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## Psychological Interventions for Parents of Youth with Chronic Pain: A Scoping Review

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## Abstract

**OBJECTIVE:** Parents are integral to their youth's chronic pain experiences and intervening with parents may improve parent and youth functioning. Existing systematic reviews are not specific to pain, or do not systematically report critical aspects to facilitate implementation of parent interventions in diverse settings. Thus, this scoping review aimed to map published parent interventions for pediatric chronic pain to summarize the participant and intervention characteristics, treatment components, methods, outcomes, feasibility, and acceptability, as well as identify gaps for future research. **METHODS:** Four databases were searched (PubMed, PsycINFO, CINAHL, and Google Scholar). Studies of any design reporting psychological interventions including parents of youth (0-18 years) with chronic pain were included. Data on study characteristics, treatment components, effectiveness, and feasibility/acceptability were extracted. **RESULTS:** Fifty-four studies met inclusion criteria from 9,312 unique titles. The majority were non-randomized Cognitive Behavioral Therapy (CBT) interventions delivered individually. Degree of parent participation ranged from 17-100%; average enrolment rate was 68%. Reported parent and youth outcomes were variable; 26% of studies did not include any parent-related outcomes. **DISCUSSION:** Parent interventions may be a helpful and feasible way to support parents and youth with chronic pain. There is variability across study characteristics, treatment content/aims, parent participation, and parent/youth outcomes.

**Key words:** parents, pediatric chronic pain, psychological intervention, scoping review

Chronic pain is recurrent and/or persistent pain lasting for longer than three months or beyond the expected time for tissue healing [1]. In children and adolescents (herein, ‘youth’), median prevalence rates range from 11-38% worldwide [2], making it a significant health concern. Pediatric chronic pain is also associated with negative effects on daily functioning and quality of life [3]. The management of pediatric chronic pain relies, in part, on bi-directional influences between youth and parents/caregivers (herein ‘parents’) [4]. For example, parent reinforcement of pain behaviors (e.g., increased attention or permission to avoid activities when in pain) may inadvertently reinforce and encourage pain, avoidance, and functional disability [5]. Further, parents commonly report their own reduced quality of life, social/financial stressors, and uncertainty over how to help their youth [6], which may also make it challenging for parents to support their youth’s pain management. Thus, intervening with parents to provide strategies for pain management, and also support parent well-being may be a crucial aspect of pediatric chronic pain management.

Published parent interventions for chronic pain vary widely in therapeutic approach, treatment aims, content, delivery, length, degree of parent participation, and outcomes. Interventions can include Cognitive Behavioral Therapy (CBT) and Acceptance and Commitment Therapy (ACT), although it is currently difficult to know which approaches are most commonly implemented, what the aims are, what skills are targeted, and how clearly these are being reported in the literature. Further, parent interventions differ widely in the degree of parent participation. Some may only include parents passively, such as receiving brief updates of the youth’s progress while others may be specifically developed for and include parents in their own treatment. The latter, or parent-targeted interventions, appear to have positive impacts on parent protectiveness, depressive symptoms, and pain-related psychological flexibility [7, 8], as well as potential positive downstream effects for youth [9]. In addition to varying therapeutic approaches and degree of parent participation, a wide range of parent outcomes have been reported, making it unclear which parent domains are most commonly assessed and provide evidence for the effectiveness of the interventions. To date, the wide

and varied literature on parent interventions for pediatric chronic pain has not yet been comprehensively and systematically mapped, which makes it difficult to understand the participant and intervention characteristics, treatment components and methods, outcomes, and feasibility/acceptability of the interventions that comprise the evidence base.

Three systematic reviews/meta-analyses have reported on randomized controlled trials (RCTs) with parents of youth with chronic pain [10–12], though there are gaps. One did not report any parent data or outcomes [10]. Another focused broadly on family-based interventions for youth with chronic medical conditions (including chronic pain), but data were pooled for intervention type, rather than medical condition, thus making it unclear how results apply to pediatric chronic pain specifically [11]. A separate meta-analysis reported data pooled by medical condition (i.e., chronic pain) and included data on the degree of parent participation, although the review only included fifteen studies for chronic pain [12]. This meta-analysis found evidence for small beneficial effects of psychological interventions on parenting behavior and parent mental health (at post-treatment and follow-up), and no evidence for a beneficial treatment effect on youth behavior/disability, mental health, or pain symptoms in studies that included an active control group [12]. While RCTs are considered the ‘gold standard’ for intervention studies, there are challenges. Since RCTs utilize strict inclusion criteria and specific minimum sample sizes, a large proportion of the current published literature base has not been systematically summarized. Further, heterogeneous treatment effects have been found in RCTs, which reduces the generalizability to diverse healthcare settings (e.g., community-based clinics, healthcare settings in diverse countries and regions, etc.) and patients, and a “one size fits all” approach to interventions for chronic conditions is unlikely to be realistic or feasible [13]. Indeed, recently published guidelines from the World Health Organization (WHO) on the management of pediatric chronic pain identified that the majority of studies included in systematic reviews come from high-income countries (e.g., Canada, United States, Western Europe) [14]. Therefore, additional sources of evidence (i.e., non-randomized studies, case studies) may need

to be consulted to facilitate the implementation of interventions in settings where RCTs may not be feasible. For example, details on the participant and intervention characteristics have not been comprehensively or systematically summarized by existing systematic reviews and drawing from a larger evidence base including non-randomized studies may provide meaningful guidance for diverse healthcare settings.

Scoping reviews utilize rigorous methods to systematically map the available evidence on a specific concept, and are recommended particularly when the literature base is vast and heterogeneous [15]. Scoping reviews aim to clarify the breadth and depth of the existing literature base, identify key characteristics and types of evidence, summarize the evidence, and identify gaps to inform future research. Further, study designs beyond RCTs are included, which can be valuable for informing evidence-based healthcare, particularly when implementing RCTs is not feasible. Thus, scoping reviews provide an overview of the existing literature on a concept, which can inform future research designs and treatment implementation in practice [15].

The published literature on parent interventions for pediatric chronic pain is varied and heterogeneous and has not been fully summarized. Information regarding the participant and intervention characteristics, methods, and outcomes has not been systematically reported. Thus, a scoping review was undertaken to provide a comprehensive overview of parent interventions for pediatric chronic pain, as well as provide greater breadth to the literature by including non-randomized studies, and greater depth by providing a summary of intervention characteristics and methods, outcomes, and feasibility/acceptability.

## **Literature Search Methods**

### **Protocol, and Registration**

A scoping review was conducted in consideration of the extent and heterogeneity of the current literature base on parent interventions for pediatric chronic pain. A scoping review protocol

was drafted a priori in accordance with published guidelines [16] and registered prospectively on May 10, 2019 (<https://osf.io/psx8k/>).

### **Eligibility Criteria**

English language peer-reviewed articles that reported original data of any design and sample size were included. Studies must have included parents of youth with chronic pain (defined as pain lasting  $\geq 3$  months); youth were defined as aged 0-18 years. Studies with a mixed population older than 18 years were included if those individuals were being treated in the same pediatric clinical setting. Parents were any primary caregiver who adopted the role of parenting the youth (e.g., biological parents, guardians). The intervention must have included an interactive parent component, and been designed to change parents' cognitions, behaviors, and/or emotions/affect, with the intention of improving parent or child outcomes [12]. Given that the aim of this scoping review was to map and summarize the current published literature on parent interventions for pediatric chronic pain, a minimum duration of parent participation was not set, in order to capture the full evidence base. Studies that included non-human participants, reported on pain associated with cancer or other life threatening diseases, or involved parents passively (e.g., providing information to read at home, brief progress updates) were excluded. Review papers, commentaries, book chapters, theses/dissertations, and conference abstracts were also excluded.

### **Search Strategy**

PubMed, PsycINFO, CINAHL, and Google Scholar were searched on May 23, 2019 using an a priori search strategy to identify relevant articles. No limits were set on publication year, to include as many articles as possible. Search strategies were based on previously published systematic reviews, and further refined through discussion with experienced librarians and amongst co-authors. Search strategies were tailored to each database and comprised a combination of key terms related to parents (e.g., *parent, caregiver, mother, father*), youth (e.g., *child, teenager, pediatric*), chronic pain

(e.g., *pain, headache, abdominal pain*), and psychological interventions (e.g., *CBT, psychotherapy, parenting program*).

Given that Google Scholar only allows a search string of 256 characters, a search string was adapted based on the terms used in the other databases. The symbol “|” indicates “OR” and spaces between terms represent “AND”. Search terms were piloted until the maximum number of results were returned, resulting in the following search string: parent|caregiver|family child|adolescent|youth|pediatric|infant|juvenile "chronic pain"|headache|"abdominal pain"|arthritis|CRPS|"inflammatory bowel"|fibromyalgia|"sickle cell" psychological|CBT|acceptance|problem-solving intervention|treatment|therapy (see Data File, Supplemental Digital Content 1, for complete search terms in each database).

### **Study Selection**

Search results were exported into EndNote, with  $n=9,312$  articles remaining after duplicates were removed. Title and abstract screening based on the eligibility criteria (e.g., studies including parents of youth with chronic pain who participated in a psychological intervention) was conducted independently by the lead author (SL) and a trained research assistant for all identified studies (interrater reliability=81%); disagreements were resolved via consensus among reviewers. One hundred sixty-two articles were assessed for full-text review. Full-text screening involved assessing the eligibility for inclusion for each article and was led by the lead author (SL) and double checked by one of two trained research assistants. Disagreements were checked, reviewed, and resolved by the lead author. Ultimately, 54 articles met criteria and were included in the final review (Figure 1).

### **Data Charting**

Cross-referencing the protocol, a standardized data extraction sheet was developed (SL) and reviewed (CMM) prior to charting the data. The extraction sheet captured information on a) participant characteristics (e.g., age, gender, ethnicity of youth and parents; pain condition; inclusion and exclusion criteria), b) treatment components and methods of psychological interventions that



included parents (e.g., therapeutic approach, aims, content, treatment activities, method of delivery, study design, degree of parent participation, who administered the intervention); b) effectiveness of the intervention (e.g., quantitative and qualitative outcomes assessed, time points of assessment, key results); and c) when applicable, feasibility and acceptability of parent interventions (e.g., referral process, recruitment and enrolment rates, adverse events). Some data were extracted in an open-ended format (e.g., treatment aims and content, outcomes assessed and sources, key findings), and some were extracted in a closed ended yes/no format (e.g., adverse events reported, homework between sessions, booster sessions, mindfulness/relaxation practice, etc.) (see Data File, Supplemental Digital Content 2, for extraction items). The data extraction sheet and extracted data for included studies are available upon request from the author. To map the current published research literature, authors were not contacted for clarification on data that were not clearly reported. Following established recommendations on conducting a scoping review, a quality/risk of bias assessment was not conducted [15].

## **Results**

See Table 1 for included studies, citations, and a summary of participant and study characteristics, treatment components, outcomes, and key findings; see Figure 2 for a map of select results. Included articles were published between 1989-2019, with the majority published since 2010 (76%). Of the 54 included articles, 10 articles published findings using the same sample, so only unique data were extracted for these studies. Counting for unique participant samples, only ( $n=44$ ) results were drawn from 2,519 youth, with an average of 73% girls and 27% boys, and an age range of 5-20 years. Most studies included youth with chronic pain broadly (56.8%,  $n=25/44$ ), with a smaller proportion including only youth with abdominal pain (18.2%,  $n=8/44$ ), headache (9.1%,  $n=4/44$ ), fibromyalgia (9.1%,  $n=4/44$ ), musculoskeletal pain (2.3%,  $n=1/44$ ), juvenile arthritis (2.3%,  $n=1/44$ ), and non-cardiac chest pain (2.3%,  $n=1/44$ ). Race/ethnicity were not reported in almost half of the studies (45%,  $n=20/44$ ); when reported, youth participants were primarily identified as White

(89%, range: 78-100%). Only 50% of studies reported the number of participating parents ( $n=1,073$ ), and only 25% ( $n=11/44$ ) specified the parent's relationship to the child, which was predominately mothers (84%,  $n=391/463$ ). Most studies were non-randomized (57%,  $n=25/44$ ), followed by RCTs (36%,  $n=16/44$ ), and case studies (7%,  $n=3/44$ ). All studies reported quantitative data, and a small number included qualitative data (15.5%;  $n=9/54$ ).

Common inclusion criteria related to youth included a chronic pain diagnosis, specific age range, English language speaking/reading/writing, and experience of pain interference on activities. Common exclusion criteria for youth included no significant cognitive/developmental delays or psychopathology, and no comorbid chronic health condition or organic cause for the pain. Only three studies reported inclusion or exclusion criteria specific to parents, which were exclusions related to parental cognitive delays or active psychosis/suicidal ideation. All parents were referred to the intervention as part of their youth's treatment program from a pediatric chronic pain clinic or other speciality medical clinic (e.g., pediatric gastroenterology). One-third of the studies did not specify exclusion criteria for parents or youth (36%,  $n=16/44$ ).

The most common therapeutic approach was CBT (59%,  $n=26/44$ ), followed by ACT (14%,  $n=6/44$ ), problem solving skills therapy (PSST; 7%,  $n=3/44$ ), or an eclectic/mixed approach (5%,  $n=2/44$ ). Four studies reported other approaches including mindfulness-based therapy (5%,  $n=2/44$ ), art therapy (2%,  $n=1/44$ ), and behavioral family systems therapy (2%,  $n=1/44$ ), and three studies (7%) did not clearly specify. Specific treatment activities for parents were extracted (i.e., homework, mindfulness, relaxation, problem-solving, vignette/case studies, role plays, debrief with youth, booster sessions, other [specify]), and these are summarized in Table 1. Of note, almost a quarter of studies (22.7%,  $n=10/44$ ) did not clearly report what parents did as a part of the intervention. Only eight (18%) studies reported parent-only interventions (i.e., treatment programming offered to parents independent of their youth's treatment), and the remainder (82%,  $n=36/44$ ) described parent participation as part of a youth's treatment program, with the degree of participation ranging from

17-100% of sessions (Table 1). Of the parent-targeted interventions, one study was CBT, two were ACT, three were PSST, one was art therapy, and one was a self-guided mindfulness intervention; seven of 8 studies were non-randomized and one was an RCT (Table 1). Most interventions were delivered by a psychologist or senior psychology trainee (68%,  $n=30/44$ ). Seven studies (16%) did not clearly report who administered the intervention, five studies (11%) reported clinicians from other fields/levels of training (e.g., general pediatrician, social workers), and two studies (5%) utilized a self-guided approach that did not include clinicians. Interventions were mainly delivered individually (61%,  $n=27/44$ ), followed by group (23%,  $n=10/44$ ), and mixed format (16%,  $n=7/44$ ). Most interventions were in-person (80%,  $n=35/44$ ), followed by telephone, web-based, or videoconferencing (20%,  $n=9/44$ ).

Outcome domains and distributions are in Figure 3 and Figure 4. Out of all included studies with extractable data ( $n=54$ ), 50 (91%) assessed and reported youth outcomes. Fourteen studies (26%) reported on youth outcomes only and did not report any parent outcomes. Of the 40 studies that included parent-reported outcomes, 8 studies (20%) only assessed parent-reported youth outcomes (i.e., no outcomes for parents). The most commonly reported outcome was youth reported pain intensity (74%,  $n=40/54$ ), followed by youth reported functional disability (51.9%,  $n=28/54$ ). The most reported parent domains were protectiveness (27.8%,  $n=15/54$ ), treatment evaluation (22.2%,  $n=12/54$ ), depression (14.8%,  $n=8/54$ ), and pain catastrophizing (13.0%,  $n=7/54$ ). Of note, some studies (e.g., [7, 17, 18]) reported on the same outcomes across more than one study, though presenting different results (e.g., comparisons between groups, follow-up data). Over half of the studies included follow-up assessments (range: 1-12 months; 58%,  $n=32/54$ ; Table 1).

Twenty-nine (54%) out of fifty-four studies reported enrolment data (those eligible to participate vs. those who participated), with the mean enrolment rate across these studies being 68% (range: 20-100%). Feasibility and acceptability were reported in 19/54 (35%) studies, and assessments of feasibility/acceptability included rating scales, standardized questionnaires, and open-

ended questions. Overall, parents reported feeling satisfied and that the interventions were acceptable (Table 1). Three studies (7%) out of forty-four reported adverse events (1 unrelated to the study), 14 (32%) reported no adverse events, and 27 (61%) studies did not clearly report adverse events.

## **Discussion**

The aim of this scoping review was to map and summarize the current published literature on parent interventions for pediatric chronic pain. Previous systematic reviews and meta-analyses [10–12] have only included RCTs, which excluded more than half of the studies (63%) in this review. Thus, this scoping review adds breadth and depth to the literature by mapping and summarizing the available evidence base on parent interventions for pediatric chronic pain including participant and intervention characteristics, treatment components and methods, outcomes, and feasibility/acceptability. See Figure 2 for an overview map of select results from studies included in this review. Further, one of the aims of this scoping review was to highlight gaps in the literature and opportunities for future research (Table 2). Thus, gaps and areas for future research will be discussed within the context of the results throughout the discussion.

Most published parent interventions for chronic pain are individual, CBT-based, and in-person. One study compared individual to group treatment and found no differences for any outcomes assessed [19]. However, open-ended questions identified that parents find social support to be a positive aspect of a group intervention [20–26]. Further, parents enjoyed the flexibility of online interventions [27, 28], though very few studies in this review were virtually delivered in this review. Virtual interventions for chronic pain have become necessary in the wake of Covid-19 [29], and virtual parent groups for other childhood conditions such as Attention-Deficit Hyperactivity Disorder (ADHD) have been implemented with similar fidelity and satisfaction as in-person group interventions [30]. Future research examining group and/or virtual parent interventions using comparison/control groups (e.g., individual vs. group, in-person vs. virtual), is needed to optimize intervention delivery, efficiency, and effectiveness. Further, only two studies reported intervention

using a self-guided approach that did not require facilitation by a psychologist/therapist (i.e., online, mobile app) [27, 31]. More research on self-guided interventions for parents is needed and may be helpful particularly in settings where interventions needing trained therapists/psychologists is not feasible (Table 2 [A]).

Participant characteristics, intervention components, and methodologies varied or were not clearly reported. Youth age and pain conditions varied widely and indicated some gaps in the literature. No study included youth younger than 5 years and only 7 (16%) included youth less than 8 years; this gap may reflect that: chronic pain in infants and young children may be less well understood [32], these patients are not commonly referred for services, or the prevalence of chronic pain in very young children may be lower. Further, four studies included youth who were >18 years old yet were treated in a pediatric clinical setting [23, 33–35]. Given differing developmental demands and expectations, it is possible that the aims, degree of parent participation, and targeted outcomes for parents of older youth/adolescents may be different compared to interventions for parents of younger youth, and this is also an area for future research (Table 2[B]). Participants were predominantly White and demographic data on race and/or ethnicity were missing for nearly half of the studies. This is a critical gap that highlights the need to extend our current research base to youth and families of diverse backgrounds (including in race and ethnicity), and the current limits of generalizability of the current evidence base. Moreover, only 50% of studies reported the number of participating parents, and 75% did not specify the parent's relationship to the child. Although participating parents were predominantly mothers in the studies that reported this information, the lack of data make it challenging to know if and how many other caregivers have participated in these studies. The preponderance of mothers may be unsurprising as caregiving duties for youth with chronic illnesses often fall to mothers [36], and mothers of youth with chronic pain report poorer functioning than fathers [37]. However, including both caregivers in pediatric chronic pain treatment may have benefits [38], suggesting that efforts to include all caregivers involved in the youth's care

and pain management may be important. Thus, there is a need for greater transparency when reporting parent demographics, as well as more inclusive recruitment and methodologies that reflect more diverse caregivers (Table 2[C]).

Treatment activities for parents (e.g., homework, which skills were practiced and how) were not clearly reported for nearly 25% of the included studies. Therefore, in addition to clearer reporting of the participants who comprise the evidence base, it is crucial that studies clearly report treatment aims, content, and methods to facilitate the translation of research into practice. The challenge of implementing psychological intervention research into clinical practice has been documented, and it has been found that most intervention studies do not report the information necessary for clinicians and stakeholders to understand how to implement the intervention in their own settings [39]. There are many potential ways to support the translation of research into clinical practice; as a first step, more detailed and accessible reporting of the interventions and its related components can help guide decision making by clinicians [39]. Additionally, journals and/or reviewers may encourage this via the use of specific reporting guidelines for intervention studies, including non-randomized designs (Table 2[D]).

The degree of parent participation varied widely across studies (17-100%). Given the wide range of youth and parent-reported outcomes that were assessed in the studies included in this review, as well as the exploratory nature of the scoping review, it is difficult to know whether the degree of parent participation plays a role in the effectiveness of a parent intervention, and the ideal “dose” of parent intervention that provides the most optimal outcomes. This may be a research question of particular interest for a future systematic review/meta-analysis. Further, it is possible that the ‘dose’ of intervention that is optimal depends upon the aim of the intervention (e.g., and intervention solely focused on behavioral change and reducing protective behaviors may require less time than one aimed to also increase parent well-being and reduce distress). Clearly reporting on the aims of the parent intervention, as well as conducting an economic/cost-benefit analysis of

interventions may inform future efforts to develop/tailor relatively brief and optimal interventions that can be feasibly delivered across a wide range of settings and participants. Further, only 8 studies in this review reported on interventions that were parent-targeted; these studies reported interventions using a range of therapeutic approaches (i.e., CBT, ACT, PSST, art therapy, mindfulness-based), and only one study was an RCT [9]. The relative lack of parent-targeted interventions may not be surprising given that all of the participants in the included studies were recruited/referred from pediatric specialty clinics. Thus, further research including parents of youth with chronic pain from more diverse settings may be important to understand the treatments needs of parents whose youth do not or cannot access these specialty clinics (Table 2[E]).

The most assessed parent outcomes were protectiveness, depressive symptoms, and catastrophizing. This is in line with theoretical frameworks (e.g., Pediatric Fear Avoidance Model of Chronic Pain) [40] and the aim of CBT, which is to target maladaptive parent behaviors and cognitions. It is promising that improvements in protectiveness, depressive symptoms, and catastrophizing were found post-treatment in this review (Table 1). However, the pool of studies reporting on these outcomes are small (15/54 for protectiveness, 8/54 for depressive symptoms, 7/54 for catastrophizing), and 25% did not include any parent outcome measures. Further, parent treatment evaluation was the second most assessed outcome, rather than a parent-specific outcome domain (e.g., depressive symptoms, quality of life, etc.). Thus, given the number of published studies on parent interventions for pediatric chronic pain, relatively less is known about the impacts on parent outcomes following the intervention. Brief registry assessment measures (e.g., PROMIS scales) may be a time-efficient option posing relatively little participant burden. Further, patient-oriented research that considers parent perspectives in research, knowledge translation, and practice [41], and assesses parent outcomes using a range of methodologies (e.g., quantitative, qualitative, youth-perspective, behavioral observations) will be important (Table 2[F]).

There are additional gaps and potential avenues for future research. First, only two studies in this review reported the use of booster sessions in treatment, although it is unclear if these booster sessions were offered only to youth or included parents as well [42, 43]. Parents expressed a desire for booster sessions when asked in open-ended formats [21, 24, 28]. A review of CBT interventions for youth with mood and/or anxiety disorders found that interventions with booster sessions appear to be more effective and sustain improvements compared to interventions without [44]. More research is needed to better understand when and how to deliver booster sessions and what content to provide, and this may be particularly valuable to consider for outcomes for which improvements are not maintained at follow-up (Table 2[G]).

Second, all participants in this review were referred/recruited from chronic pain/specialty clinics, and thus the current research base is not representative of all youth who may experience chronic pain. Differences between healthcare systems among countries, as well as systemic impacts related to sociodemographic factors such as household income, race, and class have been associated with healthcare access [45, 46]; therefore, it is vital to actively extend this research beyond families who present to pain/medical clinics by focusing on other opportunities such as community and school-based recruitment. Further, there is potentially an important role for primary care in providing earlier screening and intervention for pediatric chronic pain [47]. Future development and evaluations of integrated, brief, evidence-based interventions for youth and parents within primary care may be important.

Thirdly, in addition to the degree of parent participation, it is possible that other parent factors may moderate some treatment outcomes. For example, given that parental diagnostic uncertainty has been associated with more adverse consequences on youth pain intensity, interference, and quality of life [48], parent interventions aimed to reduce diagnostic uncertainty may be beneficial. However, it is also possible that parents who express a high degree of diagnostic uncertainty may be less open to the treatment aims of many pediatric chronic pain interventions (i.e.,



focus on returning to daily activities rather than reducing the pain). Thus, future research examining the role of parental diagnostic uncertainty on intervention outcomes may be important to tailor the delivery and/or timing of interventions for certain parents. Additionally, chronic pain tends to run in families, and the parent's own history of chronic pain may impact how the parent is likely to respond to their youth's pain [49, 50], which may be an important consideration for treatment. Examining the impact of parental chronic pain on pediatric chronic pain management, as well as the effectiveness of intervention components such as parent modelling and self-care strategies may be important avenues for future research.

This review must be considered within the context of some limitations. The stringent inclusion criterion of pain lasting for  $\geq 3$  months excluded many studies on chronic medical conditions (e.g., sickle cell disease, inflammatory bowel disease). While this decision was made in order to have greater consistency within included studies, it is likely that some studies may have had interesting and valuable information on parent interventions that are not represented in this review. Authors were also not contacted for follow-up when data were not clearly reported. This decision was made in order to map the existing published literature as it is reported, but also led to missing information, particularly related to demographics and intervention components.

### **Conclusion**

Parents play important roles in their youth's chronic pain and can benefit from interventions aimed to help them support their youth. There is a growing body of literature on parent interventions for pediatric chronic pain, which are primarily CBT, delivered individually, and in person. Research comparing treatment formats, assessing specific parent outcomes using a range of methodologies, and considering alternative avenues for recruitment and early intervention will be important to address existing gaps.

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## References

- [1] Treede R-D, Rief W, Barke A, et al. A classification of chronic pain for ICD-11. *Pain* 2015; 156: 1003–7.
- [2] King S, Chambers CT, Huguet A, et al. The epidemiology of chronic pain in children and adolescents revisited: a systematic review. *Pain* 2011; 152: 2729–38.
- [3] Gold JI, Yetwin AK, Mahrer NE, et al. Pediatric chronic pain and health-related quality of life. *J Pediatr Nurs* 2009; 24: 141–50.
- [4] Palermo TM, Valrie CR, Karlson CW. Family and parent influences on pediatric chronic pain: a developmental perspective. *Am Psychol* 2014; 69: 142–52.
- [5] Gatzounis R, Schrooten MGS, Crombez G, et al. Operant Learning Theory in Pain and Chronic Pain Rehabilitation. *Curr Pain Headache Rep* 2012; 16: 117–126.
- [6] Jordan A, Jaaniste T. Parenting in the context of pediatric pain. In: Wainwright E, Eccleston C (eds) *Work and pain: a lifespan developmental approach*. Oxford University Press, 2019.
- [7] Palermo TM, Law EF, Fales J, et al. Internet-delivered cognitive-behavioral treatment for adolescents with chronic pain and their parents: A randomized controlled multicenter trial. *Pain* 2016; 157: 174–185.
- [8] Wallace DP, Woodford B, Connelly M. Promoting psychological flexibility in parents of adolescents with chronic pain: Pilot study of an 8-week group intervention. *Clin Pract Pediatr Psychol* 2016; 4: 405–416.
- [9] Palermo TM, Law EF, Bromberg M, et al. Problem-solving skills training for parents of children with chronic pain: a pilot randomized controlled trial. *Pain* 2016; 157: 1213–1223.
- [10] Palermo TM, Eccleston C, Lewandowski AS, et al. Randomized controlled trials of psychological therapies for management of chronic pain in children and adolescents: An updated meta-analytic

- review. *Pain* 2010; 148: 387–397.
- [11] Law EF, Fisher E, Fales J, et al. Systematic Review and Meta-Analysis of Parent and Family-Based Interventions for Children and Adolescents With Chronic Medical Conditions. *J Pediatr Psychol* 2014; 39: 866–886.
- [12] Law E, Fisher E, Eccleston C, et al. Psychological interventions for parents of children and adolescents with chronic illness. *Cochrane Database Syst Rev*; 3. Epub ahead of print 2019. DOI: 10.1002/14651858.CD009660.pub4.
- [13] Shaffer JA, Falzon L, Cheung K, et al. N-of-1 randomized trials for psychological and health behavior outcomes: a systematic review protocol. *Syst Rev* 2015; 4: 87.
- [14] World Health Organization. *Guidelines on the management of chronic pain in children*. Geneva, 2020.
- [15] Peters MDJ, Marnie C, Tricco AC, et al. Updated methodological guidance for the conduct of scoping reviews. *JBI Evid Synth* 2020; 18: 2119–2126.
- [16] *Methodology for JBI Scoping Reviews*. 2015.
- [17] Fisher E, Bromberg MH, Tai G, et al. Adolescent and Parent Treatment Goals in an Internet-Delivered Chronic Pain Self-Management Program: Does Agreement of Treatment Goals Matter? *J Pediatr Psychol* 2017; 42: 657–666.
- [18] Law EF, Fisher E, Howard WJ, et al. Longitudinal change in parent and child functioning after internet-delivered cognitive-behavioral therapy for chronic pain. *Pain* 2017; 158: 1992–2000.
- [19] Kanstrup M, Wicksell RK, Kemani M, et al. A Clinical Pilot Study of Individual and Group Treatment for Adolescents with Chronic Pain and Their Parents: Effects of Acceptance and Commitment Therapy on Functioning. *Child* 2016; 3: 30.

- [20] Armbrust W, Bos JFFJ, Cappon J, et al. Design and acceptance of Rheumates@Work, a combined internet-based and in person instruction model, an interactive, educational, and cognitive behavioral program for children with juvenile idiopathic arthritis. *Pediatr Rheumatol Online J* 2015; 13: 31.
- [21] Logan DE, Simons LE. Development of a group intervention to improve school functioning in adolescents with chronic pain and depressive symptoms: a study of feasibility and preliminary efficacy. *J Pediatr Psychol* 2010; 35: 823–836.
- [22] Merlijn VP, Hunfeld JA, van der Wouden JC, et al. A cognitive-behavioural program for adolescents with chronic pain-a pilot study. *Patient Educ Couns* 2005; 59: 126–134.
- [23] Wiertz C, Goossens M, Spek EM, et al. A cognitive-behavioral program for parents of children with chronic musculoskeletal pain; A feasibility study. *Eur J Pain* 2017; 21: 1571–1581.
- [24] Huestis SE, Kao G, Dunn A, et al. Multi-Family Pediatric Pain Group Therapy: Capturing Acceptance and Cultivating Change. *Child* 2017; 4: 106.
- [25] Pielech M, Sieberg CB, Simons LE. Connecting parents of children with chronic pain through art therapy. *Clin Pract Pediatr Psychol* 2013; 1: 214–226.
- [26] Ruskin D, Campbell L, Stinson J, et al. Changes in Parent Psychological Flexibility after a One-Time Mindfulness-Based Intervention for Parents of Adolescents with Persistent Pain Conditions. *Child*; 5. Epub ahead of print 2018. DOI: 10.3390/children5090121.
- [27] Nieto R, Hernández E, Boixadós M, et al. Testing the feasibility of DARWeb: An online intervention for children with functional abdominal pain and their parents. *Clin J Pain* 2015; 31: 493–503.
- [28] Law EF, Fales JL, Beals-Erickson SE, et al. A Single-Arm Feasibility Trial of Problem-Solving Skills Training for Parents of Children with Idiopathic Chronic Pain Conditions Receiving

- Intensive Pain Rehabilitation. *J Pediatr Psychol* 2016; 42: 422–433.
- [29] Eccleston C, Blyth FM, Dear BF, et al. Managing patients with chronic pain during the COVID-19 outbreak: considerations for the rapid introduction of remotely supported (eHealth) pain management services. *Pain* 2020; 161: 889–893.
- [30] Fogler JM, Normand S, O’Dea N, et al. Implementing Group Parent Training in Telepsychology: Lessons Learned During the COVID-19 Pandemic. *J Pediatr Psychol* 2020; 2020: 1–7.
- [31] Seidman LC, Martin SR, Trant MW, et al. Feasibility and Acceptance Testing of a Mobile Application Providing Psychosocial Support for Parents of Children and Adolescents With Chronic Pain: Results of a Nonrandomized Trial. *J Pediatr Psychol*. Epub ahead of print 2019. DOI: 10.1093/jpep/jsz007.
- [32] DiLorenzo M, Pillai Riddell R, Holsti L. Beyond Acute Pain: Understanding Chronic Pain in Infancy. *Children* 2016; 3: 26.
- [33] Degotardi PJ, Klass ES, Rosenberg BS, et al. Development and evaluation of a cognitive-behavioral intervention for juvenile fibromyalgia. *J Pediatr Psychol* 2006; 31: 714–723.
- [34] Gauntlett-Gilbert J, Connell H, Clinch J, et al. Acceptance and values-based treatment of adolescents with chronic pain: Outcomes and their relationship to acceptance. *J Pediatr Psychol* 2012; 38: 72–81.
- [35] Pielech M, Wallace DP, Fitzgerald M, et al. Parent Responses to Child Pain During Intensive Interdisciplinary Pain Treatment and 1-Year Follow-Up. *J Pain* 2018; 19: 1275–1284.
- [36] Cousino MK, Hazen RA. Parenting Stress Among Caregivers of Children With Chronic Illness: A Systematic Review. *J Pediatr Psychol* 2013; 38: 809–828.
- [37] Benjamin JZ, Harbeck-Weber C, Sim L. Pain is a family matter: Quality of life in mothers and fathers of youth with chronic pain. *Child Care Health Dev* 2019; 45: 440–447.

- [38] Donado C, Turrisi T, Wihak T, et al. Differences between Mothers' and Fathers' Perception of Their Adolescents' Pain before and after Parent Training Through the Comfort Ability Pain Management Program. *J Dev Behav Pediatr* 2019; 40: 716–724.
- [39] Bharathy P, Lewis Jr. NA. Do We Report the Information that is Necessary to Give Psychology Away? A Scoping Review of the Psychological Intervention Literature 2000-2018. *Perspect Psychol Sci*, <https://psyarxiv.com/nr8kh> (2020, accessed 18 September 2020).
- [40] Asmundson GJG, Noel M, Petter M, et al. Pediatric fear-avoidance model of chronic pain: foundation, application and future directions. *Pain Res Manag J Can Pain Soc = J la société Can pour le Trait la douleur* 2012; 17: 397–405.
- [41] Amirav I, Vandall-Walker V, Rasiah J, et al. Patient and researcher engagement in health research: A parent's perspective. *Pediatrics*; 140. Epub ahead of print 1 September 2017. DOI: 10.1542/peds.2016-4127.
- [42] Kashikar-Zuck S, Ting T V, Arnold LM, et al. Cognitive behavioral therapy for the treatment of juvenile fibromyalgia: A multisite, single-blind, randomized, controlled clinical trial. *Arthritis Rheum* 2012; 64: 297–305.
- [43] Law EF, Wan Tham S, Aaron R V, et al. Hybrid Cognitive-Behavioral Therapy Intervention for Adolescents With Co-Occurring Migraine and Insomnia: A Single-Arm Pilot Trial. *Headache* 2018; 58: 1060–1073.
- [44] Gearing RE, Schwalbe CSJ, Lee R, et al. The effectiveness of booster session in CBT treatment for child and adolescent mood and anxiety disorders. *Depress Anxiety* 2013; 30: 800–808.
- [45] Toliver-Sokol M, Murray CB, Wilson AC, et al. Patterns and predictors of health service utilization in adolescents with pain: Comparison between a community and a clinical pain sample. *J Pain* 2011; 12: 747–755.

- [46] Green CR, Anderson KO, Baker TA, et al. The unequal burden of pain: Confronting racial and ethnic disparities in pain. *Pain Med* 2003; 4: 277–294.
- [47] Salamon KS, Cullinan CC. The integrated prevention model of pain-Chronic pain prevention in the primary care setting. *Clin Pract Pediatr Psychol* 2019; 7: 183–191.
- [48] Neville A, Jordan A, Pincus T, et al. Diagnostic uncertainty in pediatric chronic pain: nature, prevalence, and consequences. *PAIN Reports* 2020; 5: e871.
- [49] Wilson AC, Fales JL. Parenting in the context of chronic pain: a controlled study of parents with chronic pain. *Clin J Pain* 2015; 31: 689–98.
- [50] LM F, C S, AL H, et al. Parent chronic pain and mental health symptoms impact responses to children’s pain. *Can J pain = Rev Can la douleur* 2018; 2: 258–265.



## Figure Legend

Figure 1. PRISMA-ScR Flow Diagram of Study Selection.

Figure 2. Select results on published parent intervention for pediatric chronic pain included in this review.

Figure 3. Frequency distribution of youth outcomes assessed by self or parent proxy report (parent report denoted in brackets;  $n=54$ ).

Figure 4. Frequency distribution of parent domains assessed (total sample:  $n=54$ ; sample of studies that assessed parent outcomes:  $n=29$ ).

## List of Supplemental Digital Content

Supplemental Digital Content 1.doc [search terms in each database]

Supplemental Digital Content 2.pdf [extraction items]

Table 1. Participant and study characteristics, treatment components, outcomes, and key findings presented in alphabetical order of first author’s last name within therapeutic orientation clusters

Authors, Year	Youth age range, (Mean/Median [SD]), primary pain condition	Youth (n), Parent (n) <i>Targeted participants</i>	Study Design (Tx groups, if applicable)	Aim(s) of Parent Intervention	Reported Tx Activities	Length of Youth Tx, Length of Parent Tx (% Parent Participation)	Assessment Periods	Selected Key Findings
<b>Cognitive Behavioral Therapy (CBT)</b>								
Armbrust et al., 2015  <i>The Netherlands</i>	8-13 (Mean: 10.0 [1.4])  Juvenile Idiopathic Arthritis	64, NR  <i>Youth, parents optional</i>	Non-randomized (tx vs. waitlist)	1. Psychoeducation, encourage physical activity 2. Explore burdens of having a youth with juvenile idiopathic arthritis	NR	14 hrs, 4 hrs (28.6%)	Pre, post	<u>Parent-report (self):</u> <i>Positive aspects: “children experienced they were not the only ones with arthritis and it helped talk about it”, “peer contact”, “receive education and information”, “share experiences and receive tips”. Areas for improvement: “More involvement of parents during program”, “fewer group sessions” (open-ended questionnaires)</i> <u>Feasibility/Acceptability:</u> 75% of the parents reported they had learned something, and 95% felt their child had learned something. 97% of parents were satisfied and liked the peer support.
Coakley et al., 2018  <i>United States</i>	10-17 (Mean: 13.9 [2.0])  Chronic Pain	102, 105  <i>Youth, parents</i>	Non-randomized	1. Introduce biopsychosocial model and CBT pain management skills 2. Provide psychosocial support 3. Reduce pain catastrophizing,	Homework, mindfulness, relaxation, vignette, in vivo practise of reflective listening	6 hrs, 6 hrs (100%)	Pre, post, 1 & 3 month f/u	<u>Youth report:</u> Sig. improvements in functional disability, pain self-efficacy, pain catastrophizing, depression, and perception of parent’s miscarried helping through f/u. Anxiety & general self-efficacy decreased, but not sig. <u>Parent report (self):</u> Sig. improvements in miscarried helping, parent protectiveness,

				enhance pain self-efficacy				distraction, monitoring, minimizing, pain catastrophizing, and pain knowledge at post-tx, continued improvements at 3 months. <u>Parent report (youth):</u> Sig. improvements in child's pain self-efficacy <u>Feasibility/Acceptability:</u> 85% parents were satisfied to highly satisfied.
Degotardi et al., 2006  <i>United States</i>	8-20 (Mean: 13.9 [2.8])  Fibromyalgia	67, NR  <i>Youth, parents optional</i>	Non-randomized	1. Coach youth to apply CBT strategies 2. Overcome obstacles to resumption of activities 3. Challenge sick-role beliefs, remain supportive and compassionate	Debrief with youth	8 wks, unclear (unclear)	Pre, post	<u>Youth report:</u> Sig. improvements in sleep, functional disability, anxiety, pain intensity, fatigue, quality of life, and somatic symptoms at post-tx. <u>Parent report (youth):</u> Sig. decreased child internalizing at post-tx.
Drake & Ginsburg, 2012  <i>United States</i>	10(N/A) Headache	1, 2  <i>Youth, parents</i>	Case Study	1. Learn pain behavior/contingency management skills 2. Psychoeducation to address other parenting behaviors that may maintain pain and anxiety	Homework, relaxation, problem-solving, role plays, debrief with youth, daily diary, exposures for anxiety	8 sessions, 8 sessions (100%)	Pre, post, 1 month f/u	<u>Youth report:</u> Decrease in headache-related disability, return to full-time school, and no longer meeting criteria for any anxiety diagnoses at 1 month f/u. <u>Parent report (self):</u> Decrease in frequency of protective behaviors.
Duarte et al., 2006  <i>Brazil</i>	5-13 (Mean: 9.9 [2.2]) Abdominal	32, NR  <i>Youth, parents</i>	RCT (tx vs. standard care)	1. Modify responses to youth's pain behaviors	Relaxation, debrief with youth	200 mins, 200 mins (100%)	Pre, post	<u>Youth report:</u> Sig. fewer pain crises in tx group compared to control (87% reduction vs. 33%). No group differences for pain intensity or somatic thresholds for pain.
Eccleston et al., 2003	11-18	57, 57	Non-randomized	1. Encourage adaptation to parenting youth in	Homework, problem-solving	35 hrs, unclear (unclear)	Pre, post, 3	<u>Youth report:</u> Sig. improvements in timed physical activity, functional disability, pain, & somatic awareness at f/u. Sig. improvements

United Kingdom	(Mean: 14.28 [1.6]) Chronic Pain	Youth, parents		pain 2. Manage health related anxiety 3. Develop problem solving skills			month f/u	from pre- to post-tx for anxiety, catastrophizing, & somatic awareness. Sig. tx effect on school attendance. <u>Parent report (self)</u> : Sig. improvement in parent anxiety, depression, stress, and perception of youth functioning at post-tx.
Groß & Warschburger, 2013 Germany	7-12 (Mean: 9.15 [1.54]) Abdominal	29, NR Youth, parents	RCT (tx vs. waitlist)	1. Learn how operant mechanisms exacerbate pain experiences 2. Discuss experiences with pain management within their families	Debrief with youth	9 hrs, 1.5 hrs (16.67%)	Pre, post, 3 month f/u	<u>Youth report</u> : Sig. greater improvements in quality of life, pain-related cognitions, pain intensity/duration/frequency, and pain-related impairment from pre- to post-tx for youth in tx group compared to control.
Hicks et al., 2006 Canada	9-16 (Mean: 11.7 [2.1]) Chronic Pain	47, NR Youth, parents	RCT (tx vs. waitlist)	1. Encourage “healthy behavior”	Relaxation	7 wks, unclear (unclear)	Pre, post, 1 & 3 month f/u	<u>Youth report</u> : Sig. improvement in pain frequency at 1 month f/u, and in pain intensity and # of pain free days at 1 and 3 month f/u. No differences in quality of life between groups. <u>Parent report (youth)</u> : No differences in quality of life between groups.
Kashikar-Zuck et al., 2005 United States	13-17 (Median: 15.83 [1.26]) Fibromyalgia	30, NR Youth, parents	RCT (tx vs. self-monitoring)	1. Encourage active & discourage passive/maladaptive coping 2. Help youth manage pain independently	NR	8 sessions, 3 sessions (37.5%)	Pre, post, 2 month f/u	<u>Youth report</u> : No sig. changes in tx group for time spent in physical activity or average activity counts.
Kashikar-Zuck et al., 2012 United States	11-18 (Mean: 15.0 [1.8]) Fibromyalgia	114, NR Youth, parents	RCT (tx vs. education only)	1. Encourage youth to manage pain independently 2. Maintain normal routines 3. Modify responses to pain	Problem-solving, two booster sessions	6 hrs, 2.25 hrs (37.5%)	Pre, post, 6 month f/u	<u>Youth report</u> : Sig. tx effect for improvements in functional disability and depression compared to control. Both groups showed similar improvements in pain severity and sleep quality.

				4. Praise children for using adaptive coping			
Kashikar-Zuck, Flowers et al., 2013	11-18	114, NR		*Same as Kashikar-Zuck et al., 2012			<u>Youth report:</u> No sig. changes in tx group for time spent in physical activity or average activity counts.
Kashikar-Zuck, Sil et al., 2013	11-18	100, NR		*Same as Kashikar-Zuck et al., 2012			<u>Youth report:</u> Immediate improvements in functional disability, depression, and catastrophizing, which continued to improve through f/u. Immediate improvements in pain coping & coping efficacy, maintained at f/u. Tx group showed greater improvements in coping, coping efficacy, and catastrophizing.
Sil et al., 2014	11-18	100, NR		*Same as Kashikar-Zuck et al., 2012			<u>Youth report:</u> Tx group more likely to improve in functional disability than control group. Youth in tx group with higher baseline functional disability and higher coping efficacy more likely to achieve a clinically significant tx response. Average pain, depression and maternal pain history did not sig. predict tx response.
Law et al., 2015 <i>United States</i>	11-17 (Mean: 14.5 [1.7])  Headache	83, 83  <i>Youth, parents</i>	RCT (tx vs. standard care)	*Same as Palermo et al., 2009	4.5 hrs, 4.5 hrs (100%)	Pre, post, 3 month f/u	<u>Youth report:</u> Sig. decrease in headache frequency, pain intensity, activity limitations, anxiety, and depression at post and f/u, no differences between groups. No sig. improvements in total sleep time or sleep efficiency between groups or after treatment. <u>Parent report (self):</u> Sig. reduction in protectiveness from pre- to post-tx and from pre-tx to f/u. No differences between groups. <u>Feasibility/Acceptability:</u> Parents completed an average of 6/8 modules, and rated the intervention as “satisfiable” (average rating

								3.73/5) and “acceptable” (average rating 3.89/5) a post-tx.
Law et al., 2018  <i>United States</i>	11-17 (Mean: 15.5 [1.6])  Headache	21, 21  <i>Youth, parents</i>	Non-randomized	1. Operant training to reinforce youth’s skills practise 2. Reduce reinforcement of pain behaviors	Relaxation, booster session (for youth, unclear if also for parents)	6-9 hrs, 2-3 hrs (33.3% minimum)	Pre, post, 3 month f/u	<u>Youth report:</u> Sig. improvements in headache frequency, insomnia symptoms, sleep hygiene, sleep efficiency, and sleep onset latency from pre- to post-tx, maintained at f/u. Sig. improvements in pain intensity and total sleep time from pre-tx to f/u. Improvements in headache frequency sig associated with improved insomnia symptoms. <u>Feasibility/Acceptability:</u> Parents rated “moderate acceptability”.
Levy et al., 2010  <i>United States</i>	7-17 (Mean: 11.12 [2.6])  Abdominal	200, 200  <i>Youth, parents</i>	RCT (tx vs. education only)	1. Learn CBT strategies for managing youth’s symptoms 2. Learn strategies to reduce solicitousness and model/reinforce healthier youth pain management	Homework, relaxation, debrief with youth	NR	Pre, post, 3 & 6 month f/u	<u>Youth report:</u> Sig. greater improvements in problem-focused coping confidence, distraction, and pain minimization from pre-tx to f/u in tx group. No group differences in anxiety, depression, functional disability, or pain intensity. <u>Parent report (self):</u> Sig. greater improvements in protectiveness and perceived threat of youth’s pain in tx group . <u>Parent report (youth):</u> Sig. greater improvements in pain intensity and depression in tx group.
Levy et al., 2013	7-17	200, 200		*Same as Levy et al., 2010			12 month f/u	<u>Youth report:</u> Sig. greater improvements in GI symptoms, minimization, and distraction from pre to f/u in tx group. Both groups reported sig. improvements in pain reduction and catastrophizing. <u>Parent report (self):</u> Tx group reported further reduction in protectiveness and perceived threat of pain from 6 to 12 month f/u. <u>Parent report (youth):</u> Sig. improvements in pain, functional disability, and GI symptoms from pre-tx to 12 month f/u in both groups.

Levy et al., 2014	7-17	200, 200		*Same as Levy et al., 2010			Pre, post, 3 & 6 month f/u	<p><u>Youth report:</u> Reductions in catastrophizing mediated child GI symptoms severity at 3 and 6 month f/u.</p> <p><u>Parent report (self):</u> Reductions in perceived threat mediated parents' report of youth pain and GI symptom severity. Changes in protectiveness did not mediate changes in parent report of pain or GI symptoms, or any child reported outcomes.</p>
Lipsitz et al., 2011 <i>United States</i>	8-18 (Mean: 15.0 [3.1])  Non-cardiac chest pain	9, NR  <i>Youth, parents</i>	Non-randomized	1. Psychoeducation about pain and the principles of contingency/reinforcement	NR	200 min, 50 min (25%)	Pre, post, 6 month f/u	<p><u>Youth report:</u> Sig. improvements in pain intensity, discomfort, worry, and frequency of pain episodes at post-tx, maintained at f/u. Sig. increase in problem-focused coping at post-tx, not maintained at f/u. No sig. changes in functional disability, depression, or anxiety.</p>
Logan & Simons, 2010 <i>United States</i>	12-17 (Mean: 14.7 [NR])  Chronic Pain	40, 48  <i>Youth, parents</i>	Non-randomized	1. Reduce inadvertent maintenance and pain related disability 2. Facilitate youth-parent partnership to improve school functioning	Relaxation, problem-solving, role plays, debrief with youth	8 hrs, 8 hrs (100%)	Pre, post	<p><u>Youth report:</u> Sig. improvements in worst pain ratings, missed school days, negative mood and self-esteem, and pain interference with school at post-tx. No changes in youth perception of academic competence.</p> <p><u>Parent report (youth):</u> Sig. improvements on pain interference with school at post-tx.</p> <p><u>Parent report (self):</u> <i>Commented on usefulness of skills, increased confidence in supporting youth, and benefit of social support. Some recommended longer tx, booster sessions (open-ended questionnaires)</i></p> <p><u>Feasibility/Acceptability:</u> Mean parent satisfaction was 4.4/5 (88%). All attended the full treatment. Parents perceived it as helpful, relatively easy to engage in, and lacking negative effects.</p>



Merlijn et al., 2005 <i>The Netherlands</i>	14-18 (Mean: 15.88 [1.27]) Chronic Pain	8, 6 <i>Youth, parents</i>	Non-randomized	1. Discuss parents' role in pain management (e.g., taking pain seriously, reward healthy behaviors)	NR	13.5 hrs, 3 hrs (22.2%)	Pre, post, 12 month f/u	<u>Youth report:</u> Sig. improvements in pain intensity at post-tx, maintained at f/u. No changes in quality of life. <i>Expressed valuing participation of their parents and a peer</i> (open-ended questionnaire). <u>Parent report (self):</u> <i>Expressed meetings were useful and helped to support their child. Valued contact with other parents. Most reported changing their attitude to their youth when in pain, and felt they were more consistent in their behavior. Recommended increasing # of parents in group to increase exchange of experiences and more individual guidance when required</i> (open-ended question).
Palermo et al., 2009 <i>United States</i>	11-17 (Mean: 14.8 [2.0]) Chronic Pain	48, NR <i>Youth, parents</i>	RCT (tx vs. waitlist)	1. Provide skills in adaptive communication 2. Reinforce maintenance of activities despite pain 3. Discuss importance of modeling, supporting independence, and enhancing communication	Homework, relaxation, vignette/case studies, videos of peer models, quizzes	4.5 hrs, 4.5 hrs (100%)	Pre, post, 3 month f/u	<u>Youth report:</u> Sig. greater improvements in activity limitations and pain intensity at post-tx, maintained at f/u for tx group. Sig. decreases in depression at post-tx and f/u in both groups. <u>Parent report (self):</u> Protectiveness decreased sig. at post-tx and f/u in both groups, no tx effects. <u>Feasibility/Acceptability:</u> Mean parent satisfaction was 81.8%, mean acceptability was 76.4%.
Law et al., 2012	11-17	26, 26		*Same as Palermo et al., 2009				<u>Feasibility/Acceptability:</u> 54% of parents and 77% of youth completed all modules. Parents completed 84% of assignments on average. Youth completed 89% of assignments on average.
Palermo, Law,	11-17	273, 273	RCT (tx vs.	*Same as Palermo et al., 2009			Pre, post, 6	<u>Youth report:</u> Tx group reported greater improvements in activity limitations, parent

Fales, et al., 2016  <i>United States</i>	(Mean: 14.7 [1.6])  Chronic Pain	<i>Youth, parents</i>	education only)		month f/u	miscarried helping, and sleep quality from pre-tx to f/u. Small tx effects for depression and pain-related anxiety, not maintained at f/u. Non-sig. pain reductions in both groups. <u>Parent report (self):</u> Sig. greater improvements in protectiveness and self-blame, anxiety, and depressive symptoms from pre- to post-tx and f/u in tx group. No tx effects for parent catastrophizing, impairment in partner relationship, parent social functioning, and parent role strain. <u>Feasibility/Acceptability:</u> On average, youth and parents completed 7/8 modules with 67% of families completing all modules. Youth and parents reported satisfaction and acceptability for the CBT intervention. Mean satisfaction rating of parents was 30.2/45 (67%).
Fisher et al., 2017	11-17	183, 183		*Same as Palermo et al., 2009	Pre, post, 6 & 12 month f/u	<u>Youth report:</u> Youth where dyads agreed on one or more tx goals reported sig. lower pain intensity at post-tx and f/u. No differences on pain-related disability based on goal agreement. Most frequently chosen goal for both was “going to school” followed by “sports”. <u>Parent report (self):</u> Moderate agreement between youth and parent tx goals (61% agreed on one or both goals). Most frequently chosen for both was “going to school” followed by “sleep” for parents. <u>Feasibility/Acceptability:</u> Mean parent satisfaction rating 30.2/45 (67%).
Law et al., 2017	11-17	138, 138		*Same as Palermo et al., 2009	Pre, post, 6 & 12 month f/u	<u>Youth report:</u> Sig. improvements in activity limitations from pre to post, maintained at 6 month f/u, and further improvement at 12 month f/u.

								<u>Parent report (self):</u> Overall distress and protectiveness improved over 12 months; greatest improvement seen between pre to post. Greater protectiveness pre-tx predicted less improvements in parent distress and child disability over 12 months. No evidence of bi-directional influence of child disability on parent functioning.
Alberts et al., 2018	11-17	134, 134		*Same as Palermo et al., 2009			Pre, post, 6 month f/u	<u>Parent report (self):</u> Controlling for youth pre-tx activity limitations, parent tx engagement predicted youth activity limitation changes scores at post-tx, but not f/u. More parent log-ins associated with worsening youth activity limitations at post-tx. <u>Feasibility/Acceptability:</u> 74% of youth and 73% of parents completed all modules.
Robins et al., 2005  <i>United States</i>	6-16 (Mean: 11.85 [2.3])  Abdominal	69, NR  <i>Youth, parents</i>	RCT (tx vs. standard care)	1. Psychoeducation on recurrent pain 2. Develop more adaptive responses to their youth's pain	Relaxation, debrief with youth	200 mins, 120 mins (60%)	Pre, post, 3 & 6-12 month f/u	<u>Youth report:</u> Tx group showed sig. lower scores for abdominal pain and fewer school absences compared to controls. Both groups showed reductions in pain, somatization, and functional disability. <u>Parent report (youth):</u> Tx group showed sig. lower scores for youth abdominal pain at 3 month f/u, maintained at 6-12 month f/u. Both groups showed reductions in youth pain and somatization.
Sanders et al., 1989  <i>Australia</i>	6-12 (Mean: 9.10 [NR])  Abdominal	16, 16  <i>Youth, parents</i>	RCT (tx vs. waitlist)	1. Discuss pain behaviors from social learning perspective 2. Discriminate sick and well behaviors 3. Use praise and rewards	Relaxation, debrief with youth	NR	Pre, post, 3 month f/u	<u>Youth report:</u> Tx group showed sig. lower report of pain at post-tx, no difference between groups at f/u. <u>Parent report (youth):</u> Sig. improvements in child behaviors from pre- to post-tx and pre-tx to f/u in both groups.

Sanders et al., 1994 <i>Australia</i>	7-14 (Mean: 8.95 [1.59])  Abdominal	22, 22  <i>Youth, parents</i>	RCT (tx vs. standard care)	1. Reinforce well behavior via attention and token reinforcement 2. Modify responses to pain	Debrief with youth	5 hrs, 5 hrs (100%)	Pre, post, 6 & 12 month f/u	<u>Youth report:</u> Tx group reported sig. less pain interference at both f/u points. Pain ratings improved at each time point for both groups. <u>Parent report (youth):</u> Pain behaviors improved at each time point in both groups. Sig. less pain interference at both f/u points in tx group. <u>Feasibility/Acceptability:</u> Mothers in tx group reported satisfaction with quality of service (4.33/5, 87%) and treatment (59.4/70, 85%).
Sieberg et al., 2011 <i>United States</i>	8-14 (Mean: 11.5 [0.87])  Abdominal	8, NR  <i>Youth, parents</i>	RCT (CBT vs. CBT+Family)	1. Improve parent-child interaction 2. Improve parental responses to pain	Relaxation, problem-solving, debrief with youth	350 mins, 350 mins (100%)	Pre, post, 1 month f/u	<u>Youth report:</u> Youth in both groups improved at f/u (reported fewer anxiety disorders compared to baseline). No clinically sig. changes. <u>Parent report (youth):</u> Most youth were within normal limits at baseline and remained so through f/u; no clinically sig. changes.
Tran et al., 2017 <i>United States</i>	12-18 (Mean: 16.19 [1.59])  Fibromyalgia	22, NR  <i>Youth, parents</i>	Non-randomized	Not reported	NR	12 hrs, 4.5 hrs (37.5%)	Pre, post	<u>Youth report:</u> Sig. improvements in functional disability, depression, fear of movement, and pain catastrophizing at post-tx. Precontemplation decreased sig. and action/maintenance increased sig. post-tx.
Voerman et al., 2015 <i>The Netherlands</i>	12-17 (Mean: 14.88 [1.11])  Chronic Pain	66, NR  <i>Youth, parents</i>	RCT (tx vs. Waitlist)	Not reported	NR	Minimum 3.5 hrs, minimum 1 hr (28.6% minimum)	Pre, post, 3 month f/u	<u>Youth report:</u> Sig. improvements in pain interference, sleep problems at post, no further changes at f/u. No changes in pain-related disability, pain catastrophizing, approach or emotion-focused avoidance. <u>Parent report (self):</u> Encouragement of pain behaviors sig. decreased from pre- to post-tx. <u>Feasibility/Acceptability:</u> 57% of parents satisfied with the intervention.
Weiss et al., 2013	11-18	112, NR	Non-randomized	1. Eliminate parent behaviors that may	NR	NR	Pre, post	<u>Youth report:</u> Sig. improvements in pain acceptance, functional disability, depression, and pain catastrophizing at post-tx. Change in

<i>United States</i>	(Mean: 15.47 [1.83])  Chronic Pain	<i>Youth, parents</i>		reinforce pain behaviors				acceptance was sig. predictor of change in depression, pain catastrophizing, and functional disability.
Wiertz et al., 2017  <i>The Netherlands</i>	11-22 (Mean: 16.25 [2.11])  Musculo-skeletal	44, 65  <i>Parents</i>	Non-randomized	1. Help youth cope with pain 2. Learn about the role of parents in maintaining their youth's pain and coping (interpersonal fear avoidance model)	NR	15 hrs, 6 hrs (40%)	Pre, post	<u>Youth report</u> : Sig. improvements in pain intensity, functional disability, pain catastrophizing, fear of pain, and depression symptoms at post-tx. <u>Parent report (self)</u> : Sig. improvements in parental catastrophizing and fear of pain. <i>Liked the "explanation of pain and fear avoidance model", "examples from other parents", "personal approach", and "interactive"</i> . <i>Shortcomings were that it was "too much information at once" and "a lot of information was already known"</i> (open-ended questions). <u>Parent report (youth)</u> : Sig. improvements in functional disability.
<b>Acceptance and Commitment Therapy (ACT)</b>								
Gauntlett-Gilbert et al., 2012  <i>United Kingdom</i>	10-19 (Mean: 15.6 [1.7])  Chronic Pain	98, NR  <i>Youth, parents</i>	Non-randomized	Not specified	Mindfulness, debrief with youth	90 hrs, 90 hrs (100%) <sup>+</sup>	Pre, post, 3 month f/u	<u>Youth report</u> : Improvements in physical/social functioning, physical activity, pain-specific anxiety, catastrophizing, and acceptance at post, maintained at f/u. Improvements in depression not sustained at f/u.
Kanstrup et al., 2016  <i>Sweden</i>	14-18 (Mean: 16.0 [1.6])  Chronic Pain	30, 28  <i>Youth, parents</i>	RCT (group vs. individual)	1. Improve ability to use values and acceptance based coaching behaviors to support youth in increasing functioning even in	Homework, debrief with youth	Group format: 34 hrs, 8 hrs (23.5%)  Individual format:	Pre, post	<u>Youth report</u> : No difference between group and individual tx for any outcomes variables at any time point; sig. improvements on pain interference, pain reactivity, depression, and psychological inflexibility. No sig. changes for pain intensity or functional disability.

				presence of pain and distress		12.75 hrs, 3 hrs (23.5%)		<u>Parent report (self):</u> Sig. improvements on pain reactivity and parent psychological flexibility. No changes in overall parent emotional functioning or anxiety/depression.
Kemani et al., 2018 <i>United Kingdom</i>	11-18 (Mean: 15.5 [1.8]) Chronic Pain	164, 164 <i>Youth, parents</i>	Non-randomized	1. Support youth treatment modeling the acquisition and practice of skills 2. Acquire skills in managing challenging parenting situations	Mindfulness, role plays, debrief with youth	22 hrs, 22 hrs (100%)+	Pre, post, 3 month f/u	<u>Youth report:</u> Sig. improvement from pre to f/u on social and physical functioning, depression, general and pain-specific anxiety, pain acceptance, pain intensity, and family functioning. <u>Parent report (self):</u> Sig. improvements from pre to f/u on depression, pain acceptance, and psychological flexibility. No sig. changes in mental or physical quality of life. Changes in parent psychological flexibility were sig. associated with changes in youth's pain acceptance.
Pielech et al., 2018 <i>United States</i>	10-19 (Mean: 15.0 [1.98]) Chronic Pain	114, 114 <i>Parents</i>	Non-randomized	1. Modify parent responses to child symptoms 2. Facilitate coping with parent's own emotions and distress using acceptance based approach	Mindfulness	NR	Pre, post, 1, 6, & 12 month f/u	<u>Youth report:</u> No youth variables moderated or had an impact on changes to parent responses over time. <u>Parent report (self):</u> Sig. decreases in protectiveness, monitoring, and minimizing responses at post and f/u. Changes in parent responses (especially protectiveness and monitoring) primarily driven by perception of youth's disability.
Wallace et al., 2016 <i>United States</i>	13-18 (Median: 17 [NR]) Chronic Pain	8, 8 <i>Parents</i>	Non-randomized	1. Target psychological flexibility by helping parents recognize areas where they/their teens may be stuck to develop strategies to pursue values	Homework, mindfulness	N/A, 10 hrs (100%)	Pre, post, 3 & 6 month f/u	<u>Parent report (self):</u> Psychological flexibility sig. increased throughout tx and both f/u periods. Protectiveness decreased sig. only at f/u and not throughout tx. No changes in monitoring responses or pain interference. <u>Feasibility/Acceptability:</u> Mean satisfaction rating was 5.9/6 (98%).

Wicksell et al., 2005 <i>Sweden</i>	14 (N/A) Chronic Pain	1, 2 <i>Youth, parents</i>	Case Study	1. Learn how to coach youth towards values rather than symptom reduction	NR	10 sessions, 3 sessions (30%)	Pre, post, 2 week, 3 & 6 month f/u	<u>Youth report:</u> Sig. improvements in functional disability, emotion-focused avoidance, pain intensity and interference at post-tx, maintained at 6 month f/u. <u>Parent report (youth):</u> Increased school activities and time spent in school throughout tx. Youth back in school and no further pain related absences at post and f/u.
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**Problem Solving Skills Therapy (PSST)**

Law et al., 2016 <i>United States</i>	10-17 (Mean: 14.4 [2.0]) Chronic Pain	26, 26 <i>Parents</i>	Non-randomized	1. Learn and practise problem solving skills	Homework, problem-solving, vignette/case studies	N/A, 4-9 hrs (100%)	Pre, post, 3 month f/u	<u>Parent report (self):</u> Sig. improvements in mental health and protectiveness from pre through post and f/u. Sig. improvements in catastrophizing, problem solving, and miscarried helping from pre to post, not maintained at f/u. No changes in parenting role stress. <i>Found tx emotionally validating and skills were helpful. Appreciated flexibility of in-person or telephone; expressed desires for partial or complete web-based tx and desire for additional support after tx</i> (individual interviews). <u>Feasibility/Acceptability:</u> Mean satisfaction 32.6/45 (72%).
Palermo, Law, et al., 2014 <i>United States</i>	9-16 (Mean: 14.5 [2.74]) Chronic Pain	6, 6 <i>Parents</i>	Non-randomized	1. Learn rationale of problem solving skills therapy 2. Learn and practise learned optimism, problem orientation, and problem solving	Homework, problem-solving, vignette/case studies, role plays	N/A, 6-8 hrs (100%)	Pre, post	<u>Youth report:</u> Improvements in physical functioning and depression from pre- to post-tx. <u>Parent report:</u> Improvements in problem solving skills, stress, depression, mood, miscarried helping, catastrophizing, and maladaptive responses at post-tx. <u>Feasibility/Acceptability:</u> Parents were compliant with homework. Mean satisfaction rating 36.5/45 (74%), and mean acceptability 4.5/5 (90%).

Palermo, Law, Bromberg, et al., 2016  <i>United States</i>	10-17 (Mean: 14.3 [1.9])  Chronic Pain	61, 31  <i>Parents</i>	RCT (tx vs. standard care)	1. Learn rationale of problem solving skills therapy 2. Learn and practise learned optimism, problem orientation, and problem solving	Homework, problem-solving, vignette/case studies, role plays	N/A, 4-6 hrs (100%)	Pre, post, 3 month f/u	<u>Youth report:</u> Youth whose parents were in the tx group reported greater improvements in symptoms and pain-specific anxiety compared to control at post, not maintained at f/u. <u>Parent report (self):</u> Sig. greater improvements for tx group in pain catastrophizing (through to f/u) and mental health. Improvements in depression, anxiety, and physical health at post-tx in tx group. No differences between groups on mood disturbance. No changes in general parenting stress at post or f/u. <u>Feasibility/Acceptability:</u> Mean satisfaction was 33.9/45 (75%) at post and 34.5/35 (77%) at f/u.
<b>Eclectic</b>								
Huestis et al., 2017  <i>United States</i>	13-17 (Mean: 15.4 [NR])  Chronic Pain	17, NR  <i>Youth, parents</i>	Non-randomized	1. Introduce CBT (coping with feeling, positive behavior change) and ACT (cognitive defusion, acceptance and willingness, values) approaches to pain management 2. Multi-family concepts and techniques to pain management	Mindfulness, relaxation, problem solving, multi-family sessions	13.5 hrs, 13.5 hrs (100%)	Pre, post	<u>Youth report:</u> Sig. changes in pain catastrophizing, pain acceptance, functional disability, pain interference, and anxiety at post-tx. <u>Parent report (self):</u> Sig. changes in protectiveness. Non-sig. reductions in parent catastrophizing. “ <i>Validation</i> ”, “ <i>empathy and social support</i> ”, “ <i>increased communication and family relationships</i> ”, “ <i>better understanding of child (through hearing other parent’s experiences)</i> ”, “ <i>safe place for sharing stories</i> ”, and “ <i>psychoeducation</i> ” were most helpful parts (individual interviews). <i>Psychoeducation (35%), acceptance and values (35%), and reducing pain check-ins (15%) were helpful strategies. 65% reported increased well-being, 45% wanted more/longer sessions and boosters, and 30% benefitted from hearing other parents’ viewpoints.</i> (open-ended questions).



								<u>Feasibility/Acceptability:</u> 82% parents and 76% youth satisfied
Hechler et al., 2010 <i>Germany</i>	7-18 (children : Mean: 9.9 [0.9]; adolescents: Mean: 14.0 [1.9])  Chronic Pain	200, NR  <i>Youth, parents</i>	Non-randomized	1. Learn biopsychosocial model and parent factors 2. Support child in daily activities 3. Critically evaluate school attendance	Homework, debrief with youth	NR	Pre, post, 3 & 12 month f/u	<u>Youth report:</u> Sig. decrease in pain intensity, pain-related disability, passive pain coping & seeking social support from post through 3 and 12 month f/u. Fewer girls reported a >50% reduction in pain intensity at each time point. <u>Parent report (youth):</u> Sig. improvements in school absences from pre to 3 month f/u.
Hirschfeld et al., 2012	7-18	200, NR		*Same as Hechler et al., 2010 above				<u>Youth report:</u> Sig. improvements in pain, disability, and emotional distress at 12 month f/u. 74% reported clinically sig. change in pain intensity, 53% in disability, and 39% in school absence. <u>Parent report (youth):</u> Sig. fewer school absences at 12 month f/u
<b>Other (*Therapeutic Approach Under Author Name)</b>								
Harris et al., 2015  (Behavioral Family Systems Therapy)  <i>United States</i>	11-15 (Mean: 13.3 [1.70])  Chronic Pain	3, NR  <i>Youth, parents</i>	Case Study	1. Modify maladaptive interactions/responses 2. Problem solve to help reinforce youth coping 3. Reduce reinforcement, increase attention for non-pain behavior	Problem-solving, communication skills training, family structuring	NR	Pre, post	<u>Parent report (youth):</u> Participation in tx associated with less hospitalization-related costs at post-tx.

Nieto et al., 2015  (Not described)  <i>Spain</i>	9-15 (Median: 11 [NR])  Abdominal	15, NR  <i>Youth, parents</i>	Non-randomized	1. Learn coping strategies to reduce pain and disability from pain 2. Target parent responses to child's pain as well as parent's own pain	Problem-solving	3.5 hrs, 3.5 hrs (100%)	Pre, post	<u>Parent report:</u> All satisfied with tx and would recommend to others. 78% noted the flexibility and comfort of online tx. Recommended adding forums to talk with other parents/professionals and more face-to-face sessions. All reported using relaxation, 67% reported using coping strategies (individual interviews). <u>Feasibility/Acceptability:</u> Mean parent satisfaction "higher than 8/10".
Ochs et al., 2005  (Not described)  <i>Germany</i>	8-15 (Mean: 11.4 [NR])  Headache	76, NR  <i>Youth, parents</i>	Non-randomized	1. Psychoeducation 2. Communicate problems, questions, solutions for headache management	Relaxation	19.5 hrs, 6 hrs (25%)	Pre, post, 9 month f/u	<u>Youth report:</u> Pain reduced on average by 41% from pre-tx to f/u. <u>Parent report (self):</u> Families that reported positive changes in their interaction patterns displayed sig. greater reductions in headache burden.
Pielech et al., 2013  (Art Therapy)  <i>United States</i>	8-18 (NR)  Chronic Pain	42, 53  <i>Parents</i>	Non-randomized	1. Encourage identifying and expressing feelings associated with youth's pain journey 2. Validation for challenges as caretaker of a youth with chronic pain 3. Increase social support	NR	N/A, up to 4 hrs (100%)	Pre, post	<u>Parent report (self):</u> Indicated they would not change anything about group, the group process (being with other parents and sharing stories) was most helpful (open-ended questions). <u>Feasibility/Acceptability:</u> Average 4 parents in each group, approximately 50% of parents completed more than one module. Reported that "pain journey" session was most helpful and "invisible support" the most satisfying. Mean satisfaction ratings ranged from 4.33 to 4.58/5 for the modules (87-92%).
Revivo et al., 2019	9-18 (Mean: 14.0 [2.84])	30, 36  <i>Youth, parents</i>	Non-randomized	1. Encourage avoiding asking about pain and focusing on function	Problem-solving, debrief with youth	12 to 32 hrs, unclear (unclear)	Pre, post	<u>Youth report:</u> Sig. improvements in pain intensity, social and physical functioning, and emotional distress at post-tx. Non-sig. reductions in family functioning. 97% returned to school at post-tx.

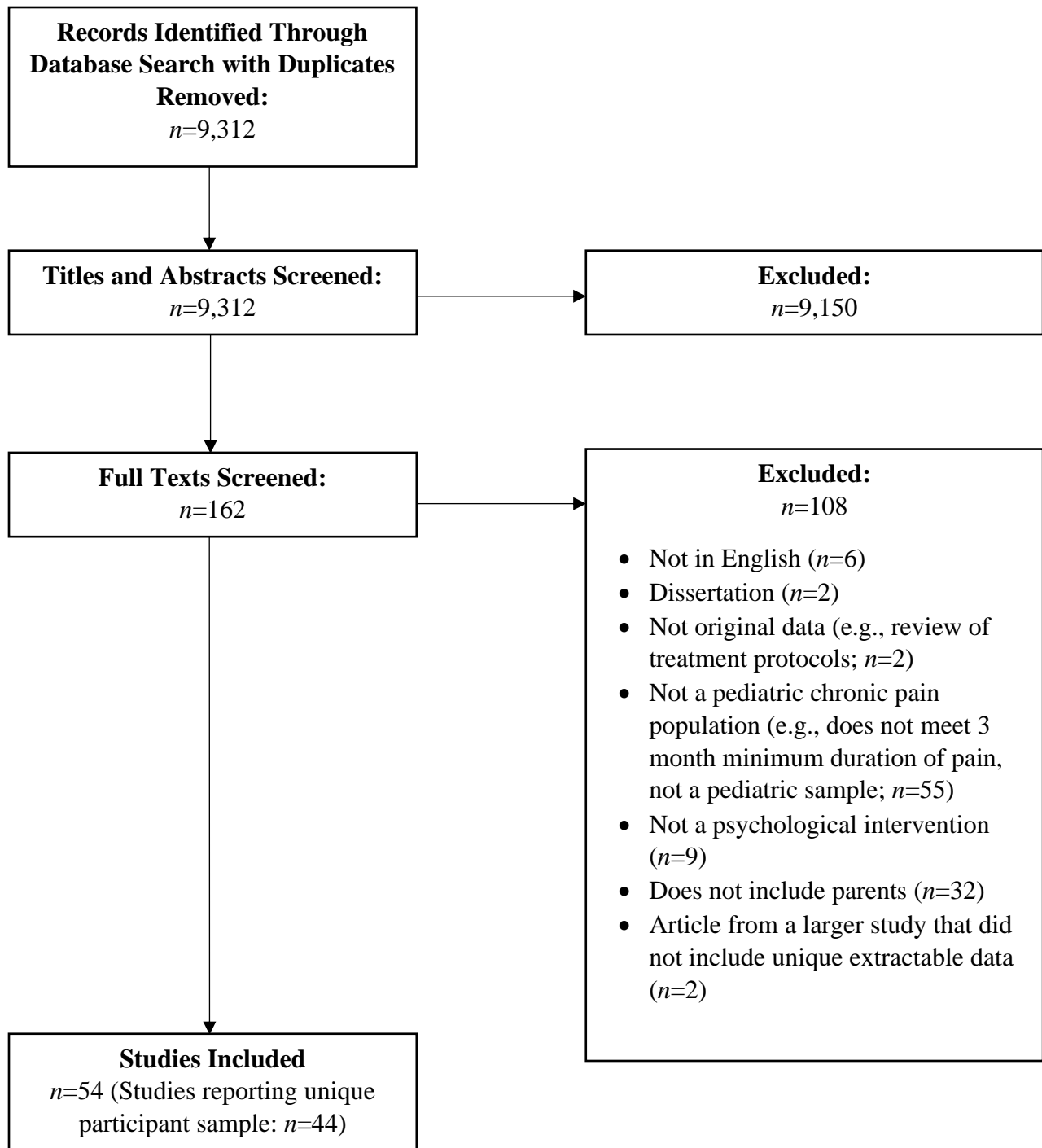
(Not described)	Chronic Pain							Parent report (self): Sig. improvements in emotional distress, catastrophizing, self-blame, maladaptive behaviors, and helplessness. Non-sig. reductions in partner relationship disruption and parent strain.
<i>United States</i>								
Ruskin et al., 2018 (Mindfulness)	12-18 (Mean: 15.5 [1.6]) Chronic Pain	14, 14 <i>Youth, parents</i>	Non-randomized	1. Introduce and practise mindfulness skills 2. Discuss the role of parent values	Mindfulness, homework	N/A, 2 hrs (100%)	Pre, post	Parent report (self): Sig. higher ability to model mindfulness for their youth. <i>Take home messages of group: “mindfulness skills”, “not alone”, “psychological flexibility”, “parent-child interactions”, “self-efficacy”, “optimism/hope”, and “awareness of values”</i> (open-ended questions). <u>Feasibility/Acceptability:</u> Mean satisfaction ratings were 8.25/10 (83%).
<i>United States</i>								
Seidman et al., 2019 (Mindfulness)	8-18 (Mean: 14.8 [2.0]) Chronic Pain	30, 30 <i>Parents</i>	Non-randomized	1. Encourage self-care, mindfulness, relaxation 2. Obtain peer support and advice from other parents and support from health experts	Mindfulness, relaxation, peer support videos from other parents	N/A, NR (100%)	Pre, post	Parent report (self): Sig. improvements in protectiveness, perceived stress, and ‘mindful discipline’ from pre- to post-tx. No changes in resilience. <i>Found peer videos helpful, would recommend the app to others</i> (open-ended questions). <u>Feasibility/Acceptability:</u> Parents engaged an average of 11.2 days on the app. Parents completed 72% of curriculum, 40% completed all.
<i>United States</i>								

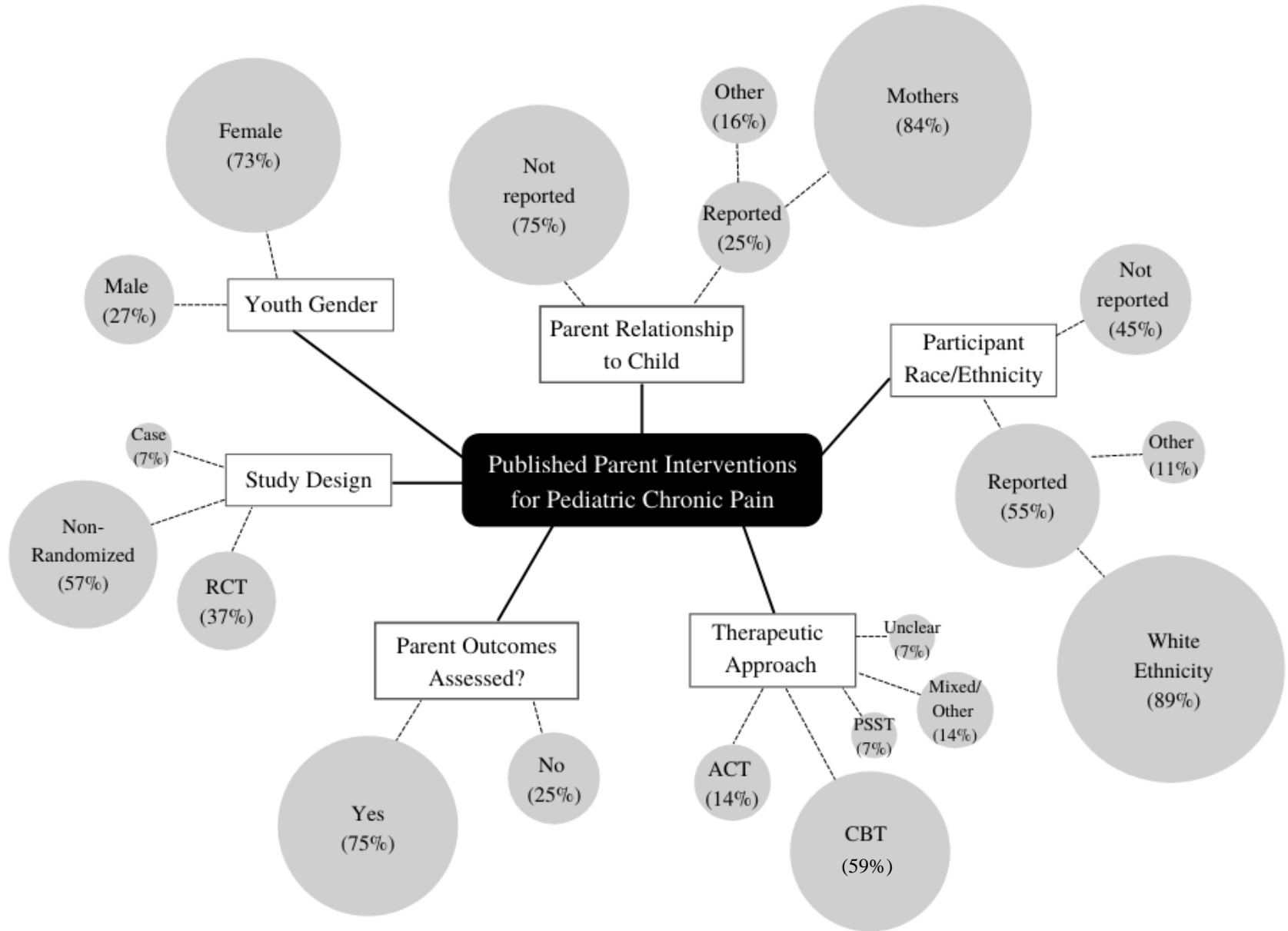
Notes: NR= Not Reported. *Qualitatively reported data are reported in italics.* Dashed lines indicate a study that was based on the same sample as a previous study where only unique data were extracted. “Parent report (self)” indicates any parent-reported parent-related outcomes, “Parent report (youth)” indicates any parent-reported youth-related outcomes. <sup>1</sup>Reported treatment activities were extracted and included: “homework/goal setting”, “mindfulness”, “relaxation”, “problem-solving”, “vignette/case studies”, “role playing”, “debrief/discussion with youth”, “booster sessions”, and “other components (specify)”; see supplementary material for full extraction sheet. \*total length of entire interdisciplinary tx program, did not specify # hours for psychology specifically.

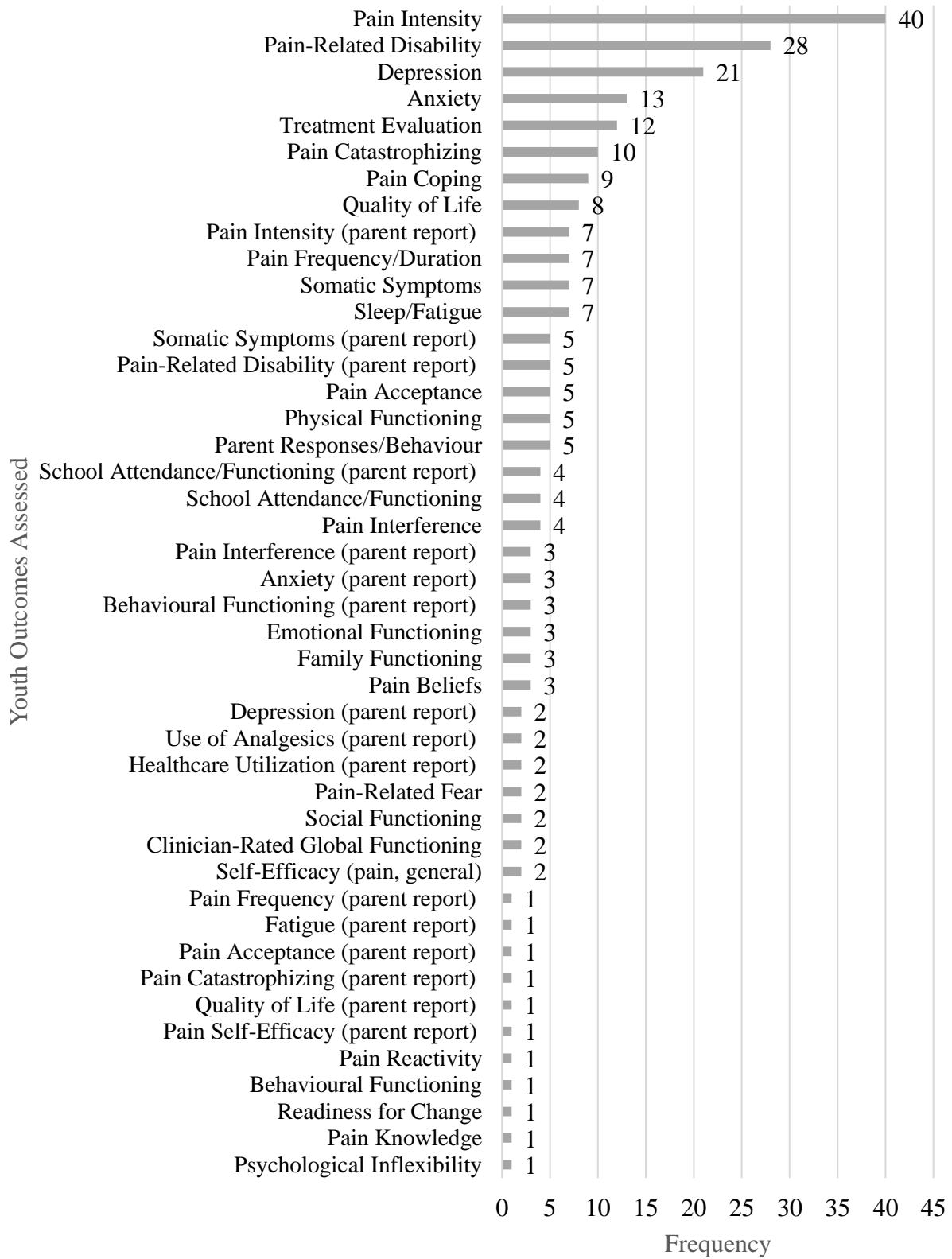
Table 2. Identified research gaps/challenges and recommendations for future research and practice.

<b>Identified Gaps/Challenges</b>	<b>Recommendations</b>
<p>A. Most interventions are individually delivered in-person by a psychologist or psychology trainee. There is a relative lack of research on group-based and/or virtual and/or self-guided interventions for parents.</p>	<ul style="list-style-type: none"> <li>• Conduct more research examining group and/or virtual and/or self-guided interventions utilizing multiple comparison groups. Further, treatment moderators that impact outcomes may be important to identify parents who may be better suited to different intervention delivery format.</li> <li>• Encourage the continued development and evaluation of virtual and self-guided therapies for pediatric chronic pain, including ones specifically tailored for parents.</li> </ul>
<p>B. Only 16% of studies included parents of youth less than 8 years and none included parents of young children less than 5 years. Four studies included parents of youth who were &gt;18 years.</p>	<ul style="list-style-type: none"> <li>• Conduct parent-engaged research including parents of younger children (e.g., 8 years and younger), through to older adolescence to better understand whether there are specific parent needs/goals for pediatric chronic pain management dependent on youth age.</li> </ul>
<p>C. The current research base on parent interventions is predominantly White mothers. Further, almost 50% of included studies did not include basic demographic data for participating parents.</p>	<ul style="list-style-type: none"> <li>• Collect and report demographic data on parents in all studies.</li> <li>• Focus on more active, inclusive recruitment methods that includes more diverse caregivers (e.g., fathers, other caregivers/family members, members of different racial/ethnic groups, etc.).</li> </ul>
<p>D. Unclear or missing information regarding intervention components and activities for parents, making it difficult for researchers/clinicians to replicate the intervention in their own settings.</p>	<ul style="list-style-type: none"> <li>• Encourage clear, detailed, and accessible reporting of interventions in published research (e.g., timing, length, activities, resources, etc.); journals and/or reviewers may support this via specific reporting guidelines for intervention studies.</li> </ul>
<p>E. The degree of parent participation varied widely across studies, and only 8 reported on ‘parent-only’ interventions (i.e., parent treatment program independent of youth’s treatment). The dose of intervention required for optimal outcomes in unclear.</p>	<ul style="list-style-type: none"> <li>• Clearly report the aims of the parent intervention, as well as the length/timing of the intervention; this may also be beneficial for future meta-analyses that examine optimal ‘doses’ of parent interventions.</li> </ul>

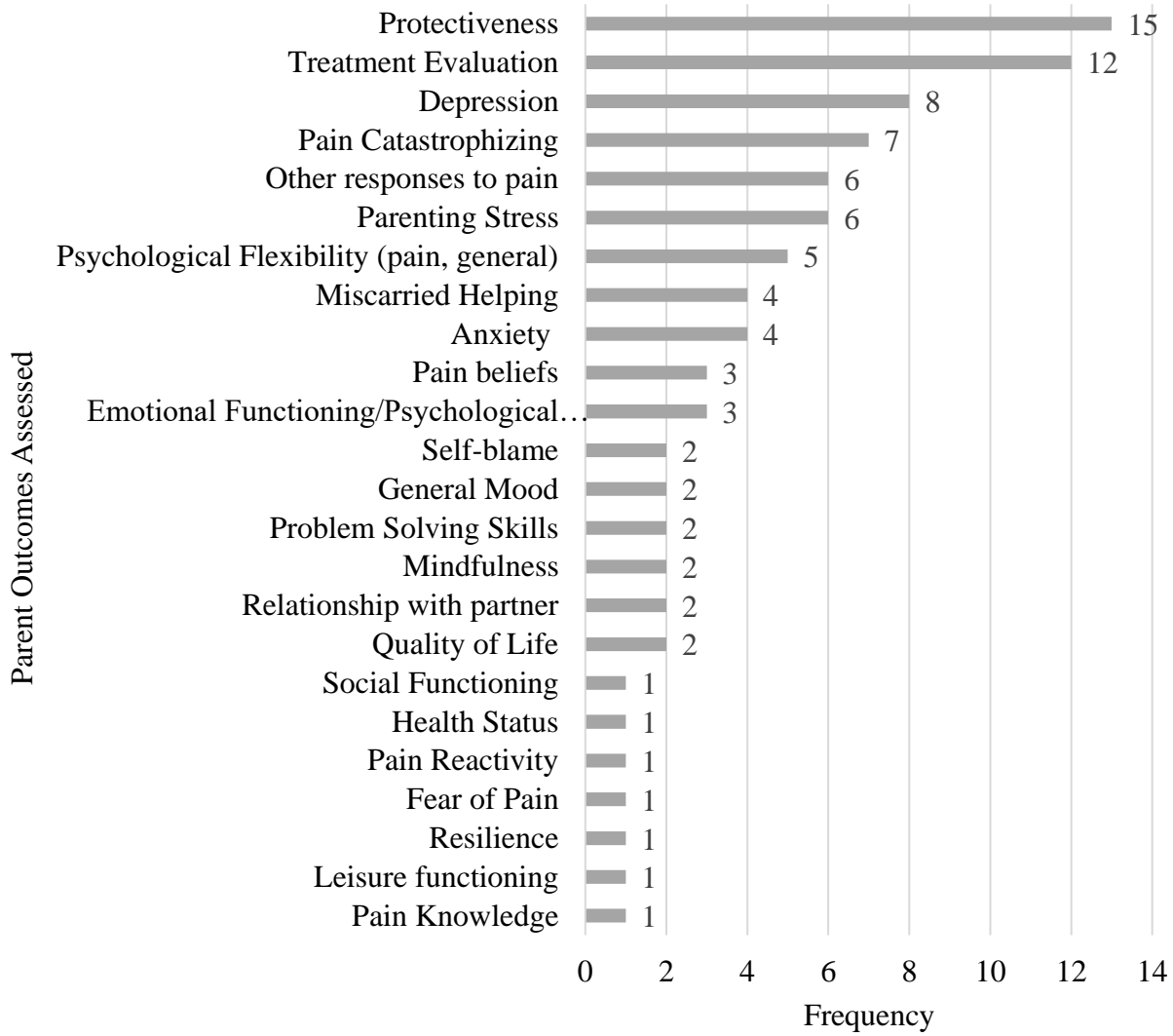
		<ul style="list-style-type: none"> <li>• Conduct more research focusing on parents of youth with chronic pain from diverse settings (i.e., not only pediatric specialty clinics) to better understand treatments needs of parents.</li> </ul>
F.	A quarter (25%) of studies including a parent intervention for pediatric chronic pain did not assess for any parent outcomes. Thus, despite the number of published studies on parent interventions for pediatric chronic pain, there is relatively little information regarding parent-specific outcomes related to the interventions	<ul style="list-style-type: none"> <li>• Consistently assess parent outcomes (e.g., parent report on themselves, on their youth) using a range of methodologies that includes quantitative, qualitative, youth-perspective, and behavioral observation data.</li> <li>• Utilize brief, registry measures (e.g., PROMIS rating scales) to assess parent outcomes with relatively little participant burden.</li> </ul>
G.	Parents express a desire for follow-up/booster sessions, but only two studies in this review included a booster session as part of the treatment program.	<ul style="list-style-type: none"> <li>• Conduct more research to better understand parent demand for booster sessions, and what these sessions would include (e.g., aims, content, delivery).</li> </ul>











## Supplemental Data File 1: Database Search Terms

### 1. PubMed

((((((((psychology[MeSH Terms]) OR psychotherapy[MeSH Terms]) OR behavior therapy[MeSH Terms])) OR ((((((intervention\*[Title/Abstract]) OR treatment\*[Title/Abstract]) OR therap\*[Title/Abstract]) OR program[Title/Abstract])) AND (((((((((psycholog\*[Title/Abstract]) OR behavior\*[Title/Abstract]) OR behaviour\*[Title/Abstract]) OR cogniti\*[Title/Abstract]) OR family[Title/Abstract]) OR relaxation[Title/Abstract]) OR acceptance[Title/Abstract]) OR hypno\*[Title/Abstract]) OR problem-solv\*[Title/Abstract]) OR parenting[Title/Abstract]))) AND (((((((((((((((((pain\*[Title/Abstract]) OR headache\*[Title/Abstract]) OR head-ache\*[Title/Abstract]) OR migraine\*[Title/Abstract]) OR "stomach ache"[Title/Abstract]) OR "stomach-ache"[Title/Abstract]) OR "abdominal pain"[Title/Abstract]) OR arthriti\*[Title/Abstract]) OR "inflammatory bowel"[Title/Abstract]) OR IBD[Title/Abstract]) OR fibromyalgia\*[Title/Abstract]) OR "sickle cell"[Title/Abstract]) OR "complex regional pain syndrome"[Title/Abstract]) OR CRPS[Title/Abstract]) OR neuropathic[Title/Abstract]) OR pain[MeSH Terms]) OR chronic pain[MeSH Terms]) OR complex regional pain syndromes[MeSH Terms]) OR inflammatory bowel diseases[MeSH Terms]) OR anemia, sickle cell[MeSH Terms]) OR headache disorders[MeSH Terms])) AND (((((((((((((((((child\*[Title/Abstract]) OR adolescen\*[Title/Abstract]) OR infant\*[Title/Abstract]) OR teenager\*[Title/Abstract]) OR youth\*[Title/Abstract]) OR baby[Title/Abstract]) OR babies[Title/Abstract]) OR toddler\*[Title/Abstract]) OR pediatric\*[Title/Abstract]) OR paediatric\*[Title/Abstract]) OR juvenile\*[Title/Abstract]) OR "young person"[Title/Abstract]) OR "young people"[Title/Abstract]) OR child[MeSH Terms]) OR adolescent[MeSH Terms]) OR infant[MeSH Terms])) AND (((((((((((((((((parent\*[Title/Abstract]) OR mother\*[Title/Abstract]) OR father\*[Title/Abstract]) OR family[Title/Abstract]) OR families[Title/Abstract]) OR caregiver\*[Title/Abstract]) OR care-giver\*[Title/Abstract]) OR maternal[Title/Abstract]) OR paternal[Title/Abstract]) OR family[MeSH Terms]) OR parents[MeSH Terms]) OR caregivers[MeSH Terms]))

### 2. PsycINFO via APA PsycNET

((**abstract:** (cogniti\*) OR **abstract:** (family)OR **abstract:** (relaxation) OR **abstract:** (acceptance) OR**abstract:** (hypno\*) OR **abstract:** (behavior\*) OR **abstract:** (behaviour\*) OR **abstract:** (psycholog\*) OR **abstract:** (problem-solv\*) OR **abstract:** (parenting) NEAR/5(**abstract:** (intervention\*) OR **abstract:** (treatment\*) OR**abstract:** (therap\*) OR **abstract:** (program)) OR (**Index Terms:** (psychotherapy)) OR (**Index Terms:** (family therapy))OR (**Index Terms:** (problem solving))) AND ((**abstract:** (pain\*)) OR (**abstract:** (headache\*)) OR (**abstract:** (head-ache\*)) OR (**abstract:** (migraine\*)) OR (**abstract:** ("stomach ache\*")) OR (**abstract:** ("stomach-ache\*")) OR (**abstract:** ("abdominal pain\*")) OR (**abstract:** (arthriti\*)) OR (**abstract:** ("inflammatory bowel")) OR (**abstract:** (IBD)) OR (**abstract:** (fibromyalgia\*)) OR (**abstract:** ("sickle cell")) OR (**abstract:** ("complex regional pain syndrome")) OR (**abstract:** (CRPS))OR (**abstract:** (neuropathic)) OR (**Index Terms:** (chronic pain)) OR (**Index Terms:** (pain)) OR (**Index Terms:** (headache)) OR (**Index Terms:** (migraine

headache)) OR(**Index Terms:** (muscle contraction headache)) OR (**Index Terms:** (rheumatoid arthritis)) OR (**Index Terms:** (complex regional pain syndrome)) OR (**Index Terms:** (sickle cell disease))) AND ((**abstract:** (child\*)) OR (**abstract:** (adolescen\*)) OR (**abstract:** (infant\*)) OR (**abstract:** (teenager\*)) OR (**abstract:** (youth\*)) OR (**abstract:** (baby)))OR (**abstract:** (babies)) OR (**abstract:** (toddler\*)) OR(**abstract:** (pediatric\*)) OR (**abstract:** (paediatric\*)) OR(**abstract:** (juvenile\*)) OR (**abstract:** (“young person”)) OR(**abstract:** (“young people”))) AND ((**abstract:** (parent\*)) OR(**abstract:** (mother\*)) OR (**abstract:** (father\*)) OR (**abstract:** (family)) OR (**abstract:** (families)) OR (**abstract:** (caregiver\*)) OR (**abstract:** (care-giver\*)) OR (**abstract:** (maternal)) OR (**abstract:** (paternal)) OR (**Index Terms:** (parents)) OR (**Index Terms:** (family)) OR (**Index Terms:** (caregivers)))

### 3. CINAHL

AB parent\* OR AB mother\* OR AB father\* OR AB family OR AB families OR AB caregiver\* OR AB care-giver\* OR AB maternal OR AB paternal OR MH parents OR MH family OR MH caregivers = 360241

AND

AB (child\* or adolescen\* or infant\* or teenager\* or youth\* or baby or babies or toddler\* or pediatric\* or paediatric\* or juvenile\* or “young person” or “young people”) OR MH child OR MH adolescence = 884080

AND

AB ( pain\* or headache\* or head-ache\* or migraine\* or "stomach ache\*" or “stomach-ache\*” or "abdominal pain\*" or arthriti\* or "inflammatory bowel" or IBD or fibromyalgia\* or "sickle cell" or "complex regional pain syndrome" or CRPS or neuropathic ) OR MH pain OR MH chronic pain OR MH arthritis, juvenile rheumatoid OR MH inflammatory bowel diseases OR MH complex regional pain syndromes OR MH anemia, sickle cell OR MH Headache = 268839

AND

AB ( (cogniti\* or family or relaxation or acceptance or hypno\* or behavio#r\* or psycholog\* or problem-solv\*) N5 (intervention\* or treatment\* or therap\* or program) ) OR MH psychotherapy OR MH family therapy OR MH problem solving OR MH behavior therapy = 101743

### 4. Google Scholar

parent|caregiver|family child|adolescent|youth|pediatric|infant|juvenile "chronic pain"|headache|"abdominal pain"|arthritis|CRPS|"inflammatory bowel"|fibromyalgia|"sickle cell" psychological|CBT|acceptance|problem-solving intervention|treatment|therapy

**Supplemental Data File 2: Extraction Items**

Author(s)
Year
EndNote Ref #
Comments
Reviewer 1:
Date of Extraction (DD/MM/YY YY)
Reviewer 2:
Date of Extraction (DD/MM/YY YY)
English text? (Y/N/Unclear)
Peerreviewed study? (Y/N/Unclear)
Original data? (Y/N/Unclear)
Pediatric Chronic Pain Population? (Y/N/Unclear)

Psychological  
Intervention  
Study?  
(Y/N/Unclear)

Intervention  
Includes  
Parents?  
*See Core  
Definition  
#3 in  
Protocol*  
(Y/N/Unclear)

Decision:  
Include or  
Exclude

Reason for  
Exclusion if  
Not Clear  
from Earlier  
Columns

Data from  
previous  
study?

If yes, note  
earliest  
study  
published  
with the data

Comments

Targeted population? (P=parents only, YP=youth and parents, YPO=youth with parents optional)
Age Range of Youth
Age of Youth (Mean)
Youth (n)

Number Boys
% boys
Number Girls
% girls
Parents (n )
Number Mothers
% mothers
Number Fathers
% fathers
Number Grandparent
% grandparent
Number Stepparent
% stepparent

Other (specify)
Inclusion Criteria?
Exclusion Criteria?
Race/Ethnicity- Youth
Race/Ethnicity - Parent
Pain Condition: Musculoskeletal (n )
% musculoskeletal
Pain Condition: Abdominal (n)
%abdominal

Pain Condition: Back (n)
% back
Pain Condition: Headache (n)
% headache
Pain Condition: CRPS (n)
% crps

Pain Condition: Fibromyalgia (n)
%fibromyalgia
Pain Condition: Sickle Cell (n)
% sickle cell
Pain Condition: Nerve/ neuropathic (n)
% nerve/neuro pathic
Pain Condition: multiple (n)
% multiple
Pain Condition: Other (specify)
Pain Condition Other (n)

Who/How  
parents  
referred to  
tx?



<p><b>Therapeutic Approach:</b>  <i>(1=CBT, 2=ACT, 3=problem solving, 4=eclectic/mixed, 5=other)</i></p>
<p>If 'other', specify</p>
<p><b>Method of Delivery (code all that apply):</b>  <i>(1=inperson, 2=telephone, 3=webbased, 4=video conferencing)</i></p>
<p>Individual, Group, Mixed?</p>
<p>Who administers the psychological intervention? (e.g., psychologist, phd psychology student, etc)</p>
<p>How many facilitators?</p>

Facilitators received intervention specific training?
<b>RCT?</b> (1=yes, 0=no)
If yes, type of randomization?
Comparison group?
<b>Nonrandomized study?</b> (1=yes, 0=no)
Comparison group?
<b>Case Study?</b> (1=yes, 0=no)
<b>Data based on a treatment program</b> (e.g., IIPT, MDT, etc)? (1=yes, 0=no)
Total Length of tx (hours or weeks)

Length of tx youth participated in (hours)
Length of tx parents participated in (hours)

Degree of parental involvement (%)
Multicenter study?
Follow-up completed?
If yes, followup period(s), in months?
Stated Goals of tx for parent
Content of Parent Intervention (specific parent topics covered)
<b>Homework/ goals between sessions?</b> <i>(1=yes, 2=unclear, 0=no)</i>

<p><b>Mindfulness ?</b>  <i>(1=yes,  2=unclear,  0=no)</i></p>
<p><b>Relaxation?</b>  <i>(1=yes,  2=unclear,  0=no)</i></p>
<p><b>ProblemSolving?</b>  <i>(1=yes,  2=unclear,  0=no)</i></p>

<p><b>Vignette/Ca  se studies?</b>  <i>(1=yes,  2=unclear,  0=no)</i></p>
<p><b>Role Plays?</b>  <i>(1=yes,  2=unclear,  0=no)</i></p>
<p><b>Debrief/Disc  ussion with  Youth and  parent  together?</b>  <i>(1=yes,  2=unclear,  0=no)</i></p>
<p><b>Booster  Session?</b>  <i>(1=yes,  2=unclear,  0=no)</i></p>

<b>Other Component of tx?</b> (specify)
<b># eligible?</b>
<b># treatment condition?</b>
<b># comparison group?</b>
<b># attrition?</b>
<b># completed post?</b>
<b># completed follow up?</b>
<b>Satisfaction Ratings?</b> (Yes/No)

If yes, enter average satisfaction as %
<b>Acceptability Ratings?</b>
If yes, enter average
<b>Focus Groups Conducted?</b>
If yes, data analysis method
If yes, sample size

If yes, main results
<b>Open-Ended questionnaires?</b>
What were the questions?
If yes, data analysis method
If yes, sample size
If yes, main results
<b>Individual Interviews?</b>
If yes, data analysis method
If yes, sample size
If yes, main results

<b>Were there any adverse events related to the study procedures?</b> (1=yes, 0=no, 2=not reported)
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<b>Youth Outcomes Assessed?</b> <i>(1=Yes, 0=No)</i>
Quantitative Data: Measure, Source
Qualitative Data: Format, Source
Key Findings/Main Results:
<b>Parent Outcomes Assessed?</b> <i>(1=yes, 0=no)</i>
Measure, Source
<b>Parent Reported Youth Outcomes Assessed?</b> <i>(1=yes. 0=no())</i>
Measure, Source

Qualitative Data: Format, Source
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Key Findings/Main Results: