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Review article

What factors do children and young people and their parents perceive to impact therapeutic interactions when receiving healthcare for chronic pain: A qualitative evidence synthesis

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ABSTRACT

In a prospectively registered qualitative evidence synthesis (PROSPERO CRD42023461067), we explored child and parent perceptions and experiences of working with health professionals during healthcare for chronic pain, focusing on the factors impacting therapeutic interactions, with the aim to enhance provision of healthcare. Inclusion criteria: studies using qualitative methods; children and young people experiencing chronic pain aged 0–18 years and/or their parents/guardians; explored experiences or perceptions of therapeutic interactions when receiving healthcare. Five databases were searched (inception to July 2026), study quality was assessed, data were extracted and thematically synthesised, and GRADE-CERQual was used to assess confidence in findings. 22 studies were included, reporting the experiences of 292 children (6–18 years) and 194 parents (84% mothers). One overarching theme was identified, with six sub-themes (underpinned by discrete review findings), presented in a novel conceptual framework to guide clinicians in nurturing therapeutic interactions. Across the 14 review findings, 5 (36%) were graded as moderate confidence, 8 (57%) as low confidence, and 1 (7%) as very low confidence. Most studies were found to be of reasonable-good methodological quality. Child and family pain healthcare experiences influence how they engage and interact with health professionals in the future, creating an ongoing cycle that shapes therapeutic interactions in healthcare both positively and negatively. The presented conceptual framework aims to encourage and guide proactive nurturing of therapeutic interactions by health professionals, to improve healthcare experiences and outcomes for children experiencing chronic pain and their families.

Perspective: This qualitative evidence synthesis reports the experiences and perspectives of children experiencing chronic pain and their parents, with a focus on therapeutic interactions with health professionals. The findings and novel conceptual framework contribute to clinical care recommendations for health professionals working with children experiencing chronic pain.

Introduction

Chronic pain in children and young people (defined as under 18 years old age and collectively referred to as 'children' from now) is highly prevalent and burdensome, affecting 1 in 5.[1] Chronic pain negatively impacts children's schooling, leisure activities and social connections,[2–5] and results in an increased utilisation of health services.[4] Not only does chronic pain affect the quality of life and functioning of children,[6,7] it has also been found to impact the family unit, including impacting parental mental health and family functioning.[2,8,9] Considering the prevalence, increased utilisation of healthcare, and the overall burden, understanding engagement with healthcare, and interactions with health professionals is crucial for optimising effective and collaborative chronic pain care.

During the provision of healthcare, health professional interpersonal and communications skills are highlighted as crucial to the effective

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functioning of the therapeutic relationship.[10,11] Additionally, therapeutic relationships in paediatric chronic pain have been identified as a key driver for positive and negative outcomes.[12] Best practice evidence for the treatment of paediatric chronic pain is classified as interdisciplinary[13] or multidisciplinary intervention, including developing a shared understanding of pain which often involves pain science education, based on the biopsychosocial model.[14] The biopsychosocial model emphasises the importance of the therapeutic relationship between the health professional and the patient[11,15] for effective clinical implementation.

Despite the importance of the therapeutic relationship between the child, parent/carers (collectively referred to as 'parents' from now) and their health professional, evidence is emerging that children with chronic pain can feel dismissed, misunderstood, invalidated and disbelieved[16–18] by their health professionals. These negative encounters subsequently influence both the therapeutic relationship, and other aspects of care,[17–19] impacting engagement in healthcare. Conversely, connected and trusted relationships with health professionals can facilitate positive turning points in a child's chronic pain journey,[12,20] empowering the child to take charge of their own recovery, rather than feeling powerless over their chronic pain journey.[20] Effective therapeutic alliances which include trust, shared goals and developmentally appropriate fun, have been shown to be a positive driver for therapeutic outcomes in musculoskeletal chronic pain.[12]

Evidence indicates that child and parent active participation in healthcare leads to improved outcomes, increased adherence and development of child and parent confidence.[21,22] However, evidence shows that interactions with health professionals can cause children with chronic pain to feel more isolated and disconnected.[16,19,23] A meta-ethnography has synthesised how children with chronic pain and families experience and understand their condition, pain services and treatments,[24] with findings and recommendations presented at a broader system and service level and focusing on the delivery of chronic pain healthcare (such as access, logistics, knowledge, inclusivity and decision-making frameworks etc.). Additionally, reviews have highlighted the lived experiences of young people with chronic musculoskeletal pain and coexisting mental health conditions,[25] and how children describe their experience of pain challenges in their daily lives,[26] both identifying that interactions with health professionals can be challenging.

While evidence exists at a broader healthcare level, and at an individual experiences level, there is a gap in understanding how cumulative therapeutic interactions impact both the child and parents' ongoing engagement in healthcare. Likewise, as much of the existing evidence is targeted towards specialist chronic pain management services, clearer evidence regarding how all health professionals can contribute to enhancing the chronic pain journey for children and their parents is needed. Synthesising qualitative research on the experiences of children and their parents of therapeutic interactions would build upon the findings from these reviews. We aim to synthesise child and parent experiences, preferences and needs regarding therapeutic interactions across the chronic pain journey, to inform healthcare provision recommendations through qualitative evidence synthesis.

Objectives:

1. To synthesise qualitative studies that examine the experiences and perceptions of children with chronic pain and their parents regarding healthcare for chronic pain, with a focus on the therapeutic interactions between the child, parent, health professional and teams of health professionals.
2. To develop a conceptual understanding of what and how different factors influence therapeutic interactions, from the child and parent perspective, during healthcare for chronic pain.
3. To explore how the findings of this review can enhance the provision of healthcare for children experiencing chronic pain.

Review questions:

1. Which factors do children with chronic pain perceive and experience as impacting therapeutic interactions with their health professional/s when engaging with healthcare for chronic pain?
2. Which factors do parents of children with chronic pain perceive and experience as impacting therapeutic interactions with their health professional/s when engaging with healthcare for chronic pain?
3. What are the differences in the perceptions of children related to their developmental age, type of chronic pain, duration of chronic pain or other demographic characteristics?

Methods

When preparing this review, we used the Cochrane Effective Practice and Organisation of care (EPOC) Protocol and Review Template for Qualitative Evidence Synthesis.[27] The protocol has been registered on the International Prospective Register of Systematic Reviews (PROSPERO) identification number CRD42023461067. As no up-to-date formal reporting guideline for qualitative evidence synthesis currently exists, the review is reported according to the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) checklist (supplementary file 1), the Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) checklist (supplementary file 2) and following Cochrane-Campbell guidance.[28]

Patient and public involvement

To ensure relevance and reduction of bias during the review, we recruited two paid lived-experience co-researchers who have experience living with chronic pain and receiving healthcare as a young person (EL) and being the parent of a young person with chronic pain (KL). They had continuous involvement and advised the project team on the following key areas:

- Lived experience of chronic pain, including accessing healthcare for treatment of chronic pain;
- Framing the question and planning the review;
- Interpretation, publication, and dissemination of findings.

Considering lived experience co-researcher availability, age, and experience, we implemented a "top and tail" approach.[29] This approach encompassed involvement at the initial stages of the review (framing the question and planning the review) and the final stages (analysis, interpretation, publication, and dissemination of findings), but not the middle stages (conducting the review – screening and selection of studies, assessing methodological limitations, extracting data). Using the ACTIVE framework continuum of involvement,[30] lived experience co-researchers (EL and KL) both contributed to and influenced the review, as detailed in Supplementary File 3. EL and KL were also consulted to help decide the best approach for disseminating our findings, including the content of outputs.

Inclusion and exclusion criteria

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

Sample: children, adolescents, teenagers, or infants with chronic pain, their parents, or guardians.

Phenomenon of interest: experience of therapeutic interactions with a health professional or teams of health professionals, while engaging with healthcare for any type of non-cancer chronic pain. Therapeutic interactions were defined pragmatically as any consistent or purposeful interactions between the health professional, child and/or parent during engagement with healthcare for chronic pain.

Design: interviews, focus groups, observation, document analysis,

open-ended surveys.

Evaluation: views, experiences, attitudes, perceptions, beliefs, feelings of living with chronic pain and receiving healthcare from a health professional or group of health professionals.

Research type: qualitative, mixed methods including qualitative methods.

Types of studies

We included eligible qualitative primary research studies of any design (including mixed methods).

Topic of interest

We included studies focusing on the perceptions of children with non-cancer chronic pain, and their parents/guardians, when working with health professionals to receive healthcare. Children are defined according to the UN Convention of the Right of a Child (UNCRC) as a person under 18 years of age.

Inclusion criteria were as follows:

- Reported the experiences, views or perceptions of therapeutic interactions by children aged 0–18 years with chronic pain (pain lasting greater than 3 months) who have sought or received healthcare specifically related to their chronic pain AND/OR the experiences, views or perceptions of therapeutic interactions by the parents or guardians of children with chronic pain who have received healthcare specifically related to their chronic pain.
- Qualitative primary research studies of any design, including mixed methods studies if it were possible to extract data that were collected and analysed using qualitative methods.
- Uses recognisable qualitative methods of data collection and analysis.
- Published or grey literature, i.e. peer-reviewed journal articles, PhD theses, published reports, book chapters, books in any language.

Exclusion criteria are as follows:

- Children with acute pain (lasting less than 3 months).
- Children with cancer pain or receiving end-of-life pain management in the last weeks or days of life.
- Reports the experiences, views or perceptions of the health professional providing care only (no report of the children/parent experience).
- Data do not differentiate between acute and chronic pain participants or between adult and child participants with chronic pain.
- Non-empirical article e.g., editorial, commentary, study protocol.
- Conference abstracts.
- Literature review e.g., systematic review.

Search strategy and study selection

We searched five electronic databases, chosen for their coverage of both qualitative research and spectrum of relevant disciplines. These included MEDLINE Ovid, CINAHL, EMBASE, PsycINFO and Scopus. In addition, we searched ProQuest for literature such as PhD theses. Grey literature was included to ensure that rich, high-quality data from unpublished studies, such as doctoral theses, were considered as an important potential data source. We conducted initial literature searches between 8th March 2024 and 30th May 2024. We repeated bibliographic database searches from 30th May 2024–20 th July 2026 to bring the review up to date prior to publication. Search terms were developed for each database collaboratively with a specialist research librarian using the SPIDER criteria, and terms adapted specifically for use with database specific filters. See Supplementary File 4 for the MEDLINE Ovid search strategy, which was adapted for all other databases. Additionally, we reviewed reference lists of included studies to screen for further studies. After duplicate citations were managed by Covidence and removed, two review authors (JN and one of RF or MA) utilised Covidence (https://www.covidence.org) to independently screen titles and abstracts to determine each citation's eligibility for inclusion. Conflicts were then resolved through either discussion between reviewers (JN and one of RF or MA) or referred to a third reviewer (EF) if consensus could not be reached. Full texts of potentially eligible articles were then independently reviewed by two reviewers (JN and one of RF or MA) to confirm eligibility. Disagreements were resolved through discussion or referred to a third reviewer (EF) if consensus could not be reached. If study eligibility could not be determined due to ambiguous reporting of the sample (such as age of participants), we attempted to contact the original study authors for clarification. Studies were excluded if authors did not respond within 14 days.

Sampling of studies

It is not necessary to include every eligible study in a qualitative evidence synthesis, because the purpose is to develop understanding not draw conclusions about intervention effectiveness.[31] Furthermore, large numbers of studies can threaten the quality of analysis in qualitative evidence synthesis by impeding in-depth data analysis.[32] 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 with the aim to include sufficient cases to explore patterns rather than attempting to include every eligible study.[32] We developed a purposive sampling framework, which would take into consideration characteristics of eligible studies e.g. context, population, and have data as rich as possible that align closely with our research objective. Using a purposive sampling framework, we identified and prioritised two dimensions for sampling that included: (i) all studies that included rich data relevant to synthesis objectives and (ii) studies which closely matched our study scope and objectives. We used a revised data richness table by Ames, Glenton and Lewin[33] which combines these two dimensions into one scale. We sampled studies that we considered a 3 or higher for data richness on this scale, with 1 corresponding to very few or thin qualitative data, and 5 being very rich data (for example, an ethnographic study).[33] Application of the purposive sampling framework and sampling decisions were made by authors JN and EF, with author JP available to resolve disagreement if necessary.

Data extraction

Data extraction was undertaken by one reviewer (JN) and checked by a second reviewer (RF, MA or JP) using a customised form created by reviewers and uploaded into Covidence. Data extracted included study aims, design (such as methodology), inclusion and exclusion criteria, recruitment method, data collection and analytical approach, personnel involved (researcher positionality related to data collection and analysis), and participant demographics (parent and child demographics, aligned with PROGRESS+ criteria, including – age, gender/sex, place of residence, race/ethnicity/culture/language, occupation, religion, education, socioeconomic status, marital status, chronic pain characteristics, chronic pain duration) where reported. Additionally, second-order data regarding the experience of therapeutic interactions (defined as themes, subthemes and interpretations of these by authors of included articles from the results' 'findings" or 'discussion and conclusions' sections), were extracted. Only data relevant to the inclusion criteria and research question of this study were extracted. For mixed methods studies (such as an online survey with closed and open-ended responses) only qualitative data from open ended questions were included and extracted. Following extraction, second-order data were copied verbatim into QSR's NVivo software for qualitative analysis.

Quality assessment

We assessed the study methodological strengths and limitations using the Critical Appraisal Skills Programme (CASP) qualitative tool.[34] Appraisal was undertaken by one reviewer (JN) and checked by another (RF, MA or JP). We did not assess criterion 10, as this related to the relevance of the study generally. We did not exclude studies based on methodological limitations; however, results of appraisal were used to inform GRADE-CERQual assessment regarding confidence in synthesised findings.

Synthesis

We used thematic synthesis,[35] which is a three-stage process including free line-by-line coding of the findings of the primary studies, the organisation of these 'free codes' into related areas to construct 'descriptive themes' and then the subsequent development of 'analytical' themes. The first stage of free line-by-line coding of key concepts was conducted by one reviewer (JN) using NVivo version 11.[36] Coding was inductive, with the set of codes expanded as additional studies were added.[35] The preliminary codes were discussed and refined by two members of the review team (JN, JP). This process created a total of 62 initial codes, relating to children with chronic pain and their parents' views and experiences of receiving healthcare for chronic pain; example codes included "we want a health professional to talk to and listen to our whole experience" and "we feel disbelieved and dismissed."

For the second stage, groups of related codes were created, and organised into broader descriptive themes by members of the review team (JN, JP). This process involved continuous reference back to the papers from which they were derived, to ensure coherence and their grounding in the views and experiences of study participants. A draft summary of findings across the studies organised by the 10 descriptive themes were then written by two of the review authors (JN, JP). This draft was reviewed by all authors (including lived experience co-researchers EL, KL) and a final version was agreed.

The third stage of our synthesis involved identifying and mapping links between descriptive themes to generate analytical themes that made sense of children and their parents' experience of the therapeutic interactions when receiving healthcare for chronic pain. These were considered independently, then together by JN and JP, and finally refined into analytical themes through discussion with the research team (JN, JP, RF, MA, EF, TNJ, EL, KL). Readers may contact the lead author (JN) to request access to NVivo files.

Assessing confidence in review findings

Two review authors (JN, JP) used the GRADE-CERQual approach to assess our confidence in each synthesised finding, with review from a third author (EF). GRADE-CERQual assesses confidence in the evidence, based on the following four key components.[37]

1. 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.
2. 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. By cogent, we mean well supported or compelling.
3. 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.
4. 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.

Each of the four components was assessed assisted by the Interactive Summary of Qualitative Findings (iSoQ) software tool,[38] then a judgement was made 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 two review authors (JN, JP) with review by a third author (EF). All findings started as high confidence, which we then downgraded if there were important concerns regarding any of the GRADE-CERQual components.

Review author reflexivity

The review team have varied professional backgrounds including physiotherapy with children who have chronic pain (JN, JP, RF), psychology (TNJ, EF), paediatric pain medicine and anaesthesiology (MA), development of qualitative evidence synthesis methodology (EF), working in/with schools (JN, KL, RF) and children's pain research (JN, JP, RF, TNJ, MA, EF). Five have clinical backgrounds (JN, RF, MA, JP, TNJ) and one (EF) has a social science background. In addition, two of the review team are lived experience co-researchers (KL, EL). They have experienced living with chronic pain and receiving healthcare as a young person (EL) and being the parent of a young person with chronic pain (KL). The review team are united in the shared beliefs that children have the fundamental right to quality and evidence-based pain treatment, and that all pain is real.

If a team member was the author of a relevant study, they were not involved in assessing methodological limitations. We aimed to maintain a reflexive stance throughout all stages of the review process and declare any potential or perceived conflicts of interest, such as interpretation of any studies by our team members.

The chief investigator (JN) kept a reflexive journal during the review process. The review process was assessed regularly and discussed between the researchers, including lived experience co-researchers. This included approximately monthly meetings with the immediate research team and quarterly (or as needed) with the wider research team (including approximately six one-hour meetings between JN & lived experience co-researchers KL and EL). By seeking lived experience co-researcher input, we aimed to reduce the risk of influencing our protocol, analysis, and interpretation of the findings based on our preconceptions and backgrounds.

We anticipated that the findings of our review may reveal a discrepancy between current delivery of pain interventions by health professionals, and the needs and wants of children with chronic pain and their families. We expected this could challenge our beliefs, values and experiences as health professionals and researchers, and we aimed to discuss and be aware of potential tensions between the perspectives of the individual and reported perspectives of the child and parent throughout the review process. We took a reflexive approach throughout the review by questioning how our professional and personal assumptions could influence our interpretation of the data and our own findings.

Results

A total of 3902 records were identified through database searching. After removing duplicates, a total of 2525 records remained, and their titles and abstracts screened against the eligibility criteria. Full texts of 76 records were reviewed, resulting in 31 texts which were eligible for purposive sampling. We contacted the corresponding author of one study [39] to clarify participant demographics, as their published inclusion criteria allowed for ages up to 19 years. The author confirmed via email that all enrolled participants were under 18 years of age; therefore, the study met our inclusion criteria and was retained.

After applying our purposive sampling framework to eligible studies, we identified 22 records which were aligned to our first two review questions and were therefore included for final review and analysis (Fig. 1 – PRISMA diagram). While 22 reports were included, these

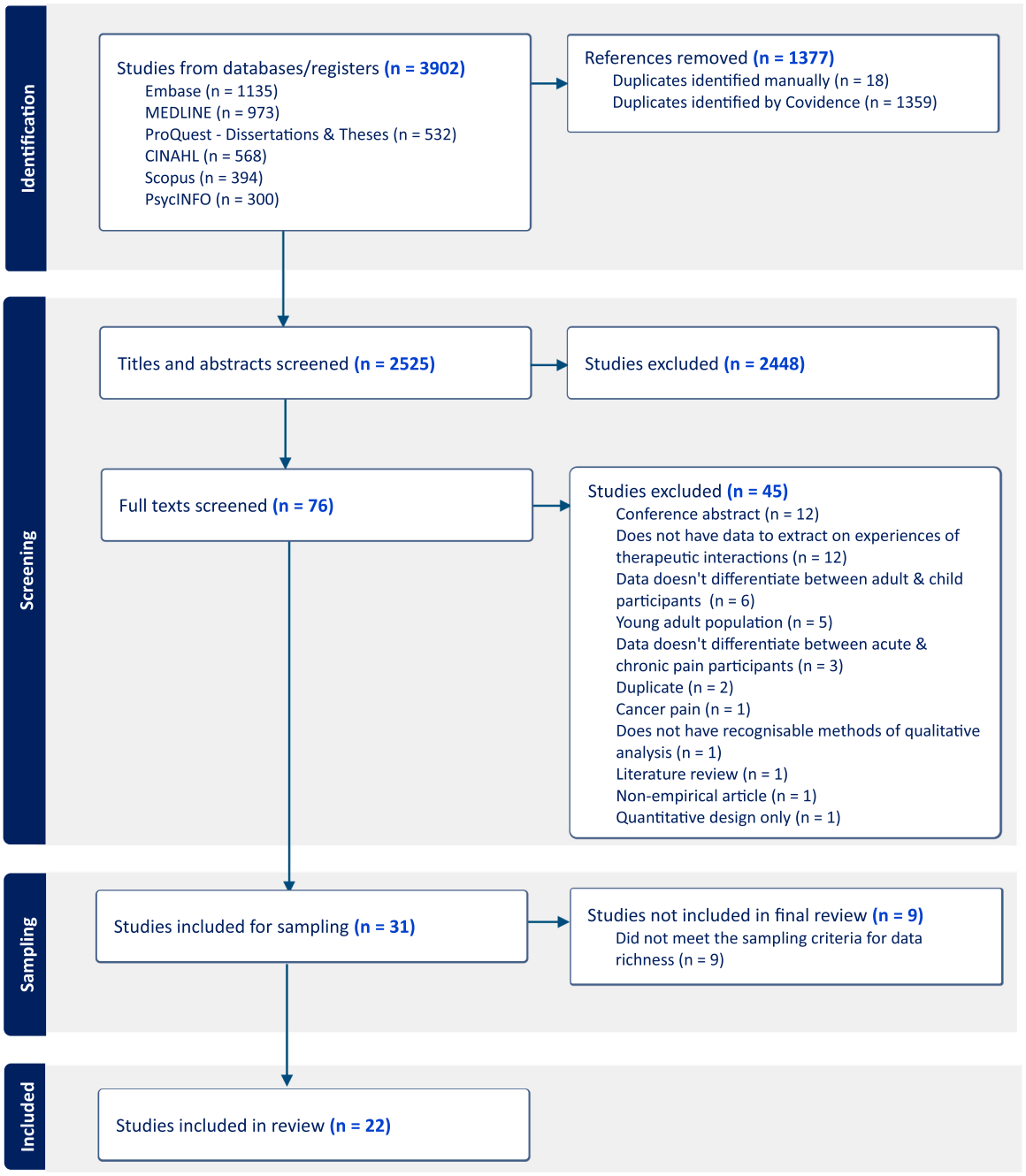

Fig. 1. Preferred Reporting Items for Systematic Reviews and Meta-Analysis (PRISMA) flowchart of included studies.

represented 21 unique datasets, as Joslin and Roberts[40] was a secondary analysis of data previously reported in Joslin, Donovan-Hall and Roberts[23] and Joslin, Donovan-Hall and Roberts [41]and therefore is not included in participant characteristics to avoid duplication. Table 1 details the purposive sampling process, including reason for exclusion for non-sampled studies.[42–50] Given the available evidence during screening, we were required to deviate from protocol, and we could not assess our final review question (to draw conclusions between different characteristics of children and their perceptions of therapeutic interactions).

Table 2 shows the characteristics of the included studies, detailing location, participant details, sample size, their aim/research question and study methodology. Collectively, the studies reported the experiences of 292 children, aged 6–18 years (with the majority sample ranging from 10 to 18 years), and 194 parents, including mothers (n = 162), fathers (n = 31) and two grandparents. The studies described a wide range of chronic pain conditions and experiences including headaches, migraine, abdominal pain, complex regional pain syndrome, functional neurovisceral pain disorder, amplified musculoskeletal pain syndrome, fibromyalgia, specific joint pain, juvenile idiopathic arthritis (JIA), Ehlers-Danlos Syndrome/Hypermobility, painful disorders of gut brain interaction (DGBIs), musculoskeletal pain and unspecified or widespread chronic pain. Duration of chronic pain ranged from 3 months to "all my life".

The included studies were conducted in Canada (n=6 studies), Norway (n=1), United Kingdom (n=9) and the United States of America (n=6). Semi-structured interviews were the predominant data collection method. Interviews (structure not specified), focus groups, journal and drawing activities, and focus groups with guided activities were also used. Quotes included in the results are qualitative data from the

Table 1
Studies eligible for sampling, including adapted data richness rating and sampling decisions.

Study (Author, Year)	Title	Study aims	Data richness score	Sampling decision
Adetayo, 2026	Elevating the voices of Black youth with painful disorders of gut brain interaction: A qualitative study of stigma and resilience.	*"The current study aims to explore experiences of pain-related and intersectional stigma across various social contexts through qualitative interviews with Black children and adolescents diagnosed with a DGBI. Recognizing that stigmatized individuals are often viewed through a deficit-based lens, strengths and sources of resilience were also explored."*	4 - A good amount and depth of qualitative data that relate to the synthesis objective. For example, includes more context and setting descriptions and a more in-depth presentation of findings.	Meets sampling criteria for data richness – include.
Brekke and Brodwall, 2020	Understanding parents' experiences of disease course and influencing factors: a 3-year follow-up qualitative study among parents of children with functional abdominal pain.	*"Aim was to 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."*	1 - very little qualitative data presented that relate to the synthesis objective. Those findings that are presented are fairly descriptive.	Did not meet the sampling criteria for data richness – exclude.
Brodwell, 2018	Parents' experience when their child has chronic abdominal pain: a qualitative study in Norway.	*"To explore the experiences of parents of children and adolescents with chronic abdominal pain who were discharged from hospital without a somatic explanation."*	3 - A reasonable amount of qualitative data that relate to the synthesis objective. For example, a typical qualitative research article in a journal with a smaller word limit and often using simple thematic analysis.	Meets sampling criteria for data richness – include.
Brown, 2023	Understand me: Youth with chronic pain on how knowledge gaps influence their pain experience.	*"To explore the perspectives of youth living with chronic pain on the interactions among their pain experiences, chronic pain resources and research."*	3 - A reasonable amount of qualitative data that relate to the synthesis objective. For example, a typical qualitative research article in a journal with a smaller word limit and often using simple thematic analysis.	Meets sampling criteria for data richness – include.
Carter, 2002	Chronic pain in childhood and the medical encounter: professional ventriloquism and hidden voices.	*"The purpose of this study was to explore, from the children's and families' perspectives, the impact of living with chronic pain."*	5 - A large amount and depth of qualitative data that relate in depth to the synthesis objective. For example, an ethnography or published qualitative article with the same objectives as the synthesis.	Meets sampling criteria for data richness – include.
Carter et. al., 2002	A pain workshop: an approach to eliciting the views of young people with chronic pain.	*"To explore the way in which the experience of chronic pain impacts on the lives of young people."*	3 - A reasonable amount of qualitative data that relate to the synthesis objective. For example, a typical qualitative research article in a journal with a smaller word limit and often using simple thematic analysis.	Meets sampling criteria for data richness – include.
Daenen, 2024	Child appraisals of injustice in the context of acute and chronic pain: An interpretative phenomenological analysis.	*"Aimed to examine the phenomenology of child pain-related injustice appraisals using an explicitly child-centred approach."*	2 - some qualitative data presented that relate to the synthesis objective, but limited number of findings.	Did not meet the sampling criteria for data richness – exclude.
Dell'Api, 2007	Childhood chronic pain and health care professional interactions: shaping the chronic pain experiences of children.	*"Develop understanding of the way in which children with chronic pain experienced, assigned meaning and described their interactions with health care professionals."*	4 - A good amount and depth of qualitative data that relate to the synthesis objective. For example, includes more context and setting descriptions and a more in-depth presentation of findings.	Meets sampling criteria for data richness – include.
de Moura, 2021	Chronic pain following inguinal herniorrhaphy: perceptions of children and adolescents.	*"Aim of the study was to analyze the perceptions of children and adolescents about chronic postsurgical pain, experienced for three years after outpatient inguinal herniorrhaphy."*	1 - very little qualitative data presented that relate to the synthesis objective. Those findings that are presented are fairly descriptive.	Did not meet the sampling criteria for data richness – exclude.
Gaughan, 2014	Parents' perspective of their journey caring for a child with chronic neuropathic pain.	*"The purpose of this study was to describe the parents' journey with their child from initial incidence of pain through the labyrinth of treatment options to successful outcome, to gain a better understanding of pa-rental beliefs about pain, and to learn how parental attitudes and behaviors influence children's response to treatment for chronic pain."*	1 - very little qualitative data presented that relate to the synthesis objective. Those findings that are presented are fairly descriptive.	Did not meet the sampling criteria for data richness – exclude.
Joslin, 2021	Exploring the Outcomes That Matter Most to Young People Treated for Chronic Pain: A Qualitative Study.	*"To establish which outcomes young people identify as important and why; and if their outcome preferences change during the course of treatment."*	3 - A reasonable amount of qualitative data that relate to the synthesis objective. For example, a typical qualitative research article in a journal with a smaller word limit and often using simple thematic analysis.	Meets sampling criteria for data richness – include.
Joslin, 2023	"You just want someone to help": Outcomes that matter to parents when their child is treated for chronic pain.	*"To establish which outcomes parents considered important to measure during their child's treatment for chronic pain and why; and discover whether these preferences changed during the course of treatment."*	4 - A good amount and depth of qualitative data that relate to the synthesis objective. For example, includes more context and setting descriptions and a more in-depth presentation of findings.	Meets sampling criteria for data richness – include.
Joslin, 2024	Adolescent and Parent Experiences and Perceived Effectiveness of Physical Interventions for Chronic Musculoskeletal Pain: A Qualitative Study.	*"This study sought to explore adolescent and parent experiences and perceived effectiveness of physical interventions for chronic musculoskeletal pain in the United Kingdom."*	3 - A reasonable amount of qualitative data that relate to the synthesis objective. For example, a typical qualitative research article in a journal with a smaller word limit and often using simple thematic analysis.	Meets sampling criteria for data richness – include.

(*continued on next page*)

Table 1 (*continued*)

Study (Author, Year)	Title	Study aims	Data richness score	Sampling decision
Kanstrup, 2019	Adolescent and Parent Experiences of Acceptance and Commitment Therapy for Pediatric Chronic Pain: An Interpretative Phenomenological Analysis.	*"Thus, the aim of this cross-sectional qualitative study was to explore the lived experiences of young people and parents with regard to participating in ACT for pediatric chronic pain."*	1 - very little qualitative data presented that relate to the synthesis objective. Those findings that are presented are fairly descriptive.	Did not meet the sampling criteria for data richness – exclude.
Lee, 2023	'That's what makes me better': Investigating children and adolescents' experiences of pain communication with healthcare professionals in paediatric rheumatology.	*"Investigate children and adolescents' experiences of pain communication from their history of interactions with healthcare professionals in paediatric rheumatology in the United Kingdom."*	4 - A good amount and depth of qualitative data that relate to the synthesis objective. For example, includes more context and setting descriptions and a more in-depth presentation of findings.	Meets sampling criteria for data richness – include.
Lee, 2025	"My child needs a chance and a choice to talk about their pain": Parents' experiences and perspectives of pain communication in paediatric rheumatology.	*"The aim of this study was to explore parents' experiences of and perspectives about pain communication, particularly in paediatric rheumatology."*	4 - A good amount and depth of qualitative data that relate to the synthesis objective. For example, includes more context and setting descriptions and a more in-depth presentation of findings.	Meets sampling criteria for data richness – include.
Lefebvre, 2020	Exploring the Needs of Parents with a Child with Chronic Pain: A Qualitative Secondary Analysis.	*"The purpose of this research study was to increase public and researcher knowledge about the unique needs of parents with children with chronic pain."*	4 - A good amount and depth of qualitative data that relate to the synthesis objective. For example, includes more context and setting descriptions and a more in-depth presentation of findings.	Meets sampling criteria for data richness – include.
Lund, 2024	Narrative Accounts of Youth and Their Mothers With Chronic Headache.	*"The study aimed to generate narrative types by positioning parents' and youth's narratives, each told independently, in relation to one another."*	4 - A good amount and depth of qualitative data that relate to the synthesis objective. For example, includes more context and setting descriptions and a more in-depth presentation of findings.	Meets sampling criteria for data richness – include.
Maciver, 2011	Parental Experiences of Pediatric Chronic Pain Management Services.	*"To examine parents' experiences of paediatric chronic pain management services in the United Kingdom."*	4 - A good amount and depth of qualitative data that relate to the synthesis objective. For example, includes more context and setting descriptions and a more in-depth presentation of findings.	Meets sampling criteria for data richness – include.
McKinnon, 2022	Caregiver perspectives of managing chronic pain in children and adolescents with dyskinetic and mixed dyskinetic/spastic CP with communication limitations.	*"This study explored the personal challenges caregivers face in supporting their child's everyday pain management, including barriers and facilitators to effective chronic pain management."*	1 - very little qualitative data presented that relate to the synthesis objective. Those findings that are presented are descriptive.	Did not meet the sampling criteria for data richness – exclude.
Meldrum, 2009	"I can't be what I want to be": children's narratives of chronic pain experiences and treatment outcomes.	*"To better understand the children's whole experiences of pain, dysfunction, treatment, and outcomes, as integrated into their individual lives, and to consider in what ways clinicians and parents can support positive outcomes in children with specific narratives."*	3 - A reasonable amount of qualitative data that relate to the synthesis objective. For example, a typical qualitative research article in a journal with a smaller word limit and often using simple thematic analysis.	Meets sampling criteria for data richness – include.
Neville, 2019	Diagnostic Uncertainty in Youth With Chronic Pain and Their Parents.	*"How diagnostic uncertainty is experienced by both youth with chronic pain and their parents."*	4 - A good amount and depth of qualitative data that relate to the synthesis objective. For example, includes more context and setting descriptions and a more in-depth presentation of findings.	Meets sampling criteria for data richness – include.
Neville, 2025	How the clinical encounter shapes diagnostic uncertainty in pediatric chronic pain.	*"Which elements of the clinical encounter influence youth and parent diagnostic uncertainty?"*	5 - A large amount and depth of qualitative data that relate in depth to the synthesis objective. For example, an ethnography or published qualitative article with the same objectives as the synthesis.	Meets sampling criteria for data richness – include.
Nieto, 2020	Understanding the Experience of Functional Abdominal Pain Through Written Narratives by Families.	*"Our aim was to increase knowledge in this field by testing an innovative written narrative methodology designed to approach the experiences of children with FAP and their parents."*	1 - very little qualitative data presented that relate to the synthesis objective. Those findings that are presented are descriptive.	Did not meet the sampling criteria for data richness – exclude.
Nutkiewicz, 2008	Diagnosis versus dialogue: oral testimony and the study of pediatric pain.	*"What children say about their relationship with their doctors to illustrate how oral testimony uncovers the dynamics of a critical relationship for patients who visit doctors with greater frequency than the general population."*	3 - A reasonable amount of qualitative data that relate to the synthesis objective. For example, a typical qualitative research article in a journal with a smaller word limit and often using simple thematic analysis.	Meets sampling criteria for data richness – include.
Sallfors, 2002	Oscillating between hope and despair - a qualitative study.	*"Aim of this qualitative study was to elucidate the life situation and psychosocial processes of living with chronic pain in children suffering from juvenile chronic arthritis (JCA)."*	1 - very little qualitative data presented that relate to the synthesis objective. Those findings that are presented are fairly descriptive.	Did not meet the sampling criteria for data richness – exclude.
Szwimer, 2019	Understanding the Lived Experiences of Adolescents Living with Chronic Pain: The Personal and Social Implications.	*"What are the psychological and social implications (barriers and facilitators) faced by adolescents living with CP?"*	3 - A reasonable amount of qualitative data that relate to the synthesis objective. For example, a typical qualitative	Meets sampling criteria for data richness – include.

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Table 1 (*continued*)

Study (Author, Year)	Title	Study aims	Data richness score	Sampling decision
			research article in a journal with a smaller word limit and often using simple thematic analysis.	
Wakefield, 2021	"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.	*"The present study aimed to examine the nature of concealment as a coping strategy used by adolescents with primary chronic pain, using focus group methodology."*	1 - very little qualitative data presented that relate to the synthesis objective. Those findings that are presented are fairly descriptive.	Did not meet the sampling criteria for data richness – exclude.
Wakefield, 2022	"There's Nothing Wrong With You": Pain-Related Stigma in Adolescents With Chronic Pain.	*"To identify and describe pain-related stigma among adolescents with chronic pain and their parents."*	3 - A reasonable amount of qualitative data that relate to the synthesis objective. For example, a typical qualitative research article in a journal with a smaller word limit and often using simple thematic analysis.	Meets sampling criteria for data richness – include.
Wakefield, 2023	Does Diagnostic Certainty Matter?: Pain-Related Stigma in Adolescents with Juvenile Idiopathic Arthritis.	*"To describe the nature of pain-related stigma experiences in adolescents with JIA and their parents."*	3 - A reasonable amount of qualitative data that relate to the synthesis objective. For example, a typical qualitative research article in a journal with a smaller word limit and often using simple thematic analysis.	Meets sampling criteria for data richness – include.
Wigley, 2002	An Exploration of the Beliefs and Understanding of Parents Regarding Their Child's Musculoskeletal Chronic Pain Syndrome: An Interpretative Phenomenological Analysis.	*"To explore the beliefs and understanding that parents hold regarding their child's musculoskeletal chronic pain syndrome and how they attempt to make sense of it in the absence of an organic explanation."*	4 - A good amount and depth of qualitative data that relate to the synthesis objective. For example, includes more context and setting descriptions and a more in-depth presentation of findings.	Meets sampling criteria for data richness – include.

Table 2
Characteristics of included reports (n=22), including characteristics of participants, where reported.

Study (Author, Year)	Location	Children – N	Children – age	Children – sex	Children – other demographics	Children – chronic pain characteristics	Parents – N	Parents – demographics	Methodology, analysis and data collection
Children only									
Adetayo, 2026	United States of America	20	8–18 years (13 – 18 years (13), 8 – 12 years (7)).	Reported as gender	Self-identified gender: Girl (11), boy (9), transgender (2) Race: black (19), Filipino & black (1)	Pain type: Painful disorder of gut brain interaction (DGBIs).	N/A	N/A	Methodology: Phenomenological approach. Data analysis: Deductive and inductive thematic analysis. Data collection: Semi-structured interviews, face to face or online via zoom.
Brown, 2023	Canada	7	12–18 years (at time of recruitment – one participant turned 19 during the study)	7 F (female or demi-girl)	Residence: major urban centre (5), other communities (2) Ethnicity: European origins or Canadian (7)	Pain type: Not reported Duration: 3 months - 5 years (median 3 years)	N/A	N/A	Methodology: Interactive description Data analysis: Inductive content analysis. Data collection: Semi-structured interviews, face to face or telephone.
Carter et. al., 2002	United Kingdom	5	13–18 years	Not reported	Not reported	Pain type: Varied including abdominal pain, headaches, bone pain and back pain. Duration: not reported	N/A	N/A	Methodology: Participant inquiry paradigm. Data analysis: Theoretical coding technique. Data collection: Focus groups with guided activities.
Dell'Api, 2007	Canada	5	10–17 years	3 F, 2 M	Language: spoke French or English (5)	Pain type: Varied including right side, all over, chest & abdomen, left leg. Duration: 6 months - 4+ years.	N/A	N/A	Methodology: Interpretive description. Data analysis: Inductive approach. Data collection: Semi-structured interviews, face to face.
Joslin, 2021	United Kingdom	21	11–18 years (mean 14.8 years)	18 F, 3 M	Language: English (21)	Pain type: Chronic musculoskeletal pain, located in lower limb (57%), multiple joints (28%), neck/back/chest (10%) and upper limb (5%). Duration: 5–108 months (mean 40 months).	N/A	N/A	Methodology: Qualitative design. Data analysis: Thematic analysis. Data collection: Semi-structured interviews, with a drawing component, mixed (face to face, telephone, zoom, online messenger).
Lee, 2023	United Kingdom	26	6–18 years (mean 14.93 years)	Not reported	Language: English (26)	Pain type: Varied, including juvenile idiopathic arthritis (16), chronic idiopathic pain syndromes/CRPS (5) and Ehlers Danlos Syndrome/hypermobility (5). Duration: 1–11 years (median 3.83 years).	N/A	N/A	Methodology: Qualitative design. Data analysis: Framework analysis. Data collection: Semi-structured interviews, telephone.
Meldrum, 2009	United States of America	53	10–18 years, (mean 14.23 years)	36 F, 17 M	Race/ethnicity: Caucasian (68%), Latino (15%), mixed race (9%), African American, Asian American or other (8%).	Pain type: Varied, including headaches (58.5%), functional neurovisceral pain disorder (37.7%), myofascial pain (34%), CRPS (9.4%), fibromyalgia (9.4%). Duration: 3 months - "all my life" (mean 50.7 months).	N/A	N/A	Methodology: Grounded theory. Data analysis: Narrative analysis. Data collection: Semi-structured interviews, face to face.

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Table 2 (*continued*)

Study (Author, Year)	Location	Children – N	Children – age	Children – sex	Children – other demographics	Children – chronic pain characteristics	Parents – N	Parents – demographics	Methodology, analysis and data collection
Nutkiewicz, 2008	United States of America	32	10–18 years (mean 14 years)	24 F, 8 M	Ethnicity: Caucasian (22), Latino (5), Asian (4), African American (1).	Pain type: Varied, including headache, abdominal pain, back pain, hand pain, foot pain, facial pain and total body pain. Duration: 1 month to "all my life" (mean 50 months).	N/A	N/A	Methodology: Oral testimony. Data analysis: Not clearly reported. Data collection: Semi-structured interviews, face to face.
Szwimer, 2019	Canada	8	14–17 years	8 F	Language: French or English (8).	Pain type: Varied, including fibromyalgia, arthritis, back pain, widespread pain, related disorders, and/or orofacial pain conditions. Duration: More than 6 months.	N/A	N/A	Methodology: Interpretive phenomenology framework. Data analysis: Interpretive phenomenology analysis. Data collection: Semi-structured interviews, face to face.
Parents only									
Brodwell, 2018	Norway	N/A	6–13 years	Not reported	Residence: mid-sized Norwegian town (15).	Pain type: Chronic abdominal pain. Pain duration: Not reported.	15	10 mothers, 5 fathers Ethnicity: Norwegian (10), "not Norwegian" (4)	Methodology: Qualitative design. Data analysis: Descriptive content analysis. Data collection: Interviews, face to face and telephone.
Joslin, 2023	United Kingdom	N/A	11–18 years (mean 14.9 years)	16 F, 5 M	Language: English (21)	Pain type: Varied, including CRPS (6), chronic primary pain (6), unknown (5), hypermobility/EDS (3) and orthopaedic (1).	21	17 mothers, 4 fathers	Methodology: Qualitative design. Data analysis: Thematic analysis. Data collection: Semi-structured interviews, mixed (face to face, telephone, zoom, online messenger).
Lee, 2025	United Kingdom	N/A	6–16 years (median 13 years)	8 F, 10 M	Not reported	Pain type: Varied, including Chronic Idiopathic Pain Syndromes (3), Ehlers Danlos Syndrome/hypermobility (3), Juvenile Idiopathic Arthritis (12). Pain duration: 8 months - 11 years (median 2.92 years).	18	16 mothers, 1 father, 1 grandmother	Methodology: Qualitative design. Data analysis: Thematic framework analysis. Data collection: Semi-structured interviews, telephone.
Lefebvre, 2020	Canada	N/A	13–18 years	Not reported	Not reported	Pain type: Varied. Duration: Longer than 2 years (79%).	13	12 mothers, 1 father Language: English (13) Education: some high school (1), postsecondary diploma (3), postsecondary degree (6), graduate degree (3). Relationship status: married/common law (11), single/widowed/ divorced (2)	Methodology: Qualitative secondary analysis. Data analysis: Qualitative descriptive approach. Data collection: Semi-structured interviews, face to face.
Maciver, 2011	United Kingdom	N/A	10–16 years (mean 13 years)	9 F, 2 M	Not reported	Pain type: Varied, including musculoskeletal pain (6), neuropathic pain/CRPS (4). Duration: 12 – 77 months (mean 42 months).	12	10 mothers, 2 fathers Age: 39 years (range 33 – 45 years) Marital status: married (10), divorced (2).	Methodology: Qualitative design. Data analysis: Interpretive thematic analysis. Data collection:

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Table 2 (*continued*)

Study (Author, Year)	Location	Children – N	Children – age	Children – sex	Children – other demographics	Children – chronic pain characteristics	Parents – N	Parents – demographics	Methodology, analysis and data collection
								Occupation: paid employment (7), unemployed (2), never had paid employment (3).	Interviews, face to face or telephone
Children and parents									
Carter, 2002	United Kingdom	3	12–13 years	2 F, 1 M	Not reported	Pain type: Varied, including knee pain, chronic abdominal pain and back pain. Duration: Not reported.	6	3 mothers, 3 fathers	Methodology: Constructivist philosophy. Data analysis: Thematic analysis. Data collection: Journal phase with "loosely" structured interviews, face to face.
Joslin, 2024[a]	United Kingdom	N/A (secondary analysis)	11 – 18 years	19 F, 5 M	Not reported	Pain type: Chronic musculoskeletal pain Duration: 5 – 120 months	N/A (secondary analysis)	17 mothers, 4 fathers	Methodology: Secondary qualitative analysis. Data analysis: Reflexive thematic analysis (experimental approach). Data collection: Semi-structured interviews, in person, phone or online via zoom.
Lund, 2024	Canada	26	11 – 18 years (mean 14.46 years, SD 2.12)	21 F	Ethnicity: White (92.4%), 2 or more ethnicities (7.6%).	Pain type: Chronic head pain (including migraine, tension-type, post-concussive, and other headache types). Duration: mean 3.5 years (SD 3.33).	26	26 mothers Pain type: Chronic head pain. Age: 36–51 years (mean 43.13 years, SD 4.32). Ethnicity: White (96.2%), 2 or more ethnicities (3.8%). Household income: $60, 000 - $89,999 (15.4%), more than $90,000 (42.3%), do not want to answer (7.7%).	Methodology: Narrative analysis using application of socio-narratology framework. Data analysis: Narrative analysis using descriptive & iterative qualitative approach. Data collection: Semi-structured interviews (separate), in person.
Neville, 2019	Canada	20	10 – 18 years (mean 14.6 years)	15 F, 5 M	Ethnicity: Caucasian (18), Latin American (1), do not want to answer (1).	Pain type: Varied, including complex regional pain syndrome (6), headaches/ migraines (2), migraines and stomach migraines (1), migraines and constipation (1), chronic pain (2), nephroptosis (1), costochondritis (1), and no diagnosis (2). Duration: 6 months – 11 years (mean 3.67 years).	20	17 mothers, 3 fathers Age: 46.8 years (range 33–55 years) Marital status: married (14), single (1), separated/divorced (3), widowed (1), common law (1) Household income: less than $90 000 (3), more than $90 000 (15), do not want to answer (2)	Methodology: Dyadic qualitative approach. Data analysis: Inductive thematic analysis. Data collection: Semi-structured interviews, face to face.
Neville, 2025	United States of America	23	10–17 years (mean 13.2 years)	14 F, 9 M	Ethnicity - Hispanic/ Latino (3), non-Hispanic/ non-Latino (17), declined to answer (1). Racialised identity: white (18), American Indian/	Pain type: Varied, headaches (56.5%), myofascial pain (of any body part excluding headaches) (34.8%), abdominal pain (30.4%), complex regional pain syndrome (8.7%).	25	21 biological mothers, 1 biological father, 2 adoptive mothers, 1 adoptive father Age: 33–56 years (mean 46.5 years)	Methodology: Longitudinal qualitative methods. Data analysis: Secondary analysis using interpretative phenomenological analysis. Data collection:

(*continued on next page*)

Table 2 (*continued*)

Study (Author, Year)	Location	Children – N	Children – age	Children – sex	Children – other demographics	Children – chronic pain characteristics	Parents – N	Parents – demographics	Methodology, analysis and data collection
					Alaska Native (1), multi-racial (1), declined to answer (1).	Duration: 3–144 months (mean 53.3 months).		Education: Some college (9), college degree (4), post graduate degree (9) Marital status: married (18), separated/divorced (2), single (1)	Semi-structured interviews, before and after clinic encounters, in person.
Wakefield, 2022	United States of America	18	12–17 years (mean 15.33 years)	16 F, 1 M, 1 gender fluid	Language: English. Race: white (14), black (1), more than one race (2), other (1). Ethnicity: Hispanic (5), not Hispanic (13).	Pain type: Varied, including amplified musculoskeletal pain syndrome (66.11%), abdominal pain (33.33%), pain amplification syndrome (27.78%), chest pain (11.11%), irritable bowel syndrome (11.11%), CRPS (5.56%), fibromyalgia (5.56%), neck pain (5.56%) and migraine (5.56%). Duration: 3 – 52 months (mean 23.28 months).	9	7 mothers, 1 father, 1 grandmother	Methodology: Focus group methodology. Data analysis: Directed content analysis. Data collection: Semi-structured focus groups.
Wakefield, 2023	United States of America	16	12–17 years (mean 15.42 years)	14 F, 2 M	Race/ethnicity: white (12), more than one race (2), black (1), Hispanic or Latino (1).	Pain type: Juvenile Idiopathic Arthritis. Duration: Not reported.	13	12 mothers, 1 father Race/ethnicity: white (11), black (1), Hispanic or Latino (2).	Methodology: Focus group methodology. Data analysis: Directed content analysis. Data collection: Focus groups, online via zoom.
Wigley, 2002	United Kingdom	9	14 – 18 years (mean 15 years)	9 F	Ethnicity: white UK (8), black Afro-Caribbean (1).	Pain type: Musculoskeletal chronic pain syndrome. Duration: 1 – 9 years.	17	9 mothers, 8 fathers Age: 39–63 years.	Methodology: Interpretative Phenomenological Analysis. Data analysis: Interpretative Phenomenological Analysis. Data collection: Semi-structured interviews, face to face

[a] Joslin (2024) was a secondary qualitative analysis of data included in Joslin (2021) and Joslin (2023) and therefore has been assigned "N/A" to number of participants.

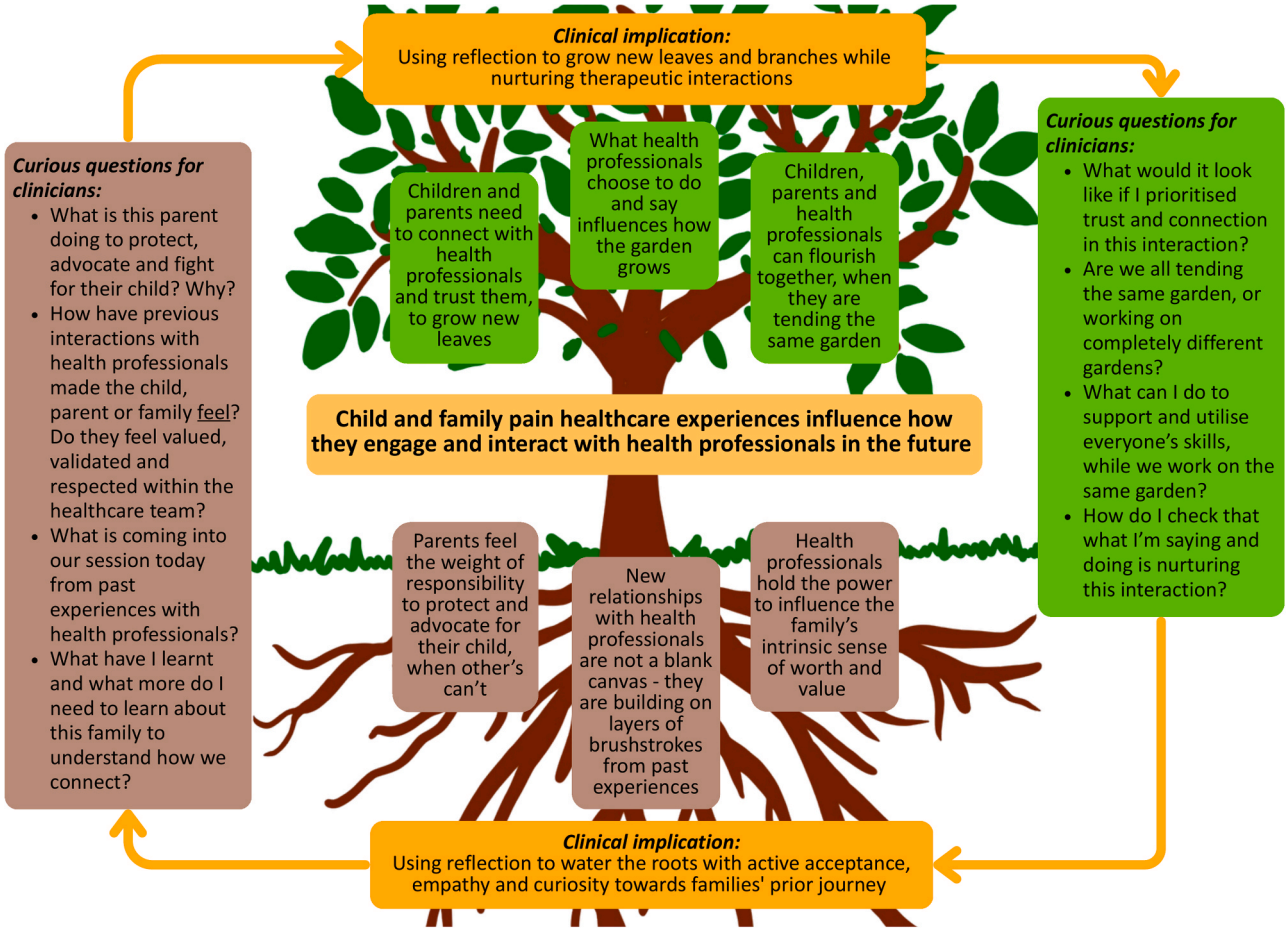

Fig. 2. A conceptual framework of the analytical themes, to guide clinicians in nurturing therapeutic interactions with children experiencing chronic pain and their parents[51].

'results' 'findings" or 'discussion and conclusions' sections, rather than direct participant quotes, aligned with third order interpretation described in thematic synthesis.

Assessment of methodological strengths and limitations

All reports were assessed using the CASP qualitative assessment tool,[34] with full assessments detailed in Supplementary File 5. Most studies were found to be of reasonable-good methodological quality, with low to moderate level of concern for methodological domains assessed using CASP. We most commonly identified methodological limitations concerning if and how study authors took the relationship between researcher and participants into consideration. Participant recruitment strategies were mostly well or moderately well designed, with only one study assessed as having serious concerns. Data collection was generally well or moderately-well designed across studies. Ethical issues were generally assessed as adequately considered, with the exception of two studies which were assessed as having serious methodological limitations in this domain. Data analysis was relatively well or moderately-well conducted with only one study having serious methodological limitations.

Synthesis themes and review findings

One overarching theme was identified with 6 sub themes, organised into a conceptual framework[51] (Fig. 2) to guide clinicians in nurturing therapeutic interactions with children experiencing chronic pain and their parents. Each sub-theme was underpinned by discrete review findings, supported by a Summary of Findings table (Table 3). Across the 14 review findings, 5 (36%) were graded as moderate confidence, 8 (57%) as low confidence, and 1 (7%) as very low confidence. Supplementary file 6 provides the detailed assessments of confidence by GRADE-CERQual domain in an Evidence Profile table.

Main theme: Child and family pain healthcare experiences influence how they engage and interact with health professionals in the future

The overarching theme of "child and family pain healthcare experiences influence how they engage and interact with health professionals in the future" is presented on a conceptual framework (Fig. 2),[51] including clinical implications for health professionals, using the metaphor of a tree. Child and parent healthcare experiences sit at the centre of the tree and represent the cyclical nature of healthcare engagement. The underground roots (which can be recognised and watered), draw health professional awareness to active acceptance of the past and how past experiences and memories of health care impact future health care interactions. These new relationships did not start in a neutral space, instead were building on and shaped by layers of previous interactions and experiences with health professionals. The tree leaves and branches (which can be nurtured and grown), draw health professional awareness to positive steps forward) and how they can change practice to nurture therapeutic relationships with children and their families.

Sub-theme 1: Health professionals hold the power to influence the family's intrinsic sense of worth and value

Participants reported that health professionals had the power to influence their intrinsic sense of worth and value, both individually and as a family unit. Children and families spoke positively about experiences with both individual health professionals and tertiary multidisciplinary chronic pain teams who listened to their story and "finally" made them feel like health professionals believed their pain was real.[18,23,39,41,52–58]

Table 3
Summary of GRADE-CerQUAL findings.

#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE-CERQual Assessment	References
1	**In Canada, Norway, the United Kingdom and the United States of America, children and their parents could feel validated and valued or judged and misunderstood by health professionals.** Children and their parents reported feeling validated by health professionals, when receiving healthcare for chronic pain. Children valued being seen as a whole person, rather than just being seen as someone with pain. In addition, parents valued being seen as a member of the healthcare team and as the expert of their child. Conversely, children and their parents reported also feeling judged and misunderstood by health professionals, when receiving healthcare for chronic pain. In addition, they reported that health professionals influenced how they saw themselves, and how others saw them. In some cases, parents reported feeling blamed and shamed by health professionals, for their child's chronic pain.	Moderate confidence	Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy, and Moderate concerns regarding relevance	Brodwall et al. 2018; Brown et al. 2023; Carter 2002; Carter et al. 2002; Dell'Api et al. 2007; Joslin et al. 2021; Joslin et al. 2023; Lee et al. 2023; Lefebvre et al. 2020; Maciver et al. 2011; Neville et al. 2019; Szwimer 2019; Wakefield et al. 2022; Wakefield et al. 2023; Wigley 2002; Adetayo et al. 2026; Joslin & Roberts 2024; Lee et al. 2025; Neville et al. 2025; Lund et al. 2024;
2	**In Canada, the United Kingdom and the United States of America, children and their parents reported that the process of accessing healthcare for chronic pain is frustrating, difficult and negative.** Children and their parents reported that the process of searching for a diagnosis, including repetitive tests & questions and moving between different health professionals constantly, was pointless and that they were over it. In additional, receiving what they perceived as unsuccessful treatment left a negative impact. Some children reported that limited or unsuccessful treatment made them concerned that they had a serious or life threatening illness. Children and their parents reported that dealing with health professionals was difficult and in some cases, traumatic.	Low confidence	Moderate concerns regarding methodological limitations, Minor concerns regarding coherence, Minor concerns regarding adequacy, and Moderate concerns regarding relevance	Carter 2002; Dell'Api et al. 2007; Joslin et al. 2021; Lee et al. 2023; Meldrum et al. 2009; Neville et al. 2019; Nutkiewicz 2008; Wakefield et al. 2022; Wakefield et al. 2023; Wigley 2002; Adetayo et al. 2026; Joslin & Roberts 2024; Lee et al. 2025; Neville et al. 2025; Lund et al. 2024;
3	**In Canada, the United Kingdom and the United States of America, children felt positively that health professionals were doing the best they could.** In some cases, children reported feeling positive about their experiences with health professionals, when accessing healthcare for chronic pain. In addition, some children reflected that some health professionals were probably doing the best job they could, right now, reflecting an acceptance of the healthcare provided.	Low confidence	No/Very minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Serious concerns regarding adequacy, and Minor concerns regarding relevance	Carter et al. 2002; Joslin et al. 2021; Lee et al. 2023; Meldrum et al. 2009; Szwimer 2019; Joslin & Roberts 2024;
4	**In Canada, the United Kingdom and the United States of America, children did not trust health professionals, engaging in protective behaviours during interactions.** Some children experiencing chronic pain reported becoming wary and guarded during interactions with health professionals, to avoid disappointment or being let down, yet again. Some children reported feeling scared of doctors or nervous to report pain to health professionals. For some, they did not want to feel like a burden to the health professional, particularly when reporting pain or struggling to vocalise their experience of living with pain.	Low confidence	Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Serious concerns regarding adequacy, and Minor concerns regarding relevance	Carter 2002; Dell'Api et al. 2007; Lee et al. 2023; Meldrum et al. 2009; Szwimer 2019; Wakefield et al. 2023; Lee et al. 2025; Neville et al. 2025;
5	**In Canada, Norway, the United Kingdom and the United States of America, parents felt they had a responsibility to ensure their child receives the right healthcare.** Parents reported that they needed to fight with health systems and health professionals, to access the right services for their child, and felt this was their responsibility as a parent. Some parents also reflected on the difficult balance of protecting their child, and listening to the health professional recommendations. At times this balance caused parents distress, particularly if treatment recommendations caused an increase in their child's pain (such as physiotherapy).	Moderate confidence	Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy, and Minor concerns regarding relevance	Brodwall et al. 2018; Carter 2002; Joslin et al. 2023; Maciver et al. 2011; Neville et al. 2019; Wigley 2002; Joslin & Roberts 2024; Lee et al. 2025; Neville et al. 2025; Lund et al. 2024;

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Table 3 (*continued*)

#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE-CERQual Assessment	References
6	**In Canada, Norway, the United Kingdom and the United States of America, children and their parents didn't think health professionals understood, or knew what they were doing.** Children and their parents didn't believe that their health professional was helpful or effective and didn't think their health professional knew what they were doing. In addition, even when the health professional was providing a diagnosis or saying they understood, children and their parents reported that they didn't think the health professional actually understood. Some children and their parents reported that they didn't believe in the diagnosis or management plan, and at times, this made them worry that something more serious had been missed. Occasionally, children reported that health professionals tried to fit their pain experience into a template that didn't fit.	Moderate confidence	Minor concerns regarding methodological limitations, Moderate concerns regarding coherence, No/Very minor concerns regarding adequacy, and Minor concerns regarding relevance	Brodwall et al. 2018; Brown et al. 2023; Carter 2002; Carter et al. 2002; Dell'Api et al. 2007; Joslin et al. 2021; Joslin et al. 2023; Lee et al. 2023; Lefebvre et al. 2020; Meldrum et al. 2009; Neville et al. 2019; Nutkiewicz 2008; Szwimer 2019; Wakefield et al. 2022; Wakefield et al. 2023; Wigley 2002; Adetayo et al. 2026; Joslin & Roberts 2024; Lee et al. 2025; Neville et al. 2025; Lund et al. 2024;
7	**In Canada, the United Kingdom and the United States of America, when children and their parents believed in the diagnosis and management plan, they felt they were on the right track, with the right people.** For some children and parents, this meant being treated by specialist providers (such as tertiary pain specialist teams) who were seen as the expert in chronic pain who they could trust. For some, the "right" health professionals were those who listened, validated and worked as a team with the parent and child, to reduce the pain experience. For others, this was receiving a diagnosis or treatment plan that aligned with existing beliefs and expectations regarding pain treatment and relief.	Low confidence	Minor concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Moderate concerns regarding adequacy, and Moderate concerns regarding relevance	Joslin et al. 2023; Lefebvre et al. 2020; Maciver et al. 2011; Meldrum et al. 2009; Neville et al. 2019; Wigley 2002; Adetayo et al. 2026; Joslin & Roberts 2024; Neville et al. 2025;
8	**In Canada, Norway, the United Kingdom and the United States of America, children and their parents had varying preferences & expectations regarding health professional behaviour, treatment pathways, and knowledge.** Children and their parents wanted health professionals to listen to their whole experience, while also being available, present and familiar. Some children and their parents expected health professionals to provide the "right" diagnosis which would lead to pain relief, while also having pre-existing knowledge and information to provide about their condition. Some children specifically expressed hope for future medical appointments, whilst conversely, some children reported that they lowered expectations of health professionals in general.	Low confidence	Moderate concerns regarding methodological limitations, Moderate concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	Brodwall et al. 2018; Brown et al. 2023; Carter 2002; Carter et al. 2002; Dell'Api et al. 2007; Joslin et al. 2021; Joslin et al. 2023; Lee et al. 2023; Lefebvre et al. 2020; Maciver et al. 2011; Meldrum et al. 2009; Neville et al. 2019; Nutkiewicz 2008; Szwimer 2019; Wakefield et al. 2022; Wakefield et al. 2023; Wigley 2002; Adetayo et al. 2026; Joslin & Roberts 2024; Lee et al. 2025; Neville et al. 2025; Lund et al. 2024;
9	**In Canada, the United Kingdom and the United States of America, perceived health professional beliefs about the child's pain experience could be validating, or invalidating.** Children and their parents reported that they felt disbelieved or dismissed by health professionals, and that their health professional did not believe the pain was real. When the health professional used a psychosocial or psychological "label", reinterpreted or misinterpreted their pain narrative, this also made some children and their parents question if the health professional believed in their pain. Some children and their parents reported that their health professional believed their pain was real, and reflected that having a diagnosis proved the pain was real to other health professionals. Some children concealed their symptoms from health professionals, as they thought they wouldn't be believed, or perceived that the health professional thought they were choosing not to change their own pain.	Very low confidence	Moderate concerns regarding methodological limitations, Moderate concerns regarding coherence, No/Very minor concerns regarding adequacy, and Moderate concerns regarding relevance	Carter 2002; Carter et al. 2002; Dell'Api et al. 2007; Joslin et al. 2021; Joslin et al. 2023; Lee et al. 2023; Lefebvre et al. 2020; Maciver et al. 2011; Meldrum et al. 2009; Neville et al. 2019; Nutkiewicz 2008; Szwimer 2019; Wakefield et al. 2022; Wakefield et al. 2023; Wigley 2002; Adetayo et al. 2026; Lee et al. 2025; Neville et al. 2025; Lund et al. 2024;
10	**In Canada, the United Kingdom and the United States of America, children wanted to talk about, and be asked about their pain, on their terms.**	Low confidence	Moderate concerns regarding methodological limitations, Minor concerns regarding coherence, Moderate concerns	Carter 2002; Carter et al. 2002; Dell'Api et al. 2007; Lee et al. 2023; Szwimer 2019; Adetayo et al. 2026; Lee et al. 2025;

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Table 3 (*continued*)

#	Summarised review finding	GRADE-CERQual Assessment of confidence	Explanation of GRADE-CERQual Assessment	References
	Children reported that being asked to rate, describe and talk about their pain experience was challenging and can be repetitive, particularly when being seen by multiple health professionals. Children also identified that it was important for them to be included in conversations about their pain and be given the opportunity to tell their own story, without the pressure of specific medical terminology or frameworks.		regarding adequacy, and Minor concerns regarding relevance	
11	**In Canada, the United Kingdom and the United States of America, health professional communication had mostly negative impacts on the child and parent's pain experience.** Children and their parents reported that poor communication from the health professional impacted their pain experience and journey, resulting in feelings of disconnect and mistrust. They also reported that poor or lacking communication between health professionals themselves, including receiving conflicting information, left a negative impact. Some children specifically reported that health professionals did not listen or talk directly to them, and that comparing them to other children was unhelpful. Some children reported that receiving no information or explanation from health professionals, made them fear the worst.	Moderate confidence	Moderate concerns regarding methodological limitations, Minor concerns regarding coherence, Minor concerns regarding adequacy, and Minor concerns regarding relevance	Carter 2002; Dell'Api et al. 2007; Joslin et al. 2021; Lee et al. 2023; Meldrum et al. 2009; Neville et al. 2019; Nutkiewicz 2008; Szwimer 2019; Wigley 2002; Adetayo et al. 2026; Lee et al. 2025; Neville et al. 2025; Lund et al. 2024;
12	**In Canada, Norway, the United Kingdom and the United States of America, when they felt supported by health professionals, children and their parents felt less alone.** Children and their parents reported that when they felt supported by health professionals, who were caring and interested in them, they felt less alone in their journey. Conversely, some children and parents reported that they felt unsupported and abandoned by health professionals, making them feel alone. A small number of children and their parents felt that their health professional did not care or were uninterested in them.	Moderate confidence	Moderate concerns regarding methodological limitations, Minor concerns regarding coherence, No/Very minor concerns regarding adequacy, and No/Very minor concerns regarding relevance	Brodwall et al. 2018; Carter 2002; Carter et al. 2002; Dell'Api et al. 2007; Joslin et al. 2021; Joslin et al. 2023; Lee et al. 2023; Lefebvre et al. 2020; Maciver et al. 2011; Meldrum et al. 2009; Neville et al. 2019; Nutkiewicz 2008; Szwimer 2019; Wakefield et al. 2023; Wigley 2002; Adetayo et al. 2026; Joslin & Roberts 2024; Lee et al. 2025; Neville et al. 2025; Lund et al. 2024;
13	**In Canada, the United Kingdom and the United States of America, children and parents felt that developing trust with health professionals was difficult.** Children and their parents reported that due to previous medical experiences and interactions with health professionals, they did not trust current or future health professionals. Even when trust was gained, some children and families reported engaging cautiously with health professionals to protect themselves. Children and their parents reported that it was difficult and took time to develop and maintain trusting, authentic relationships with health professionals.	Low confidence	Moderate concerns regarding methodological limitations, No/Very minor concerns regarding coherence, Minor concerns regarding adequacy, and Moderate concerns regarding relevance	Brown et al. 2023; Carter 2002; Dell'Api et al. 2007; Joslin et al. 2021; Joslin et al. 2023; Maciver et al. 2011; Neville et al. 2019; Wakefield et al. 2023; Joslin & Roberts 2024; Lee et al. 2025; Neville et al. 2025; Lund et al. 2024;
14	**In Canada, the United Kingdom and the United States of America, children and parents valued trust in therapeutic relationships.** Children and their parents reported that the foundation of trusting relationships could include validation, effective teamwork, being supported (both emotionally and practically), understanding the diagnosis and being treated as an individual. Children and their parents expressed a feeling of relief, when they could trust health professionals. Some parents reported that they could relax and respond differently as a parent, when they felt the health professional was on their side and understood their child.	Low confidence	Minor concerns regarding methodological limitations, Minor concerns regarding coherence, Moderate concerns regarding adequacy, and Moderate concerns regarding relevance	Carter 2002; Joslin et al. 2021; Joslin et al. 2023; Lefebvre et al. 2020; Maciver et al. 2011; Neville et al. 2019; Joslin & Roberts 2024; Neville et al. 2025;

Children expressed the need to be seen, perceived and treated by health professionals a whole individual person, rather than just being seen as a person with pain.[40,57–59] When health professionals validated their individual experience, children and families reported this as a meaningful turning point in their chronic pain journey,[40,57] and it formed a "solid foundation" for building relationships moving forward.[53,54] When families felt validated and valued, they began to feel hope[56] and relief that they were believed and that "they weren't making it up".[23,39,40,53,55,57,58] Parents felt valued when they were recognised and respected as "an expert of their child"[53] and as knowledgeable and essential contributing members of the healthcare team.[52–54,59]

Participants also reported the negative impact health professional behaviour had on their sense of value and worth. Children and families spoke negatively about experiences with a range of health professionals, including doctors (general practitioners, specialist doctors, paediatricians), nurses and allied health professionals in both tertiary and community settings, particularly in the period before receiving a diagnosis or treatment which reduced chronic pain symptoms.[18,23,39–41,52,54,56–64] Children and their parents felt judged and misunderstood by health professionals,[5,18,23,39,52,56–59,61,62,64] and reported that health professionals did not understand,[56,57] and often brought their own "preconceived notions of pain".[18,39,52] Additionally, participants reported feeling shamed[41,60,63] and blamed[41,54,60,63] by health professionals. Parents felt like they were labelled as "bad parents" if their child's pain did not improve or got worse[41,63] or that they were "wasting precious medical time" by seeking medical care.[63]

Sub-theme 2: New relationships with health professionals are not a blank canvas - they are building on layers of brushstrokes from past experiences

Children and their parent's previous relationships with health professionals impacted the development and expectations of new therapeutic relationships. Families spoke of their experiences accessing healthcare, reporting a never-ending cycle of unsuccessful treatment (nicknamed a "lengthy doctor merry-go-round" by one family[58]), tests and bouncing between health professionals,[17,18,52,58,62–65] and the negative impact this left. They entered new therapeutic interactions feeling frustrated and "over it", with a negative view of health professional input. Every new contact felt like "starting all over again",[52] and children began to feel like health professionals had simply "run out of ideas."[65]

Some children described their past experiences with health professionals as traumatic[52,58,62] and harmful,[64] reflecting on experiences of being mistreated,[57] feeling scared, fearful[40,59] and even "dehumanised" [52]by these interactions. Subsequently, some children reported entering new interactions feeling wary and guarded,[18,52] to protect themselves from health professionals. They "developed ways of protecting themselves by lowering their expectations and being guarded",[18] because of previous experiences. Children reported that they became cautious and sceptical about health professional's ability to help them,[18,52,58,62] and subsequently became withdrawn during interactions with health professionals.[18] Conversely, some children still reported feeling positive about experiences with health professionals,[19,23,39,40] and acknowledged graciously that the health professional was likely doing the best they could.[17,56]

Sub-theme 3: Parents feel the weight of responsibility to protect and advocate for their child, when others can't

This sub-theme represents parental responsibility while accessing healthcare for chronic pain, and how this impacts therapeutic interactions. To advocate for their child within the healthcare system, parents specifically reported their role as needing to "fight" or "battle" with health professionals to access satisfactory treatment for their child.[41,52,54,63,64] When faced with uncertainty or explanations from health professionals felt inadequate, parents reported needing to "assume the responsibility of finding a resolution for the pain",[55,58,60,64] and felt this was part of "being successful in their role as a parent".[55] Some parents described reaching a point of frustration or hopelessness where they turned away from the medical system completely and took "matters into their own hands" to manage their child's pain.[58,64] Finally, parents discussed how difficult it was to balance protecting their child while listening to health professional recommendations,[40,59] particularly if the professional advice or treatment was provoking pain.[40,54,63]

Sub-theme 4: Children, parents and health professionals can flourish together, when they are tending the same garden

This sub-theme represents the family expectations of healthcare experiences, perception of health professional competence and preferences regarding how children and their families want to work as a team with health professionals. These findings were reflected across a range of health professionals, including general practitioners, physicians, "specialist" doctors, nurses and allied health professionals (physiotherapy, psychology), in both community and tertiary settings. Specific types of health professional were not necessarily more highly regarded than others, with some families reporting increased frustration that "specialist" or "expert" health professionals were still not able to help them with diagnosis, treatment or reducing the pain experience.[18,19,52,55,60–65] Instead, children and parents acknowledged individual health professional behaviour, interactions and relationships,[17,19,23,39–41,52–57,59,60,63,65] as well as valuing multidisciplinary tertiary chronic pain health care teams in several studies.[53–55,58,63]

Children and their parents wanted health professionals to talk to about their pain journey[17,18,39,41,52,60,63,65] but it was crucial to feel like the health professional was listening to their story and to feel heard.[17–19,40,41,52–55,57–59,65] It was important to children and their parents to feel like the health professional listened and understood, prior to them reinterpreting their pain story with a professional lens [39,52] or attempting to fit the pain experience into a "preconceived medical mould".[18,58,59] Families expressed that they were seeking a diagnosis which made sense to them, often with the aim of receiving treatment which reduced the child's experience of pain, due to the significant impact the pain had on their lives.[17–19,23,39,41,52–58,60,63–65] Additionally, families wanted health professionals who were knowledgeable and familiar with chronic pain[5,23,40,55–57,61,62] and were available, present and familiar.[17,23,39,41,52,53,60]

Overwhelmingly, participants reported that they didn't feel like their health professional knew what they were doing, causing them to search for the next person who may be able to help or to disengage completely from the process.[5,17–19,23,39,41,52,53,55–65] Even when the health professional was saying they understood or was providing a diagnosis, families perceived or felt "that the clinician is also uncertain about the pain"[55] and still did not understand.[18,19,23,39,41,52,55–58,61,63] This uncertainty in the health professional or diagnosis also drove fears that something more sinister or serious had been missed,[40,57,58] fuelling an "unrelenting search for the 'right' diagnosis and cause of the pain".[55] Alternatively, when families trusted the health professionals' decisions and management, believed in the diagnosis and felt like a valued member of the medical team, they perceived that they were finally "on the right track with the right people".[19,40,41,53–55,57,58,63]

Sub-theme 5: What health professionals choose to do and say influences how the garden grows

This sub-theme conveys the influence of health professional verbal and non-verbal behaviours, and how this is perceived by children and their families, during health care for chronic pain. Families' perceptions of health professional beliefs about the child's pain experience were a significant element in family's narratives. They felt disbelieved, dismissed and minimised by health professionals,[17–19,23,52,55–59,61,62,64,65] and perceived that the health professional did not believe the pain was real.[17–19,23,41,52–58,61–64] Discussion or implication of a psychological component of the pain made some families feel more discomfort and further uncertainty regarding the reality of their child's pain, particularly if they perceived the health professional to be implying the pain was "all in their head".[23,41,52,54,57,59,61,63] Lastly, when health professionals talked about the child's pain experience, it was important that their narrative was not misinterpreted or reinterpreted in a way that no longer aligned with the child and family,[58,59] for example the health

professional articulating their perception of the child's pain experience through their "professional filter" and seeing "the child's pain stemming from friendship problems".[52,65]

Finally, health professional communication during health care for chronic pain impacted the child and parent's experience. Children and their parents reported that their experiences were influenced by good communication with them, but also communication amongst health professionals themselves.[17,18,52,55,56,58,63,65] Receiving conflicting information from different health professionals left a negative impact,[58,59] causing children to become frustrated and "disenchanted".[17,18,23,52] Children reported that their health professional rarely listened or talked directly to them,[57–59,64] despite wanting to be actively involved in the conversation, leaving them "with a strong impression that their perspective was not important".[17,19,52,56] Children found being asked to rate, describe and talk about their pain challenging and at times repetitive,[17,52,56,59] however they had clear preferences to be asked about their pain in a respectful, personalised and appropriate way.[17,18,39,52,57,59] This was echoed by parents, who reported a clear preference for health professionals to talk directly to their children, in a tailored and developmentally sensitive way.[52,59]

Sub-theme 6: Children and parents need to connect with health professionals and trust them, to grow new leaves

The final sub-theme represents child and parent experience of connecting with and trusting health professionals. Feeling connected to and supported by health professionals made families feel less alone, even if health professionals were unable to find a cause for the pain,[18,19,23,39,41,52–54,56–59,62] for example, "most parents indicated the need for a strong support network of healthcare providers in order to cope with the ambiguity and unpredictability of the chronic illness".[53] Children and parents valued health professionals who were caring,[17,39–41,52,56,59,60] helpful[19,56] and interested in them as people, not just interested in their pain.[17,39] Equally, when children and parents felt unsupported by health professionals, this resulted in them feeling isolated, alone, neglected and abandoned by these relationships.[18,19,23,41,53,58,64] At times, health professionals were even perceived as uninterested[17,55,64,65] or as not caring about the child.[19,65]

In addition to connection, families valued and needed to trust their health professionals. Families spoke positively about health professionals who they felt they could trust, or who they perceived as trustworthy,[23,41,52–54,58] and parents specifically reported a sense of relief when they could entrust their child's care to a health care team.[40,41,53] Alternatively, trust in health professionals was often undermined by past experiences,[58,59,64] leading to cautious and guarded interactions,[18,23,41,52,54,55,62] "even when trust in clinicians was expressed".[55] Participants described treating new health professionals with professional mistrust [18,52,62] and reported that while it takes time and effort to build trust in new relationships (and repairing damaged relationships)[5,23,58] this was a "prerequisite to treatment".[40,59]

Discussion

This study explored child and parent perceptions and experiences of working with health professionals during healthcare for chronic pain, focusing on the factors impacting therapeutic interactions, with the aim to enhance provision of healthcare.

To complement and extend the existing literature in this field, our synthesis focused on developing a clinically translatable conceptual model[51] to guide clinicians in enhancing therapeutic interactions and relationships with children experiencing chronic pain and their parents. We found that child and family experiences and expectations of health professionals' change how they engage and interact with health professionals in the future, creating an ongoing cycle that shapes therapeutic interactions in healthcare.[51] Due to this cyclical nature of therapeutic interactions, the aim of this framework is to encourage and guide proactive nurturing of therapeutic interactions by health professionals with a focus on curious reflection.

Our findings extend on an emerging body of high-quality evidence reporting that child and family experiences with the health system but also with individual health professionals, can be challenging and negative[12,24–26] (Finding 2). Previous experiences with health professionals not only had the power to impact future healthcare engagement behaviours from children and their families (Finding 4) but also had the ability to impact the family's intrinsic sense of worth and value (Finding 1). With recent evidence showing that feeling dismissed, invalidated or unsupported by health professionals can negatively impact the child's mental health,[25] it is unsurprising that children protect themselves by being guarded or sceptical in therapeutic relationships or even disengage from healthcare completely.[24,25,64] Likewise, parents reported the complex dynamics and burden of parental advocacy (Finding 5). They felt the responsibility to both protect and advocate for their child within the health system, while simultaneously feeling shamed, blamed, misunderstood and judged by health professionals. Subsequently, it is again unsurprising that parents protect themselves and their children by being compelled to "fight" for appropriate care or take "flight" from health services completely.[64]

The conceptual framework in Fig. 2 [51] recommends strategies that nurture the growth of therapeutic relationships during healthcare for paediatric chronic pain. Children and their parents not only valued connection and trust, but it was a requirement before moving forward (Finding 13, Finding 14). In a recent study by Joslin, Allen and Carter,[12] they found that children and parents placed more importance on relational trust, than trust in technical skills. This finding is echoed across the body of research, with children and their parents consistently seeking trusting and genuinely connected relationships where they are believed, listened to, and seen as an individual[12,24–26] (Finding 12). Linking to trust and connection, children and their parents wanted to be perceived and valued as a member of the multidisciplinary healthcare team, and they had strong preferences for individualised care that was specific to their situation, goals and preferences (Finding 7, Finding 10). These preferences are confirmed across the literature[12,24,25] and highlight the need to perceive the journey as a "joint effort"[12] or as tending the same garden together, rather than separately (as per Fig. 2).

By utilising intentional and reflective verbal and non-verbal communication strategies, health professionals can nurture therapeutic relationships. The perception of health profession communication by the child and their parents had the power to either nurture or damage therapeutic interactions (Finding 1). Some children did feel positively that the health professionals were doing the best they could, and they held hope for future interactions (Finding 3). Overwhelmingly across this body of work and existing research, children and their parents wanted to be actively listened to, supported by and believed by health professionals[12,24–26] (Finding 6, Finding 7, Finding 9). Children valued feeling like they were heard by health professionals and had individual preferences regarding how they wanted to talk about their pain (Finding 10).

The aim of this conceptual framework is to encourage health professionals to approach interactions with children and their parents curiously, rather than replacing pre-existing models of care, such as trauma-informed care. Effective trauma-informed care is often paired with the gold standard of a multidisciplinary team approach to chronic pain care, however, also often requires additional training, support from behavioural or psychology professionals (which mono-disciplinary practitioners may not have access to) and standardised guidelines.[66] This framework provides an easily accessible and translatable tool that clinicians could use to reflect on the child or family experience and ways of nurturing future interactions (even in short interactions), which may positively impact the delivery of future healthcare, including other models of chronic pain care.

Clinical and research implications

This review provides consumer driven findings and factors that

children and their parents perceive to impact therapeutic interactions when engaging with health professionals, presented in an accessible conceptual framework to guide clinical practice[51] (Fig. 2). Firstly, by acknowledging and actively integrating curiosity and acceptance of previous experiences into patient care, health professionals can create opportunities to build new foundations for a more positive future healthcare experience. Secondly, by implementing proactive strategies to nurture therapeutic interactions, there is an opportunity to improve and harness therapeutic interactions as a valued clinical tool, when working with children experiencing chronic pain and their families. To drive reflection, curiosity and individualised pain care, clinicians are encouraged to review the "curious questions for clinicians" which are directly linked to the themes informed by the voices of children and their families. Clinicians may use this conceptual framework as a tool to nurture current and future interactions but also guide further professional and personal development (such as engaging in further training in trauma-informed or chronic pain specific biopsychosocial models of care).

Considering reports of child and parent perceptions of the health profession behaviour (rather than observed health professional behaviour) it may be crucial for health professionals to intentionally seek feedback from children and their parents regarding how they are being perceived during healthcare for chronic pain. Recent evidence shows that health professionals perceived child and parent factors to be both a facilitator and barrier to providing care to children experiencing chronic pain,[67] however didn't necessarily perceive themselves as a barrier to care, despite identifying as needing to develop professionally.[67] Children, parents and health professionals have reported difficulty navigating healthcare for chronic pain, with an emphasis on interactions between the child, parent and health professional triad and the ability to work together as a team. Future research could bring these groups together to collaborate on recommendations regarding how to improve therapeutic interactions, create thriving therapeutic relationships and subsequently improve the child and family experience of receiving healthcare for chronic pain.

Strengths and limitations

A strength of this review is the diversity in the data, including types of chronic pain, age of children and healthcare context. The decision not to limit by chronic pain type, age or context was purposeful; to reflect how crucial therapeutic interactions are across all healthcare contexts. A third (5 out of 14, 36%) of our findings are moderate confidence, as assessed using the GRADE-CERQual approach. The interdisciplinary research team was diverse, with vast experiences and expertise professionally and personally, aiding in deepening reflexivity and clinical relevance (to both health professionals and children and their parents). Additionally, our lived experience co-authors provided key advice and contributions to ensure this review remained grounded as a co-design research project.

There are some limitations of our review process. Evidence syntheses are reliant on the available evidence and its quality. The majority (8 out of 14, 57%) of our findings are low confidence and one (out of 14, 7%) was very low confidence. Additional evidence could increase our confidence in those findings. Due to the narrow focus of our review and associated available evidence, we could not assess our final review question and draw conclusions between different characteristics such as age or gender of the child, type of pain, cultural or ethnic background etc. Additionally, there was a lack of evidence for certain populations, such as children under the age of 10 years old with chronic pain, and children with concurrent primary disabilities such as learning disabilities or physical disabilities. The available data were limited to research in a small number of countries published in English (although we did not limit by language), limiting the global and cultural relevancy of the review findings generally. It is also important to acknowledge that while this review highlights the child and parent experience and perception of therapeutic interactions, we did not collect or assess data on the type or quality of healthcare received. We excluded publications focusing on chronic cancer pain and those which focused on end-of-life pain management, so our results may not apply to those populations.

Conclusion

To the best of our knowledge this is the first qualitative evidence synthesis to focus on children experiencing chronic pain and their parent's perspectives and experiences of working with health professionals, and what impacts therapeutic interactions. Additionally, we developed a novel conceptual framework and understanding of nurturing therapeutic interactions during healthcare for chronic pain. Children and families' experiences and expectations of health professionals change how they engage and interact with health professionals in the future. This flow-on effect forms a cycle of interactions which impacts families' journeys. Therefore, therapeutic interactions need to be consciously nurtured to grow in the future. Health professionals are well placed to practice active acceptance of the prior journey, as well as implementing strategies to proactively improve and nurture therapeutic interactions moving forward.

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Conflict of Interest

The other authors declare no conflict of interest.

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Appendix A. Supporting information

Supplementary data associated with this article can be found in the online version at doi:10.1016/j.jpain.2026.106424.

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