medical advice • Western medical practitioners • Chinese medicine practitioners	• Self-care strategies • Dysmenorrhoea as 'normal pain' that has to be endured • Embarrassment associated with menstruation (impairs communication about period pain) • Mothers assume responsibility for their child's pain management • Girls suffer unnecessary pain
Epidermolysis bullosa	Williams 2008 • Talking about those with worse epidermolysis bullosa • The importance of belonging • Physical activity and identity • Self as 'wrong' • Self as 'burden' • Self as different • Self as weak • Special treatment • Expression of feelings as unacceptable • Helplessness • Lack of understanding regarding epidermolysis bullosa • Negative treatment from others: visibility and contagion • Control over physical activity • Coping with pain • Defining self in terms of physical activity	• Young people's beliefs on their own experiences (causes feelings of guilt) • Support from peers with epidermolysis bullosa (young people) • Self-identity (young people) • Stigma (young people) • Describing pain is difficult for young people • Young people's dependence on mother • Young people gaining a sense of choice by prioritising physical activity • Young people dealing with feelings about/managing condition
Headache	Helvig 2013 • Disengage and isolate self • Mind overload • Unsettling manifestations: physical • Unsettling manifestations: psychological	• Uncontrolled pain • Unknown cause of pain

Table 1. Findings of included studies *(Continued)*

	• Maintaining control • Press on and endure the burden	

Juvenile idiopathic arthritis	Britton 2002a
	• Siblings perspective
	  o Play, leisure and troubled sibling relationships
	• Recognition of grandparents contributions
	• Perspectives of children with arthritis
	  o Feeling different
	  o Children and pain
	• Mothers' experiences
	  o Cycles of parental grieving (chronic sorrow)
	• Fathers' experiences
		• Wider family support
		• Shared sense of parent child identity with regard to juvenile idiopathic arthritis
		• Parent's life greatly changed
		• Parental helplessness and powerlessness
		• Parental healthcare professionals communication
		• Feeling different
		• Life greatly changed
		• Enhanced sibling protectiveness and compassion
		• Cyclical mastery of skills and self-perception
		• Cycles of parental grieving (chronic sorrow)
		• Normal to be in pain
		• Becoming a carer not just a parent
		• Experiences of health services

	Britton 2002b
	• The families' experience of splinting
	• Families' experiences of exercise programmes
	  o Time taken to undertake exercise routine
	  o Stages in families deciding their own level of adherence
	  o Parents' feelings about supervising the exercise routine
	  o Pain and boredom
	  o Maternal 'sense of mastery'
	  o Maternal reticence to seek advice
	  o Learning that exercises were important
	  o Conflicting advice from professionals
	  o Conflict between parents
	• Unpredictable times of adversity
	• Predictable times of distress
	• Model of families' experience of living with a child with arthritis
		• Psychosocial impact of disease and management is key
		  o Psychosocial impact neglected by healthcare professionals
		  o Ill child focus in home
		  o Conflict over physiotherapy
		• Parents knowledge of regimen affects adherence and efficacy
		• Pain and boredom from physiotherapy
		• Inconsistent healthcare professionals advice undermines trust
		• Family factors affecting physiotherapy adherence
		• Barriers to accessing services
		  o Consequences of difficulties accessing services

	Rossato 2007
	• Care delivery for the child to grow up
	  o Wanting to see the child free from pain
	    ■ Having to live with uncertainties
	    ■ Living in function of the child
	    ■ Overcoming barriers
	    ■ Wanting to get out of this nightmare
	  o Wanting to see the child lead a normal life
	  o Leading the child's life normally
	  o Preparing the child to live with the disease situation
	  o Waiting for a miracle
	• Wanting a good future
		• Managing uncertainty
		• Want miracle, end nightmare
		• Balance
		• Complexity of a diagnosis
		• Establishing normalcy over time

Table 1. Findings of included studies *(Continued)*

	Guell 2007
	• Normal childhoods
	  ◦ Feeling healthy
	  ◦ Hiding illness
	  ◦ Normalising abnormality
	• In the face of uncertainty
	  ◦ Disciplining the body
	  ◦ Facing diagnosis
	  ◦ Learning the language
	  ◦ Taking control
	• Sheltered bodies and mature minds
	  ◦ Cosseting childhoods
	• Taking responsibility and making decisions
		Not applicable

	Waite-Jones 2008 • Social contagion • Social comparison • Social and emotional adjustment • Emotional contagion • Amplified ambivalence	Not applicable

	Cartwright 2015
	• Striving to be a normal teenager
	• Resilience though taking control
	  ◦ Taking charge and overcoming limitations
	  ◦ Social support as an enabler
	  ◦ Minimisation and distraction
	  ◦ Disclosure or concealment
	• Burden of juvenile idiopathic arthritis
	  ◦ The future and managing uncertainty
	  ◦ Physical vulnerability and isolation
	• Acceptance and self-growth
		Not applicable

	Brandelli 2021 • Shifting roles • Altered relationships • Emotional well-being • Internal conflict	Not applicable

	McDonagh 2021
	• Struggle for help
	  ◦ Divergence in care
	  ◦ A fight for everything
	  ◦ Need for support
	• Mothers know best
	  ◦ Parent and child communication
	  ◦ Social support between mothers
	• Daily impacts
	  ◦ Living a life for 2 people
	• Not a regular family
		Not applicable

Table 1. Findings of included studies *(Continued)*

Mixed types of chronic pain	Carter 2002a • No one's pain is the same, it is always there • Getting on with it • It depends... some are OK	Not applicable
	Carter 2002 • The quest for a diagnosis and referral fatigue • Professional judgement and disbelief • Professionals who believed the family • Communication or ventriloquism	Not applicable
	Maciver 2010 • Complex parenting • Development of adaptative responses to child's distress	• Parental efficacy • Stepping back • Loss of normal parenting role • Fearful responses from parents • Being on call • Disrupted development
	Maciver 2011 • The in-patient pain management programme experience • Practical and emotional support • Relationships with professionals • Misaligned expectations • Pain conveying difficult messages to parents • Disenchantment	Not applicable
	Maciver 2005 • The prediagnosis phase: diagnosis • Prediagnosis: parental responses searching for information • The prediagnosis phase • Prediagnosis phase: expectations • Prediagnosis: medical disbelief • Treatment: wheelchairs and walking misaligned goals • Treatment: the role of the psychologist • Treatment: tertiary referral service pain clinic • Treatment: tertiary referral serviced inpatient pain management • Treatment: pain conveying difficult messages to parents • Treatment: continuing disbelief • Treatment: expectations • Treatment: being in hospital • Parenting: striking a happy balance • Parenting: uncertainty • Parenting: sadness • Parenting: sleep deprivation • Parenting: pacing and balance • Parenting: not being able to plan for the future • Parenting: not being normal • Parenting: non-normative, failed and disrupted parenting • Parenting: normal childhoods and normal families • Parenting: marital tension	Not applicable

Table 1. Findings of included studies *(Continued)*

• Parenting: losing the opportunity to be spontaneous • Parenting: loss of work • Parenting: impact on self emotional and practical consequences • Parenting: living a restricted life • Parenting: fear of the future • Parenting: helplessness • Parenting: engulfment • Parenting: encouraging communication • Parenting: encouraging discouraging participation in activities • Parenting: dealing with the emotional impact on the child • Parenting: developing adaptative responses to the child's distress • Parenting: being on call • Parenting: complex parenting • Parenting: anger, depression and behaviour problems • Parental: practical consequences • Parental: emotional consequences • Healthcare struggling for support	
Dell'Api 2007 • Difficulties in living a normal life • Wiping their hands clean • The search for understanding • They don't believe me • Seeing is believing • Sometimes they are helpful, sometimes they are not • Pain is something that cannot be cured • Perceptions of chronic pain influenced by healthcare professional interactions • If they cannot see it, it is not there • Impact of previous experiences on current encounters with healthcare professionals • I must be dying • Fears for the future • Guarded alliance living with scepticism	Not applicable
Jordan 2007 • What is next • Not going back • In limbo • Diagnosis as proof of pain • Fight for resources	Not applicable
Borghi 2014 • Seeking a life that is closer to normality • Using various alternatives for managing pain • Living with a damaged self-image	Not applicable
Jordan 2016 • Helplessness	Not applicable

Table 1. Findings of included studies *(Continued)*

	• Re-evaluation • Containment	
	Suder 2016 • Uphill climb to regain life • Uncertainty of disease • Unknown future • Push through the pain • Pain becoming the main occupation • Pain identity • Occupational loss • Invisible disease • Loss of independence • Changes in self • Fabrication of symptoms	Not applicable
	Jordan 2018 • An externally imposed lens on identity • Paradoxes of developmental progress	Not applicable
	Neville 2019 • Mistrust in the medical system • Haunted by something missing • The function of a diagnosis	Not applicable
	Baert 2020 • You are making it up • Describing pain • Not everybody gets a healthy child • The problem is a problem with the mother • At least it is not cancer	Not applicable

	Jones 2022
	• Tug of war: push and pull
	  ○ The shifting sands of peer relationships
	  ○ Restricted choices
		Not applicable

Table lists authors' findings (first- or second-order constructs) in included studies and our second-order constructs, which were developed if the included study had only descriptive findings

Table 2. Development of third-order constructs within pain condition groupings

Pain condition grouping	Second-order constructs from included primary studies (either the authors' or the review authors')	Common or unique second-order constructs from included studies (Phase 5 translation)	Third-order constructs (interpreted by review authors) (Phase 6 synthesising translations)
Sickle cell disease	Atkin 2000	• Mastery versus engulfment	Control (perceived control and per-

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

• Mastery • Engulfment Atkin 2001 • Dynamic nature of coping Dyson 2011 • Impact of social class (young people)	• Making sense of sickle cell disease pain	ceived lack of control) (children and young people and parents)
Atkin 2000 • Balance Atkin 2001 • Why me? Sense of difference • Religion and coping Atoui 2015 • Maintaining sense of normalcy • Downplaying pain and acceptance • Defined and limited by pain • Psychosocial and physical limitations	• Trying to be normal • Sense of difference: why me?	Trying to live a normal life (children and young people and parents)
Atkin 2000 • Embrace medical model Atkin 2001 • Medical model and coping • Relationships with healthcare professionals • Healthcare professionals lack of knowledge and ignorance Renedo 2019 • Body management and basic care needs ignored • Being denied timely and adequate pain relief • Feeling out of place, unwelcoming adult wards • Trying hard to stay out of hospital	• Mistrust in medical system • Healthcare professionals lack of knowledge (of sickle cell disease pain) inadequate pain relief in hospitals • Importance of healthcare professionals relationship	Loss of faith and trust in medical systems
Atkin 2001 • Healthcare professionals lack of knowledge and ignorance Renedo 2019 • Trying hard to stay out of hospital • Feeling out of place, unwelcoming adult wards • Being denied timely and adequate pain relief Dyson 2011 • Field of clinic: school routines undermines self-care	• Schools and hospitals undermine self-care	Self-management of painful episodes (adolescents)

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	Atkin 2000 • Mastery • Engulfment • Balance Atkin 2001 • Guilt and coping • Religion and coping • Emotional coping strategies • Social support • Maintaining a sense of normalcy • Dynamic nature of coping • Medical model and coping • Embrace medical model Atoui 2015 • Psychosocial and physical limitations • Downplaying pain and acceptance	• Coping strategies: effective versus ineffective	Coping strategies and vulnerabilities (children and young people and parents)
	Atkin 2001 • Disabling attitudes and discrimination Atoui 2015 • School issues Dyson 2011 • Field of school: pain and condition undermines learning • Habitus: transforming fragile dispositions through school policies • Field of clinic: school routines undermines self-care • Habitus: lack of understanding • Capital: being excluded from school and peers • Field of school: school lacks support structure	• Schools undermine self-care and learning	Unsafe and unprepared schools (children and young people)
	Atkin 2001 • Emotional coping strategies Atoui 2015 • Family as a source of support and a source of guilt Njifon 2019 • Adults' behaviour (Comportement des adultes) • Is the sick child a brother? (Le malade est-il un frère?) • The children's guilt (La culpabilité des enfants) • Anger and aggression directed at the sufferer (Agressivité dirigée contre le malade) • The never-ending fear (Une peur qui ne cesse jamais)	• Ambivalent family relationships • Guilt of child/siblings • Role of parents as carers and acceptance/resignation	Ambivalent family relationships (children and young people and parents)

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

• The way in which the illness affects the family unit (Du «on» à l'impact de la maladie sur le groupe familial) • Loneliness and adults' lack of interest (La solitude et le manque d'intérêt des adultes)		
Atkin 2001 • Peer relationships • Why me? Sense of difference • Disabling attitudes and discrimination Atoui 2015 • Psychosocial and physical limitations Dyson 2011 • Habitus: the dilemma of disclosure • Capital: being excluded from school and peers • Habitus: pressure to account for themselves or to explain condition • Field of school: pain and condition undermines learning • Habitus: lack of understanding	Same as second-order constructs in column 2 - no common concepts identified	Ambiguity of social relationships
Atoui 2015 • Psychosocial and physical limitations • Defined and limited by pain Njifon 2019 • Death of the ill child and survival of the illness (Mort Du Malade et Survie De La Maladie)	Same as second-order constructs in column 2 - no common concepts identified	Disabling and psychosocial effects of pain/sickle cell disease
Atkin 2001 • Disabling attitudes and discrimination Atoui 2015 • School issues • Defined and limited by pain Dyson 2011 • Field of school: school lacks support structure • Habitus: lack of understanding • Habitus: transforming fragile dispositions through school policies • Habitus: the dilemma of disclosure Renedo 2019 • Being denied timely and adequate pain relief • Body management and basic care needs ignored Atkin 2000 • Service provision, coping and racism	• Racism and disabling attitudes (in schools, health services) towards young people • Schools and hospitals undermine self-care • Pain is invisible and disbelieved (by healthcare professionals and teachers) (inefficient, ineffective pain management (and interferes with self-care))	Racism and disabling attitudes

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

Unspecified chronic pain	Nutkiewicz 2008 • (Children and young people perceive that) healthcare professionals ignore young people's lived experience of chronic pain • Holistic biopsychosocial care is what makes a good doctor Kanstrup 2019 • Psychological approach helpful for reframing the experience of pain versus a last-ditch treatment • Pain education component of acceptance and commitment therapy treatment aids understanding chronic pain as biopsychosocial	Same as second-order constructs in column 2 - no common concepts identified	Biomedical perspective of pain a barrier to effective treatment, biopsychosocial perspective is a facilitator/the need for holistic biopsychosocial care
Neurological conditions	Carter 2002b • Dealing with uncertainty • Expression of pain Carter 2017 • Learning to know without a rule book or guide • Developing a sense of knowing Hunt 2003 • A process of elimination: hypothesis testing • Intuition • Comparing with normal: knowing the child • Inferring	• Parents become experts in assessing their non-verbal child’s pain • Healthcare professionals do not know the child like parents do	Parent’s expert and intuitive/subjective knowledge of their child’s pain
	Carter 2002b • Making decisions managing pain Carter 2017 • Learning to endure and finding a balance Hunt 2003 • Clinical and ethical decision-making	• Parents often have to manage pain and make difficult decisions about this on their own • Healthcare professionals rarely witness pain episodes, so can distance themselves from making the hard decisions	Parents managing pain and making difficult decisions about this alone
	Carter 2002b • Dealing with uncertainty Carter 2017 • Learning to be a convincing advocate	• Parents as advocate for effective pain management	Parents as healthcare advocates
	Carter 2002b • Dealing with uncertainty • Expression of pain Carter 2017 • Developing a sense of knowing • Learning to know without a rule book or guide	• Healthcare professionals do not know the child like parents do • Fragmented medical systems are a barrier for diagnosing pain and pain management	Visible diagnosis, invisible child/pain

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	• Learning to be a convincing advocate Hunt 2003 • Comparing with normal: knowing the child • Management of pain		
	Castle 2007 • Enlisting help Hunt 2003 • Paying attention to parents and child • Clinical and ethical decision-making • Identifying pain	• Parents value healthcare professionals that listen to them and respect their expertise	Healthcare professionals should believe the pain is real/establishing the legitimacy of the pain
	Carter 2017 • Developing a sense of knowing Castle 2007 • Enlisting help Hunt 2003 • Paying attention to parents and child • Clinical and ethical decision-making • Identifying pain	• Parents value healthcare professionals that listen to them and respect their expertise	Parents value validation from healthcare professionals
	Carter 2002b • Learning to live with pain Castle 2007 • Fighting the pain • Being in pain • Looking ahead • Doing anything to get rid of the pain • Making sense of the pain • The experience of chronic pain • Doing anything to get rid of the pain	• Some children feel that the pain takes over their lives whereas others see pain as just another obstacle • Some are desperate for a cure and would try any treatment but ended giving up the fight	Children's and parent's varied experiences/perceptions of pain
Musculoskeletal conditions	Khanom 2020 • Daily life with pain • Preflare period • Pain flare period Forgeron 2008 • Strategies to help young people to do well in school • Management strategies Ahlqwist 2012 • Positive aspects of treatment/physio programme • Seeking information	• Finding equilibrium in everyday life (with pain management • Pain management strategies (including pacing) • Developing awareness (and being aware of inherent capabilities) • Seeking information	Young people's strategies to restore 'control' of daily life and pain

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

• Coaching from the physiotherapist • Gaining energy from pain-free moments • Mobilising their own resources • Management strategies		
Forgeron 2008 • Healthy is being normal • Relating to peers and society interferes with being normal • Struggling to be normal • Trying to be normal at school Khanom 2020 • Postflare period Ahlqwist 2012 • Gaining energy from pain-free moments • Mobilising their own resources • Management strategies	• Young people trying to live a normal live (which is challenged by peers/school and pain/restrictions) • Young people see restrictions caused by pain as unhealthy (pain is not ‘normal’ and healthy) • Frustration young people trying to succeed in school despite missed schooling • Finding equilibrium in everyday life (with pain management/young people)	Young people’s desire to live a normal life challenged by all aspects associated with chronic pain (which causes feeling of powerlessness and frustration)
Ahlqwist 2012 • Mobilising their own resources Forgeron 2008 • Relating to friends • Relating to peers and society interferes with being normal • Struggling to be normal • Trying to be normal at school Khanom 2020 • Pain flare period • Postflare period	• Pain affects young people’s relationship with family members • Pain complicates young people’s relationship with friends • Trying to live a normal live (which is challenged by peers/school and pain/restrictions)	Pain affects social role of young people (with family, friends and peers)
Ahlqwist 2012 • Mobilising their own resources Forgeron 2008 • Dealing with the pain • Healthy is being normal • Relating to peers and society interferes with being normal • Struggling to be normal Khanom 2020 • Pain flare period	• Young people see restrictions caused by pain as unhealthy (pain is not ‘normal’ and healthy) • Identity crisis/issues: stigma, lower self-esteem, feel abnormal • Stigma: feel stigmatised by acquaintances/ strangers reactions to and treatment of them • Paradox of children and young people viewing themselves as different/abnormal but not wanting to be seen by others as different • Negative spiral of chronic pain	Pain negatively affects young people’s self-identity (stigma, lower self-esteem, feel abnormal but want to be treated as normal)

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	Ahlqwist 2012 • Compliance with physiotherapy	• Adherence/compliance	N/A (no third-order constructs could be developed)
Abdominal pain	Brodwall 2018 • Desire for a specific diagnosis and discussion with a professional Smart 2005 • Beliefs about doctors • Interactions with doctors • Beliefs about the pain	• Factors preventing parents to seek psychosocial support	The complexity of (accessing and accepting) psychosocial support (parents)
	Brodwall 2018 • Desire for a specific diagnosis and discussion with a professional Smart 2005 • Interactions with doctors	Same as second-order constructs in column 2 - no common concepts identified	Importance of diagnosis (for parents)
	Brodwall 2018 • Desire for a specific diagnosis and discussion with a professional • Interpreting and handling the child's pain Smart 2005 • Beliefs about doctors • Interactions with doctors	Same as second-order constructs in column 2 - no common concepts identified	Parents interaction/relationship with healthcare professionals and desired outcomes
	Smart 2005 • Beliefs about mothers • Interactions with doctors	Same as second-order constructs in column 2 - no common concepts identified	Parents/mother (feel like they) have to recognise and manage child's pain (by using intuition/sense of knowing)
	Brodwall 2018 • Desire for a specific diagnosis and discussion with a professional Smart 2005 • Beliefs about doctors • Beliefs about the pain • Interactions with doctors	Same as second-order constructs in column 2 - no common concepts identified	Parents biomedical versus psychosocial orientation
	Brodwall 2018 • Interpreting and handling the child's pain Smart 2005 • Beliefs about mothers	• Mothers feeling judged by healthcare professionals (maternal competence) • Child health is a mother's responsibility	Mothers feel responsible for child's health and feel judged by healthcare professionals

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	• Interactions with doctors		
Complex regional pain syndrome	Gaughan 2014 • Fear • Parent distress • Lack of control • Family: community • Disabled parenting Jones 2020 • Adjusting to loss	• Parental and child suffering: children and young people experience loss, grief, hopelessness; parents also suffer	Chronic pain makes the future uncertain
	Gaughan 2014 • Lack of control • Disabled parenting • Family: community • Schism in parenting • Parent distress • Searching • Fear • Parent distress Jones 2020 • Adjusting to loss • Centrality of loss	• Parents perceive that pain is controlling whole family life • Chronic pain interferes with coping, leading to withdrawal from activities and 'new normal' • Unbalanced family dynamics • Loss of identity (children and carer) • Non-normative parenting • Searching for information to regain control over parenting (sometimes created more fear)	Parent and child loss of control
	Gaughan 2014 • Family: community • Disabled parenting Jones 2020 • Adjusting to loss	• Parents' dilemma of disclosing condition/social disbelief • The importance of parents being understood • Children's anticipation of social loss	Importance of social context
	Gaughan 2014 • Empowerment • Disabled parenting • Readmission Jones 2020 • Adjusting to loss • Centrality of loss	• Factors affecting adherence • Children wish to learn how to cope better with pain • Parents search tirelessly for a cure • Importance of adapting parenting skills as a treatment outcome	Important treatment outcome
	Jones 2020 • Adjusting to loss	• Children's pursuit of meaning	N/A (no third-order constructs could be developed)
	Gaughan 2014 • Family: community	• Protecting other family members (grandparents) • Siblings needs are neglected	N/A (no third-order constructs could be developed)

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

Dysmenorrhoea	Wong 2016 - Family - Friends	- Embarrassment associated with menstruation (impairs communication about period pain) between girls and family - Mothers assume responsibility for their child's pain management	N/A (no third-order constructs could be developed)
	Wong 2016 - Chinese medicine practitioners	- Girls suffer unnecessary pain (without effective pain relief)	N/A (no third-order constructs could be developed)
Epidermolysis bullosa	Williams 2008 - Self as 'burden' - Talking about those with worse	- Young people's beliefs on their own experiences (causes feelings of guilt)	N/A (no third-order constructs could be developed)
	Williams 2008 - The importance of belonging - Self as 'wrong' - Self as different - Special treatment - Negative treatment from others: visibility and contagion - Lack of understanding regarding epidermolysis bullosa - Control over physical activity - Coping with pain	- Support from peers with epidermolysis bullosa (young people's views) - Self-identity (young people) - Stigma (young people) - Young people gaining a sense of choice by prioritising physical activity - Young people dealing with feelings about/managing condition	N/A (no third-order constructs could be developed)
	Williams 2008 - Expression of feelings as unacceptable	- Describing pain is difficult for young people	N/A (no third-order constructs could be developed)
	Williams 2008 - Helplessness	- Young people's dependence on mother	N/A (no third-order constructs could be developed)
Headache	Helvig 2013 - Disengage and isolate self - Mind overload - Unsettling manifestations: physical - Unsettling manifestations: psychological - Maintaining control - Press on and endure the burden	- Uncontrolled pain - Unknown cause of pain	N/A (no third-order constructs could be developed)
Juvenile idiopathic arthritis	Britton 2002a - Cycles of parental grieving (chronic sorrow) - Cyclical mastery of skills and self-perception - Parent's life greatly changed Britton 2002b - Unpredictable times of adversity	- Negative impact of juvenile idiopathic arthritis on child's mental health - Unrecognised negative mental health impacts and psychosocial impacts on parents, siblings and families: unmet psychosocial needs of families	Negative psychosocial/mental health impacts of juvenile idiopathic arthritis on whole family (child, parents, siblings)

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	- Predictable times of distress - Psychosocial impact neglected by healthcare professionals Waite-Jones 2008 - Emotional contagion - Physical vulnerability and isolation Cartwright 2015 - Burden of juvenile idiopathic arthritis - Physical vulnerability and isolation	- Parental ongoing grieving	
	Guell 2007 - Facing diagnosis Britton 2002a - Family life greatly changed Rossato 2007 - Balance my node - Complexity of a diagnosis Britton 2002b - Psychosocial impact of disease and management is key - Family factors affecting physio adherence - Conflict over physio - Ill child focus in home	- Juvenile idiopathic arthritis dominates and strains family life and changes family dynamics - Emotional impact of diagnosis on parents: relief and fear - Psychosocial impacts of prescribed treatment: distress, conflict, uses family leisure time	Juvenile idiopathic arthritis and its management dominates and strains family life and changes family dynamics
	Britton 2002a - Cyclical mastery of skills and self-perception Guell 2007 - Normalising abnormality - Feeling healthy - Hiding illness Cartwright 2015 - Physical vulnerability and isolation - Acceptance and self-growth - Striving to be a normal teenager - Minimisation and distraction	- Impact on child's identity - Want to be a normal child and young person like peers - Acceptance and self-growth - Coming to accept juvenile idiopathic arthritis and come to terms with it - Children and young people: disclosure versus concealment of juvenile idiopathic arthritis (conflicting feelings about disclosing)	Impact on child's self-identity
	Britton 2002a - Feeling different Rossato 2007 - Balance - Establishing normalcy over time Guell 2007	- Want to be a normal child and young person like peers - Children and young people: disclosure versus concealment of juvenile idiopathic arthritis (conflicting feelings about disclosing) - Trying to achieve a 'new normality'	Trying to achieve a 'new normality'

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	• Normalising abnormality • Facing diagnosis • Taking control Waite-Jones 2008 • Social comparison Cartwright 2015 • Taking charge and overcoming limitations	• Child and family try to gain control over juvenile idiopathic arthritis and pain • Illness management (medical and parental) dominates child's life (and body)	
Mixed conditions	Carter 2002 • The quest for a diagnosis and referral fatigue • Professional judgement and disbelief • Professionals who believed the family • Communication or ventriloquism Carter 2002a • It depends... some are OK Maciver 2005 • Healthcare struggling for support • The prediagnosis phase • Prediagnosis: medical disbelief • Prediagnosis phase: expectations • The prediagnosis phase: diagnosis • Treatment: tertiary referral service pain clinic • Treatment: continuing disbelief • Treatment: wheelchairs and walking misaligned goals • Treatment: pain conveying difficult messages to parents • Treatment: being in hospital Maciver 2011 • Relationships with professionals (analysed with Maciver 2005 treatment: continuing disbelief) • Disenchantment (analysed with Maciver 2005: continuing disbelief) • Practical and emotional support (analysed with Maciver 2005 treatment: tertiary referral service pain clinic) • Misaligned expectations (analysed with Maciver 2005: treatment expectations) • The in-patient pain management programme experience (analysed with Maciver 2005 treatment: expectations) • Practical and emotional support Jordan 2007 • Diagnosis as proof of pain • Fight for resources Neville 2019	• The importance of diagnosis • Fighting for care/treatment (parents) • Medical encounters: the importance of communication (being listened to and believed) • Families and healthcare professionals misaligned goals • Parents and young people's disenchantment with healthcare professionals and services • Realising that curing pain might be an unrealistic goal (parents and young people) • Parents role as experts questioned by professionals • Being treated based on a biomedical model when the pain is biopsychosocial • Contradictory advice from healthcare professionals impacts young people negatively • Mothers perceive they are blamed	Medical encounters: the importance of communication (being listened to and believed)

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	• Mistrust in the medical system • Haunted by something missing • The function of a diagnosis Dell'Api 2007 • Wiping their hands clean • They do not believe me • Seeing is believing • Sometimes they are helpful, sometimes they are not • If they cannot see it, it is not there • The search for understanding • Guarded alliance living with scepticism • Pain is something that cannot be cured • Fears for the future • I must be dying Suder 2016 • Fabrication of symptoms Baert 2020 • You are making it up • The problem is problem with the mother Sorensen 2017 • Healthcare professionals cannot explain pain condition		
	Carter 2002a • Getting on with it Borghi 2014 • Using various alternatives for managing pain Maciver 2005 • Parenting: sadness • Parenting: not being normal • Parenting: normal childhoods and normal families Maciver 2010 • Loss of normal parenting role • Disrupted development (analysed with Maciver 2005 parenting: normal childhoods and normal families) Sorensen 2017 • Relationship with family • Disruption of social life Dell'Api 2007 • Difficulties in living a normal life	• How children and young people think about pain (young people descriptions of pain) • Pain affects/impact young people physically and emotionally • Young people recognises impact of pain on parents and siblings (and respond by hiding their pain) • Parents and young people: loss of normality • Pain makes belonging to a social group difficult • Altered relationships with pain-free siblings • Strategies to cope/manage pain mothers perceive they are blamed	Parents and young people: loss of normality (or loss of a normal life and childhood)

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	Jordan 2007 • Not going back Suder 2016 • Uphill climb to regain life • Occupational loss Baert 2020 • The problem is problem with the mother		
	Carter 2002 • Professional judgement and disbelief • Professionals who believed the family • Communication or ventriloquism Maciver 2005 • Treatment: the role of the psychologist • Prediagnosis phase: expectations • Prediagnosis: medical disbelief • Treatment: being in hospital Maciver 2011 • Pain conveying difficult messages to parents (analysed with Maciver 2005 treatment: the role of the psychologist) Sorensen 2017 • Healthcare professionals cannot explain pain condition Neville 2019 • The function of a diagnosis Dell'Api 2007 • They do not believe me	• Perception of psychologist affects how families experience services	Biomedical model versus biopsychosocial (families and healthcare professionals)
	Maciver 2005 • Parenting: developing adaptative responses to the child's distress • Parenting: being on call • Parenting: anger, depression and behaviour problems • Prediagnosis: parental responses searching for information • Parenting: pacing and balance • Parenting: encouraging discouraging participation in activities • Parenting: striking a happy balance • Parenting: non-normative, failed and disrupted parenting • Parenting: complex parenting	• Parents have to manage their child's behaviour and emotions (that are affected by chronic pain) • (Parents) searching for information • Parents trying to achieve quality of life (pacing/balance) • Parenting roles • Gendered nature of parental response to child's pain (and gender inequality) • Parents experience of chronic pain is based on fear and anxiety which leads to being on call	Non-normative parenting

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	• Parenting: anger, depression and behaviour problems • Parenting: marital tension • Parenting: loss of work Maciver 2010 • Being on call (analysed with Maciver 2005 - Parenting: being on call) • Stepping back (analysed with Maciver 2005 parenting: complex parenting) Jordan 2016 • Re-evaluation • Containment		
	Carter 2002a • No one's pain is the same, it is always there Carter 2002 • The quest for a diagnosis and referral fatigue Suder 2016 • Being a survivor • Pain becoming the main occupation • Loss of independence • Changes in self Maciver 2005 • Parenting • Parenting: impact on self, emotional and practical consequences • Parenting: engulfment • Parenting: developing adaptative responses to the child's distress • Parenting: dealing with the emotional impact on the child • Parenting: encouraging communication (analysed together with Maciver 2005 parenting: dealing with the emotional impact on the child) • Parenting: being on call • Parental: emotional consequences • Parental: practical consequences • Parenting: helplessness • Parenting: living a restricted life • Parenting: pacing and balance • Parenting: striking a happy balance • Parenting: uncertainty • Parenting: not being able to plan for the future • Parenting: losing the opportunity to be spontaneous • Parenting: anger, depression and behaviour problems	• Pain affects/impacts parents physically and emotionally • Pain affects/impacts young people physically and emotionally • Parents' experience of chronic pain is based on fear and anxiety, which leads to being on call • (Parental) helplessness • Uncertainty and fear of future (parents and young people) • Children and young people and parental trauma • Young people on living with pain • Contradictory advice from healthcare professionals impacts young people negatively	Pain affects/impact parents and children and young people physically and emotionally

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	Maciver 2010 • Fearful responses from parents • Being on call (analysed with Maciver 2005 parenting: being on call) • Parental efficacy (analysed together with Maciver 2005 parenting: helplessness) Jordan 2016 • Helplessness Jordan 2007 • In limbo • What is next Sorensen 2017 • Relationship with family • Emotional responses • Disruption of activities • Decreased physical function • Healthcare professionals cannot explain pain condition Suder 2016 • Uncertainty of disease • Unknown future • Being a survivor Neville 2019 • Haunted by something missing		
	Carter 2002a • Getting on with it Suder 2016 • Push through the pain Sorensen 2017 • Finding different ways to cope Baert 2020 • Not everybody gets a healthy child	Getting on with it (children and young people and parents)	Getting on with it (children and young people and parents)
	Carter 2002a • No one's pain is the same, it is always there Borghi 2014 • Describing pain Sorensen 2017 • Pain descriptions	• Pain identity • Pain is invisible • How children and young people think about pain (young people descriptions of pain) • Owning their pain	N/A (no third-order constructs could be developed)

Table 2. Development of third-order constructs within pain condition groupings *(Continued)*

	• School absences Suder 2016 • Make a picture that described your chronic pain • Pain identity • Invisible disease Jordan 2018 • An externally imposed lens on identity		
	Sorensen 2017 • School absences	• School adaptations can positively affect young people's quality of life	N/A (no third-order constructs could be developed)
	Baert 2020 • At least it is not cancer	• Mothers longing for understanding and validation	N/A (no third-order constructs could be developed)

Table shows development of our interpretive synthesis findings progressing from second-order constructs derived from included studies, to identifying (translating) common or unique second-order constructs and developing (synthesising) third-order constructs.
Abbreviation: N/A, not applicable.

Table 3. Definition and characteristics of included chronic pain conditions

Condition/chronic pain classification (ICD-11)	Definition	Causes/origin	Symptoms	Pain symptom presentation and severity/intensity
Cerebral palsy/chronic secondary musculoskeletal, visceral and neuropathic pain and primary headache or orofacial pain	Defined as a group of permanent disorders of the development of movement and posture, causing activity limitations	The cause is attributed to nonprogressive disturbances that occurred in the developing foetal or infant brain	Musculoskeletal pain was from muscle spasms, dyskinesia, spasticity, contractures, joint misalignment, deformities, postural asymmetries and osteoporosis. Gastrointestinal pain included abdominal pain, acid reflux and constipation. Headache or orofacial pain was from temporomandibular disorders, and trauma was from dyskinesia and spams. Neuropathic pain is experienced as burning, squeezing, pricking or freezing pain.	Constant and fluctuating pain varying widely from mild to severe
Complex regional pain syndrome/chronic primary pain	Neuropathic pain disorder	Usually develops after minor trauma or surgery	Disabling pain, swelling, vasomotor instability, sudomotor abnormality and impairment of motor function	Constant/continuous severe pain
Dysmenorrhoea/chronic secondary visceral pain	Painful cramping, usually in the lower abdomen, which occurs shortly before or during menstruation, or both	Classified as primary (hormonal cause) and secondary (caused by underlying conditions such as endometriosis, adenomyosis, fibroids, endometrial polyps or pelvic inflammatory	Lower abdominal pain, nausea, bloating, diarrhoea, constipation, vomiting, indigestion, irritability, headache and lower back pain	Symptoms can fluctuate according to menstrual cycle and pain intensity varies widely from mild to severe

Table 3. Definition and characteristics of included chronic pain conditions *(Continued)*

		disease, or by intrauterine device insertion)		
Epidermolysis bullosa/chronic secondary pain	Rare inherited skin fragility or blistering disorders	Inherited group of conditions	Blistering of the skin on hands and feet or widespread, associated with pain, itching, burning sensation and pruritus; rare subtypes can include pyloric atresia, muscular dystrophy, cardiomyopathy and/or nephropathy	Constant severe pain
IBD/chronic secondary visceral pain	Group of chronic idiopathic inflammatory bowel disease including Crohn's disease and ulcerative colitis	Unknown aetiology, but it is related to an abnormal immune response to gut microflora in genetically susceptible individuals	Frequent symptoms are abdominal pain, diarrhoea, constipation, nausea, and vomiting	Fluctuating condition with periods of activity and remission; pain can range from mild to severe
Juvenile idiopathic arthritis/chronic secondary pain	A group of conditions that involve joint inflammation, which lasts for more than 6 weeks in people under 16 years of age	Autoimmune or autoinflammatory conditions with unclear cause/trigger but involves environmental and genetic factors	Pain, swelling and limitation of movement, and in more severe cases growth delay, joint contractures, eye problems, joint disease requiring joint replacements and permanent disability	Fluctuating condition with periods of activity and remission; pain intensity varies from mild to moderate
Juvenile idiopathic arthritis: Down syndrome–associated arthritis (DA)/chronic secondary pain	Down syndrome is defined as a chromosomal abnormality. DA is an aggressive, erosive, inflammatory arthritis that affects people with Down syndrome	DA is an autoimmune condition	Arthritis is an imported underdiagnosed occurrence in Down syndrome and can cause joint pain and swelling	Arthritis from Down syndrome fluctuates with periods of activity and remission. Pain can vary broadly in intensity, ranging from no pain at all to severe pain.
Migraine/chronic primary headache or orofacial pain	Recurrent headaches with or without aura	Unknown aetiology, but it is associated with genetic factors	Episodes of moderate-to-severe headache, most often unilateral and generally associated with nausea and increased sensitivity to light and sound	Fluctuating condition with periods of activity and remission; pain usually ranges from moderate to severe
Musculoskeletal conditions/chronic musculoskeletal pain	Musculoskeletal impairments comprise more than 150 different conditions that affect joints, bones, muscles or multiple body areas or systems	Impairments in the muscles, bones, joints and adjacent connective tissues leading to temporary or lifelong limitations in functioning and participation	Main symptom is usually pain and limitations in mobility and dexterity	Often characterised by persistent pain varying widely from mild to severe
Recurrent abdominal pain/chronic secondary visceral pain	Defined as at least 3 episodes of pain that occur over at least 3 months and affect the child's ability to perform normal activities, normally functional (nonorganic) abdominal pain	Somatic/unknown or associated with underlying condition, such as acid reflux, bacterial infection, food intolerance, abdominal migraine, IBD, surgical conditions	Abdominal pain	Fluctuating condition with periods of activity and remission; pain ranges widely from mild to severe

Table 3. Definition and characteristics of included chronic pain conditions *(Continued)*

Sickle cell disease/chronic secondary visceral pain	Group of haemoglobin conditions, particularly common in people of African or Caribbean descent	Inherited condition; acute painful sickle cell crises (vascular occlusion crisis) are caused by blockage of the small blood vessels	Sickle cell crises (very painful episodes affecting different parts of the body), infections and anaemia	Sickle cell crises can be very severe and last up to a week; it can happen every month or a few times a year

Abbreviations:

- DA, Down syndrome-associated arthritis
- IBS, irritable bowel syndrome
- ICD-11, International Classification of Diseases

Table 4. Richness assessment results for included studies

Study	Research question	Richness	Explanation of assessment
Ahlqwist 2012	3, 4	3	Contextual data: only told age and gender of children and recruited via a prior study. Paper lacks information about the interventions. Findings: the context of the findings is not that clear in terms of the characteristics of the young people. Includes information about what children and young people (CYP) thought that was useful from the interventions (being taken seriously, being listened to, taking control) and what CYP considered as good pain management.
Atkin 2001	1, 2, 3, 4	2	The context was extensive. Has some good sections on pain experience and management, particularly in relation to how pain is viewed by services and health professionals. It is a 'thick' paper but more on living with sickle cell disease (SCD) than chronic pain. This paper is relevant for review questions (RQ) 3 and 4 on services.
Atkin 2000	2, 3	2	Rich background and context. Aims: examine both mothers' and fathers' perspectives on the nature and appropriateness of service provision (RQ3). The majority of the study focus on SCD in general, with all its complexities. Some mention of chronic pain and how it affects family dynamics, but those data are not as rich. Some findings specifically discuss pain and coping with a child's pain - there was a small amount of rich data specifically about chronic pain and its management.
Atoui 2015	2, 3	2	Contextual data: reasonable level of detail on children’s background - gender, age, diagnosis, currently pain-free during interview, father’s socioeconomic status, the recruitment/treating centre and some data on Lebanese culture in findings. Findings: the data go beyond the descriptive level with different layers of complexity involving family dynamic and work. There were rich data on chronic pain and how it affects CYP's daily lives. It does have some data on the meanings, intentions and circumstances behind the facts, but not very thick/rich, so we gave this a 2 in richness.

Table 4. Richness assessment results for included studies *(Continued)*

Baert 2020	2, 3	2	Contextual information is good, but it does not provide the results by country (so we do not know which piece of data is from which context). Focus groups were conducted in Belgium, Scotland and USA. This resource seems to be more relevant to question 3. It has thick data on the review questions, but because of the lack of differentiation between countries, we give this resource a 2 in richness.
Borghi 2014	1, 2	2	A. Some contextual data, but it could be more robust. Findings: most of the paper focusses on how children describe and experience their pain according to Piaget's stages of development. There is some mention of pain management, but most of it is quite descriptive. Data are relevant to chronic pain and focus on concepts/descriptions of pain and daily life. There are some data on meanings, but was considered on the low end of 2 on the richness scale.
Brandelli 2021	2, 3	2	Contextual information provided. Findings: authors reached a certain level of interpretation that will be useful. There was an in-depth view of treatment and how it affects family life and particularly mothers. It is explanatory. Definitely at least a 2 on the richness scale.
Britton 2002a	1, 2, 3	2	Context is moderately described, and there are fairly thick qualitative data. Qualitative data includes how chronic pain affects daily life, how the family perceive chronic pain and what they think about the healthcare professional. We gave this a 2 on the richness scale because it is not fully aligned with our synthesis objective and data were not very detailed and thick.
Britton 2002b	3	3	Thick description including a proposed model: the information is relevant to the synthesis aim. This study looked at how families manage JIA at home with a focus on exercise and splint use. There was not a lot of direct mention of chronic pain, but we rated this study as a 3 given that managing JIA is managing pain.
Brodwall 2018	1, 2, 4	2	Good contextual data. Provides insight on parents' views on chronic pain and their interactions with healthcare professionals. Findings: largely descriptive but with a bit about meanings; data on what parents think is causing the functional abdominal pain and what treatment they want - a 2.
Carter 2002a	1, 2, 3, 4	3	Thick data on how children perceive their on pain with rich context; information about what children think about the pain management strategies and why, as well as on how children perceive healthcare professionals and what experiences they had.
Carter 2002	1, 2, 3	3	Really good description of the children and families. Findings: thick description with lots of information that can be used for the synthesis. This resource really focused on the interactions with healthcare professionals and had rich, qualitative data on how families and CYP with pain experience and think

Table 4. Richness assessment results for included studies *(Continued)*

			about their interactions with healthcare professionals and what they consider as bad and good interactions.
Carter 2002b	1, 2, 3	3	Rich in context and great description of pain types. Findings: rich, qualitative data on how the guardians (usually mothers) conceptualise pain, what they think and their experience with pain. There is rich data on how parents manage a pain condition and their interactions with HCP. It also goes into pain management and the relationship with the health services, which will be really useful for RQ3 and RQ4.
Carter 2017	1, 2, 3	3	Context: really good description of the type/frequency of pain. It shares the experiences of mothers managing/understanding pain and what they think of the approach of healthcare professionals. It developed a model about the pain knowledge from the parents' perspective. The qualitative data are thick and provides interpretation of what the mothers say.
Cartwright 2015	1, 2	2	Context: some/moderate amount of data. Findings: some sections specifically focus on pain but others on the disease symptoms more broadly; some data of relevance to the desired outcomes for teens, which was of relevance to RQ4. The data presented focus on the meaning and impact of living with JIA and adolescents' feelings about the illness. We gave this source a 2 because it was not always clear that the data were specifically about pain versus other symptoms (fatigue, mobility), although it does explore meanings and intentions.
Castle 2007	2, 3, 4	2	Very good contextual data: additional information about condition, pain type, activities that generate pain Findings: not a lot explanatory here re meanings, intentions and circumstances, but the level of description and amount of relevant data make it a 2
Dell'Api 2007	3	3	Robust contextual data (demographic, pain, condition, information about treatment and management). The paper focusses on the interaction between CYP and healthcare professionals. Findings: rich data exploring how CYP feel when seeking help from healthcare professionals. They do have themes that refer to meanings and intentions. The data seemed a bit descriptive at first, but further meaning if it were added in the discussion.
Dyson 2011	2	2	Contextual data are moderate: age, education, ethnicity, gender, interview venue and more specific context given in findings. This study is quite rich. It has some data on pain, but it mostly discusses complex aspects of living with SCD; relevant to RQ2. Although, there are rich findings, not all data relate to chronic pain or to participants under 18 years old, so a 2 was given.
Forgeron 2008	2, 3, 4	3	Good contextual data (demographic, pain location, frequency and impact, duration and intensity). Findings: rich data on how CYP live their lives with pain including different aspects such as school, social circles, transitioning to adult care; described as a descriptive analysis, but it is rich and has a lot of meaning - a 3.

Table 4. Richness assessment results for included studies *(Continued)*

Gaughan 2014	3, 4	3	Good amount of contextual data (where interview took place, demographic data, pain condition, pain duration, details of family dynamics re reacting to child pain). This paper provides a closer look into the experiences of parents. Findings: this has rich data and is detailed; does talk about meanings. The material on impact on family is important for our focus on the family and not just the child - a 3.
Guell 2007	1, 2	2	Not a lot of contextual data (no demographic data), but rich in the sense of background information (observation in the family homes and services); ethnographic study with fairly thick qualitative descriptions/interpretation (rather than quotes); fairly detailed context of the young participants and their setting included families from London and Germany, but it does not present the results separately. It is about how living with JA is conceptualised and managed by the young people themselves. It brings relevant information about pain management and coping strategies. Rich data in some aspects but has the major problem of not identifying where the families are from, therefore a 2.
Helvig 2013	1, 2	2	Moderate amount of contextual data: no information about families or socioeconomic background. Findings: first few themes might be useful, but theme 3 is very descriptive; mainly about how they react to and cope with migraines; definitely not a very rich, conceptual paper, but quite a lot of the data were on pain not other migraine symptoms; some data on the intentions behind their behaviour and a bit more re meanings in the discussion section.
Hunt 2003	2, 3, 4	3	Context: good amount of contextual data (children's ages and conditions, sources of pain, pain cues where interview took place). Findings: most of the study described how parents and healthcare professionals recognise pain in severe neurological impairments; includes data on disease management, which has relevant information about how parents perceive health services for RQ4 - a 3.
Jones 2020	1, 2	3	Plenty of contextual information; robust qualitative data on expectations for future whilst coping with CRPS; aligns with review questions 1 and 2.
Jones 2022	2	2	Context: some demographic data on CYP, including type of pain, gender, first language and the outcome of assessment with national specialist pain service; includes various pain conditions; mainly focusses on impact of pain on life of adolescents. Findings: used Braun and Clarke's thematic analysis but have got some depth of data around peer relationships and autonomy; some robust longitudinal data
Jordan 2007	1, 2, 3	3	Context: good amount of contextual data (diagnosis, some family demographics, children's age range, pain duration, focus group location) but no data on socioeconomic status or ethnicity.

Table 4. Richness assessment results for included studies *(Continued)*

			Findings: robust rich data on the lives of parents caring for CYP with pain, their burdens and how pain affects the child's milestones and the family dynamics. It also includes the struggle between family and healthcare professionals with 'validating' the pain through a diagnosis of a condition.
Jordan 2016	1, 2	3	Good contextual data. Findings: rich data on how fathers experience pain. The data go beyond the descriptive level with different layers of complexity involving family dynamic, work, masculinity.
Jordan 2018	1, 2	3	Robust context is provided. Findings: rich data on how CYP perceive living with chronic pain and how they think about their pain. It explores how pain impacts their lives, relationships, identity, independence and how the experience of chronic pain can disrupt and alter adolescent developmental trajectories at an individual level.
Kanstrup 2019	1, 3	3	Good contextual data: describes the acceptance and commitment therapy (ACT) treatment given to families in a bit of detail. Demographics: child and parent age, child pain duration and location. Findings: quite a bit on the meaning of experiences to the participants and how they experienced ACT. They have interpreted data; it really explores what the young people think about the therapy and interaction with healthcare professionals.
Khanom 2020	1, 2, 3	3	Good background information and context; report age, ethnic group, diagnosis and time since diagnosis; no data on socio-economic status (SES) or home environment. Findings: this study looked at how CYP described a pain flare; small amount on use of and perceptions of pain relief medications relevant to RQ3. The findings do include meanings and intentions; this will be rich enough for a meta-ethnography.
Maciver 2005; Maciver 2010; Maciver 2011	1, 2, 3, 4	3	Contextual data: very detailed; rich data on interview process/location, methods, detailed demographic information and parental occupation, child diagnosis, use of medications, which healthcare professionals involved, detailed case descriptions of each of 12 families; rich on how parents perceive pain and how caring for a child with chronic pain affects their lives. It goes beyond the descriptive with added meaning. A good amount of context and thick qualitative descriptions. Data on what families see as 'good' management/services. Findings: very thick; has data on RQ4 re expectations of services.
McDonagh 2021	3, 4	3	Context: demographic data; geographical area, age, gender of child, parental gender (mothers). Findings: data on inequitable treatment of kids with Down syndrome and difference in care/support for verbal versus nonverbal children. Has explanatory data and meanings (rich description); includes data on RQ4 and what services they want.

Table 4. Richness assessment results for included studies *(Continued)*

McKinnon 2022	3, 4	2	Context: moderate amount of contextual data; caregiver work status, child's age, gender, type of schooling, motor type, child's capability and disability, previous bony hip or spinal surgery, number of prescribed medications, children's pain presentations, and pharmacological and non-pharmacological treatments; detailed regarding cerebral palsy and impacts and pain; nothing on SES. Findings: largely descriptive rather than conceptual – relevant to review questions 3 and 4. There are some explanatory data, but not very rich on a conceptual level - a 2.
Neville 2019	1, 3, 4	3	Good contextual data; ages, socioeconomic background, recruitment setting, diagnosis, pain duration and intensity, ethnicity, household annual income, marital status Findings: rich data on RQ3 and RQ4; lots on meanings, e.g. meaning to them of a diagnosis, lots on services and healthcare professionals and parent and child responses to the diagnosis or uncertainty of diagnosis - a 3
Njifon 2019	1, 2	2	Context: explains cultural beliefs around SCD in Cameroon (very different to UK) seen as caused by witchcraft, sorcery or ancestors; is stigmatised; explains the restrictions on children being allowed to talk to outsiders about the illness in the family Findings: rich data on how children feel about their brother's illness, their beliefs and their fears about his future death. Most findings make some reference to painful crises/the consequences, etc. Rich in parts and quite descriptive in others, but not all data are on pain - a 2.
Nutkiewicz 2008	3, 4	3	Good contextual data: child age, gender, ethnic group, site of pain, pain duration, average number of doctors seen Findings: insight on what CYP think about the doctors' approach; gives key concepts/themes; lots on meanings; rich and descriptive
Renedo 2019; Renedo 2020	3, 4	2	Context: moderate contextual data; demographic data, information about recruitment. Paper discusses transition from paediatric to adult clinics in SCD, as we are not focusing transition per se some data will not be relevant to our RQs. Emphasis on the lay perspective. Not all data are from under participants 18 years old - some are from CYP ages 19 to 21 years. It does refer to intentions and gives explanation for events. Has some relatively thick data in relation to our review questions but not all from participants under 18 years of age. Although not large quantities of data on chronic pain, it is quite rich and relevant to question 3 and 4.
Rossato 2007	2, 3	2	Really good contextual data; transparent about whether the JIA is active or not, parental age, civil status, religion, family income and education level; children according to age, gender, diagnosis time and education level. It does have concepts and a model but the amount of data to support each concept is not large and so not that detailed, so gave it a 2.
Smart 2005	1, 2, 3, 4	3	Context: some data on family demographics and health details given; child's pain severity, existence of family member ill

Table 4. Richness assessment results for included studies *(Continued)*

			health, child age group. Some detail on SES and ethnic group (white, middle-class mothers). Nothing on family home environment. Quite detailed sections on beliefs about doctors and interaction with doctors relevant to RQ3. Also some data for RQ4. Gave a 3 because of high relevance for RQs and quite rich findings even though only moderate contextual data given.
Sorensen 2017	1, 2, 3	2	Contextual data: child age, language, where recruited from, gender, pain diagnosis and duration. Could have included more contextual data. Findings: seems to have clear themes in parts but mixes descriptive and interpretive data, e.g. theme 3.1 does not seem very conceptual, it is descriptive but fairly detailed description (with more meanings given in discussion though). Themes 3.2 and 3.3 have more on meanings.
Suder 2016	1, 2, 3	3	Really good contextual data, child age, gender, 'race,' rural/urban, background and detailed case history section for each participant. Findings: rich description. Findings/context are reported for each participant separately. Pretty rich, detailed data. There are 4 common themes drawn from all the interview case study sections. Gives views about services; difficulty of getting a proper diagnosis and how chronic pain impacts on their daily life; change the definition of self.
Waite-Jones 2008	3, 4	2	Context: moderate amount of contextual data (sibling gender, age, relationship to child with juvenile idiopathic arthritis (JIA), age gap and age at JIA onset; some data on family structure; interview location). Findings: siblings' point of view. Discusses how siblings have dealt with the experience of chronic pain and how it affects the family dynamics. Rich enough for a meta-ethnography.
Williams 2008	1, 2	3	Contextual data - small to moderate amount for a thesis. Findings: not completely focused on pain but discusses pain management for the condition epidermolysis bullosa and how it affects daily life. Rich data with robust context. The thesis also includes different coping mechanisms children adopt to deal with the condition and with pain. Also includes data on how CYP describe pain from epidermolysis bullosa.
Wong 2016	1, 2, 3	2	Context: not a lot of background information. Contextual data: age, self-care habits, pain intensity, ethnicity (Chinese), if received menstrual education, interview setting unclear. The aim was to explore the self-care strategies amongst Hong Kong Chinese adolescent girls with dysmenorrhoea. Findings: the focus of this study is on coping strategies. It also talks a bit about Western medicine versus Chinese medicine. Descriptive data on pain relief strategies used by girls; some data on the circumstances, meanings. Narrowly gets a 2 because it has data on meanings but not conceptual level.

CYP: children and young people
JIA: juvenile idiopathic arthritis
RQ: review question
SCD: sickle cell disease

Table 5. Richness assessments of all studies assessed for sampling strategy

Study	Relevance to review questions	Richness
Ahlqwist 2012	3, 4	3
Allgood 2018	1, 2, 3	1
Asmussen 1999	2, 3, 4	1
Atkin 2000	2, 3	2
Atkin 2001	1, 2, 3, maybe 4	2
Atoui 2015	2, 3	2
Baert 2020	2, 3	2
Barlow 1998	2, 3	1
Barlow 1999	1, maybe 2	1
Beyer 2004	3, 4	1
Borghi 2014	1, 2	2
Bradshaw 2016	3, 4	2
Brandelli 2021	1, 2, 3	2
Brekke 2020	2	1
Britton 2002	None	1
Britton 2002a	1, 2, 3	2
Britton 2002b	1, 2, 3, 4	3
Brodwall 2018	1, 2, 4	2
Carter 2002a	1, 2, 3	3
Carter 2002	3, 4	3
Carter 2002b	1, 2	3
Carter 2017	1, 2, 3	3
Cartwright 2015	1, 2	2
Castle 2007	2, 3, 4	2

Table 5. Richness assessments of all studies assessed for sampling strategy *(Continued)*

Conboy 2008	2, 3	1
Constantinou 2021	1, 2, maybe 3	1
Cox 2022	1	1
Cunningham 2019	3	1
de Monte 2009	1, 2, 3, 4	2
Dell'Api 2007	3	2
Dyson 2011	2	2
Forgeron 2008	2, 3, 4	3
Gaughan 2014	3, 4	3
Ghio 2018	1, 2	1
Ghio 2021	2	1
Gorodzinsky 2012	3	1
Guell 2007	1, 2	2
Hackett 2003	2	1
Heffernan 2021	2	2
Helvig 2013	1, 2	2
Hendry 2012	1, 2, 3	2
Hilário 2022	1, 2, 3	1
Hulgaard 2020	1, 3	3
Hulgaard 2020a	2, 3	3
Hunt 2003	3, 4	3
Hurtubise 2021	2, 3, 4	1
Jensen 2019	2	1
Jones 2009	2, 3	2
Jones 2020	1, 2	3
Jordan 2007	1, 2, 3, 4	3
Jordan 2016	1, 2, 3, 4	3
Jordan 2018	1, 2	3

Table 5. Richness assessments of all studies assessed for sampling strategy *(Continued)*

Joslin 2021	1, 2, 3	1
Kanstrup 2019	1, 3	3
Kanstrup 2019	3	1
Khair 2015	NA	1
Khanom 2020	1, 2, 3	3
Lee 2020	4	1
Leksell 2017	2, 3	2
Maciver 2010	1, 2	3
Maciver 2005	1, 2, 3, 4	3
Maciver 2011	2, 3, 4	3
McDonagh 2021	2, 3	3
McKinnon 2022	2, 3	2
McKinnon 2020	2, 3	1
Miles 2020	3, 4	1
Moulin 2015a	3, 4	2
Neville 2019	1, 3, 4	3
Nguyen 2015	1, 2	1
Nilsson 2016	1,3	1
Njifon 2019	1, 2	2
Nutkiewicz 2008	3, 4	3
O'Donnell 2013	2, 3, 4	1
Ostojic 2022	3	1
Pate 2019	1	1
Randall 2020	1, 2	1
Renedo 2020	2, 3, 4	2
Renedo 2020	3	2
Rossato 2007	2, 3	2
Santos 2018	2, 3	2

Table 5. Richness assessments of all studies assessed for sampling strategy *(Continued)*

Serafimova 2022	1, 2	1
Skarstein 2018	2, 3	1
Skogvold 2019	2, 3	2
Smart 2005	1, 2, 3, 4	3
Soni-Jaiswal 2016	NA	1
Sorensen 2021	3	1
Sorensen 2017	1, 2, 3	3
Suder 2016	1, 2, 3	3
Waite-Jones 2008	3, 4	2
While 2004	1, 2, 3	1
Williams 2008	1, 2	3
Wong 2016	1, 2, 3	2
Yuwen 2017	2	1

NA, not applicable.

Table 6. Development of third-order constructs from thematic analysis of translated findings from across all studies

Translated findings (common or unique constructs) from across all studies	Our new second-order constructs	Our new third-order constructs
• Family systemic impact • Pain affects children and young people's self-identity • Impact on siblings • Shrinking social worlds	Pain organises the family system	Pain organises the family system and the social realm
• Adapted parenting • Children and young people and parents as experts in living with pain • Family systemic impact • Adjusting to the ‘new normal’	Adapted parenting	
• Family systemic impact • Impact on siblings • Adapted parenting • Adjusting to the ‘new normal’	Pain’s adverse psychosocial impacts on the whole family	
• Uncertain future	Pain forces families to manage uncertainty	
• Adjusting to the ‘new normal’ • Getting on with it	Pain forces adjustment and adaptation	

Table 6. Development of third-order constructs from thematic analysis of translated findings from across all studies *(Continued)*

• Parents longing for others to understand • Support from peers and family • Pain affects children and young people's self-identity	Pain's influence on disclosure, social support and social relationships	
• Shrinking social worlds • Racism and disabling attitudes • Adjusting to the 'new normal'	School and the social realm	
• Mismatch between family expectations and experiences • Disconnect between biomedical and biopsychosocial understandings	Families' striving for diagnosis and a cure	Families struggling to navigate health services
• Mismatch between family expectations and experiences • Disconnect between biomedical and biopsychosocial understandings (of pain)	Family expectations of services influence experiences	
• Disconnect between the world of healthcare and the world of the family • Disconnect between biomedical and biopsychosocial understandings (of pain) • Children and young people and parents as experts in living with pain • Parents dilemmas in managing pain • Transitioning to adult services • Being listened to and believed by healthcare professionals	Chasm between health services and families' needs	
• Being listened to and believed by healthcare professionals • Children and young people and parents as experts in living with pain • Disconnect between biomedical and biopsychosocial understandings	Importance of being listened to and believed by healthcare professionals	
• Children and young people's self-management strategies	Pain self-management	Families managing pain independently
• Parents helping child to manage pain • Adapted parenting	Parents helping children and young people to manage pain	
• Effectiveness of treatment strategies	Experiences and perceptions of interventions and treatments	Families' experiences and perceptions of specific interventions and treatments
• Engagement and adherence to interventions	Adherence to and engagement with interventions and treatments	
• Racism and disabling attitudes	Discrimination and racism in health services	Children and families experiencing prejudice and discrimination
• Racism and disabling attitudes	Prejudice and discrimination at school	
• Cultural/gender barriers to help seek	Sexism	

Table 7. Matrix integrating qualitative evidence synthesis findings with Cochrane Reviews of intervention effects

Cochrane Review	Review inclusion criteria include children under 5 years or with LD or autism	Subgroup analyses by participant ethnic origin planned/conducted	Outcomes assessed including absence of pain measure (review inclusion criteria)	Whole-family interventions or outcomes included in review inclusion criteria	Parental or sibling outcomes included in review inclusion criteria	Child psychological or social outcomes included in review inclusion criteria
Abbott 2017	No (inclusion criteria age 5 to 18 years, LD not stated)	Not conducted	Pain (including absence of pain)	No	No	Quality of life and social/psychological functioning
Anie 2015	All children (inclusion criteria) but none under 5 or with LD/autism in included trials	Planned but insufficient studies	Pain status (not absence), coping strategies, health services utilisation, health benefits and general health	No	No	Quality of life and mood
Cooper 2017d	All children (inclusion criteria) but none under 5 or with LD/autism in included trials	Not planned	Pain intensity and relief (not absence), sleep duration and quality, physical function, carer impression of change, rescue analgesia, treatment acceptability, adverse events	No	No	Quality of life but no included trials measured this
Cooper 2017b	All children (inclusion criteria) but none under 5 or with LD/autism in included trials	Not planned	Pain relief (not absence), carer impression of change, rescue analgesia, sleep duration and quality, physical function, treatment acceptability, adverse events	No	No	Quality of life but no included trials measured this
Cooper 2017a	All children (inclusion criteria) but none under 5 or with LD/autism in included trials	Not planned	Pain relief (not absence), carer impression of change, rescue analgesia, sleep duration and quality, physical function, treatment acceptability, adverse events	No	No	Quality of life but no included trials measured this
Cooper 2017c	All children (inclusion criteria) but none under 5 or with LD/autism in included trials	Not planned	Pain relief (not absence), carer impression of change, rescue analgesia, sleep duration and quality, physical function, treatment acceptability, adverse events	No	No	Quality of life but no included trials measured this
de Bruijn 2021	No (inclusion criteria age 4 to 18 years but none under 5 or with LD/autism in included trials	Not planned	Treatment success, pain change (including absence of pain), adverse events, defaecation pattern	No	No	Quality of life, depression, anxiety, school attendance
Eccleston 2017	Yes included children under 5 in sample but	Not planned	Pain relief (not absence), carer impression of change, rescue analgesia, sleep du-	No	No	Quality of life but no included

Table 7. Matrix integrating qualitative evidence synthesis findings with Cochrane Reviews of intervention effects *(Continued)*

	none with LD/autism in included trials		ration and quality, physical function, treatment acceptability, adverse events			trials measured this
Fisher 2018	All children (inclusion criteria) but only mean age provided. None with LD/autism in included trials	Not planned	Pain intensity (including absence of pain), pain-related disability, adverse events	No	No	Depression and anxiety
Fisher 2019	All children (inclusion criteria) but none under 5 or with LD/autism in included trials	Not planned	Pain symptoms (including absence of pain), disability, treatment satisfaction, adverse events	No	No	Depression and anxiety
Law 2019	All children (inclusion criteria) but only mean age provided. None with LD/autism in included trials	Not planned	Child behaviour, child medical symptoms, adverse events	Family functioning	Parenting behaviour, parent mental health	Child mental health such as depression and anxiety
Martin 2017	No (inclusion criteria age 5 to 18 years, LD not stated)	Not planned	Pain intensity, duration and frequency (including absence of pain)	No	No	Quality of life, social and psychological functioning, school attendance
Newlove-Delgado 2017	No (inclusion criteria age 5 to 18 years, LD not stated)	Not planned	Pain intensity, duration and frequency (including absence of pain), adverse events	No	No	Quality of life, social and psychological functioning, school attendance and social disruption
Leite 2023	No (inclusion criteria age 4 to 18 years) but none under 5 or with LD/autism in included trials	Not planned	Pain intensity (including absence of pain), disability, adverse events, fear avoidance, physical activity level	No	Caregiver distress	Quality of life, anxiety and depression

LD, learning disabilities

Table 8. Evidence for chosen intervention within Cochrane Reviews

Cochrane Review	Evidence for the chosen intervention (programme theory)	Is the theory biopsychosocial?
Abbott 2017	CBT aims to improve the child's mental health and coping strategies, specifically in helping them to understand the onset and progress of their RAP. It offers a strategy to help manage it, along with anxiety management and specific behavioural techniques. FT seeks to alter environmental factors that might reinforce the child's pain behaviour within the family and to identify and treat factors that may precipitate it. The mode of action for how hypnotherapy may help RAP is not completely understood and is likely to be from a combination of effects on gastrointestinal motility, visceral sensitivity, psychological factors and direct effects within the central nervous system. Hypnotherapy and	No (psychological or social)

Table 8. Evidence for chosen intervention within Cochrane Reviews *(Continued)*

	guided imagery may bring about cognitive changes through directly influencing cognitions, which helps to improve symptoms, or through influencing pain and gut functioning, leading to a change in cognition. Most forms of yoga involve a series of physical postures along with breathing and meditation techniques that are intended to reduce anxiety, improve body tone and increase feelings of well-being. Written self-disclosure, a therapy in which the patient writes down their thoughts and feelings about something deeply distressing, is hypothesised to help with pain through a number of mechanisms, including changes in insight, the creation of a story about emotional and painful experience, and adaptation of habituation to emotional stimuli.	
Anie 2015	CBT has been considered as adjuncts to routine medical treatment for the management of sickle cell pain. These interventions aimed to improve the ability of people with sickle cell disease to cope with their pain, have shown encouraging results in children and adults, and with incorporated treatment manuals	No (biopsychological, including CBT)
Cooper 2017d	Different antiepileptic drugs have different mechanisms of action, not all of which are well understood, especially in terms of how a given drug produces pain relief in any particular individual with any particular chronic pain condition. Antiepileptic drugs are thought to reduce the ability of the neurone to fire at high frequency. The 2 standard explanations are enhanced GABA inhibition (valproate, clonazepam), or a stabilising effect on neuronal cell membranes, possibly by modulating ion channels. A third possibility is action via NMDA receptor sites.	No (biomedical, using antiepileptic drugs)
Cooper 2017b	Opioid receptors are G-protein–coupled receptors and are located primarily in the central nervous system. Once agonistic opioids have bound to the opioid receptor, they produce intracellular effects throughout the coupled G-protein that result in an inhibition of the nociceptive transmission. Activation results in neural inhibition by decreasing the release of excitatory neurotransmitters from the presynaptic terminals	No (biomedical, using opioids)
Cooper 2017a	The mechanism of action for paracetamol remains uncertain. The main proposed mechanism is the inhibition of COX enzymes through metabolism by the peroxidase function of these isoenzymes. This process results in inhibition of phenoxyl radical formation from a critical tyrosine residue important for the COX activity of COX-1 and COX-2 and prostaglandin synthesis.	No (biomedical, using paracetamol (acetaminophen))
Cooper 2017c	Different antidepressant drugs have different mechanisms of action, thus producing a variety of neurological effects and analgesic outcomes. Reinforcement of the descending inhibitory pathways by increasing the amount of norepinephrine (noradrenaline) and serotonin in the synaptic cleft at both supraspinal and spinal levels is considered to be a major mechanism, as well as blockage of sodium channels. Other suggested mechanisms include postsynaptic alpha-adrenergic, H1-histaminergic and muscarinic cholinergic receptor-blocking effects, and NMDA antagonism.	No (biomedical, using antidepressants)
de Bruijn 2021	The exact mechanism of action of antidepressants, particularly for the treatment of functional abdominal pain disorders in children and adolescents, is poorly understood. These drugs work through their effect on prominent monoaminergic neurotransmitters (serotonin, noradrenalin and dopamine) in the central nervous system.	No (biomedical, using antidepressants)
Eccleston 2017	Damage to the peripheral nerves is followed by an inflammatory reaction that relates to increased production of prostaglandins, amplifying sodium currents and calcium influx in peripheral nociceptive neurones, and enhancing neurotransmitter release in the central nervous system and depolarisation of second-order nociceptive neurones. Preclinical data suggest an immune pathogenesis of neuropathic pain, but clinical evidence of a central role of the im-	No (biomedical, using NSAIDs)

Table 8. Evidence for chosen intervention within Cochrane Reviews *(Continued)*

	mune system is less clear. NSAIDs inhibit the production of prostaglandins, and thus could lessen the peripheral and central sensory hypersensitivity that occurs with nerve injury-associated inflammation.	
Fisher 2018	Behavioural strategies include relaxation training, biofeedback and behavioural management programmes (e.g. teaching parents strategies to reinforce adaptive behaviours such as school attendance). Cognitive strategies include hypnosis, stress management, guided imagery and cognitive coping skills. CBT programmes incorporate elements of both behavioural and cognitive strategies. Parent interventions may include operant strategies, communication strategies, or PST. PST is aimed at decreasing distress in parents of children with chronic pain by teaching problem-solving skills, including steps to define a problem, generate possible solutions, implement a solution, and then evaluate.	Yes (psychological therapies including behaviour management and biofeedback)
Fisher 2019	Psychological therapies are used in paediatric pain practice to reduce pain symptoms, disability and negative mood associated with pain conditions, and to modify social-environmental factors to enhance the child's adaptive functioning.	No (psychosocial and psychological therapies)
Law 2019	CBT is founded in behavioural analysis and operant theory, cognitive theory, and social learning theory. Associations between cognitions, emotions and behaviours are emphasised and are believed to interact to influence desired outcomes. Thus, treatment is focused on altering maladaptive social/environmental, behavioural and cognitive factors in order to reduce symptoms and prevent relapse. FT is based on family systems theory and emphasises the role of the family context in an individual's emotional functioning. There are several types of FT, including structural FT, strategic FT and behavioural systems FT. Treatment aims to alter maladaptive patterns of interaction within the family in order to improve symptoms. MI focusses on the patient's motivation for and commitment to behaviour change. Specific strategies include exploring and resolving ambivalence, rolling with resistance, and eliciting and supporting the patient's own arguments for change. A unique feature of MI is the focus on the patient's own values and goals, as opposed to imposing external values and strategies for change. MST is an intensive family- and community-based intervention founded in the social ecological model and family systems theory. Treatment targets of MST are broad and include the child, their family and broader systems such as the child's school or medical team. MST incorporates a wide range of intervention techniques based on the individual needs of the child and family, including cognitive and behavioural skills training, parent operant training and FT. PST is based on the social-problem-solving model, which emphasises the role of constructive problem-solving attitudes and skills in fostering enhanced social competence and reduced emotional distress. Specific problem-solving skills are taught in sequential steps that typically include defining the problem, generating alternative solutions, decision-making, and solution implementation and evaluation.	No (psychosocial and psychological therapies)
Martin 2017	Conventional analgesics have been proposed to work by interrupting abnormal physiological pain responses, which become pathological. Antispasmodics have been proposed to alter gut dysmotility, including peppermint oil, which has antispasmodic actions. Serotonin (5-hydroxytryptamine) agonists may relieve symptoms by causing vasoconstriction and stimulation of the release of other vasoactive substances, thus inhibiting neurogenic inflammation; this has been found in migraine headaches.	No (biomedical and pharmacological interventions)
Newlove-Delgado 2017	Probiotic-based interventions containing living micro-organisms are thought to improve symptoms through restoring the gut's microbial balance. It has also been suggested that they might alter the intestinal inflammatory response in the lining of the gut. Fibre-based interventions might be effective in children with irritable bowel syndrome in particular, by modifying bowel habits and the	No (biomedical and dietary interventions)

Table 8. Evidence for chosen intervention within Cochrane Reviews *(Continued)*

	transit time through the gut, as well as by decreasing intracolonic pressure. Alterations in diet, such as low FODMAP interventions, may work in irritable bowel syndrome by reducing osmotic effects, fermentation and gas production, hence decreasing distension and pain.	
Leite 2023	There is evidence that exercise and physical activity act on physical and psychological mechanisms to reduce pain and disability (e.g. fear avoidance belief model). These may have influences at the cognitive level in terms of reducing fear and anxiety related to pain and movement, and also build physical strength and endurance.	Yes (biopsychosocial, using physical activity and education)

- CBT, cognitive behavioural therapy
- COX, cyclooxygenase
- FODMAP, fermentable oligosaccharides, disaccharides, monosaccharides and polyols
- FT, family therapy
- GABA, gamma-aminobutyric acid
- MI motivational interviewing
- MST, multisystemic therapy
- NMDA, N-methyl-D-aspartate
- NSAID, non-steroidal anti-inflammatory drug
- PST, problem-solving skills therapy
- RAP, recurrent abdominal pain

Table 9. Implications of the meta-ethnography for practice and research

Implications for research	
Broad area	**Specific focus**
Primary qualitative in-depth studies to produce conceptually rich findings to explore	Experiences and perceptions of under-researched populations: • children under 5 years old; • children with learning disabilities and/or autism; • common pain conditions such as abdominal pain, headache, musculoskeletal pain; • rarer pain conditions such as Ehlers-Danlos syndrome, HIV/AIDs, osteogenesis imperfecta; • fathers of children with chronic pain; and • siblings of children with chronic pain. Families' experiences of pain management and services: • experiences of pain assessment and treatment, such as pain management plans; • perceptions and experiences of opioid use in children with chronic pain; and • experiences of social care services.
Development and testing of family-centred interventions	• A triage approach to make sure that children and young people get the right care, at the right time, from the right service • Family-centred pain services • Targeted interventions to manage family understandings of pain and expectations of services • Develop treatments that are more acceptable to families
Outcomes	• Family-centred outcomes should be included in future trials of chronic pain interventions
Implications for practice	

Table 9. Implications of the meta-ethnography for practice and research *(Continued)*

Broad area	Specific focus
Pain management	• Consider the concept of 'total pain' to facilitate biopsychosocial pain management • Provide family-centred psychosocial support • Use shared decision-making frameworks, alongside appropriate clinical pathways, which signpost to all the available and appropriate treatment options • Tailor pain management plans to the family and child's preferences, needs and lifestyle • Manage children and young people's pain and expectations while awaiting test results and diagnosis • Tailor interventions to family's preferences and needs so that they are not boring or excessively time-consuming, not painful and with minimal side effects • Utilise family systems interventions for children with chronic pain and their family • Healthcare professionals should signpost families to appropriate existing high-quality information resources, e.g. to provide basic pain education while waiting on a diagnosis
Healthcare professional training and education	Improve chronic pain assessment and management education for undergraduates, postgraduates and qualified healthcare professionals
Healthcare professional communication	• Explore children and families' experiences of the impact of chronic pain and their priorities for pain management and aim to address those. • Use open, empathetic communication to help children and young people and their families to develop a trusting relationship • Seek to understand the child and family's experience of living with chronic pain • Provide biopsychosocial explanations of pain management to families by building on their prior experiences of the biopsychosocial impact and aspects of pain • Clearly communicate the purpose of any tests, examinations and treatments • Manage family expectations realistically about the possibility of a cure (which will be condition-dependent) from the outset of their contact with health services
Clinical guidelines	Develop child-specific chronic pain clinical guidelines for specific contexts
Chronic pain assessment and triage	• Develop and use assessment tools specific to chronic pain • Improve tools to assess chronic pain in children, e.g. for children with special needs, incorporate parental assessment and advice • Use children's expertise and knowledge of their pain • Healthcare professionals should recognise and make use of parental expertise in assessing and responding to their child's pain, particularly for children who have communication difficulties • Use screening and assessment tools to assist with triage of children • Consider early referral to tertiary specialist pain services for some pain conditions, such as complex regional pain syndrome
Care pathway	Develop a clear clinical care pathway with specialist condition-specific branches or pathways where appropriate
Services	• Increase availability and accessibility of specialist multidisciplinary pain management for children with complex pain problems • Make chronic pain services accessible to all children and families who need them • Develop child-specific, child- and family-centred service models
Prejudice and discrimination	• Address direct and indirect prejudice and discrimination towards patients in health systems including through education of healthcare professionals and examining inequitable provision of services and impacts of policies • Ensure health and social care policies and interventions do not exacerbate or create inequality by increasing the care burden on women

APPENDICES

Appendix 1. Search strategies

Search strategy for MEDLINE(R) and epub ahead of print, in-process, and other nonindexed citations and daily (OVID)MEDLINE

1. Qualitative Research/ or Interview/ or Nursing Methodology Research/,
2. (ethnonursing or phenomenol* or emic or etic or hermeneutic* or heuristic* or semiotic* or theoretical sampl*).ti,ab.,
3. (qualitative adj3 (study or research or method* or analysis or cod* or them* or interview* or question*1 or data)).ti,ab.,
4. (thematic analysis or ethnological research or ethnograph* or life stor*).ti,ab.,
5. (theme*1 adj2 (qualitative or analysis or coding or codes or grouping or identif*)).ti,ab.,
6. (grounded adj2 (theor* or study or studies or research or analys?s)).mp.,
7. (data adj1 saturat*).ti,ab.,
8. ("social construct*" or postmodern* or post-structural* or post structural* or poststructural* or post modern* or post-modern* or feminis* or action research or cooperative inquir* or co operative inquir* or co-operative inquir* or humanistic or existential or experiential).mp.,
9. (field adj (study or studies or research)).ti,ab.,
10. (human science or biographical method or participant observ*).ti,ab.,
11. ((purpos* adj4 sampl*) or (text* adj1 analysis) or (focus group* or observational method* or "content analysis" or "narrative analysis")).mp.,
12. (unstructured or open-ended or open ended or narratives or life world or life-world or conversation analys?s or personal experience* or theoretical saturation).mp.,
13. ((lived or life or patient or carer* or guardian* or parent* or mother* or father* or family*) adj2 (account or accounts or perspective* or interpretations or experience*)).ti,ab.,
14. ((children* or adolescent*) adj2 (account or accounts or perspective* or interpretations or experiences or experience)).ti,ab.,
15. or/1 to 14,
16. (adolescen* or preadolescen* or baby or babies or infan*2 or toddler* or preschool* or pre-school* or child or children or childhood or girls or boys or kid or kids or juvenile or teen* or preteen* or youth or youngster*).ti,ab.,
17. (pupil or pupils or school-aged or school pupil* or schoolchild* or paediatric* or pediatric*).ti,ab.,
18. exp child/ or adolescent/ or Parent-Child Relations/,
19. ((carer* or caregiver* or family or families) and (child or children or young*)).ti,ab.,
20. (parent*1 or mother*1 or father*1 or daughter*1 or son or sons).ti,ab.,
21. or/16 to 20,
22. exp Chronic Pain/ or exp Complex Regional Pain Syndromes/,
23. ((chronic or longterm or long?term or persist* or sustain* or continued or continuous or recurr*) adj5 (pain* or cephalalgi* or ache or aches)).ti,ab.,
24. ((chronic or longterm or long?term or persist* or sustain* or recurr* or frequent) adj5 (headache or migraine or cramps or cramping)).ti,ab.,
25. (pain* adj3 (condition or conditions or disorder or disorders or illness or illnesses or disease or diseases or recurrent or debilitating or complex or long*)).ti,ab.,
26. (((chronic or long-term) adj3 (condition or conditions or disorder or disorders or illness or illnesses or disease or diseases)) and pain*).ti,ab.,
27. (pain* adj3 (neuropathic or syndrome*)).ti,ab.,
28. (pain* and (sickle cell disease or arthritis or chronic pancreatitis or lupus or costochondritis or tietze syndrome or "ehler's" or fibromyalgia or irritable bowel syndrome or ibs or reflex sympathetic dystrophy or non-cardiac chest pain or chronic fatigue syndrome or myalgic encephalomyelitis or "me/cfs" or endometriosis or Dysmenorrhea or Inflammatory bowel disease or IBD)).ti,ab.,
29. exp Pain/ and exp Chronic Disease/,
30. or/22 to 29,
31. 15 and 21 and 30.

Search strategy for HMIC

1. Qualitative Research/,
2. Interviews/,
3. (ethnonursing or phenomenol* or emic or etic or hermeneutic* or heuristic* or semiotic* or theoretical sampl*).ti,ab.,
4. (qualitative adj3 (study or research or method* or analysis or cod* or them* or interview* or question*1 or data)).ti,ab.,
5. (thematic analysis or ethnological research or ethnograph* or life stor*).ti,ab.,
6. (theme*1 adj2 (qualitative or analysis or coding or codes or grouping or identif*)).ti,ab.,
7. (grounded adj2 (theor* or study or studies or research or analys?s)).mp.,
8. (data adj1 saturat*).ti,ab.,
9. ("social construct*" or postmodern* or post-structural* or post structural* or poststructural* or post modern* or post-modern* or feminis* or action research or cooperative inquir* or co operative inquir* or co-operative inquir* or humanistic or existential or experiential).mp.,
10. (field adj (study or studies or research)).ti,ab.,
11. (human science or biographical method or participant observ*).ti,ab.,
12. ((purpos* adj2 sampl*) or (text* adj1 analysis) or (focus group* or observational method* or "content analysis" or "narrative analysis")).mp.,
13. (unstructured or open-ended or open ended or narratives or life world or life-world or conversation analys?s or personal experience* or theoretical saturation).mp.,
14. ((lived or life or patient or carer* or guardian* or parent* or mother* or father* or family*) adj2 (account or accounts or perspective* or interpretations or experience*)).ti,ab.,
15. ((children* or adolescent*) adj2 (account or accounts or perspective* or interpretations or experiences or experience)).ti,ab.,
16. 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15,
17. (adolescen* or preadolescen* or baby or babies or infan*2 or toddler* or preschool* or pre-school* or child or children or childhood or girls or boys or kid or kids or juvenile or teen* or preteen* or youth or youngster*).ti,ab.,
18. (pupil or pupils or school-aged or school pupil* or schoolchild* or paediatric* or pediatric*).ti,ab.,
19. exp children/,
20. child parent relation/,
21. ((carer* or caregiver* or family or families) and (child or children or young*)).ti,ab.,
22. (parent*1 or mother*1 or father*1 or daughter*1 or son or sons).ti,ab.,
23. 17 or 18 or 19 or 20 or 21 or 22,
24. ((chronic or longterm or long?term or persist* or sustain* or continued or continuous or recurr*) adj3 (pain* or cephalalgi* or ache or aches)).ti,ab.,
25. (pain* adj3 (condition or conditions or disorder or disorders or illness or illnesses or disease or diseases or recurrent or debilitating or complex or long*)).ti,ab.,
26. (((chronic or long-term) adj3 (condition or conditions or disorder or disorders or illness or illnesses or disease or diseases)) and pain*).ti,ab.,
27. (pain* adj3 (neuropathic or syndrome*)).ti,ab.,
28. (pain* and (sickle cell disease or arthritis or chronic pancreatitis or lupus or costochondritis or tietze syndrome or "ehler's" or fibromyalgia or irritable bowel syndrome or ibs or reflex sympathetic dystrophy or non-cardiac chest pain or chronic fatigue syndrome or myalgic encephalomyelitis or "me/cfs" or endometriosis or Dysmenorrhea or Inflammatory bowel disease or IBD)).ti,ab.,
29. exp pain/,
30. exp chronic disease/,
31. 24 or 25 or 26 or 27 or 28 or 29 or 30,
32. 32. 16 and 23 and 31.

Search strategy for CINAHL (via EBSCO)

S29 S5 AND S16 AND S28

S28 S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27

S27 MH (qualitative studies OR phenomenological research OR semi-structure interview OR thematic analysis OR ethnographic research)

S26 AB (children* or patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 experience*))

S25 AB (children* or patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 interpretation*))

S24 AB (children* or patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 (perspective*))

S23 AB ("thematic analysis" or "ethnological research" or ethnograph* or "life stor*" or "focus group*" or phenomenological))

S22 AB (qualitative N3 (study or research or method* or analysis or cod* or them* or interview* or question* or data))

S21 TI (patient or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 experience*))

S20 TI (patient or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 interpretation*))

S19 TI (patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 (perspective*))

S18 TI ("thematic analysis" or "ethnological research" or ethnograph* or "life stor*" or "focus group*" or phenomenological))

S17 TI (qualitative N3 (study or research or method* or analysis or cod* or them* or interview* or question* or data))

S16 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15

S15 TI (pain* and ("sickle cell" or arthritis or "chronic pancreatitis" or lupus or costochondritis or tietze or "ehler's" or fibromyalgia or "irritable bowel" or dystrophy or endometriosis or "myalgic encephalomyelitis" or Dysmenorrhea or "Inflammatory bowel" or ibs or ibd or "me/cfs"))

S14 TI (pain* N3 (condition or conditions or disorder or disorders or illness or illnesses or disease or diseases or recurrent or debilitating or complex or long* or syndrome or neuropathic))

S13 TI (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 migraine*))

S12 AB (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 pain*))

S11 AB (pain* and ("sickle cell" or arthritis or "chronic pancreatitis" or lupus or costochondritis or tietze or "ehler's" or fibromyalgia or "irritable bowel" or dystrophy or endometriosis or "myalgic encephalomyelitis" or Dysmenorrhea or "Inflammatory bowel" or ibs or ibd or "me/cfs"))

S10 AB (pain* N3 (condition or conditions or disorder or disorders or illness or illnesses or disease or diseases or recurrent or debilitating or complex or long* or syndrome or neuropathic))

S9 AB (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 migraine*))

S8 AB (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 pain*))

S7 MH Chronic pain or MH "Complex Regional Pain Syndromes+"

S6 MH (pain or "pain management") and ("chronic disease"))

S5 S1 OR S2 OR S3 OR S4

S4 AB (("school-aged" or "school pupil*" or schoolchild* or p#ediatric* or parents or parent or guardian or guardians or mother or mothers or father or fathers))

S3 AB (adolescen* or preadolescen* or baby or babies or infan* or toddler* or preschool* or pre-school* or child or children or childhood or girls or boys or kid or kids or juvenile or teen* or preteen* or youth or youngster*)

S2 TI (adolescen* or preadolescen* or baby or babies or infan* or toddler* or preschool* or pre-school* or child or children or childhood or girls or boys or kid or kids or juvenile or teen* or preteen* or youth or youngster*)

S1 MH (child or adolescence or patient-family relations)

Search strategy for Scopus

((TITLE-ABS-KEY (qualitative)) OR (TITLE-ABS-KEY ("thematic analysis" OR "ethnological research" OR ethnograph* OR "life stor*" OR "focus group*" OR phenomenological OR "lived experienc*"))) AND (((KEY (("child" OR adolescent OR "parent-child relations"))) OR (TITLE-ABS ((adolescen* OR preadolescen* OR baby OR babies OR infants OR infancy OR toddler* OR "pre-school*" OR preschool* OR child OR children OR childhood OR girls OR boys OR kids OR juvenile OR teens OR teenager* OR preteen* OR youth OR "school?aged" OR "school?pupil*" OR schoolchild* OR p?ediatric* OR parents OR guardians OR mothers OR fathers)))) AND ((TITLE-ABS ("chronic migraine*")) OR (TITLE-ABS-KEY ((chronic OR "long?term" OR sustain* OR recurr* OR conditions OR disorder OR complex OR neuropathic) W/3 (pain*)))))

British Education Index (EBSCO)

S14 S13 AND S5

S13 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12

S12 TX (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 pain*))

S11 TX (pain* and ("sickle cell" or arthritis or "chronic pancreatitis" or lupus or costochondritis or tietze or "ehler's" or fibromyalgia or "irritable bowel" or dystrophy or endometriosis or "myalgic encephalomyelitis" or Dysmenorrhea or "Inflammatory bowel" or ibs or ibd or "me/cfs"))

S10 TX (pain* N3 (condition or conditions or disorder or disorders or illness or illnesses or disease or diseases or recurrent or debilitating or complex or long* or syndrome or neuropathic))

S9 TX pain AND KW (("Chronic illness" OR "chronic diseases" OR "chronically ill"))

S8 KW ("Chronic pain" OR "Complex regional pain")

S7 SU ("Chronic pain" OR "Complex regional pain")

S6 TX pain AND SU (("Chronic illness" OR "chronic diseases" OR "chronically ill"))

S5 S1 OR S2 OR S3 OR S4

S4 TX (("school-aged" or "school pupil*" or schoolchild* or p#ediatric* or parents or parent or guardian or guardians or mother or mothers or father or fathers))

S3 TX (adolescen* or preadolescen* or baby or babies or infan* or toddler* or preschool* or pre-school* or child or children or childhood or girls or boys or kid or kids or juvenile or teen* or preteen* or youth or youngster*)

S2 KW (children OR "school age" OR adolescence OR pediatrics)

S1 SU (children OR "school age" OR adolescence OR pediatrics)

Child development and adolescent studies (EBSCO)

S29 S5 AND S16 AND S28

S28 S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27

S27 MH (qualitative studies OR phenomenological research OR semi-structure interview OR thematic analysis OR ethnographic research)

S26 AB (children* or patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 experience*))

S25 AB (children* or patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 interpretation*))

S24 AB (children* or patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 (perspective*))

S23 AB ("thematic analysis" or "ethnological research" or ethnograph* or "life stor*" or "focus group*" or phenomenological))

S22 AB (qualitative N3 (study or research or method* or analysis or cod* or them* or interview* or question* or data))

S21 TI (patient or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 experience*))

S20 TI (patient or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 interpretation*))

S19 TI (patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 (perspective*))

S18 TI ("thematic analysis" or "ethnological research" or ethnograph* or "life stor*" or "focus group*" or phenomenological))

S17 TI (qualitative N3 (study or research or method* or analysis or cod* or them* or interview* or question* or data))

S16 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15

S15 TI (pain* and ("sickle cell" or arthritis or "chronic pancreatitis" or lupus or costochondritis or tietze or "ehler's" or fibromyalgia or "irritable bowel" or dystrophy or endometriosis or "myalgic encephalomyelitis" or Dysmenorrhea or "Inflammatory bowel" or ibs or ibd or "me/cfs"))

S14 TI (pain* N3 (condition or conditions or disorder or disorders or illness or illnesses or disease or diseases or recurrent or debilitating or complex or long* or syndrome or neuropathic))

S13 TI (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 migraine*))

S12 AB (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 pain*))

S11 AB (pain* and ("sickle cell" or arthritis or "chronic pancreatitis" or lupus or costochondritis or tietze or "ehler's" or fibromyalgia or "irritable bowel" or dystrophy or endometriosis or "myalgic encephalomyelitis" or Dysmenorrhea or "Inflammatory bowel" or ibs or ibd or "me/cfs"))

S10 AB (pain* N3 (condition or conditions or disorder or disorders or illness or illnesses or disease or diseases or recurrent or debilitating or complex or long* or syndrome or neuropathic))

S9 AB (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 migraine*))

S8 AB (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 pain*))

S7 MH Chronic pain or MH "Complex Regional Pain Syndromes+"

S6 MH (pain or "pain management") and ("chronic disease"))

S5 S1 OR S2 OR S3 OR S4

S4 AB (("school-aged" or "school pupil*" or schoolchild* or p#ediatric* or parents or parent or guardian or guardians or mother or mothers or father or fathers))

S3 AB (adolescen* or preadolescen* or baby or babies or infan* or toddler* or preschool* or pre-school* or child or children or childhood or girls or boys or kid or kids or juvenile or teen* or preteen* or youth or youngster*)

S2 TI (adolescen* or preadolescen* or baby or babies or infan* or toddler* or preschool* or pre-school* or child or children or childhood or girls or boys or kid or kids or juvenile or teen* or preteen* or youth or youngster*)

S1 MH (child or adolescence or patient-family relations)

PsycInfo (EBSCO)

S29 S5 AND S16 AND S28

S28 S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27

S27 SU (qualitative OR phenomenological OR ethnography OR "thematic analysis")

S26 AB (children* or patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 experience*))

S25 AB (children* or patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 interpretation*))

S24 AB (children* or patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 (perspective*))

S23 AB ("thematic analysis" or "ethnological research" or ethnograph* or "life stor*" or "focus group*" or phenomenological))

S22 AB (qualitative N3 (study or research or method* or analysis or cod* or them* or interview* or question* or data))

S21 TI (patient or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 experience*))

S20 TI (patient or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 interpretation*))

S19 TI (patient or patients or carer* or guardian* or parent* or mother* or father* or family* or lived) N3 (perspective*))

S18 TI ("thematic analysis" or "ethnological research" or ethnograph* or "life stor*" or "focus group*" or phenomenological))

S17 TI (qualitative N3 (study or research or method* or analysis or cod* or them* or interview* or question* or data))

S16 S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15

S15 TI (pain* and ("sickle cell" or arthritis or "chronic pancreatitis" or lupus or costochondritis or tietze or "ehler's" or fibromyalgia or "irritable bowel" or dystrophy or endometriosis or "myalgic encephalomyelitis" or Dysmenorrhea or "Inflammatory bowel" or ibs or ibd or "me/cfs"))

S14 TI (pain* N3 (condition or conditions or disorder or disorders or illness or illnesses or disease or diseases or recurrent or debilitating or complex or long* or syndrome or neuropathic))

S13 TI (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 migraine*))

S12 AB (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 pain*))

S11 AB (pain* and ("sickle cell" or arthritis or "chronic pancreatitis" or lupus or costochondritis or tietze or "ehler's" or fibromyalgia or "irritable bowel" or dystrophy or endometriosis or "myalgic encephalomyelitis" or Dysmenorrhea or "Inflammatory bowel" or ibs or ibd or "me/cfs"))

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S8 AB (chronic or longterm or "long?term" or persist* or sustain* or continued or continuous or recurr*) N3 pain*))

S7 SU ("Chronic pain" OR "Complex regional pain")

S6 SU pain AND SU (("Chronic illness" OR "chronic disease"))

S5 S1 OR S2 OR S3 OR S4

S4 AB (("school-aged" or "school pupil*" or schoolchild* or p#ediatric* or parents or parent or guardian or guardians or mother or mothers or father or fathers))

S3 AB (adolescen* or preadolescen* or baby or babies or infan* or toddler* or preschool* or pre-school* or child or children or childhood or girls or boys or kid or kids or juvenile or teen* or preteen* or youth or youngster*)

S2 TI (adolescen* or preadolescen* or baby or babies or infan* or toddler* or preschool* or pre-school* or child or children or childhood or girls or boys or kid or kids or juvenile or teen* or preteen* or youth or youngster*)

S1 SU (children OR "school age" OR adolescence OR pediatrics)

Box 1 Key:

ti,ab: keyword search in title and abstract

*: truncates a keyword

adj: number of words away one search term is from the other, in any order

/: subject heading

?: option for any letter, eg ‘analys?s’ would pick up analysis or analyses

mp: multi-purpose

CINAHL: Cumulative Index to Nursing and Allied Health Literature

HMIC: Health Management Information Consortium

Appendix 2. Methodological limitations: level of concern for methodological domains assessed using CASP

Study	Was there a clear statement of the aims of the research?	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research?	Was the recruitment strategy appropriate to the aims of the research?	Were the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	Overall assessment of limitations	Explanatory comments
Ahlqwist 2012	Low	Low	Low	High	Moderate	High	Moderate	Low	Low	Moderate	No mention of authors' roles or potential bias. Given high concerns re recruitment strategy, moderate concerns re data collection and risks of possible bias, overall judged as moderate limitations
Atkin 2001	Low	Low	Low	Moderate	Low	Moderate	High	Moderate	Low	Low	Recruitment – not explained why 7 localities were chosen, but they had the whole population of those children and young people (CYP) with sickle cell disease (SCD)/thalassaemia. Was a service evaluation – little information provided about the service. Reflexivity is implicit in matching interviewer gender and ethnicity to interviewee. Authors explained how interview questions were formulated, e.g. with PAG, literature. Ethics not mentioned but as was service evaluation, probably exempt from ethics approval. Does not mention other ethical issues at all – possibly a reporting issue as this is part of a bigger study. Findings – not explained who analysed data and whether there was team involvement for rigour, but they ap-

(Continued)

											pear credible and trustworthy in the way they were presented
Atkin 2000	Low	Low	Low	Moderate	Low	Moderate	Moderate	Moderate	Low	Low	Recruitment – not explained why 7 localities were chosen, but they had the whole population of those CYP with SCD/thalassaemia. Was a service evaluation – we do not know what the service was. Reflexivity is implicit in matching interviewer gender and ethnicity to interviewee. Authors explained how interview questions were formulated, e.g. with project advisory group, literature. Ethics not mentioned but as was service evaluation, probably exempt from ethics approval. Does not mention other ethical issues at all – possibly a reporting issue as this is part of a bigger study. Findings – not explained who analysed data and whether there was team involvement for rigour, but they appear credible and trustworthy in the way presented. Low limitations – some weaknesses but probably reporting weaknesses
Atoui 2015	Low	Low	Low	Moderate	Low	High	Low	Low	Low	Low	Recruitment – seems appropriate, although they do not give rationale for all choices. They are interested in adolescents in Beirut and recruit them. Could have expanded on the criteria for inclusion/exclusion Do not explain why recruit child only if 0 on pain scale, but presumably for ethical reasons. Relationship – no information given. Ethics – issues considered re: consent/assent, distress during interview, confidentiality Analysis – do not explain how themes developed but only a minor concern. Low limitations – some weaknesses but mainly reporting weaknesses

(Continued)

Baert 2020	Low	Low	Low	Moderate	Moderate	High	High	Low	Moderate	Moderate	Design – justify why chose focus groups. Recruitment – do not say why 3 different countries included. Do not say why people opted out of the research or what the prior study in Ghent was that they used in order to recruit their participants. The focus group questions were chosen by the researchers and piloted on university students, so no input from parents/children with pain/expert advisors. They report the questions, but they ask a lot about unfairness which is quite leading when they wanted to explore injustice. Reflexivity – nothing reported. Ethics – had ethical approval in all 3 countries but nothing about informed consent, confidentiality, distress, post–focus group support/signposting to support, etc. Findings – do not discuss impact of country differences on the findings. Moderate limitations because of concerns over recruitment and data quality and hence meaningfulness of findings
Borghi 2014	Low	Low	Low	Low	Moderate	High	Low	Moderate	Moderate	Moderate	Aim and rationale well explained. Choice of method/design explained in aim. Recruitment – seems to be 1 clinic only and excluded CYP under 6 years only because they can't give 'clear accounts as easily'. Could have clearer inclusion and exclusion criteria, but overall the authors explained how they recruited their participants by contacting the doctors and the guardians/parents. Data collection – minor issue is they have not justified the choice of only 1 clinic, do not justify choice of semi-structured interview. Settings for data collection were not described, not really sure about the format of the data either. No reflexivity or information about

(Continued)

											the authors. Nothing on ethics – parents approved their child's very detailed interview transcript, even for older children, yet the ethical implications of this are not discussed. Data analysis – some data on this re use of Piaget's theory but not fully clear how themes arrived at, no discussion of contradictory data or researcher's role in selecting quotations. Described theoretical reference but not much information on analysis. Findings are not very clear – not much discussion against original question – no triangulation, I think the findings were too focused on Piaget's theory. Do not explore evidence for and against their arguments and are not critical of Piaget – e.g. was there no evidence NOT in support of Piaget's theory? Moderate limitations overall given above concerns
Brandelli 2021	Low	Low	Low	Moderate	Moderate	High	High	Moderate	Low	Moderate	No real justification of sample size as congruent with interpretative phenomenological analysis (IPA) approach save one comment at start of results. Some further discussion of what was included in the interview schedule needed. Researcher relationship – some attempt to note this but really only mentions graduate student with clinical training; what about knowledge of pain, etc? Ethics – approval mentioned but little other detail. Analyses – rather thin in terms of interpretation and theme titles, not fitting with IPA level of interpretation and also focus on idiographic. Findings – an overall clear statement of findings was absent (attempted), lack of quality (some but not sufficient).

(Continued)

											Recruitment was focused on an already-recruited sample with low scores on a particular questionnaire which did not match well to the main aim of the study. Moderate limitations overall given above concerns
Britton 2002a; Britton 2002b	Low	Low	Moderate	Moderate	Moderate	Moderate	Moderate	High	Low	Moderate	Quite poorly reported overall. Design – used longitudinal qualitative interviews and diaries but do not justify the design (why longitudinal was needed) nor the choice of methods. Recruitment – not much detail given and do not justify why only chose families of girls and not boys and girls. If the aim was to design a resource for all families, then boys with juvenile idiopathic arthritis (JIA) should have been included. Data collection – some details but questions asked not provided. Reflexivity – generic statements but specific detail of how it was achieved. Ethics – had ethical approval but no info given on informed consent, anonymity, burden on families especially children with JIA. Data analysis – sparse information – say 'More detailed information is available in part 1 (Britton and Moore 2002).' Findings come across as convincing but no information on triangulation, evidence for and against their arguments – possibly yellow but gave it green Britton (part 3) #5920 – not a clear statement for aim (maybe because this is part of a sequence of studies?) but the rationale and the relevance are there. Study design was decided after applying a questionnaire which guided the fieldwork. It briefly mentions methods utilised for data collection and referred to full descrip-

(Continued)

											tion elsewhere. No information provided about data analysis – it goes straight into findings. I rated it as moderate overall given the lack of information on data analysis, which is a major problem. Overall moderate risk of bias, but the detail is hinted to be contained in another publication. Consequently, it is hard to judge methodological quality in this paper alone. Design and data collection is a hotchpotch of different approaches (no justification and some data were generated by participants opting to make videos which was not in the original design). Recruitment not well described (opportunity sample perhaps?). Bias is touched upon but not described. Unclear whether all findings are from a small number of participants (no identifiers provided). Combining the information from the publications, overall moderate limitations given moderate concerns in most domains
Brodwall 2018	Low	Low	Low	Low	Low	Moderate	High	Moderate	Low	Low	Relationship – the interviewer is a general practitioner and psychiatrist. Participants knew she was a doctor, although she introduced herself as a scientist without responsibility for taking care of the family. Some information about the first author but not how this would have affected the study. Data analysis needs to be further described – more info is needed – how they performed the qualitative content analysis. Not clear how codes, categories and themes were developed but several researchers involved. Ethical issues – not explored.

(Continued)

											Low limitations overall given most key domains had low concerns
Carter 2002a	Low	Low	Low	High	Low	Moderate	Moderate	Low	Low	Low	Need more information about recruitment strategy. Mentions that letter was sent but no detail of how these CYP were found (e.g. hospital, clinic…). Consent in writing was obtained but no mention of ethical approval. Data analysis – could have presented more information about how thematic analysis was done, which themes were derived and how. Low limitations overall because minor concerns in most key domains
Carter 2002	Low	Low	Low	Moderate	Moderate	Moderate	Moderate	Moderate	Low	Moderate	The research design seems justified, but it was not explicitly stated. Recruitment – some information but it could have detailed this process more, e.g. why some participants did not take part, from where the participants were recruited. Does not state interview setting, but it is very clear on how data were collected. It also described how the questions for the interview were formulated. The relationship between participants and researcher is not explicitly described. Data analysis refers to participant checking but not what participants said/reported, etc. data. Needed more information about saturation. No deviant case presentation, but findings are otherwise well presented, coherent and linked with the study aim. Moderate limitations – some weaknesses but lack of description is more of a reporting weakness
Carter 2002b	Low	Low	Low	Low	Moderate	Moderate	Low	Low	Low	Low	No discussion about the study design. More information could have been provided about data collection,

(Continued)

											e.g. which type of data was obtained, how the interview was structured. Low limitations overall
Carter 2017	Low	Low	Moderate	Moderate	Low	High	Moderate	Moderate	Low	Moderate	Explains the design. The study aim seems quantitative (frequency, intensity…). They explained recruitment strategies really well. Sample size is small, and there are missing survey data for 2 children. Data collection clear – stated place and methods, also explained how the interview was structured. Reflexivity – no mention of how the researchers might have affected the study/data collection. Data analysis could have included how the researchers avoided bias and more information about how the codes were created. The findings are really clear and relevant to the research question. Father's perspective included without consent. Moderate limitations overall given above concerns
Cartwright 2015	Low	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	Reflexivity – information given on researchers' backgrounds – some of the reflexivity is implicit rather than explicit so maybe issue of reporting not conduct. Ethics – not much reported – just got written consent and had approval. Low limitations overall given few concerns
Castle 2007	Low	Low	Low	Moderate	Low	High	Moderate	Low	Low	Moderate	Recruitment – convenience sample – no explanation of refusal to participate, choice of recruitment setting not explained, only included 6 CYP and only those who could talk, yet focus is on cerebral palsy in which speech impairment is common. Mi-

(Continued)

											nor issues with data collection reporting – do not say where interviews occurred or whether recorded. Relationship – not explicit who did interviews – there are 3 authors, lead author is an occupational therapist as are co-authors. Other impacts of relationship not discussed. Ethics – had approval, sought informed consent, use pseudonyms – no other ethical issues discussed, e.g. burden on participants, distress and how handled, etc. Data analysis – use of triangulation of methods (interview and pre-interview questionnaire), supervisory input, describe the methods and give reference to method. Refers to reflexivity before and during interviews and their analysis. Findings seem convincing – minor issue is that contradictory findings are not made that obvious. Overall moderate limitations because of small convenience sample and other methods issues
Dell'Api 2007	Low	Low	Low	Moderate	Moderate	High	High	Low	Low	Moderate	No information on ethical issues or on relationship. Do not know who interviewer was. No interview schedule provided. Ethical concerns over data collection from children in the hospital whilst awaiting first appointment to tertiary pain service – stressful situation anyway. Recruitment strategy not justified nor obviously related to the aim – only 5 children recruited. Age 10 to 17 but age not justified. Some rigorous data analysis processes, e.g. second coder, member checking but not clear how got from line-by-line coding to themes.

(Continued)

											Overall moderate limitations given above concerns
Dyson 2011	Low	Low	Moderate	Moderate	Moderate	High	Moderate	Low	Low	Low	Design not justified, nor is choice of interviews as method. Recruitment – some was opportunistic from quantitative sample, some purposive. Data collection – no information on choice of interviews or the questions asked. Reflexivity – nothing reported. Ethics – had approval, got signed informed consent from CYP and carers but process not explained. Some detail of the analysis process. Findings rich. Overall low limitations because mainly reporting issues rather than conduct issues
Forgeron 2008	Low	Low	Low	Low	Low	High	Low	Moderate	Low	Low	Only concerns were no reflexivity provided. Data analysis warranted more description, e.g. how the themes were developed, etc., so low limitations overall
Gaughan 2014	Low	Moderate	Low	Low	Low	High	High	Low	Low	Moderate	Aim – seems to want to link parental attitudes to child's response to the pain program – that seems a quantitative research question. Concerns about possible bias – all authors were from the hospital pain clinic under investigation. The parents were interviewed while the child was still in the pain programme, and it is not clear how power issues were handled nor informed consent processes – seems the researcher may have been directly involved in the care of the participants' child. Moderate limitations given above concerns
Guell 2007	Low	Low	Low	Moderate	Low	Low	High	High	Low	Moderate	Recruitment – did not explore the impact of mixed UK and German sample. Reflexivity – does talk about rapport with CYP and not taking notes until after fieldwork to avoid

(Continued)

											disrupting visits/conversations (ethnography) but does not explore the impact of the decisions around including families in Germany instead of just UK on the data and findings. Ethics – not explicitly discussed at all re recruitment, consent, confidentiality, etc., and no mention of ethics approval. We do not know how the data were analysed other than researcher identified recurring topics/themes – could be more to do with the style of reporting an ethnography. Findings – they are convincing even though they are not subject to triangulation in the same way as recorded interviews with transcripts – no audio recordings made, just field notes – but does not explain about differences between UK and Germany in terms of experiences for all of the findings, no respondent validation used. The findings do read convincingly though overall. Moderate limitations based on above concerns
Helvig 2013	Low	Low	Low	Moderate	Low	High	Low	Moderate	Low	Moderate	Sampling – very small convenience sample – recruited through friends and colleagues. Migraine diagnosis based on parental report only. Relationship – not reported. Analysis – no triangulation, etc. Some proof of rigour – 2 researchers interpreting data to create summaries but not clear if both did coding, not clear how arrived at themes. Findings seem clear but are not very in depth. Moderate limitations overall
Hunt 2003	Low	Low	Low	Low	Low	Moderate	Moderate	Low	Low	Low	Recruitment – we do not know who declined to take part or how centres selected the 5 parents they were asked to recruit. The sample population and recruitment were well de-

(Continued)

											scribed. Reflexivity – good reflexivity re data analysis, less in how interviews were conducted. Ethics – no information given other than they had ethical approval and gave participants information sheets and consent forms – probably reporting issue rather than poor conduct issue so overall low limitations
Jones 2022	Low	Low	Low	Moderate	Low	Moderate	Low	Low	Low	Low	Overall statement – no concerns about design, data collection or ethical issues; very minor concerns about findings; only minor concerns about reflexivity (relationships between participants) and findings. Some concerns about recruitment strategy because of lack of rationale and all from single service. Analysis – give example matrix of temporal analysis. Used Braun and Clarke's approach. Use quotations in findings section and say selected from across interviews. Low limitations overall
Jones 2020	Moderate	Low	Moderate	Moderate	Moderate	Low	Low	Low	Low	Moderate	The aim is not clearly defined but is implied. The authors talked about exploring the relative frequencies of hoped- and feared-for future self… not sure whether qualitative is the best design for this. Not stated where the interviews were conducted. Did not explain why some participants did not take part
Jordan 2007	Low	Low	Low	Low	Moderate	Low	Low	Moderate	Low	Low	Data collection – no information on where the interviews were conducted. Data analysis could have included more information about how the themes were derived. Overall low limitations given few concerns

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Jordan 2016	Low	Low	Low	Low	Moderate	Low	Low	Low	Low	Low	Only concern is need more information about format of data and interview. Clear findings are presented. Overall low limitations given few and minor concerns
Jordan 2018	Low	Low	Moderate	Low	Low	Low	Low	Low	Low	Low	Design was not mentioned. Overall low limitations given very minor concerns
Kanstrup 2019	Low	Low	Low	Moderate	Low	Moderate	Low	Moderate	Low	Low	Ethics – ethical approval, ethical approach to recruitment described. Description of how interviewer positioned herself and explained her role to participants and adapted her language for CYP. Used and justified IPA. Interviewer's prior experience of delivering acceptance and commitment therapy not reflected on as a bias in data collection/analysis. Only 8 people from 1 service participated. Low limitations overall given few concerns
Khanom 2020	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	Low	Very clearly described study. Some description of bias/data collection but none specifically around being responsive to events. Deviant case analysis not described, but otherwise findings/analysis is good and merits a low limitations score
Maciver 2005; Maciver 2010; Maciver 2011	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Most aspects were really well detailed. Recruitment strategy clear, although non-responders not described; smallish sample (n = 12 from 10 families). No mention of data saturation/sufficiency, but methods generally very well described. Ethical issues, e.g. consent, etc., all described. Low limitations overall

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McDonagh 2021	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	Low	The topic is appropriate for qualitative methodology, but they did not explain why explicitly. Relationship with participants – the authors did not provide any information about the researcher, it only briefly mentions that one of the reviewers was a skilled qualitative researcher. Saturation/theoretical sufficiency is not discussed. Low limitations overall given minor concerns
McKinnon 2022	Low	Low	Low	Low	Low	Moderate	Low	Low	Low	Low	Include some information about the researchers but not how their professional background could have affected the data collection. One of the authors already knew participant from a previous study. Sampling frame described in accompanying paper; subsample of larger study. No discussion of saturation. Low limitations overall
Neville 2019	Low	Low	Moderate	Moderate	Low	High	Moderate	Low	Low	Moderate	Design – do not explain or justify the design. Recruitment strategy was not justified – did not use diagnostic uncertainty as a recruitment criterion. Do not explain why they excluded certain children, e.g. those with autism. Relationship – no information. Ethics – information given on informed consent process but no information on ethical issues of interviewing youth and parents separately and whether confidentiality was maintained for each party and how. Moderate limitations given above concerns
Njifon 2019	Moderate	Low	Low	Moderate	Low	Moderate	High	Moderate	Low	Moderate	Not a standard journal article format – main issues are lack of detail in reporting. Aim is unclear; therefore, hard to judge whether qualitative methodology and design were appropriate. Recruitment – no informa-

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											tion. Very small sample – one family. No information on ethics. Analysis – only told it was thematic. Mostly issues of poor reporting, i.e. issues not reported or not fully reported, rather than actual methodological limitations, so moderate limitations overall
Nutkiewicz 2008	Moderate	Low	Moderate	High	Low	High	High	Moderate	Low	Moderate	An oral history study so nonstandard reporting – most issues related to lack of detail being reported. Aim stated in several different ways in paper and not clear as a result. Design – observation of communication would be more appropriate if interested in the communication between paediatric pain patients and their doctor but also say aim is about what children say about their relationship with their doctors. No information on recruitment strategy other than recruited from university pain clinic. Ethics – not reported. Little information on analysis – just told it was coded. Overall moderate limitations given above concerns
Renedo 2019; Renedo 2020	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Reflexivity – implicit in description of choice of interview questions and choice of recruitment location, explicit that interviewer has no links with health services for SCD or any research participants and was White (Caucasian) without SCD. Relationship – some consideration of interviewer status and relationship between researcher and participant. Analysis – followed some of the steps of grounded theory but not clear exactly what was done. Findings were fairly clear. Overall low limitations

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Rossato 2007	Low	Low	Low	Low	Moderate	High	Low	Low	Moderate	Low	Clear statement of aims consistent with use of grounded theory. Recruitment seemed more convenience than purposeful sampling. Data seem to be collected in the clinic. Had ethical approval. Limitations were not discussed nor the full process like other pieces of research. No reflexivity section. Overall low limitations – mainly reporting issues rather than concerns with conduct
Smart 2005	Low	Low	Low	Low	Moderate	Moderate	Moderate	Low	High	Moderate	The researchers were involved in the participants' treatment; therefore, issue of potential bias. Non-responders are not described, but otherwise recruitment is well described. Data collection is only briefly described; researchers are psychiatrists which is explained as appropriate re: biopsychosocial approach, but the idea of somatising is used without critical reflexivity regarding how this can invalidate people's experiences of pain. Ethics approval and informed consent confirmed, but no further discussion of any ethical parameters. Analysis is described relatively well; deficits about bias, etc., are mediated by team analysis which makes it potentially more robust. Could have mentioned saturation of data and provided more details about how the interview was conducted. The findings did not mesh well with the aims of the study – lots of data about their perceptions of self as parents, etc., which were not connected with the stated aims. The data are quite focused on doctors and psychological concepts which are not what the research questions were about.

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											Overall moderate limitations given above concerns
Sorensen 2017	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Data analysis – not clear how moved to categories and themes but demonstrates rigour otherwise. Ethics - issues not discussed. Low limitations given few and minor concerns
Suder 2016	Low	Low	Low	Moderate	Low	Moderate	Low	Moderate	Low	Moderate	Recruitment – narrow recruitment strategy so some sample bias. Data collection – minor concerns – some of the questions had complex, formal vocabulary, e.g. Which activities or occupations help give you identity or meaning in your life? Has chronic pain changed your involvement in those occupations? Relationship – some aspects considered, but do not know what participants were told about the researcher's professional occupational therapy background. Analysis – framework used for analysis might have affected the findings – possibly some deductive analysis although says it was a thematic analysis and phenomenological. Seem to exclude data that do not fit with their themes. Multiple analysts reviewed data in various stages of the analysis. Moderate limitations overall given above concerns
Waite-Jones 2008	Low	Low	Moderate	Moderate	Low	Low	Low	Low	Low	Low	Recruitment – all participants from a support group so some sample bias but did have diversity in age/gender of siblings and fathers and mothers and 1 grandparent. Reflexivity/ethics – first author has JIA and volunteered at the support group she recruited from – these issues not fully explored re her impact on ethical aspects of recruitment, e.g. power dynamics. She does reflect on her

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											impact on the interview data and analysis. Low limitations overall given high-quality analysis and findings
Williams 2008	Low	Low	Low	Low	Low	Low	Low	Low	Low	Low	Only minor concern is they could have given more details about data collection, e.g. did they use icebreakers or prompts, etc.? Low limitations overall
Wong 2016	Low	Low	Low	High	Low	High	Moderate	Moderate	Moderate	Moderate	Recruitment – no information given except they sampled from those in a survey as part of a mixed methods study. Data collection – little information given, location not stated – minor concerns. Relationship – no information. Ethics – no information given. Analysis – only one analyst but did 'peer debriefing'. Content analysis used – a bit rudimentary and possibly lacking disconfirming analysis. Findings – disconfirming data not very apparent, quite quantitative reporting. Overall, moderate limitations given above concerns – many issues are related to reporting issues not conduct issues

CASP: critical appraisal skills programme
CYP: children and young people
IPA: interpretive phenomenological analysis
JIA: juvenile idiopathic arthritis
SCD: sickle cell disease

Appendix 3. Details of patient and public involvement and stakeholder engagement

Recruitment

Patient and public involvement group

We conducted patient and public involvement (PPI) recruitment in three main stages: 1) during proposal development in 2019, 2) when the meta-ethnography started in 2020 and 3) prospective recruitment during the meta-ethnography as needed (e.g. to fill the gaps in experiences of specific contexts/conditions, recruitment of healthcare professionals and academics with specialised expertise). Further details on each stage are below.

1. During development of the meta-ethnography research grant proposal in 2019, we recruited 10 lay people, including three children and young people with chronic pain (one was also a patient representative for a third-sector organisation); four parents; two adult patient representatives from the third sector; and two adult members, one with chronic pain and one with a chronic illness, from a university PPI Research Partnership Group (designed to assist with developing research relevant and useful to patients, carers, family members and healthcare professionals). Recruitment routes included national pain services, social media (Facebook and Twitter), third-sector organisations (charities) and the university Research Partnership Group.
2. In 2020, we tailored the recruitment strategy to try to recruit a diverse core PPI group with a variety of experiences, ages, ethnic backgrounds and socioeconomic statuses. We included children aged 8 years to 18 years and parents or/and informal carers (i.e. not healthcare professionals) of children with chronic pain aged 3 months to 18 years. We included all types of chronic pain, both primary (e.g. fibromyalgia) and secondary pain conditions (e.g. arthritis), except for pain associated with cancer. We advertised via pain services, social media and third-sector organisations. We contacted multiple charities and third-sector organisations in an attempt to recruit a diverse group, including the Sickle Cell Society, Fibromyalgia Action UK, Great Ormond Street Hospital, Pain UK, The Brain Charity, CCAA (Children's Chronic Arthritis Association) Kids with Arthritis, Pain Relief Foundation, Action on Pain, Coeliac UK, Guts Charity, Dystonia UK, Endometriosis UK, Sick Children Trust, Action for ME (myalgic encephalomyelitis), A Way With Pain, MS (multiple sclerosis) Trust, Diabetes UK, Fibro Awareness UK, Pain Concern and Independent Nurse. We also invited all PPI members to join the project advisory group during recruitment.
3. We carried out prospective recruitment during the meta-ethnography as needed (e.g. to fill gaps in terms of experiences with specific context/conditions). In 2019 to 2020, we recruited healthcare professionals, representatives of third-sector organisations (chronic pain-related charities) and academics with relevant experience via email to join the advisory group.

Participants

Incorporating a range of stakeholders, purposefully selected for heterogeneity of chronic non-cancer pain experience, from the project outset we intended to maximise the likelihood that the research was acceptable and relevant to children and families and healthcare professionals.

Patient and public involvement group

In 2020, we recruited 12 children (10 female, one male and one non-binary) and eight parents (all female) for the core PPI group. The group was composed of young people from 8 to 20 years old living with chronic pain from different underlying conditions, including Ehlers-Danlos syndrome, fibromyalgia, migraines, general chronic pain and chronic lumbar paravertebral muscle spasm, chronic headaches and complex regional pain syndrome (CRPS). Parents and/or informal carers in the group were all mothers of children with pain from cystic fibrosis, CRPS or Ehlers-Danlos syndrome. We did not have any fathers directly involved despite recruitment attempts. All members lived in the UK in England, Scotland or Wales. We tried to recruit children and parents from a variety of ethnic backgrounds, e.g. through specific third-sector organisations, but were unsuccessful – all were White. We also used social media and online surveys for wider PPI engagement, which may have reached a more ethnically diverse group of children and families, but their feedback was anonymous. Most PPI involvement was UK-based, but we gained an international PPI perspective through online surveys shared via social media.

Project advisory group

The project advisory group, with whom we engaged for advice on specific tasks or issues, comprised 27 members, including 10 children with chronic pain and 7 mothers of children with chronic pain (also part of the PPI group), 6 healthcare professionals and 7 other stakeholders. The group included six clinicians/academic clinicians, including a consultant in paediatric anaesthesia and pain medicine who is a senior clinician and research lead at a specialist pain service; a clinical academic and consultant in pain medicine who is national lead clinician for chronic pain for the Scottish Government and vice chair of the National Advisory Committee on Chronic Pain; a clinical academic who is chair of pain medicine, honorary consultant in anaesthesia and pain medicine, and chair of the 2018 Scottish Intercollegiate Guidelines Network guideline development group for children's chronic pain; one general practitioner; and two physiotherapists. There were two patient representatives from the third-sector, including one from Pain Concern and Children's Health Scotland, a representative from Healthcare Improvement Scotland (Scottish Government), and an academic expert in qualitative evidence synthesis. We were not successful in recruiting representatives of the UK National Institute for Health and Care Excellence or the UK government. We did not seek to recruit internationally for the advisory group, given the funder's focus on the UK context.

PPI training

We surveyed the training and support needs of our core PPI group members before commencing PPI activity in three age-specific online surveys for adults, adolescents and younger children. We tailored training for PPI members to their needs and evolved as the project progressed in line with their wishes. As a result, we provided six online training sessions on the following:

1. How to use Zoom video conferencing software (three sessions)
2. Defining research
3. Defining qualitative research
4. Defining meta-ethnography

Two review authors (MSB, EF) conducted this training, which eight PPI members attended. All members described the training as useful and appropriate to their needs.

Involvement and engagement methods

Strategies to involve PPI favoured flexibility and inclusivity to allow everyone to participate individually or in a group. We used a combination of online workshops and interim online communication (email, teleconference calls and social media, e.g. Facebook and Twitter pages) across the life of the research. For instance, we used online surveys and questionnaires to enable those who could not join the online workshops to voice their opinions.

We engaged with members of the advisory group strategically, generally focused on specific tasks. We also used workshops and interim online communication (email, teleconference calls and social media, e.g. Facebook and Twitter pages) to engage advisory group members through the duration of the research. Table 4 describes the different stages in which PPI and advisory group members were involved in the meta-ethnography.

PPI methods of involvement

We were flexible in response to how children and young people with chronic pain and their families wanted to be involved and tailored our involvement methods to their needs. The PPI group was involved in two online workshops in April and December 2021. All members decided the date and time for the meeting via an online poll. We sent members plain language material relevant to the workshop in advance (including a participant list, agenda and slides), and offered them an online briefing meeting in which they received information about the structure and aim of the meeting and could ask any questions.

We tailored all meetings to the children’s needs, for example short duration, frequent breaks, appropriate language and visual formats (e.g. cartoons). We designed all meetings and workshops to be engaging and to appeal to children and young people. We also prioritised flexibility, including multiple rest breaks and providing a structured schedule in case members wanted to attend a specific section of the workshop. Meetings lasted from one hour to two hours, and we reassured participants they could leave or take breaks at any time. Following introductions, we invited all members to co-create and agree ground rules for the meeting to help create a safe space. A fun activity or icebreaker, such as sharing an image of your favourite cartoon or desired superpower, was always part of the schedule, and it helped to facilitate engagement. For our meetings and workshops involving our PPI members, we used creative and fun ways to get children involved. For example, in an analysis workshop we presented key themes from study findings using visual methods, such as cartoons, and invited them to share their relevant experiences. At the end of the workshops, we offered members an individual follow-up debrief call and provided them with a list of support organisations. Between workshops, we collaborated with and consulted the PPI group by email communication and online surveys.

Project advisory group methods of engagement

The project advisory group (PAG) engaged in two online meetings in May 2021 and April 2022. The meetings were chaired by two skilled chairs independent of the review authors and their institutions: Bernie Carter, professor with expertise in children’s chronic pain at Edge Hill, and Professor Richard Hain, clinical consultant and lead clinician in paediatric palliative medicine at Ty Hafan children’s hospice. All members decided the date and time for the meetings in advance via an online poll, we sent members material relevant to the meeting in advance, and we also offered them an online briefing meeting. We designed the meetings to be flexible, including multiple rest breaks. In between meetings, we also conducted engagement with the advisory group via email. Table 4 shows the key aspects of the research in which the core PPI group were involved.

Table 4. Patient and public involvement in different stages of the meta-ethnography

Phase	Activity	Level of patient and public involvement	Method of involvement
Planning of review	Feedback on study aims, objectives, review questions, lay summary and dissemination strategy	Consultation	Email
Protocol	Finalised the study protocol, i.e. the literature search strategy	Collaboration and consultation	Email
Selection and sampling of studies	Finalised inclusion/exclusion criteria, e.g. the types of chronic non-cancer pain included and the characteristics of the population included. Sampled studies for synthesis.	Collaboration and consultation	Separate online workshops for PPI (1 April 2021) and PAG (6 May 2021)
Analysis and synthesis	Decided how studies would be organised/grouped for analytic synthesis, e.g. grouping them by type of chronic pain or age of participants	Collaboration	Email
Analysis and synthesis	Analysed and interpreted primary study findings, e.g. clarify and enhance meaning of study findings, check whether our interpretation of the study findings was different from or the same as children and families' interpretations, check whether their experiences were similar or different to those of the people in the studies and check whether important areas were missing from research	Consultation and collaboration	Separate online workshops for PPI (9 December 2021) and PAG (28 April 2022)
Dissemination	Producing outputs, dissemination Invited members to co-present a conference paper. Invited the group to co-develop lay, patient and policy outputs. The group is helping ensure that the development of lay dissemination materials for children and families is appropriate and relevant.	Collaboration and consultation	Video conference, email, online. Co-presented at a conference

In Table 4, 'consultation' refers to when the review authors prepared information about research and discussed this with the PPI group, who were asked to comment on and present their views and experiences in response. The ACTIVE (Authors and Consumers Together Impacting on eVidencE), framework for involving users in systematic reviews calls this the PPI group 'influencing' the research (Pollock 2019). 'Collaboration' refers to when children and families were involved in performing the research as well as in setting priorities and making decisions. The ACTIVE framework calls this the PPI group 'controlling' the research (Pollock 2019).

PPI contributions to the review

We recorded the contribution and impact of the PPI group prospectively throughout the study and integrated into this review and other dissemination outputs where appropriate. We reimbursed PPI members for their time and out-of-pocket expenses in line with INVOLVEguidance.

PPI input, based on their experiences, contributed to finalising the study design and helping to define sampling strategy and subgroups for synthesis. They contributed to analysis and interpretation of findings and helped identify important areas that were missing from the existing research. PPI members helped us decide the best approach for disseminating our findings, including deciding the content of outputs and co-presenting at a nursing research conference.

PPI contributions to analysis and interpretation

We collaborated with our PPI group throughout the analysis and synthesis process to seek their perspectives, experiences and understanding of the data. We discussed, clarified and interpreted preliminary findings from included studies in the December 2021 PPI workshop, attended by two parents and three young people, and during the online advisory group meeting in April 2022, attended by four parents and two young people. We used the software Storyboard (www.storyboardthat.com) to create cartoons to convey findings to prompt discussion. No healthcare professionals or other stakeholders attended that advisory group meeting despite being invited. The findings discussed in December 2021 were the following:

1. Why children might not communicate pain verbally
2. Why it is important for children and parents to be acknowledged and understood by healthcare professionals, friends and family
3. What families want from treatment and services
4. Differences between accepting versus being resigned to pain, often referred to in included studies as 'coping'
5. The meaning of 'control' in relation to pain and whether 'coping' strategies are used to achieve control over the pain condition

The findings discussed in April 2022 were the following:

1. How families and doctors/healthcare professionals think about pain and treatments
2. Stigma associated with psychological approaches to managing pain
3. Discrimination and prejudice in health services
4. The lack of a clinical pathway for chronic pain management

PPI members provided different perspectives on, and/or interpretation of, some of the above included study findings and helped us to further develop and refine our interpretations of data. The core PPI group also helped fill gaps in the data, e.g. around disengagement with health services, and brought experiences of pain conditions not represented in the included studies, such as Ehlers-Danlos syndrome. We compared our findings with their experiences, identifying important areas that were missing from the existing research.

Appendix 4. Characteristics of eligible studies

Author	Country	Recruitment setting	Aim	Participant details	Chronic pain condition	Data collection	Data analysis	Funder
Ahlqwist 2012	Sweden	Unclear	Generate a substantive theory, based on interviews with adolescents with lower back pain, explaining how they succeed in managing their main concerns in daily life	12 years to 18 years n = 14 8 females 6 males Ethnic origin not stated	Musculoskeletal pain	Interview	Grounded theory	Swedish Association of Registered Physiotherapists and Renee Eanders Foundation
Ahola 2018	Canada	Information not extracted from unsampled studies	Explore the topics of discussion during open-ended peer mentoring sessions between adolescents and mentors living with chronic illness	12 years to 17 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Canadian Institutes of Health Research Catalyst Grant, Pain in Child Health, J.S.'s Early Research Award
Ajinkpang 2022	Ghana	Information not extracted from unsampled studies	Explore the knowledge of caregivers	2 years to 14 years No further information extracted from unsampled studies	Sickle cell disease	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Ali 2017	USA	Information not extracted from unsampled studies	Assess the feasibility of a mindfulness-based stress reduction (MBSR) programme	10 years to 19 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Center for Complementary and Integrative Health and National Center for Advancing Translational Sciences
Allgood 2018	USA	Information not extracted	Explore patient-reported descriptions of the pain experience	10 years to 19 years	Cystic fibrosis	Information not extract-	Information not extract-	Unfunded

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		from unsampled studies	amongst adolescents and adults living with cystic fibrosis	No further information extracted from unsampled studies		ed from unsampled studies	ed from unsampled studies	
Asmussen 1999	USA	Information not extracted from unsampled studies	Investigated how otitis media impacts the day-to-day lives and experiences of children and their families	Infant to 9 years No further information extracted from unsampled studies	Otitis media	Information not extracted from unsampled studies	Information not extracted from unsampled studies	SmithKline Beecham, Henry J Kaiser Family Foundation, American Academy of Pediatric's Friends of Children Fund
Atkin 2000	UK	Health professional records	Examines how parents cope with their caring responsibilities	Age of children not reported n = 62 17 couples (child has thalassaemia) 25 parents (8 couples), child has an SCD 34 mothers 25 fathers 3 guardians Ethnicity of families: 11 Caribbean in origin 1 Indian 1 Algerian 1 Nigerian 3 mixed ethnic origin	Sickle cell disease and thalassaemia	Interview	Not reported	National Health Service (NHS) Executive

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Atkin 2001	UK	Health professional records	Provide a detailed understanding of young people's experience of living with these conditions	Average age = 14.2 years n = 26 14 females 12 males Ethnicity: 19 'African Caribbean' 6 'mixed' 1 'Indian Hindu'	Sickle cell disease	Interview	Case comparative	National lottery
Atoui 2015	Lebanon	Paediatric clinics	Explore adolescents' lived experience and daily life with sickle cell disease (SCD) in Lebanon	12 years to 17 years n = 12 Ethnicity/nationality: 6 Lebanese Muslim 6 Palestinian Muslim	SCD	Interview	Thematic analysis	Not reported
Baert 2020	USA, UK, Belgium	Paediatric hospitals	Explore parents' views of the meaning of injustice	9 years to 20 years n = 21 Mothers of 14 females and 7 males Ethnicity: All White	Mixed conditions	Interview	Interpretative phenomenological analysis (IPA)	International Association for the Study of Pain (IASP) grant
Bagge-Petersen 2020	Denmark	Information not extracted from unsampled studies	Explores ethnographically the self-care practices of children affected by haemophilia or juvenile idiopathic arthritis (JIA) in Denmark	7 years to 17 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Center of Telemedicine, Copenhagen, Center for Health Technology (CACHET)

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Barlow 1998	UK	Information not extracted from unsampled studies	Gain greater insight and understanding into the experience of parents in terms of the stressors encountered and the resultant impact on parental well-being	8 years to 15 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Barlow 1999	UK	Information not extracted from unsampled studies	Gain insight and understanding of the needs and preferences of children with juvenile chronic arthritis and their parents	8 years to 15 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Health Service Executive
Beneitez 2020	Spain	Information not extracted from unsampled studies	Gain knowledge about adolescents' social needs living with JIA, particularly focused on their friendships	11 years to 18 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Open University of Catalonia PhD doctoral fellowship
Beyer 2004	USA	Information not extracted from unsampled studies	Examine caregivers' views of the effectiveness of home comfort for children with vaso-occlusive episodes	5 years to 19 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute of Nursing Research
Borghi 2014	Brazil	Paediatric hospital	Understanding the experience of children and adolescents under palliative care when managing pain daily	6 years to 17 years n = 6 4 females 2 males Ethnic origin not stated	Mixed conditions	Interview	Thematic oral history	Not reported
Bradshaw 2016	UK	Information not extracted from unsampled studies	Evaluate the effectiveness of the service in reducing the impact of pain in the lives of the young patients	10 years to 17 years No further information extracted from unsampled studies	Unspecified	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported

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Brandelli 2021	Canada	Recruited from a larger study	Explore the lived experiences of parents with self-identified challenges with their child's pharmacologic and/or nonpharmacologic JIA treatments	4 years to 16 years n = 10 10 mothers Ethnic origin not stated	JIA	Interview	IPA	IWK (Izaak Walton Killam) Health Centre, Arthritis Society, Maritime SPOR (strategy for patient-oriented research) Support Unit, Nova Scotia Graduate Scholarship, Nova Scotia Health Research Foundation, Dalhousie Medical Research Foundation, Canada Foundation for Innovation, Canadian Institutes of Health Research
Brekke 2020	Norway	Information not extracted from unsampled studies	Investigate the course of the child's abdominal pain, what may have helped, how the family's situation had been influenced, and whether they had any unmet needs	8 years to 17 years No further information extracted from unsampled studies	Abdominal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Norwegian Committee on Research in General Practice
Britton 2002	UK	Information not extracted from unsampled studies	Investigate families' experiences and perspectives	7 years to 8 years or 11 years to 13 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Arthritis Research Campaign

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Britton 2002a	UK	Juvenile arthritis clinic	To investigate the experiences of families who currently live with a child with JIA	7 years to 8 years or 11 years to 13 years n = 27 9 children 14 parents 4 siblings Ethnic origin not stated	Arthritis	Questionnaire, diary and interview	Ethnographic processes	Arthritis Research Campaign
Britton 2002b	UK	Juvenile arthritis clinic	Explore and describe the experiences of families of children with JIA	7 years to 8 years or 11 years to 13 years n = 27 9 children 14 parents 4 siblings Ethnic origin not stated	Arthritis	Interview and video diaries	Grounded theory	Arthritis Research Campaign
Brodwall 2018	Norway	Hospital	Explore the experiences of parents of children with chronic abdominal pain discharged from hospital without a somatic explanation	5 years to 15 years n = 15 parents Ethnic origin not stated	Abdominal pain	Interview	Content analysis	Norwegian Committee on Research in General Practice
Bruce 2022	Canada	Information not extracted from unsampled studies	Understand the changes in quality of life for adolescent patients with SCD a year after transplant	13 years to 18 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Stollery Children's Hospital Foundation, Women and Children's Health Research Institute
Burbage 2015	USA	Information not extracted	Educate and provide support for families with a child who has JIA	7 years to 18 years	Arthritis	Information not extracted from un-	Information not extracted from un-	Not reported

(Continued)

		from unsampled studies	as well as assess parent perceptions	No further information extracted from unsampled studies		sampled studies	sampled studies	
Carter 2002a	UK	Paediatric hospital	Explore the way in which the experience of chronic pain impacts on the lives of young people	13 years to 19 years n = 5	Mixed conditions	Focus group	Theoretical coding technique	Not reported
Carter 2002b	UK	Paediatric hospital	Explore the ways in which parents of children with profound special needs assess and manage their children's pain	5 years to 16 years n = 15 15 parents/carers (12 families) Ethnic origin not stated	Neurological conditions	Interview	Thematic analysis	Not reported
Carter 2002	UK	Unclear	Explore, from the children's and families' perspectives, the impact of living with chronic pain	12 years to 13 years n = 11 3 children 7 parents 1 sibling Ethnic origin not stated	Mixed conditions	Interview and journal	Thematic analysis	Nestlé Charitable Scholarship
Carter 2017	UK	Paediatric hospital	Explore the frequency, regularity and intensity of parent-reported pain episodes experienced by children with profound cognitive impairment and their parents' knowledge and skills in assessing their child’s pain	2 years to 16 years n = 8 8 mothers Ethnic origin not stated	Neurological conditions	Interview and survey	Thematic analysis	Not reported
Cartwright 2015	UK	Adolescent arthritis clinic	Explore adolescents' experiences of living with JIA, with particular focus on the process of adjustment	13 years to 17 years n = 10 7 female 3 male	Arthritis	Interview	IPA	Not reported

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				Ethnic origin not stated (except state bias towards White participants)				
Castle 2007	Australia	Paediatric hospital	Explore the experience and impact of chronic pain on the lives of adolescents and young adults with cerebral palsy	14 years to 24 years n = 6 2 females 4 males Ethnic origin not stated	Cerebral palsy	Interview	Phenomenology	Not reported
Conboy 2008	USA	Information not extracted from unsampled studies	Understand the experiences of adolescents involved in acupuncture treatment	13 years to 22 years No further information extracted from unsampled studies	Endometriosis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Constantinou 2021	UK	Information not extracted from unsampled studies	Explore the health-related quality of life and health behaviours of children with SCD and healthy siblings	5 years to 12 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Corey 2021	USA	Information not extracted from unsampled studies	To characterise parent experiences during a multidisciplinary exposure-based treatment for children with chronic pain who express high fear of pain and pain-related disability	8 years to 17 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	American Pain Society/Sharon S. Keller Chronic Pain Research Grant, Deborah Munroe Noonan Memorial Research Fund
Cotton 2012	USA	Information not extracted from unsampled studies	Examine use of religious coping in children with SCD	5 years to 12 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute of Child Health and Human Development

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Cox 2022	UK	Information not extracted from unsampled studies	Explore how parental dyads experience and demonstrate resilience in response to parenting an adolescent with CRPS	11 years to 25 years No further information extracted from unsampled studies	CRPS	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Cunningham 2018	USA	Information not extracted from unsampled studies	Evaluate the feasibility and acceptability of Aim to Decrease Anxiety and Pain Treatment (ADAPT)	10 years to 19 years No further information extracted from unsampled studies	Abdominal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institutes of Health (NIH) grants
Cunningham 2019	USA	Information not extracted from unsampled studies	Develop and refine the Treatment and Education Approach for Childhood-onset Lupus (TEACH) protocol	10 years to 19 years No further information extracted from unsampled studies	Childhood-onset systemic lupus erythematosus (cSLE)	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institutes of Arthritis and Musculoskeletal and Skin Diseases, Cincinnati Children's Research Foundation Academic Research Centers award
Curtis 2019	Germany	Information not extracted from unsampled studies	Develop a theory- and evidence-based medication adherence app to support children and adolescents with SCD	10 years to 19 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Charité
Dell'Api 2007	Canada	Paediatric hospital	Develop an understanding of the way in which children with chronic pain experienced, assigned meaning to and described their interactions with healthcare professionals	10 years to 17 years n = 5 3 females 2 males Ethnic origin not stated	Mixed conditions	Interview	Interpretive description	Not reported
de Monte 2009	Australia	Information not extracted	Understand the children's perspective of living with JIA	8 years to 16 years	Arthritis	Information not extract-	Information not extract-	Not reported

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		from unsampled studies		No further information extracted from unsampled studies		ed from unsampled studies	ed from unsampled studies	
de Moura 2021	Brazil	Information not extracted from unsampled studies	Analyse the perceptions of children and adolescents about chronic postsurgical pain	8 years to 15 years No further information extracted from unsampled studies	Inguinal herniorrhaphy	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Dogan 2022	Germany	Information not extracted from unsampled studies	Gain further insight into the mechanisms and prerequisites for the effectiveness of this specialised aftercare programme	9 years to 16 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	German Innovation Fund of The Federal Joint Committee
Donovan 2013	USA	Information not extracted from unsampled studies	Understand the impact of migraines on adolescents' social functioning from multiple informants	12 years to 17 years No further information extracted from unsampled studies	Headache	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Eunice Kennedy Shriver National Institute of Child Health and Human Development
Donovan 2019	USA	Information not extracted from unsampled studies	Describe the experiences of adolescents with irritable bowel syndrome (IBS)	13 years to 17 years No further information extracted from unsampled studies	IBS	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute of Diabetes and Digestive and Kidney Diseases
dos Santos 2022	Brazil	Information not extracted from unsampled studies	Understand the experiences of being a teenager with sickle cell disease	Adolescents No further information extracted from unsampled studies	Sickle cell disease	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Council for Scientific and Technological Development
Dyson 2011	UK	Support groups, counselling centres, and clinics	Examines the experiences of young people living with SCD in schools in England	5 years to 25 years n = 32 Ethnicity: 24 Black African	SCD	Interview	Thematic analysis	Not reported

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				15 Black Caribbean 1 British Asian (Indian)				
Evans 2010	USA	Information not extracted from unsampled studies	Examine sex-specific parent-child relationships in the development of chronic pain in preadolescent and adolescent children	11 years to 19 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute of Mental Health (NIMH) grant and Mayday Fund
Evans 2018	USA	Information not extracted from unsampled studies	Explore the full range of teens' experiences with the yoga programme	14 years to 17 years No further information extracted from unsampled studies	IBS	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Center for Complementary and Integrative Health (NCCAM) grant, Oppenheimer Seed Grant for Complementary, Alternative and Integrative Medicine, University of California, Los Angeles (UCLA) Clinical and Translational Science Institute Grant and UCLA Children's Discovery and Innovation Institute
Forgeron 2008	Canada	Paediatric pain clinic	Explore the self-identified needs of adolescents living with chronic pain	13 years to 17 years n = 6	Musculoskeletal pain	Focus groups and interview	Thematic analysis	Rising Researcher Support Award

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				Ethnicity: all Caucasian (understood to be White)				
Forgeron 2013	Canada	Information not extracted from unsampled studies	Explore peer relationships and, particularly, close friendships of adolescents with chronic pain to understand and identify factors that affect these relationships	14 years to 18 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Canadian Institute of Health Research doctoral fellowship, IWK Ruby Blois Scholarship and IWK grant
Gaughan 2014	USA	Paediatric hospital	Describe the parents' journey with their child from initial incidence of pain through the labyrinth of treatment options	11 years to 17 years n = 13 8 mothers 5 fathers Ethnic origin not stated	CRPS	Interview	Content analysis	Ian Katz Fund
Gernet 2011	France	Information not extracted from unsampled studies	Explore the emotional representations of sickle cell children followed up at Bordeaux University Hospital	7 years to 15 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Ghio 2018	UK	Information not extracted from unsampled studies	Investigate the extent to which adolescents' illness beliefs could be assessed using the revised illness perception questionnaire (IPQ-R)	11 years to 16 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Arthritis Research UK
Ghio 2021	UK	Information not extracted from unsampled studies	Explore the coping goals and related personal models (cognitive and emotional profiles) of JIA of both the adolescents and their parent	11 years to 16 years No further information extracted from unsampled studies	JIA	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Arthritis Research, UK National Institute for Health Research, Manchester Musculoskeletal Biomed-

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								ical Research Unit Funding Scheme
Gibler 2022	USA	Information not extracted from unsampled studies	Refine the School Anxiety Inventory	12 years to 17 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	University of Cincinnati Department of Psychology Seeman-Frakes Graduate Student Research grant
Goldenberg 2013	USA	Information not extracted from unsampled studies	Utilise peers who have learnt to self-manage their own chronic pain to assist patients with social coping skills to reduce isolation	17 years No further information extracted from unsampled studies	Diffuse chronic body pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute of Child Health and Human Development
Gomez-Ramirez 2016	Canada	Information not extracted from unsampled studies	Describes the predominant emotional experiences reported by parents of children with JIA in 2 Canadian cities	2 years to 16 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Canadian Rheumatology Association
Gordon 2013	Canada	Information not extracted from unsampled studies	Investigate how children with inflammatory bowel disease(IBD) and their families perceived their school experiences in Quebec	10 years to 18 years No further information extracted from unsampled studies	IBD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Gorodzinsky 2012	USA	Information not extracted from unsampled studies	Assesses treatment provided at a multidisciplinary chronic pain clinic	Age not reported No further information extracted from unsampled studies	Unspecified	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Gorodzinsky 2013	USA	Information not extracted from unsampled studies	The experiences of youth with chronic pain and their siblings and their perspectives on how pain experiences influence family dynamics	12 years to 18 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported

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Gremillion 2022	USA	Information not extracted from unsampled studies	To better understand the challenges experienced by adolescents with chronic pain and obesity, with a specific focus on physical activity	13 years to 17 years No further information extracted from unsampled studies	Obesity	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Unfunded
Guell 2007	UK	Self-help organisation and hospital	Explores the everyday life and coping of children living with juvenile arthritis	7 years to 16 years n = 4 families Ethnic origin not stated	Arthritis	Observation	Ethnography	Not reported
Hackett 2003	UK	Information not extracted from unsampled studies	Gather in-depth qualitative information on play and leisure experiences from junior school-aged children with JIA	7 years to 11 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Arthritis Research Campaign
Haridasa 2019	USA	Information not extracted from unsampled studies	Identify the perceptions of children with SCD in the school environment	6 years to 10 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Heffernan 2021	Ireland	Information not extracted from unsampled studies	Explore beliefs about and experiences of worry and pain amongst a purposeful sample of adolescents with chronic pain	12 years to 17 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Helvig 2013	USA	Unclear	Explored the experience of living with migraines in 6 adolescents	12 years to 17 years, average age 14 years n = 6 4 females Ethnicity: 2 African Americans, 4 Caucasians (understood to be White)	Headache	Interview	Not reported	Not reported
Hendry 2012	UK	Information not extracted	Explore the perceived impact of disease-related foot problems	7 years and 9 years old	Arthritis	Information not extract-	Information not extract-	Not reported

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		from unsampled studies	and foot care in JIA from the perspectives of patients, parents, paediatric rheumatologists and health professionals	No further information extracted from unsampled studies		ed from unsampled studies	ed from unsampled studies	
Hilário 2022	Portugal	Information not extracted from unsampled studies	Explore children's and parents' experience of uncertainty and perceptions of risk resulting from chronic pain in childhood	7 years to 17 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Fundação para a Ciência e a Tecnologia
Hollier 2018	USA	Information not extracted from unsampled studies	Assess acceptability of a proposed guided imagery therapy app designed to treat functional abdominal pain disorders	7 years to 12 years No further information extracted from unsampled studies	Abdominal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	US National Institutes of Health, Texas Medical Center Digestive Diseases Center, US Department of Agriculture
Hulgaard 2020	Denmark	Information not extracted from unsampled studies	Explore illness perceptions of youths with functional disorders and their parents	11 years to 15 years No further information extracted from unsampled studies	Functional disorders	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Helsefonden, Psychiatric Research Fund
Hulgaard 2020a	Denmark	Information not extracted from unsampled studies	Explore parents' experiences of challenges related to their care for a child receiving treatment for functional disorders	11 years to 16 years No further information extracted from unsampled studies	Functional disorders	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Helsefonden, Psychiatric Research Fund
Hunt 2003	UK	Neuro-disability centre, charitable trust, and paediatric hospices	Gain an understanding of the context in which pain occurs and of issues that could affect pain assessment and management in this group	Children aged 2 years to 18 years, average age 11 years n = 25 parents Ethnic origin not stated	Neurological impairment	Interview	Grounded theory	Not reported
Hurtubise 2021	Canada	Information not extracted	Describe and compare the treatment effects and outcomes as perceived by youth and their par-	12 years to 18 years	Mixed conditions	Information not extracted from un-	Information not extracted from un-	Vanier Scholarship, Canadian Child

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		from unsampled studies	ents enroled in intensive interdisciplinary pain treatment or multimodal treatment	No further information extracted from unsampled studies		sampled studies	sampled studies	Health Clinical Scientist, Pain in Child Health programs
Iliyasu 2021	Nigeria	Information not extracted from unsampled studies	Explore caregivers' perceptions on socio-behavioural and environmental influences on hospitalisation for pain and blood transfusion of children with SCD	3 years to 11 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Unfunded
Jacobson 2013	USA	Information not extracted from unsampled studies	Examine the content validity of the patient-reported outcomes measurement information system (PROMIS) paediatric measures	8 years to 18 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	American Institutes for Research and a range of university funding
Jacobson 2015	USA	Information not extracted from unsampled studies	Evaluate the overall conceptual scope and content validity, or fit, of the PROMIS pain domain framework	8 years to 18 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	American Institutes for Research and a range of university funding
Jensen 2019	USA	Information not extracted from unsampled studies	Identify commonalities and differences in symptom experiences across age groups to better assist individuals to adjust to symptoms across the lifespan	5 years to 17 years No further information extracted from unsampled studies	Neurofibromatosis type 1	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Neurofibromatosis Therapeutic Acceleration Program (NTAP)
Jones 2009	Australia	Information not extracted from unsampled studies	To assist occupational therapists and other healthcare professionals to facilitate children's ability to live with JIA and participate optimally in home exercise programmes	8 years to 18 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Jones 2020	UK	Social media and newsletters	Explore the relative frequencies of hoped-for and feared-for future selves and how these are expressed in the future narratives of adolescents with complex regional pain syndrome (CRPS)	14 years to 25 years, average age 19 years n = 50 44 females	CRPS	Interview	Thematic analysis	Not reported

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				5 males 1 not declared Ethnic origin not stated				
Jones 2022	UK	NHS tertiary pain service	Explore how adolescents make sense of their experience of chronic pain in the context of development	12 years to 22 years, average age 15.7 years n = 9 8 females 1 male Ethnicity: all White British	Mixed conditions	Interview	Thematic analysis	Pain Relief Foundation
Jordan 2007	UK	Paediatric rheumatology and pain management clinic	Investigate parental experiences of caring for an adolescent with chronic pain	13 years to 18 years n = 17 parents 11 mothers 5 fathers 1 grandmother Ethnic origin not stated	Mixed condition	Focus group	IPA	Bupa Foundation
Jordan 2016	UK	Pain management centre	Examine the specific experiences of what it is like to be a father of an adolescent with chronic pain	11 years to 18 years n = 6 fathers Children were 3 females and 3 males Ethnicity: all White British	Mixed conditions	Interview	IPA	Unfunded
Jordan 2018	UK	Pain management centre	Examine how adolescents make sense of their own development in the context of living with chronic pain	12 years to 17 years n = 10 7 females	Mixed conditions	Interview	IPA	Royal United Hospitals Bath NHS Foundation Trust

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				3 males Ethnic origin not stated				
Joslin 2021	UK	Information not extracted from unsampled studies	Gain the opinions of young people during their multidisciplinary treatment for chronic pain	11 years to 18 years No further information extracted from unsampled studies	Chronic musculoskeletal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Unfunded
Kanstrup 2019	Sweden	Hospital pain service	Explore the lived experiences of young people and parents with regard to participating in acceptance and commitment therapy for paediatric chronic pain	12 years to 18 years, average age 16 years n = 8 4 adolescents (female) 4 parents Ethnic origin not stated	Unspecified chronic pain	Interview	IPA	Mayflower Charity Foundation for Children, Sven Jerring Foundation, Claes Groschinskys Memorial Foundation
Kashikar-Zuck 2016	USA	Information not extracted from unsampled studies	Obtain information about the feasibility, safety and tolerability of the 8-week (16-session) group-based fibromyalgia integrative training (FIT Teens) intervention for adolescents with juvenile fibromyalgia and gather impressions of acceptability, format and content	12 years to 18 years No further information extracted from unsampled studies	Juvenile fibromyalgia	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute of Arthritis and Musculoskeletal and Skin Diseases, Cincinnati Children's Hospital Medical Center
Khair 2015	UK	Information not extracted from unsampled studies	Understanding self-management of haemophilia, from a child's perspective, in the 21st century in the UK where intensive prophylactic therapy is given from early childhood	4 years to 16 years No further information extracted from unsampled studies	Haemophilia	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Bayer HealthCare Pharmaceuticals
Khanom 2020	UK	Paediatric hospital	Explore adolescents' lived experience of pain flares, including what pain flares are, why they occur, how they are managed and	13 years to 17 years n = 10 8 females	Musculoskeletal pain	Interview	IPA	Versus Arthritis grant

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			what lasting effects they have on adolescents	2 males Ethnicity: 9 White British 1 Asian British				
Kroon 2018	USA	Information not extracted from unsampled studies	Determine which cognitive behavioural therapy for health anxiety (CBT-HA) treatment components paediatric headache patient stakeholders would report to be most helpful and essential to reducing headache frequency and related disability	13 years to 17 years No further information extracted from unsampled studies	Headache	Information not extracted from unsampled studies	Information not extracted from unsampled studies	US Department of Health and Human Services, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases
Kulandaivelu 2018	Canada	Information not extracted from unsampled studies	Examine the perspectives of adolescents with SCD, their parents and healthcare professionals	12 years to 19 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Lauridsen 2020	Denmark	Information not extracted from unsampled studies	Explore the physical, psychological and social consequences of a life with nonspecific spinal pain amongst Danish children	9 years to 12 years No further information extracted from unsampled studies	Musculoskeletal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Foundation of Chiropractic Research and Postgraduate Education
Law 2017	USA	Information not extracted from unsampled studies	Inform adaptation of web-based management of adolescent pain (Web-MAP) for youth with headache	10 years to 16 years No further information extracted from unsampled studies	Headache	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Seattle Children's Research Institute Center for Child Health Behavior and Development, National Institute of Neurological Dis-

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								orders and Stroke
Law 2017a	USA	Information not extracted from unsampled studies	Adapt problem-solving skills training (PSST) for parents of children receiving intensive pain rehabilitation and evaluate treatment feasibility, acceptability and satisfaction	14 years (mean) No further information extracted from unsampled studies	Idiopathic chronic pain conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	The Center for Child Health, Behavior and Development of Seattle Children's Research, Eunice Kennedy Shriver National Institute of Child Health and Human Development
Le 2019	Canada	Information not extracted from unsampled studies	Describe parents' experiences with paediatric chronic pain	12 years to 17 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Women and Children's Hospital Research Institute
Lee 2020	UK	Information not extracted from unsampled studies	Investigate patient preferences, feasibility and influence of several time-sampling strategies in remote multidimensional pain reporting	7 years to 16 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute for Health Research Biomedical Research Centre Funding Scheme, National Institute for Health Research, Manchester Biomedical Research Centre
Leksell 2017	Sweden	Information not extracted from unsampled studies	Deepen knowledge of how parents of children diagnosed with JIA perceive the orofacial manifestations of the disease, its	3 years to 18 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Swedish Rheumatism Association

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			treatments and their encounters with dental care providers					
Lipstein 2016	USA	Information not extracted from unsampled studies	Compare factors considered by parents to those considered by adolescents making decisions about chronic disease treatments	12 years to 18 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Academic Paediatric Association Young Investigator Award
Maciver 2005	UK	Paediatric hospital	Examine parents' experiences prediagnosis and their experiences of accessing specialist pain management services for the child	10 years to 16 years n = 12 10 mothers 2 fathers Ethnic origin not stated	Mixed conditions	Interview	Thematic analysis	Not reported
Maciver 2010	UK	Paediatric hospital	Examining parents' experiences of paediatric chronic pain management services in the UK	10 years to 16 years n = 12 10 mothers 2 fathers Ethnic origin not stated	Mixed conditions	Interview	Thematic analysis	Not reported
Maciver 2011	UK	Paediatric hospital	Examining parents' experiences of paediatric chronic pain management services in the UK	10 years to 16 years n = 12 10 mothers 2 fathers Ethnic origin not stated	Mixed conditions	Interview	Thematic analysis	Not reported
McDonagh 2021	Ireland	Social media platforms	Exploring the impacts and experiences of parents caring for a child with Down's arthritis	7 years to 15 years n = 10 10 mothers	Down's arthritis	Interview	IPA	Unfunded

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				Ethnic origin not stated				
McKinnon 2020	Australia	Information not extracted from unsampled studies	Explore the lived experiences of chronic pain and dyskinesia through the unbiased lens of children and adolescents with cerebral palsy able to communicate experiences by either verbalising or using augmentative and alternative communication	9 years to 18 years No further information extracted from unsampled studies	Cerebral palsy	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Australian Government Research Training Program Scholarship, Centre for Research Excellence in Cerebral Palsy, Murdoch Children's Research Institute, Top-Up Scholarship
McKinnon 2022	Australia	Paediatric hospital	Explore the personal perspectives of caregivers regarding challenges faced within everyday pain management of their children	9 years to 18 years n = 10 10 mothers Ethnic origin not stated	Cerebral palsy	Interview	IPA	The Research Foundation, Murdoch Children's Research Institute, Victorian Governments Operational Infrastructure Support Program
McNeill 2004	Canada	Information not extracted from unsampled studies	Examine the experience of fathers who have a child with juvenile rheumatoid arthritis	8.7 years average No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Meldrum 2008	USA	Information not extracted from unsampled studies	Understand the impact of chronic or recurrent pain on children within the context of their own lives and experiences	8 years to 18 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	NIMH grant, Mayday Fund
Meldrum 2009	USA	Information not extracted	Understand the impact of chronic or recurrent pain on children	10 years to 19 years	Mixed conditions	Information not extracted from un-	Information not extracted from un-	NIMH grant, Mayday Fund

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		from unsampled studies	within the context of their own lives and experiences	No further information extracted from unsampled studies		sampled studies	sampled studies	
Miles 2020	UK	Information not extracted from unsampled studies	Explore how patient expertise and patient involvement in their own care works in practice for young people with SCD	13 years to 21 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute for Health Research Health Services and Delivery Research Programme
Mitchell 2007	USA	Information not extracted from unsampled studies	Assess how healthcare service delivery and other intervention strategies can be improved and optimised	7 years to 13 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Moulin 2015	Switzerland	Information not extracted from unsampled studies	Explore how these adolescents and their parents experience the condition and its impact on their daily lives	12 years to 20 years No further information extracted from unsampled studies	Medically unexplained symptoms	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Academic Society of the Canton de Vaud (Societe Academique Vaudoise)
Moulin 2015a	Switzerland	Information not extracted from unsampled studies	Understand the experiences with, and perceptions of, the health care of adolescents who have medically unexplained symptoms and their parents	14 years to 19 years No further information extracted from unsampled studies	Medically unexplained symptoms	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Academic Society of the Canton de Vaud (Societe Academique Vaudoise)
Neto 2018	Portugal	Information not extracted from unsampled studies	Explore the views of adolescents with chronic idiopathic neck pain towards an intervention consisting of pain neuroscience education and exercise administered in the school setting	10 years to 19 years No further information extracted from unsampled studies	Musculoskeletal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Neville 2019	Canada	Paediatric pain clinic	Investigate how diagnostic uncertainty is experienced by both youth with chronic pain and their parents	10 years to 18 years n = 37 20 children	Mixed conditions	Interview	Thematic analysis	Not reported

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				17 mothers Ethnicity: 18 White (Caucasian) 1 Latin American 1 not stated				
Newton 2019	USA	Information not extracted from unsampled studies	Understand the health-related quality of life and symptomatic experience of ulcerative colitis	12 years to 17 years No further information extracted from unsampled studies	Ulcerative colitis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Eli Lilly and Company
Nguyen 2015	Switzerland	Information not extracted from unsampled studies	Develop a new patient-reported outcome that meets scientific and regulatory standards for instrument development and can be used as a primary end point to assess change in dysmenorrhoea severity overtime in clinical trials	14 years to 17 years No further information extracted from unsampled studies	Dysmenorrhoea	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Nicholas 2007	Canada	Information not extracted from unsampled studies	Develop an evaluative disease-specific measure of quality of life in paediatric IBS	7 years to 19 years No further information extracted from unsampled studies	IBS	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Nieto 2015	Spain	Information not extracted from unsampled studies	Test the feasibility of an online intervention (DARWeb) for children with functional abdominal pain and their families	9 years to 15 years No further information extracted from unsampled studies	Abdominal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Fundación La Caixa Ministerio de Economía y Competitivad
Nieto 2019	Spain	Information not extracted from unsampled studies	Exploration of the effects of DARWeb on different outcomes (i.e. abdominal pain severity, disability and quality of life) from the point of view of the different actors involved (parents and children)	9 years to 15 years No further information extracted from unsampled studies	Abdominal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Fundación La Caixa (Recercaixa, 2012 to 2013), Ministerio de Economía y Competitivad (Spanish government)

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Nieto 2019a	Spain	Information not extracted from unsampled studies	Evaluate post-treatment efficacy of an online psychosocial intervention for children with functional abdominal pain (DARWeb)	9 years to 15 years No further information extracted from unsampled studies	Abdominal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Fundació La Caixa Ministerio de Economía y Competitividad
Nieto 2020	Spain	Information not extracted from unsampled studies	Learn about the specific experiences of families (parents and children) with a child with functional abdominal pain from their point of view	9 years to 15 years No further information extracted from unsampled studies	Abdominal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Fundación La Caixa Ministerio de Economía y Competitividad
Nilsson 2011	Sweden	Information not extracted from unsampled studies	Deepen our understanding of adolescents’ experiences of living with temporomandibular disorder pain	16 years to 19 years No further information extracted from unsampled studies	Temporomandibular disorder	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Public Dental Service of Östergötland, Swedish dental societies, Malmö University
Nilsson 2016	Sweden	Information not extracted from unsampled studies	Explore adolescents' explanations of temporomandibular disorder pain, their pain management strategies and treatment-seeking behaviour	10 years to 19 years No further information extracted from unsampled studies	Musculoskeletal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Swedish dental societies, Malmö University
Njifon 2019	Cameroon	Research presentation	Focusses on how a brother and sister without SCD experience their brother's illness on a daily basis and the influence of this disease on family dynamics	9 years to 16 years n = 2 siblings Ethnicity: Black African	SCD	Interview drawings	Thematic analysis and analysis of drawings	Not reported
Nkhoma 2021	Malawi	Information not extracted from unsampled studies	Explore stakeholders' perspectives and experiences on pain self-management for adolescents living with HIV and chronic pain in Malawi	10 years to 17 years No further information extracted from unsampled studies	HIV/AIDS	Information not extracted from unsampled studies	Information not extracted from unsampled studies	King's College London Faculty Challenge Fund
Nsangou 2019	France	Information not extracted from unsampled studies	Better understand the impact of the disease on body image by linking the illness with what the child says and knows about it	9 years to 12 years	SCD	Information not extracted from un-	Information not extracted from un-	Not reported

(Continued)

				No further information extracted from unsampled studies		sampled studies	sampled studies	
Nutkiewicz 2008	USA	Paediatric pain clinic	Examines the communication between paediatric pain patients and their doctor	10 years to 18 years n = 32 24 females 8 males Ethnicity: 22 Caucasian (understood to be White) 5 Latino 4 Asian 1 African American	Unspecified chronic pain	Interview	Grounded theory	National Institute of Mental Health
O'Donnell 2013	UK	Information not extracted from unsampled studies	Explore the experiences of young people with chronic oral ulcers attending the paediatric oral medicine clinic in a UK dental hospital	1 year to 9 years and 10 years to 19 years No further information extracted from unsampled studies	Chronic oral ulcers	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Ostojic 2022	Australia	Information not extracted from unsampled studies	Investigate the acceptability and feasibility of biofeedback-assisted relaxation training for chronic pain management in children with cerebral palsy	9 years to 18 years No further information extracted from unsampled studies	Cerebral palsy	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Cerebral Palsy Alliance Research Foundation, National Health and Medical Research Council (NHMRC) Centre of Research Excellence in Cerebral Palsy
O'Sullivan 2018	Ireland	Information not extracted	Explore the self-management needs of Irish adolescents living with JIA, from their own per-	12 years to 18 years	Arthritis	Information not extracted from un-	Information not extracted from un-	Wellcome Trust – Humanities

(Continued)

		from unsampled studies	spective and of their parents and healthcare professionals	No further information extracted from unsampled studies		sampled studies	sampled studies	and Social Sciences, The James Flaherty Research Scholarship
Palmer 2008	Canada	Information not extracted from unsampled studies	Gaining a rich description and a contextual understanding of the experiences of a young chronic pain sufferer, aged 6, and her family members	6 years to 10 years No further information extracted from unsampled studies	Musculoskeletal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Social Sciences and Humanities Research Council
Panepinto 2012	USA	Information not extracted from unsampled studies	Develop the new PedsQL$^{\text{TM}}$ Sickle Cell Disease Module for paediatric patients with SCD and support its content validity	2 years to 18 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institutes of Health
Pate 2019	Australia	Information not extracted from unsampled studies	Explore the concept of pain in children with and without persistent pain	8 years to 12 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Macquarie University Research Training Programme full-time scholarship
Peláez-Ballestas 2013	Mexico	Information not extracted from unsampled studies	Explain the phenomenon of experiencing JIA within a specific cultural context	17 years to 66 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Race 2016	Canada	Information not extracted from unsampled studies	Examine perspectives of children who have JIA and their parents	8.3 years to 16.3 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Canadian Institutes of Health Research
Randall 2020	USA	Information not extracted from unsampled studies	Understand the health-related quality of life and symptomatic experience of children (2 years to 11 years) living with ulcerative colitis	2 years to 11 years No further information extracted from unsampled studies	Abdominal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Eli Lilly and Company

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Renedo 2019	UK	Hospital and community network	Explore how young people with SCD experience health care during a period of transition	13 years to 18 years n = 21 Ethnic origin not stated	SCD	Interview	Grounded theory and thematic analysis	National Institute for Health Research Health Services and Delivery Research Programme
Renedo 2020	UK	Specialist healthcare services, networks with patient advocates	Understand healthcare transitions of young people with SCD	13 years to 21 years n = 48 30 females 18 males Ethnic origin not stated	SCD	Interview	Grounded theory	National Institute for Health Research Health Services and Delivery Research Programme
Risko 2018a	USA	Information not extracted from unsampled studies	Explore the lived experiences of adolescents engaged in an intensive interdisciplinary pain treatment programme	10 years to 19 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Unfunded
Rossato 2007	Brazil	Paediatric clinic	Understand the meaning of the experience of families of children living in pain situations due to JIA	6 years to 17 years n = 12 families 12 mothers 2 fathers 12 children with JIA (11 females, 1 male) 2 siblings Ethnic origin not stated	Arthritis	Interview	Grounded theory	Not reported
Ruskin 2017	Canada	Information not extracted from unsampled studies	Explore the experience of adolescents who participated in an 8-week mindfulness group adapted for adolescents with chronic pain	12 years to 18 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from un-	Information not extracted from un-	Pain Centre Seed Grant (Hospital for Sick Children)

(Continued)

						sampled studies	sampled studies	
Sällfors 2001	Sweden	Information not extracted from unsampled studies	Gain a deeper understanding of how children cope with their chronic pain condition	6 years to 17 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Swedish Rheumatism Association, Norrbacka-Eugenia Foundation, Renee Eander Foundation
Sällfors 2002	Sweden	Information not extracted from unsampled studies	Obtain a deeper understanding of children's experiences of living with chronic pain in daily life	6 years to 17 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Swedish Rheumatism Association, Norrbacka-Eugenia Foundation, Renee Eander Foundation
Sällfors 2003	Sweden	Information not extracted from unsampled studies	Explore parents' experience of living with a child with chronic pain related to juvenile chronic arthritis	7 years to 17 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Sällfors 2009	Sweden	Information not extracted from unsampled studies	Deepen the understanding of female adolescents' daily living with chronic arthritis	14 years to 17 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Swedish Social Insurance Agency, Spenshult Hospital for Rheumatic Diseases, Norrbacka-Eugenia Foundation
Santos 2018	Portugal	Information not extracted from unsampled studies	Explore the situations perceived by child patients, their parents and siblings as the most distressing and stressful when living with osteogenesis imperfecta	4 years to 16 years No further information extracted from unsampled studies	Osteogenesis imperfecta type 1	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported

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Secor-Turner 2011	USA	Information not extracted from unsampled studies	Identify challenges that teens experience as a result of living with juvenile arthritis	14 years to 29 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Agency for Healthcare Research and Quality, University of Minnesota-Academic Health Center
Serafimova 2022	UK	Information not extracted from unsampled studies	Describe the experience of pain, its impact and treatments in children with chronic fatigue syndrome/myalgic encephalomyelitis	11 years to 17 years No further information extracted from unsampled studies	Chronic fatigue syndrome/myalgic encephalomyelitis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Unfunded
Shaygan 2021	Iran	Information not extracted from unsampled studies	To assess a smartphone-based pain management application	12 years to 19 years No further information extracted from unsampled studies	Unspecified	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Research Affairs of Shiraz University of Medical Sciences
Shaygan 2022	Iran	Information not extracted from unsampled studies	Explore the experience of chronic pain amongst adolescents	12 years to 17 years No further information extracted from unsampled studies	Unspecified	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Research Affairs of Shiraz University of Medical Sciences
Skarstein 2016	Norway	Information not extracted from unsampled studies	Gain a deeper understanding and increase our knowledge about adolescents who suffer from frequent pain and have a high consumption of over-the-counter analgesics	14 years to 16 years No further information extracted from unsampled studies	Unspecified	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Department of Nursing and the Akershus University College of Applied Sciences
Skarstein 2018	Norway	Information not extracted from unsampled studies	Describe pain management and conditions that may influence the development of identity in adolescents frequently using analgesics	10 years to 19 years No further information extracted from unsampled studies	Unspecified	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Department of Nursing and the Akershus University College of Applied Sciences

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Skogvold 2019	Norway	Information not extracted from unsampled studies	Explore which strategies adolescents use to cope with chronic tension-type headache in everyday life	14 years to 19 years No further information extracted from unsampled studies	Headache	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Norwegian Fund for Postgraduate Training in Physiotherapy
Slotter 2021	USA	Information not extracted from unsampled studies	Gain further insight into how adolescents with chronic pain perceive their peer relationships	12 years to 17 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Smart 2005	UK	Paediatric clinics and schools	Exploring the way in which mothers understand and cope with their children's recurrent abdominal pain and how this might be related to beliefs and values held about their relationship with their children	6 years to 14 years n = 28 mothers Ethnic origin not stated (except states predominantly White middle class)	Abdominal pain	Interview	Grounded theory	NHS Executive Northern and Yorkshire Region
Soni-Jaiswal 2016	UK	Information not extracted from unsampled studies	Explore in-depth concerns of children with mucopolysaccharidosis and their parents, with an emphasis on the impact of head and neck disease on their lives	6 months to 16 years No further information extracted from unsampled studies	Mucopolysaccharidosis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Unfunded
Sorensen 2017	Norway	Hospital pain clinic	Explore adolescents' experiences of complex persistent pain	12 years to 19 years n = 6 4 females 2 males Ethnic origin not stated	Complex persistent pain	Interview	Hermeneutic analysis	Unfunded
Sorensen 2021	Norway	Information not extracted from unsampled studies	Explore how regular needle injections affect children with rheumatic diseases and their parents in their daily living	6 years to 18 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Extra Foundation for Health and Rehabilitation, Norwegian League

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								Against Rheumatism
Ståh-le-Öberg 2009	Sweden	Information not extracted from unsampled studies	Illuminate pain in children with cerebral palsy from the parents' experience	10 years to 19 years No further information extracted from unsampled studies	Cerebral palsy	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Swedish Association of Registered Physiotherapists, Jerringfonden and the County Council of Västerbotten
Stiles-Shields 2022	USA	Information not extracted from unsampled studies	Assess the paediatric patient and parent-reported experience of 1) coping with and managing symptoms associated with median arcuate ligament syndrome and 2) the diagnostic, treatment and recovery process for paediatric median arcuate ligament syndrome	15 years to 28 years No further information extracted from unsampled studies	Median arcuate ligament syndrome	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Comer Development Board and Cohn Family Foundation
Stinson 2008	Canada	Information not extracted from unsampled studies	Explore the self-management needs of adolescents with JIA	12 years to 20 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Canadian Arthritis Network
Stinson 2012	Canada	Information not extracted from unsampled studies	Explore the information needs of parents and school-age children with JIA	8 years to 11 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Canadian Arthritis Network
Stinson 2014	Canada	Information not extracted from unsampled studies	Conduct a user-centred needs assessment to inform the development of an integrated web- and smartphone-based self-management programme for adolescents with chronic pain, called iCan-Cope with Pain™	10 years to 19 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Canadian Pain Society Small Grant Award
Stinson 2017	Canada	Information not extracted from unsampled studies	Explore the use, decision-making process and communication about the use of over-the-counter medication with healthcare pro-	12 years to 18 years	Mixed conditions	Information not extracted from un-	Information not extracted from un-	Church and Dwight

(Continued)

			fessionals in a multidisciplinary chronic pain team setting in adolescents living with chronic pain and their primary caregiver	No further information extracted from unsampled studies		sampled studies	sampled studies	
Suder 2016	Canada	Physician offices and paediatric hospital	Understand the lived experience of adolescents who live with chronic pain	Average age 16 years n = 10 8 females 2 males Ethnicity: all Caucasian (understood to be White)	Mixed conditions	Interview	Phenomenology	Not reported
Szwimer 2020	Canada	Information not extracted from unsampled studies	Enquire into the experiences of female adolescents living with chronic pain	14 years to 17 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Tong 2013	Australia	Information not extracted from unsampled studies	Elicit parental and adolescent perspectives on paediatric rheumatology care and service delivery	14 years to 66 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	George Weston Fund
Valenzuela 2013	USA	Information not extracted from unsampled studies	To understand how children and adolescents with SCD perceive their lives and disease using Photovoice	8 years to 17 years No further information extracted from unsampled studies	Sickle cell disease	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institutes of Health National Heart, Lung, and Blood Institute
Van Gulik 2020	Netherlands	Information not extracted from unsampled studies	Elicit the experiences during school life and the perspectives and expectations regarding future work participation of adolescents with JIA	14 years to 18 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Unfunded
van Scheppingen 2008	Netherlands	Information not extracted	Gain a more in-depth understanding of the wide-ranging and complex problems parents of	2 years to 19 years	Epidermolysis bullosa	Information not extracted from un-	Information not extracted from un-	Johanna Kinderfonds, the stichting

(Continued)

		from unsampled studies	children with epidermolysis bullosa have to deal with	No further information extracted from unsampled studies		sampled studies	sampled studies	BIO Kinderrevalidatie Fonds Adriaanstichting
van Tilburg 2006	USA	Information not extracted from unsampled studies	Investigate the most common parental fears, worries and cognitions about recurrent abdominal pain	5 years to 13 years No further information extracted from unsampled studies	Abdominal pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute of Diabetes and Digestive and Kidney Diseases
Voigtman 2002	Saudi Arabia	Information not extracted from unsampled studies	Describe the Qatif sociocultural response to children with sickle cell disease and pain	7 years to 14 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Waite-Jones 2008	UK	Support group	To address the research question 'What is it like to have a sibling with JIA?'	12 years to 18 years n = 32 8 children 16 parents 8 siblings Ethnicity: all White British	Arthritis	Interview	Grounded theory	Not reported
Wakefield 2018	USA	Information not extracted from unsampled studies	Examine pain-related stigma in the literature documenting paediatric and adult health-related stigma	12 years to 17 years No further information extracted from unsampled studies	Unspecified	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Goldfarb Pain and Palliative Medicine Fund
Wakefield 2021	USA	Information not extracted from unsampled studies	Examine adolescent motivations for using concealment and the possible benefits and harmful consequences of this form of coping	12 years to 17 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute of Arthritis, Musculoskeletal and Skin Diseases of the National Institutes of Health, Goldfarb Pain

(Continued)

								and Palliative Medicine Fund
Wakefield 2022	USA	Information not extracted from unsampled studies	Identify and describe pain-related stigma amongst adolescents with chronic pain and their parents	12 years to 17 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute of Arthritis, Musculoskeletal and Skin Diseases of the National Institutes of Health, Goldfarb Pain and Palliative Medicine Fund
Walter 2017	USA	Information not extracted from unsampled studies	Determine the dimensions of the health challenge of adolescent headache	14 years to 18 years No further information extracted from unsampled studies	Headache	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Neuroscience Nursing Foundation
While 2004	UK	Information not extracted from unsampled studies	Explore the lived experience of young people with SCD as they transferred to adult services	12 years to 16 years No further information extracted from unsampled studies	SCD	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Not reported
Williams 2008	UK	Unclear	Investigate the experiences of young people with epidermolysis bullosa	10 years to 14 years n = 11 5 females 6 males Ethnicity: 1 Black British 1 British Asian 8 White British	Epidermolysis bullosa	Interview	IPA	Not reported
Wong 2016	China/Hong Kong	Secondary school	Explore the self-care strategies amongst Hong Kong Chinese	Average age 15 years	Dysmenorrhoea	Interview	Content analysis	Association of Hong Kong

(Continued)

			adolescent girls with dysmenorrhoea	n = 28 Ethnicity: Hong Kong Chinese				Nursing Staff Professional Development Fund
Woodgate 1998	Canada	Information not extracted from unsampled studies	Elicit detailed descriptions of adolescents' chronic illness experiences	13 years to 16 years No further information extracted from unsampled studies	Mixed conditions	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Health Sciences Centre Foundation Nursing Research Award
Yeung 2017	Canada	Information not extracted from unsampled studies	Explore how children aged 10 years to 18 years describe their neuropathic pain	10 years to 18 years No further information extracted from unsampled studies	Neuropathic pain	Information not extracted from unsampled studies	Information not extracted from unsampled studies	Physiotherapy Practice Council
Yuwen 2017	USA	Information not extracted from unsampled studies	Describe parents' experiences in caring for 2-year to 5-year-old children with JIA	2 years to 5 years No further information extracted from unsampled studies	Arthritis	Information not extracted from unsampled studies	Information not extracted from unsampled studies	National Institute of Nursing Research, with additional scholarships and small grant

ADAPT: Aim to Decrease Anxiety and Pain Treatment
CBT-HA: cognitive behavioural therapy for health anxiety
CRPS: complex regional pain syndrome
cSLE: childhood-onset systemic lupus erythematosus
DARWeb: online psychosocial intervention for children with functional abdominal pain
FIT: fibromyalgia integrative training
HCP: healthcare provider
IASP: International Association for the Study of Pain
IBD: inflammatory bowel disease
IBS: irritable bowel syndrome
IPA: interpretative phenomenological analysis
IPQ-R: revised illness perception questionnaire
IWK: Izaak Walton Killam
JIA: juvenile idiopathic arthritis
MBSR: mindfulness-based stress reduction
NCCAM: National Center for Complementary and Integrative Health
NHRMC: National Health and Medical Research Council
NHS: National Health Service
NIH: National Institutes of Health
NIMH: National Institute of Mental Health
NTAP: Neurofibromatosis Therapeutic Acceleration Program
PROMIS: Patient-Reported Outcomes Measurement and Information System
PSST: problem-solving skills training
RTP: Research Training Program
SCD: sickle cell disease
SPOR: strategy for patient-oriented research
TEACH: Treatment and Education Approach for Childhood-onset Lupus
UCLA: University of California, Los Angeles
Web-MAP: web-based management of adolescent pain

HISTORY

Protocol first published: Issue 7, 2022

CONTRIBUTIONS OF AUTHORS

All authors contributed to data curation, formal analysis, investigation, methodology, resources and writing (review and editing). EF, JN, LF, IU, LC and RT contributed to funding acquisition and conceptualisation. EF also contributed to the conceptualisation, resources, supervision, project administration, visualisation and writing the original draft. MSB also contributed to project administration, visualisation and writing the original draft. KT also contributed to visualisation. EF is the guarantor of the review. Between August 2021 and December 2022, RT contributed as a freelance researcher, separately from her Cochrane role.

DECLARATIONS OF INTEREST

Emma France declared no financial conflicts of interest. She reports a grant from the National Institute for Health and Care Research for research that is published in this review; paid to institution. She reports a consultancy contract for a different type of review for the World Health Organization on the topic of the review, which fed into a guideline; paid to institution. She reports payments for workshops or seminars on meta-ethnography from the Agency for Healthcare Research and Quality, USA; Evidence Synthesis Ireland; Ludwig-Maximilians-Universität München, Germany; University of Oslo, Norway; University of Stavanger, Norway; and Oslo Metropolitan University, Norway; personal payments. She also reports being an unpaid member and co-convenor of the Cochrane Qualitative and Implementation Methods Group and an unpaid Associate Scientific Editor of the Cochrane-Campbell Handbook for Qualitative Evidence Synthesis, whose publications we used, and is an author of the meta-ethnography reporting guidance we used for this review.

Jane Noyes declared no financial conflicts of interest. She reports being involved in developing and publishing the original GRADE-CERQual publications we used. She reports leading the Cochrane Qualitative and Implementation Methods Group and is a member of its Methods Executive and Editorial Board whose publications we used, and is an author of the meta-ethnography reporting guidance we used. She reports being co-investigator on a grant from the National Institute for Health and Care Research for research that is published in this review; paid to institution. She reports a consultancy contract for a different type of review for the World Health Organization on the topic of the review, which fed into a guideline; paid to institution.

Liz Forbat declared no financial conflicts of interest. She reports being co-investigator on a grant from the National Institute for Health and Care Research for research that is published in this review; paid to institution.

Isabelle Uny declared no financial conflicts of interest. She is an author of the meta-ethnography reporting guidance we used. She reports being co-investigator on a grant from the National Institute for Health and Care Research for research that is published in this review; paid to institution.

Abbie Jordan declared no financial conflicts of interest. She also declared an unpaid leadership or role in the Pain in Childhood SIG of IASP and Society of Pediatric Psychology - international committee. She has authored several qualitative study publications on children's chronic pain, some of which met the review's inclusion criteria. She reports being co-investigator on a grant from the National Institute for Health and Care Research for research that is published in this review; paid to institution.

Line Caes declared no financial conflicts of interest. She has authored several qualitative study publications on children's chronic pain, some of which met the review's inclusion criteria. She reports being co-investigator on a grant from the National Institute for Health and Care Research for research that is published in this review; paid to institution.

Ruth Turley declared no financial conflicts of interest. She is an author of the meta-ethnography reporting guidance we used. She reports being co-investigator on a grant from the National Institute for Health and Care Research for research that is published in this review; paid to institution. She works for Cochrane (in a learning role), which has published systematic reviews related to chronic pain.

Mayara Silveira Bianchim declared no financial conflicts of interest. She is an intern in the Cochrane Qualitative and Implementation Methods Group. She reports being employed on a grant from the National Institute for Health and Care Research for research that is published in this review; paid to institution.

Katie Thomson declared no financial conflicts of interest. She reports being employed on a grant from the National Institute for Health and Care Research for research that is published in this review; paid to institution. She declared NHS Fife Consultancy work for an unrelated topic (personal payment), and receiving payment for a presentation at The Occupational Therapy Speaker Show and also receiving support for attending the meeting (personal payment). She also declared her voluntary role within the Scottish Western Region of Occupational Therapists.

SOURCES OF SUPPORT

Internal sources

- None, Other

  There were no internal sources of support

External sources

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- NIHR, UK

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DIFFERENCES BETWEEN PROTOCOL AND REVIEW

We completed the original literature search of all sources (including bibliographic databases, reference list checking of included studies, website searches and contacting experts) in September 2020. To bring the literature search up-to-date prior to publication we re-ran the bibliographic database searches and contacted our expert panel for new and ongoing studies in September 2022. The update searches did not follow the full protocol. Due to time constraints, we did not re-run the website searches or check the reference lists of the newly included studies identified from our updated search. Furthermore, the 'OpenGrey' database was discontinued in 2020, so the update search could not be re-run.

In the protocol, we had planned to perform 'cluster searches', which involve identifying 'clusters' of related study reports to reconstruct the study context (Booth 2013b), if a relevant study lacked contextual information. Due to the large volume of studies and lack of resource, we did not perform cluster searching, although as part of our richness assessments we did record which included studies we felt needed more information about the study context. In the protocol, we had planned to search the ASSIA (Applied Social Sciences Index & Abstracts) bibliographic database but could not because of lack of institutional access.

INDEX TERMS

Medical Subject Headings (MeSH)

*Analgesics, Opioid; Anthropology, Cultural; *Chronic Pain [therapy]; Family; Quality of Life

MeSH check words

Adolescent; Child; Humans