University of Southampton

Faculty of Environmental and Life Sciences

School of Psychology

How can schools support the education of children and young people experiencing chronic pain: Perspectives of teachers and other school staff.

by

Lauren Carol Baggley

Thesis for the degree of Doctorate in Educational Psychology

June 2021

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Abstract

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Chronic pain (CP) is a prevalent health problem in school aged children and young people (CYP). A body of evidence suggests CP has a profound impact on many aspects of CYP's lives including in an academic context. CP is associated with poor school attendance, poor academic performance and overall impairment in school functioning. Research commonly uses attendance to measure this impact however, school functioning is a multi-dimensional concept including social, cognitive and emotional aspects. There is also disparity in the measures used to determine school functioning. Given the wide ranging impact of CP, it is important that CYP experiencing CP are well supported in school by adults who feel competent supporting their needs. However, to date there has been limited research eliciting school staff's perspectives on managing CP in school. In this thesis, I sought to address the gaps in the literature through two studies. In a systematic literature review I explored the assessment and measurement of the impact of CP on the school functioning of school aged CYP. Overall, CP was found to negatively impact numerous aspects of school functioning including attendance, performance, academic self-efficacy, limiting physical activities, emotional and social functioning and overall school functioning. Wide and varied outcome measures were used to determine the impact of CP. In an empirical study, I conducted semi structured interviews with 12 members of school staff in various roles about their experiences supporting children and young people with CP at school. Through thematic analysis, four themes were developed concerning staff's perceived misunderstanding of chronic pain as a biopsychosocial phenomenon, the wide ranging impact of chronic pain, lessons learned from the Covid-19 pandemic and managing chronic pain in a school setting. Promising implications were identified for supporting students with CP with greater flexibility and a blended learning approach in future.

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Research Thesis: Declaration of Authorship

Print name: Lauren Carol Baggley

Title of thesis: How can schools support the education of children and young people experiencing chronic pain: Perspectives of teachers and other school staff.

I declare that this thesis and the work presented in it are my own and has been generated by me as the result of my own original research.

I confirm that:

1. This work was done wholly or mainly while in candidature for a research degree at this University;
2. Where any part of this thesis has previously been submitted for a degree or any other qualification at this University or any other institution, this has been clearly stated;
3. Where I have consulted the published work of others, this is always clearly attributed;
4. Where I have quoted from the work of others, the source is always given. With the exception of such quotations, this thesis is entirely my own work;
5. I have acknowledged all main sources of help;
6. Where the thesis is based on work done by myself jointly with others, I have made clear exactly what was done by others and what I have contributed myself;
7. None of this work has been published before submission

Signature: .... Date: 07/06/2021

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Definitions and Abbreviations

CP	Chronic Pain. Pain that persists for more than three months and continues beyond the normal period of tissue healing.
CYP	Children and Young People
CASP	Critical Appraisal Skills Checklist
EP	Educational Psychologist
HRQOL	Health Related Quality of Life
IASP	International Association for the Study of Pain
JCA	Juvenile Chronic Arthritis
JIA	Juvenile Idiopathic Arthritis
JPFS	Juvenile Primary Fibromyalgia Syndrome
LSA	Learning Support Assistant
MMAT	Mixed Methods Appraisal Tool
PE	Physical Education
SENCo	Special Educational Needs Coordinator
WHO	World Health Organisation

Chapter 1 Introduction

Introduction to the topic

The overall purpose of this research was to explore the wide ranging impact of chronic pain (CP) on children and young people's (CYP) school functioning, and to understand the experiences of school staff supporting CYP with CP in an educational context. The aim of the current study was to better understand how schools can support the education of CYP experiencing CP, from the perspectives of a range of school staff. This chapter provides information regarding the context and rationale for the research, the methodology and epistemological position and the researcher's interest in the area. A brief description of the structure of the thesis is also given.

Chronic pain defined by the International Association for the study of Pain (IASP) as "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al, 2020, p.1)is considered a significant health problem among school aged children. CP is common, it is thought to be experienced by between one quarter to one third of children worldwide (World Health Organization (WHO), 2020) and has profound, wide ranging impacts on many aspects of CYP's lives including school life. CYP with CP commonly experience high school absence rates (Groenewald, Giles, & Palermo, 2019; Sturge, Garralda, Boissin, Doré, & Woo, 1997). This is particularly concerning as the school setting is a fundamental and influential system in CYP's lives (Bronfenbrenner & Mahoney, 1975) providing important structure, developmental opportunities and relationships with key adults that are central to positive development (Brendtro, 2006). Students with CP who are regularly absent therefore risk regularly missing out on the developmental opportunities and beneficial routine provided by school. Moreover, the impact of CP on CYP's school functioning also has broader implications for adulthood. Long term follow up research reports that the impact of CP on CYP's school attendance and performance is long lasting, impacting life outcomes, higher level education and employment (Kashikar-Zuck et al., 2010).

The biopsychosocial model of CP (Turk & Gatchel, 2018) is suggested to be the most heuristic approach to the assessment, treatment and prevention of CP (Bevers et al., 2016) The model recognises the interconnected biological, psychological and social aspects of an individual's pain experience and thus acknowledges individual differences in symptoms and presentation (Gatchel et al., 2007) The model also emphasises how a person responds to and manages the symptoms of their illness. In contrast, the biomedical model focuses instead on anatomical processes and tends not to consider the psychological and social processes which may create unique experiences in different individuals. As this research aims to explore the wide ranging experience of CP, and the biopsychosocial model is a multidimensional, widely used model of CP (Taylor et al., 2013) which acknowledges the differing individual experience of pain, due to the varying interaction between the three factors. The biopsychosocial model is thus used as the frame of reference for this research.

The biopsychosocial model is a helpful framework to understand CP in CYP because paediatric CP is nuanced and complex. Pain in children is experienced differently to pain in adulthood (Hathway, 2014) and there are complex developmental, social, and psychological needs to be taken into account which vary widely dependent on a CYP's developmental stage and chronological age. CYP have unique needs when assessing the experience and impact of their pain (Finley, Chorney & Campbell, 2014) as CP in CYP is experienced during a time that CYP are developing physically, emotionally and psychologically. For example, children may not have developed the communication and language skills to adequately communicate their pain, and may differ in their behavioural response to pain due to their developmental stage (Hathway, 2014). The demands placed on CYP at different developmental stages of their lives may also influence the extent to which CYP experience the impact of CP. For adolescents, for example, the potential social restrictions experienced due to their CP at a developmental stage of life when image and personal relationships are important (Dahl et al., 2018; Ellis et al., 2020) may be considered a severe impact of CP, more so than for a younger child who may find managing the emotional impact of CP very difficult due to not yet developing the coping strategies necessary to manage adverse experiences (Liossi and Howard, 2016.) Historically, CP has been dichotomised as caused by physical means, or as mostly psychological in cause, which is resisted by many children and families experiencing CP (Williams et al., 2009.) However, research suggests a biopsychosocial basis to CP, in which CP results from complex interactions between nociceptive, affective, sociocultural, behavioural and cognitive factors (Liossi and Howard, 2016.)This interaction contributes to the complex and subjective experience of CP for CYP, even when the cause of the CP may be unknown, and means that information on a wide range of biopsychosocial factors and developmentally relevant factors are considered when assessing the impact of CP for CYP.

Early intervention and the implementation of supportive adaptations in school for these CYP are key (Gold et al., 2009; Rajapakse, Liossi, & Howard, 2014), without this the impact of CP on school functioning worsens, and barriers become more difficult to address. However, limited research to date eliciting school staff's perspectives regarding managing pain in an educational context suggests that staff feel they lack competence and are inadequately educated about managing CP in a school setting, meaning they often struggle to effectively manage CYP with CP in school (Logan & Curran, 2005). In addition, research exploring accommodating approaches employed by schools for CP found wide variations and inconsistency in the type of support offered (Logan, Coakley, & Scharff, 2007; Logan, Catanese, Coakley, & Scharff, 2007). It is concerning that CP remains poorly recognised and managed among professionals in key systems in CYP's lives as it is important that CYP experiencing CP are well supported to access school by adults who feel competent in managing their symptoms and supporting their needs.

Therefore, in order to support school staff to manage CYP's CP in school and to improve outcomes, it is necessary to understand the perspectives of school staff working with CYP with CP. By developing an understanding of the experience of working with CYP with CP from the perspectives of school staff, and identifying the specific areas that school staff find more difficult to accommodate, it is hoped that specific supportive recommendations could be made to schools which will in turn improve CYP's school success.

At the time this study was conducted, during the Covid-19 pandemic, national school closures were implemented in order to reduce transmission of the virus. 8.8 million students in the UK were not attending school (Lewis, Munro, Smith, & Pollock, 2021) and the detrimental impact of not attending school on CYP's general development, mental health and wellbeing was an issue of national concern (Hazell, 2021; Williams, 2020).

For the first time, a vast majority of students experienced accessing their schoolwork in the same way as their peers with CP who regularly find it difficult to physically attend school, school staff began to use virtual platforms to teach and maintain a connection with students. This unique context provided the opportunity to observe a naturally occurring intervention, by exploring the benefits and drawbacks of virtual working during the pandemic it was hoped that schools could consider continuing to use these methods for CYP with CP, to assist them in accessing school when they are unable to physically attend and to maintain the vital connection to school.

Finally, it is recognised that school staff involved in the care of CYP with CP are not limited to teachers. Educational psychologists are well placed to support school staff with information needs, implementing supportive adaptations and advising regarding learning policies such as a virtual learning approach. Research suggests that school psychologists are well placed to provide a link between healthcare recommendations for CP and school systems (Shriver, Matthews & Allen, 1999). However, to date there is no known research eliciting the views of EP's specifically regarding the support of CYP with CP in schools. Therefore, this research included the views of a wide range of staff involved in supporting the education of CYP with CP, including EP’s, Learning Support Assistants (LSA’s) and Special Educational Needs Coordinators (SENCO’s).

In summary, this research aimed to address gaps in the literature and to provide a unique contribution in the form of eliciting the perspectives of a range of school staff involved in the support of CYP experiencing CP. The research also seized the opportunity to explore how this support was implemented in the context of school closures and virtual learning, to see what, if anything could be gained from this approach, and whether successful strategies could continue to be used for CYP with CP in the future. The findings of the research provide valuable information about the perspectives of school staff working with CYP with CP, methods that are effective, barriers to be overcome, and the support needs of school staff.

Personal interest

Before training as an Educational Psychologist (EP), I worked as a member of pastoral support staff in a nurture provision at a mainstream secondary school. A number of students accessed this provision due to difficulties accessing their mainstream classes, including a number of students with medical conditions who experienced CP. My role consisted of supporting the students both with their learning and emotional wellbeing, with the aim of supporting a successful transition back to mainstream education. Sadly, the impact of the students’ CP often created multiple barriers to doing so.

The students were often absent due to painful symptoms, fatigue caused by a lack of sleep due to pain or over exerting themselves on the days they did attend school resulting in increased pain symptoms the next day, as well as hospital appointments and treatment side effects. Through conversations with the students I realised the reasons for their absence were far more complex. The students discussed how difficult they found returning to school following an absence, they had missed large chunks of teaching input causing them to feel behind with their work and under pressure to catch up- sometimes these feelings of stress exacerbated their pain and caused further absence. The students also felt isolated, they experienced great difficulty maintaining friendships when they were frequently absent and not attending mainstream classes when they were at school, their friendship groups quickly moved on without them and they did not feel they belonged as a valued member of the class. They spoke of feeling embarrassed by adaptations made for their CP in school, like any other student of their age they were conscious about appearing different to their peers and they worried about not being believed, particularly when their symptoms were less obvious. For some students this had led to instances of bullying, causing further reluctance to attend school.

The longer students were absent, the more anxious they felt about returning to school. This resulted in the students getting stuck in a vicious cycle of absence and school avoidance which was difficult to break. In addition, while school staff in the setting were hugely sympathetic to the student's needs and worried about them often, they felt they were not knowledgeable about CP to a level that they would feel confident implementing support. Staff worried most commonly about embarrassing the student, saying the wrong things or implementing the wrong support which may make the pain worse. This experience, in turn with my training in educational psychology led to my interest in eliciting the voices of those supporting CYP with CP. I strongly felt that identifying the barriers to supporting CYP with CP in school was key in order to implement the support needed both at an individual and organisational level, and to empower staff to provide the necessary support to improve the outcomes and school success for students with CP.

Epistemology and methodology

This study employed a qualitative approach using semi-structured virtual interviews and held a social constructivist epistemology. Epistemology concerns the rules that individuals use for making sense of their world (Hoffman, 1981). The social constructivist position entailed an understanding that meanings are developed through subjective experience (Cresswell, 2003) and that knowledge can be best understood through the lens of the individual. Meanings were therefore constructed and interpreted through the researchers interactions with participants (Burr, 1995). Social constructivist epistemology was considered fitting for this research as the study aimed to understand participant's views and perspectives based upon their experience of the world and not biased by the researchers view. Social constructivism posits that more than one account of reality exists and explores individual's views about their lived experiences as opposed to seeking expert knowledge on a topic. Therefore, semi structured interviews promoting an open discussion about participants experiences were considered appropriate to facilitate participants to freely discuss their personal views and perspectives from their experiences.

Further, qualitative methodology, in particular thematic analysis of semi structured interviews, was chosen to facilitate gathering rich perspectives from participants about their experiences, which may be more difficult to access in the same detail in more formal methods (Pope & Mays, 1995). Qualitative methodology generates knowledge grounded in individuals experiences (Sandelowski, 2004) and thematic analysis generates insight into both the similar and differing rich experiences from the perspective of individuals (King, 2004). Therefore, this approach was felt to be most appropriate when considering the research aims to understand the perspectives of school staff.

While the context of the pandemic at the time of this research meant virtual interviews were necessary, there were a number of advantages to using this approach. The interview process was more accessible to participants with busy schedules who could arrange to take part in the interviews from home at a convenient time. The virtual nature of the interviews also meant that participants from a wide geographical spread were able to take part.

Ethical considerations

While the nature of the research was unlikely to cause participants distress due to the open natured discussion of their experiences, ethical considerations were fundamental in the design of the study. It was acknowledged for example that participants may find it difficult to speak about their feelings of competence when working with students with CP. To ensure this was taken into consideration, participants were provided with an information sheet prior to consenting to take part in the study. This information sheet detailed the nature of the interview and explained participant's right to pause or stop the interview, and to withdraw from the research at any time without giving a reason. This was reiterated to participants at the outset of the interview and participant's expressions were carefully monitored throughout the interviews to detect any discomfort.

It was also acknowledged that participants may feel uncomfortable discussing negative aspects of their job, or criticising aspects of the support their school provides. Therefore, confidentiality and anonymity was also made clear both in the participant information sheet and at the outset of each interview. Participants were informed prior to signing the consent form that the interviews would be recorded in order to create transcripts, and that only the researcher and supervisors would have access to these recordings, which would be deleted subsequent to transcription. Participants were also assured that measures would be taken to maintain confidentiality by assigning pseudonyms to each participant and omitting any identifiable information from transcripts. It was important to acknowledge that while unlikely, it was recognised that it may be possible for participants to be identified, as they may have been known to one another in their working practice. Therefore, the information sheet reiterated that participants' involvement in the study could not be maintained as anonymous, however the procedures discussed would maintain confidentiality as much as possible.

Dissemination

A summary of key findings will be offered to the participants in the form of a one to two page document which will be emailed to participants following completion of the thesis. Opportunities for publication in professional peer reviewed journals will be sought, with the intention that findings will inform the support needs of school staff managing the needs of students with CP in a school setting, such as training and supervision needs. Further, the findings of the research will inform the development of supportive educational materials for parents and carers of children with life limiting conditions, and school staff supporting children with life limiting conditions in school. These materials are currently being developed and are available in draft format in Appendix M.

Structure

Chapter two reports a systematic review of the assessment and measurement of the impact of chronic pain on school functioning in children and adolescents. Chapter three details an introduction to the current study, followed by a description of the methodology used to address the aims, the findings of the current study and a discussion of these findings. Implications of the research and directions for future research opportunities are also discussed.

Chapter 2 Assessing and measuring the impact of chronic pain on the school functioning of children and adolescents.

Abstract

Chronic pain (CP) is considered a significant health problem in school aged children which impacts many aspects of everyday life including school functioning. The aim of this review is to provide a comprehensive review of the impact of CP on the school functioning of school aged children and young people, and to determine how the impact of CP on school functioning is measured. Studies were identified by searching six databases. The search strategy included concept blocks pertaining to pain, study population and school setting. Eligible studies had a sample of school aged children (5-18 years old), school staff or healthcare professionals working directly with students experiencing CP and reported a school functioning outcome. 92 studies were included in the final review. Overall, CP was found to negatively impact numerous aspects of school functioning including school attendance, performance, academic self-efficacy, limiting physical activities, emotional and social functioning and overall school functioning. Wide and varied outcome measures were used to determine the impact of CP on children's school functioning. Teachers and school staff's support and positive perceptions of students with CP were found to be a potentially protective factor against the negative impact of CP in some school functioning domains. In summary, CP has a significant impact on school aged children's school functioning including school attendance, performance, academic self-efficacy, limiting physical activities, emotional and social functioning. However, some studies indicated no effect, and some reported that CP motivated students to be successful at school. The impact of CP was determined using a wide range of outcome measures. Implications for supporting children and young people with CP in a school setting are discussed.

2.1 Introduction

Chronic pain (CP) defined by the International Association for the study of Pain (IASP) as “an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage” (Raja et al, 2020, p.1) is considered a significant health problem among children. It has a profound impact on many aspects of everyday life including family life, school life, social life and peer relationships (Palermo & Kiska, 2005). CP also has a negative impact on children’s emotional wellbeing (Gureje, 2007) and is associated with higher depressive and anxious symptoms, low self-esteem, and increased behaviour problems (Varni et al., 1996), with previous research finding adolescents who suffer from CP are at increased risk for suicide ideation and attempts (Van Tilburg, Spence, Whitehead, Bangdiwala, & Goldston, 2011). While prevalence rates vary, international data suggests that prevalence of self-reported CP in adolescents is high, with 44.2% of adolescents reporting weekly CP (Gobina et al., 2019). Prevalence of CP has also been found to increase with age for most pain types, with headache prevalence for example found to generally increase with age in a review of 37 studies (Albers, Heinen, & Straube, 2015) and is typically more common in girls, headache for example is found more prevalent in girls across a number of international studies (King et al., 2011). CP is thought to be experienced by between one quarter to one third of children worldwide (World Health Organization (WHO), 2020).

A specific context in which CP detriments children and young people is in their academic lives. The social and academic opportunities provided by a school setting are fundamental to healthy development (Korpershoek, Canrinus, Fokkens-Bruinsma, & de Boer, 2020; Osher, Kendziora, Spier, & Garibaldi, 2014; Storli & Hansen Sandseter, 2019) therefore, the well documented impairment CP causes in school functioning is concerning. CP is associated with poor attendance along with overall school impairment (Logan, Simons, & Carpino, 2012), difficulties with concentration, keeping up with schoolwork and school avoidance (Khan et al., 2015) as well as detriments in participation in school activities, social functioning and perceptions of academic competence (Alsaggaf & Coyne, 2020).

Sleep disturbance is common in school age children with CP, and is associated with negative effects on daytime functioning (Long, Krishnamurthy, & Palermo, 2008).

Further to this, research shows that many adolescents with CP miss significant amounts of teaching through school absence, often experience declining grades, and perceive their pain to interfere with their school success (Logan, Simons, Stein, & Chastain, 2008). When such impairments in school functioning are left unattended they can deteriorate or result in nonattendance, creating a further barrier to children experiencing the developmental opportunities that school provides. A large body of CP research commonly uses school attendance to indicate the impact of CP on school functioning. However, school functioning is a multi-dimensional concept that includes attendance, academic performance/achievement, academic competence, physical activities, and social relationships (Haraldstad, Sorum, Eide, Natvig, & Helseth, 2011; Khan et al., 2015). Broadly, any social, cognitive, or emotional aspect of behaviour that impacts a student either directly or indirectly in the school setting can be considered as school functioning (Gorodzinsky, Hainsworth, & Weisman, 2011).

Previous reviews have considered the impact of CP on school functioning, reporting that CP negatively impacts cognitive functioning (Dick & Riddell, 2010), functioning in everyday life (Palermo, 2000), school attendance (Sato et al., 2007) peer relationships and social inclusion (Forgeron et al., 2010). A more recent worldwide review including 14 eligible papers that considered the impact of CP on adolescent’s school functioning reported mixed results (Alsaggaf & Coyne, 2020). Specifically, CP appeared to negatively impact adolescents' school attendance, academic performance/achievement, academic competence, physical activities, and social functioning. However, it was also reported that adolescents with CP had better academic performance and competence than their healthy peers, perhaps due to school support received by these students. The review concluded that as most of the eligible studies focused on school attendance, further research should explore the association between adolescents' CP and various school functioning domains in order to provide a more comprehensive view of the impacts paediatric CP can have.

Further to this, as school functioning is a multi-dimensional concept, various methods and outcome measures are used to assess school functioning. A review of the measures used to assess school functioning in CYP with CP reported disparity in the assessment methods used, which focused primarily on school absence (Gorodzinsky et al., 2011). The authors recommended further study of the impact of CP on the wide ranging dimensions of school functioning such as assessment of academic performance, ability to participate in school activities, perceived academic and social competence.

Considering these important questions, the aims of this systematic review are to explore the impact of CP on the school functioning of school aged children and young people, and to determine and compare how the impact of CP on school functioning is measured.

2.2 Method

Design

The review followed the Preferred Reporting Items for Systematic Review and Meta-Analysis Protocols (PRISMA) guidelines (Moher et al., 2015). A protocol was prepared and is available on request. The protocol was not registered on PROSPERO (International prospective register of systematic reviews) as this registration database does not accept the registration of trainee research.

Literature search

A systematic search strategy was used including three concept blocks pertaining to (i) pain (e.g. abdominal pain, arthritis), (ii) study population (e.g. teen* teach*) and (iii) school (e.g. institute, college). A comprehensive search of the MEDLINE, PsycINFO, CINHAL (title, abstract via EBSCO Host), Web of Science (title), and Cochrane Library (title, abstract, keywords) databases was conducted. A search of non-traditional publications, commonly known as ‘grey literature’, was conducted using Open Grey. All databases were searched from database inception to the date of search (between 1st March 2020 and 31st May 2020). Full search terms are available in Appendix A. The study selection process is outlined in the PRISMA diagram (See Figure 1; Page et al., 2021).

Inclusion Criteria

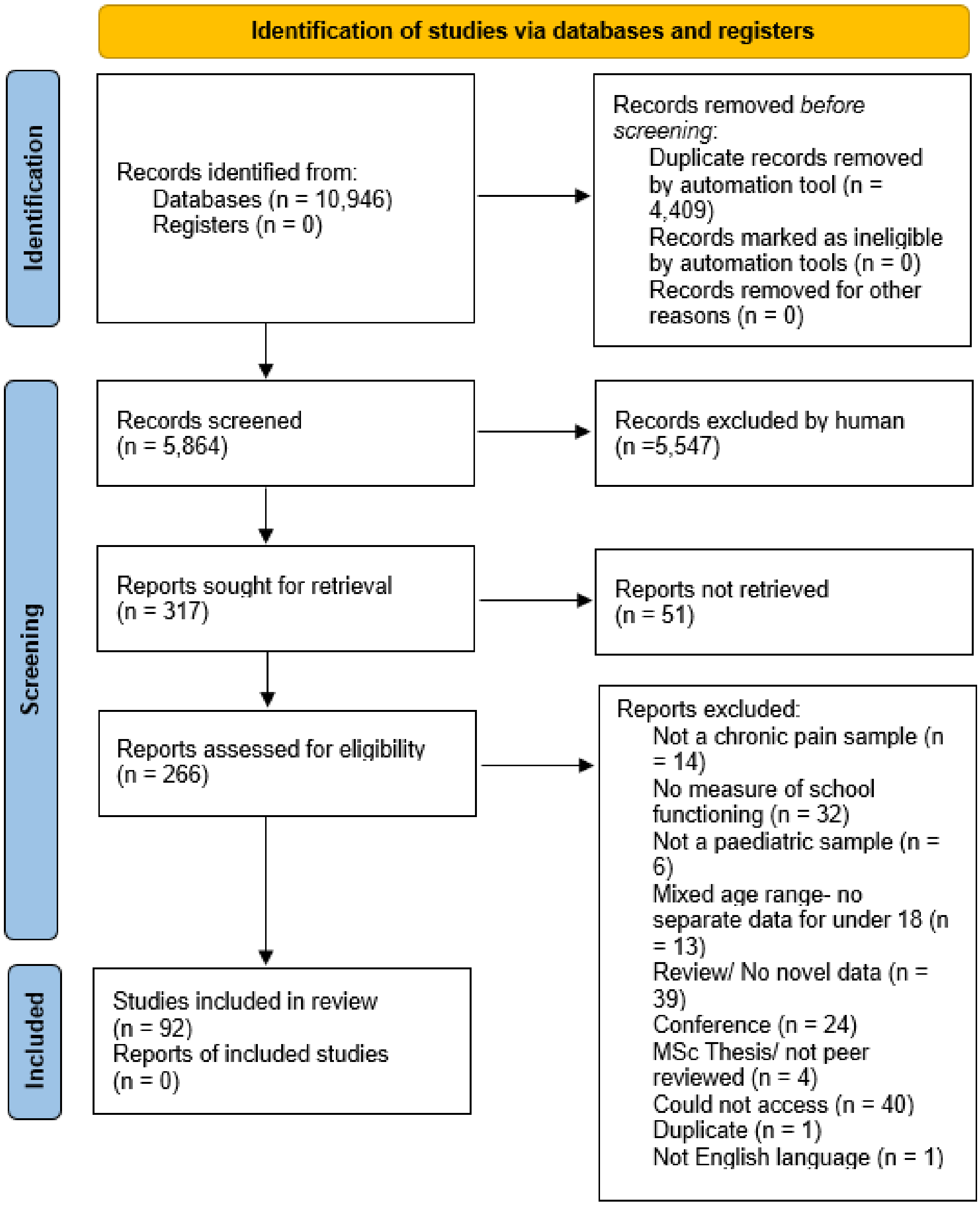
The inclusion and exclusion criteria adhered to the SPIDER (sample, phenomenon of interest, design, evaluation, and research type) criteria (Cooke, Smith, & Booth, 2012) detailed in Table 1. For inclusion in the review, studies were required to have a sample of children or adolescents experiencing chronic pain of school age (5-18 years old), school staff working in a direct role with children and adolescents experiencing chronic pain (Teachers, Support Staff, SENCo's, School Counsellors, School Nurses, Educational Psychologists), Families (parents and care givers) caring for a child or adolescent experiencing chronic pain and healthcare professionals working with children and adolescents experiencing chronic pain (Clinicians, Physicians, Doctors, Nurses, Psychologists, Occupational Therapists, Physiotherapists, Counsellors). Included studies had to detail an outcome pertaining to school functioning, be in English language and could include case studies, PHD theses and observational studies (case-control, cross-sectional, retrospective and prospective cohort studies). Included studies were published between the years of the databases inception and 2020.

Table 1 Inclusion and Exclusion Criteria using the SPIDER Tool

Criteria	Inclusion criteria	Exclusion criteria
Sample	Children and adolescents experiencing chronic pain of school age (5-18 years old) School staff who work in a direct role with children and adolescents experiencing chronic pain (Teachers, Support Staff, SENCo's, School	Children and adolescents not of school age (under 5 and over 18 years old) School staff not working in a direct role with children and adolescents

Criteria	Inclusion criteria	Exclusion criteria
	Counsellors, School Nurses, Educational Psychologists)	
	Families (parents and care givers) caring for a child/adolescent experiencing chronic pain.	Families (parents and care givers) who do not care for a child/adolescent experiencing chronic pain.
	Healthcare professionals working with children and adolescents experiencing chronic pain (Clinicians, Physicians, Doctors, Nurses, Psychologists, Occupational Therapists, Physiotherapists, Counsellors)	Healthcare professionals not working directly with children and adolescents experiencing chronic pain.
Phenomenon of interest	Chronic Pain	Acute Pain, Non- Chronic Pain conditions
Design	Case studies, PHD theses, observational studies (case-control, cross-sectional, retrospective and prospective cohort studies)	Medical trials, Masters theses, Conference abstracts.
Evaluation	School Functioning Outcome	No School Functioning Outcome
Research	Quantitative, Qualitative and Mixed Methods.	-
Settings	Research conducted in all countries	-
Publication Years	Inception- 2020	-
Language	English Language	Languages other than English

Figure 1 PRISMA 2020 flow diagram for study selection



Data Extraction

Data from eligible studies were extracted into a supplementary table (Appendix B) by one member of the research team (LB), and were subsequently checked for accuracy by another member of the team (DS).

Study Quality Assessment

The Critical Appraisal Skills Programme (CASP) checklist (CASP, 2018) was used to critically evaluate the qualitative studies and the Mixed Methods Appraisal Tool (MMAT), version 2018 (Hong et al., 2018) for the quantitative studies. This tool consists of five closed questions assessing the research question, research design, and integration of qualitative and quantitative methods, integration of qualitative and quantitative data and consideration of methodological limitations in mixed methods studies. This tool has been used widely in systematic reviews and has the advantage of assessing qualitative and quantitative elements of mixed-methods research (Noyes, Booth & Flemming et al, 2018). One author performed the risk of bias assessment which was then checked by a second author (DS). Any disagreements were resolved by discussion with a third author (CL) as necessary.

2.3 Results

Search Results

The search of the six databases resulted in 6,537 articles. Of these, 673 duplicates were removed and the remaining 5,864 articles were screened by title and abstract screening by one reviewer (LB) and a random 20% were checked by a second reviewer (DS) with high agreement (97.6%), removing 5,547 citations. 51 citations could not be retrieved therefore, the 266 remaining full-text citations were assessed for their eligibility and 174 were excluded (see figure 1 for reasons) which resulted in 92 papers eligible for inclusion. The final review included 92 eligible studies, which included 80 quantitative studies and 12 qualitative studies.

Methodological Quality

A detailed summary of methodological quality is available in Appendix C. To briefly summarise, three studies met the full CASP checklist criteria (Condon, O’Regan, MacDermott, & Killeen, 2017; Hackett, 2003; Waite-Jones & Swallow, 2018). All 12 qualitative studies provided rigorous details concerning the process of data analysis, had an appropriate recruitment strategy in relation to the aims, clearly stated their findings and discussed the contribution of the findings to existing research. Nine studies provided sufficient detail of ethical considerations. Four studies adequately considered the relationship between the researchers and participants (Barlow, Shaw, & Harrison, 1999; Condon et al., 2017; Hackett, 2003; Waite-Jones & Swallow, 2018).

Considering the quantitative data, one study met all of the MMAT quantitative randomised control trial criteria (Armbrust et al., 2016). 31 of 36 studies met all of the MMAT non randomised criteria, 36 provided full outcome data, 36 recruited participants using methods that minimised selection bias, 35 of these studies provided information regarding the appropriate measure used, and 32 provided information regarding whether groups of participants were comparable in terms of key demographics.

37 of 43 studies met all of the MMAT descriptive criteria. All 43 studies used a sampling strategy relevant to the study aims and detailed an acceptable response rate (above 60%), 42 studies provided inclusion and exclusion criteria, 39 studies detailed appropriate measurements used however for four studies there was insufficient information regarding the measures used.

School functioning outcome measures

School functioning outcomes and the measures used varied widely between studies. The most commonly reported outcomes were school attendance, commonly measured by The Paediatric Quality of Life core scales (Varni, Seid, Knight, Uzark, & Szer, 2002), inventory (Varni, Seid, & Kurtin, 2001) and school functioning subscale (Varni et al., 2001) and numerically by days of school missed among other measures. School performance, also commonly measured by The Paediatric Quality of Life core scales, inventory and school functioning subscale and limited physical activities, measured by a range of standardised questionnaires and inventories, checklists and bespoke question items. Social impact, emotional impact, quality of life and school functioning were also commonly measured and used a wide range of outcome measures (Appendix D)

Narrative Review

Summary of identified studies

The characteristics of the included studies are shown in Appendix E. Included studies were conducted over a wide geographical range. A large number were conducted in the USA (n = 35) and the United Kingdom (n = 10) as well as the Netherlands (n = 5), Germany (n = 4), Norway (n = 3), and Sweden (n = 3). Studies were also conducted in Egypt, India, Turkey and Brazil (n = 2 respectively) and the Czech Republic, Iceland, Canada, Serbia, Iran, Israel, Finland, Qatar, Malaysia, Thailand, Ireland, Scotland, Japan, Croatia, Bulgaria, Denmark, Greece, France, Lithuania, Switzerland, Spain, Australia, Belgium and China (n =1 respectively). Included studies were published between 1987 and 2020, with 28 studies published in the last five years and 48 in the last ten years.

Most studies were conducted with children and young people across both primary and secondary school age groups. For the included quantitative studies, 58 were conducted across age groups, 19 were secondary school age (12-18) and 4 primary age (5-11). For the qualitative studies, the majority were conducted across age groups (n = 10) with 1 study conducted with primary school children only. Sample sizes ranged from 8–10,390 and participants included children and adolescents, parents, school staff and health professionals. Most studies included a paediatric population diagnosed with at least one CP condition.

Quantitative studies (N = 80)

School Attendance

The majority of quantitative studies (n = 40) reported the negative impact of CP on school attendance. Most used days of school missed per week as the outcome measure. Other outcome measures used were questionnaires, home schooling status, clinician rated school avoidance, visual analog scales and checklists of school problems including “problems attending”. Four studies reported interventions to improve attendance in children with CP, one study reported positive school attendance (Armbrust et al., 2016) and three studies reported no effect of CP on attendance.

A large, nationally representative sample of 8641 children and adolescents aged 6-17 reported that 68% of those with chronic school absence experienced CP (Groenewald et al., 2019). Another study found twice as many children with chronic daily headache compared with children with episodic headache (46.5% versus 20.5%) missed at least seven days of school due to their condition in an academic year (Rousseau-salvador, Amouroux, Annequin, & Salvador, 2014). In addition, children and adolescents with sickle cell disease were absent from school on 21% of 3186 school days, with half of the absences on days that pain was reported (Shapiro et al., 1995). A study of 219 children with CP aged 7-19 also reported that under half of children attended school full time, and the amount of children being home schooled was ten times higher than the national rate (Evans, Taub, Tsao, Meldrum, & Zeltzer, 2010). In contrast, one study reported that CP did not impact attendance. A study conducted in the Netherlands stated that of 80 children and adolescents with JIA aged 8-13, 70% had full school attendance with no absences due to JIA (Armbrust et al., 2016)

One study noted that differences in absence have been found amongst groups with CP. Children with systemic JRA were reported to be more likely to miss school, averaging 8.6 days per year, than children with polyarticular disease, averaging 2.6 days or children with pauciarticular disease, averaging 1.6 days (Whitehouse, Shope, Sullivan, & Kulik, 1989). Differences are also found for pain severity, with attendance significantly lower in a more severely affected JIA group (Sturge et al., 1997).

A study of school teachers reported that absenteeism and the negative effect of pain on ability to engage in school activities were the most common pain-related challenges teachers experienced (Solé et al., 2018). In addition, associations between pain and school absence were lower when children perceived their teachers to be highly supportive of competence and autonomy (Vervoort, Logan, Goubert, De Clercq, & Hublet, 2014).

Two studies reported the association of fatigue with CP and school absenteeism. Nijhof, Van De Putte, Wulffraat, & Nijhof (2016) reported that children with JIA and paediatric rheumatic diseases experienced significantly higher severe fatigue than healthy controls and in turn a significantly higher percentage of school absence (21.2% versus 11.6%, respectively). In contrast one study reported a minimal relationship between fatigue, absenteeism and school performance for children with rheumatic disease (Stoff, Bacon, & White, 1989).

Finally, four studies reported on interventions to improve school attendance. Multidisciplinary evaluations focusing on returning to functioning were found to significantly improve school attendance and functioning (Claar, Kaczynski, Minster, McDonald-Nolan, & Lebel, 2013). Another study found that a supportive intervention designed to improve school functioning in adolescents aged 12-17 with CP reported a significant decrease in school absence following intervention (Simons, Logan, Chastain, & Stein, 2010).

The majority of studies report that CP negatively impacts school attendance. It is suggested that fatigue caused by CP may in part cause high levels of absence. Interventions to support children and young people with CP to attend school are reported to be successful in improving attendance. One study however, reported that CP did not impact attendance and three studies found no effect of CP on school attendance.

School performance

Twenty-nine studies reported the impact of CP on school performance, including academic achievement and ability to function well in school, using a range of outcome measures including school examination grades, educational assessments and behavioural checklists and questionnaires.

One study found adolescents with CP are impacted in many areas of academic performance, such as missing a significant amount of school, experiencing a decline in grades, and perceiving their pain to interfere with their school success (Logan et al., 2008). This study also reported that various domains of school impairment were found to be highly inter-correlated ,suggesting that impairment in one domain is associated with impairment in other domains of school functioning. Similarly, amongst 10,650 children and adolescents, greater pain was associated with poorer outcomes across most school functioning domains (absenteeism, school-related pressure/satisfaction, and bullying) but not academic performance (Vervoort et al., 2014). Further studies report that students with a CP condition achieved significantly poorer grades than their healthy peers (Çagliyan Türk & Şahin, 2020; Durmaz et al., 2013).

A number of studies suggested poorer school performance in children with CP may be caused by poor attendance. 80.1% of 851 students with chronic headache reported that their school performance was impacted by frequent absence from school (Bessisso, Bener, Elsaid, Al-Khalaf, & Huzaima, 2005). Breuner, Smith, & Womack (2004) report a significant difference in school performance between high and low absenteeism groups, and students with juvenile fibromyalgia reported both more absences and lower school grades than their healthy peers (Durmaz et al., 2013).

One study found that inattention and distractibility caused by CP were highly related to school achievement in 46 children with rheumatic disease aged 5-18 years (Stoff et al., 1989). However, further studies report that CP does not appear to correlate directly with academic performance (Boey, Omar, & Phillips, 2003) and that complex, disabling pain did not indicate overall cognitive impairment, or atypical achievement in 57 children and adolescents with CP aged 8–18 (Ho, Bennett, Cox, & Poole, 2009).

One study suggested that CP may in fact motivate students to perform well. Adolescents with chronic tension headaches reported a significant desire to achieve superior marks at school and to succeed in life when compared to their healthy peers. Further, 46.1% of these adolescents were reported by their teachers to be excellent students and 33.3% very good. Other studies found no significant differences between children with JIA and their healthy comparable peers in school-related problems (Mihaylova et al., 2018; Rusoniene et al., 2018) or psychosocial quality of life (Pratsidou-Gertsi et al., 2018).

Findings in relation to the impact of CP on school performance are mixed, with some studies reporting a negative impact on school performance and others reporting no correlation. One study reported that CP motivated young people to succeed in school, and school staff observed them to be excellent students (Mandić, Baraban, & Boranić, 2003)

Academic Self efficacy

23 studies reported the impact of CP on young people's academic self-efficacy, which includes feelings of academic competence, and confidence in self-ability to achieve academically and function at school. Standardised questionnaires and scales were used as outcome measures.

Fujita et al (2009) reported of 50 children experiencing chronic daily headache, 48% were also found to suffer with school phobia. Of these children, all reported psychosocial and school problems. In a study of 30 adolescents with CP, those reporting lower school functioning endorsed more anxiety symptoms related to school and academic failure relative to those reporting higher functioning (Jastrowski, Gibler, Beckmann, Lynch-Jordan, & Kashikar-Zuck, 2017). In addition, adolescents with primary pain conditions reported poorer school self-concept and school self-efficacy when compared with both adolescents with JIA and healthy peers (Logan, Gray, Iversen, & Kim, 2017).

In another study, recurrent pain in 1524 school children doubled the likelihood of perceived problems with academic achievement, an association that was not explained by sleep disturbance, concentration or school absenteeism (Ragnarsson et al., 2019). In contrast, one study found that adolescents with CP are viewed by themselves and their teachers as academically competent (Logan et al., 2008).

In summary, the majority of studies report that CP negatively impacts young people's perceptions of their academic self-efficacy. However, one study reported that adolescents perceived themselves as academically competent (Logan et al., 2008).

Limited Physical Activities

23 studies reported the impact of CP in limiting physical activities in school such as physical education classes, academic and social activities. Outcome measures included standardised questionnaires and inventories, checklists and bespoke question items.

Decreased participation in sports or physical education (PE) classes were most commonly reported. For example, the proportion of children with JIA aged 10-16 spending 3 or more hours per week participating in club sports was reported as significantly lower than healthy controls (Nørgaard & Herlin, 2019). In another study, school activities were significantly lower in children with Leprosy compared to controls in the same age group of 13-18 years (Neder et al., 2015).

In two studies, increased daily symptoms of pain, stiffness, and fatigue were found to be significant predictors of reduced participation in school and social activities for children with juvenile arthritis (Schanberg, Anthony, Gil, & Maurin, 2003) and increases in daily stress, mood, and disease symptoms were significantly related to decreased participation in social activities (Schanberg, Gil, Anthony, Yow, & Rochon, 2005).

Data on specific school activities such as handwriting tasks is limited. One study looked specifically at handwriting difficulty, reporting that handwriting ability was decreased in children with JIA in comparison to healthy controls (Haberfehlner et al., 2011). Writing also represented the most frequent problem reported by 135 children with juvenile rheumatoid arthritis (Whitehouse et al., 1989).

In contrast, one study reported that participation in school sports increased for children with JIA from 31% in 2000 to 64% in 2015 and exemption rates simultaneously decreased (Milatz et al., 2019). In addition Whitehouse et al (1989) reported that 52% of 135 children with juvenile rheumatoid arthritis attended PE classes and participated fully.

The majority of studies find that CP impacts participation in physical activities at school including PE classes, classroom tasks and social activities. Some studies report increased or full participation in school sports and PE classes.

Social Functioning

17 studies reported the social impact of CP in school. Most asked children to respond using questionnaires, however other measures including a numerical scale to indicate bullying instances, and peer report questionnaires were also used.

The impact of CP on social functioning, including peer relationships, bullying and social image was widely reported by a number of studies. A study of 60 children with chronic abdominal pain reported that children with pain experienced higher levels of victimization than their healthy peers (Greco, Freeman, & Dufton, 2007). Children with JIA also reported concerns that they may be accused by others of fabricating their illness (Chomistek et al., 2019)

Another study reported that 55 adolescents with juvenile primary fibromyalgia syndrome (JPFS) were perceived by their peers as being more isolated, less popular and with fewer reciprocated friendships. Adolescents with JPFS were also more likely to be seen as being sick a lot, less athletically competent, and less physically attractive by their peers (Kashikar-Zuck et al., 2007). Children and adolescents experiencing recurrent pain reported “going to school” and “playing with friend” as the most limiting impacts of their recurrent pain (Palermo, Witherspoon, Valenzuela, & Drotar, 2004) and children with JIA were reportedly poorly adjusted both socially and educationally compared to healthy controls (Yadav & Yadav, 2013). These children also reported feeling lonely, and being teased more frequently about their arthritis by their peers.

Social functioning and CP were found to have important effects on school performance. Lower social functioning scores were significantly associated with pain, physical limitations, somatic symptoms and school impairment (Simons et al., 2010). Amongst children and adolescents with JIA, those with low self-concept reported feeling discriminated against more often in social situations and were more likely to believe arthritis hindered their relationships due to restrictions on activity, impaired appearance, and feeling different to their healthy peers (Ungerer, Horgan, Chaitow, & Champion, 1988). Finally, one study found that teacher support of competence was a protective factor against the effects of severe pain upon bullying experiences at school for children and adolescents with CP (Vervoort et al., 2014).

The majority of studies find that CP significantly impacts children's social functioning at school, with children reporting bullying instances, difficulty with peer relationships, and feeling they were perceived negatively by their peers. Negative social perceptions of the student with CP were also reported by peers. Teacher support was found to be a protective factor against bullying at school for CYP with CP.

Emotional Impact

13 studies reported the emotional impact of CP, including feelings of depression and anxiety which in turn impacted school functioning. Outcome measures included standardised questionnaires, Likert scales and anxiety and depression inventories.

Adolescents aged 12-17 with CP reported significantly more cognitive, behavioural, and psychophysiological symptoms of school anxiety relative to healthy controls (Jastrowski et al., 2017). In addition, a study of 27 adolescents with sickle cell disease reported that increases in stress and negative mood were associated with more school absences and reductions in activities (Gil et al., 2003). In addition, a study of 3000 high school students aged 16-18 reported that prevalence of CP was most highly associated with perceived heavy learning burden, and perceived pressure from parents, teachers and classmates (Zhang et al., 2015).

Two studies considered the role of protective parenting in relation to emotional impact and school functioning. Claar et al (2013) found that children with chronic headache reported greater feelings of depression, and protective parenting was also related to greater school difficulties for this group when compared to adolescents with migraine. In addition, when controlling for the influences of pain intensity and depressive symptoms, parental pain catastrophizing and parental protective responses to child pain were found to independently predict child school attendance rates and reports of overall school impairment (Logan, Simons, & Carpino, 2012).

Studies also reported associations between CP and feelings of anxiety. Increased anxiety was related to poorer school functioning in 349 youths with CP (Khan et al., 2015). Anxiety was also reported to be directly related to problems with school avoidance, difficulty with concentration, and keeping up with schoolwork. Similarly, youth with JFM showed significantly higher anxiety and depressive symptoms, and lower quality of life in all domains (Kashikar-Zuck et al., 2013). Finally, higher levels of depressive symptoms predicted more school impairment in 217 adolescents who were clinically referred for CP (Logan, Simons, & Kaczynski, 2009).

The majority of studies find that CP significantly impacts children’s emotional functioning and this in turn impacts school functioning in various domains. Children experiencing CP were reported to experience higher rates of anxiety and depression which impacted school functioning in terms of absence, difficulty concentrating, reduced activities and school related anxiety. In addition, protective parenting in response to children’s emotional experiences was also found to impair school functioning.

Quality of life

Five studies reported the impact of CP on children and adolescents general quality of life including school functioning, using The Paediatric Quality of Life Inventory and the Paediatric Quality of Life core scales as outcome measures.

One study considered the impact of CP on sleep quality, finding that children cited disturbed sleep as the most common impact of their CP (Haraldstad, Sørum, Eide, Natvig, & Helseth, 2011). A study in the Netherlands found that 152 children and adolescents with JIA reported a significantly lower health related quality of life in the majority of domains compared to both healthy controls and children with other chronic health conditions (Haverman et al., 2012)

Similarly, 10% of children with chronic headache had a generic quality of life score of 70.1, indicating a poorer quality of life than that of children with asthma, diabetes, or cancer (Kernick, Reinhold, & Campbell, 2009). Nyame et al (2010) also reported that headache severity moderately correlated with increased feelings of anxiety, functional disability, and a diminished quality of life. Another study found that children with migraines reported lower quality of life than healthy controls (Powers, Patton, Hommel, & Hershey, 2003). All of the included studies therefore report that CP impacts children's quality of life, including ability to function at school, negatively.

School functioning

13 studies reported the impact of CP on children and adolescents general school functioning, which included various domains such as attendance, academic performance, school-related pressure, school-related satisfaction and peer victimization, using The Paediatric Quality of Life Inventory school functioning subscale, checklists and bespoke item lists.

The majority of studies report that CP negatively impacts school functioning. School functioning is reported as significantly poorer for children with juvenile fibromyalgia (Çagliyan Türk & Şahin, 2020) hypermobility (Fatoye, 2008) and chronic migraine (Kashikar-Zuck et al., 2013). Further, children with chronic fatigue syndrome reported school issues (keeping up with work, expectations, and attendance) as disability related problems (Garralda & Rangel, 2004). In the same study, children with JIA reported adaptations that were made to support their functioning in school. These mostly related to mobility, for example help carrying books or walking between classrooms.

Similarly, Logan et al (2008) reported that students with more severe pain received more adaptations in school, however students receiving more adaptations reported greater impairment in school functioning (lower attendance and greater ratings of pain interference with school performance). In contrast, a number of studies report no significant difference between students with CP conditions and their non-affected peers in problems with school functioning (Aggarwal et al., 2018; Pratsidou-Gertsi et al., 2018; Rusoniene et al., 2018).

One study considered the difficulties teachers experience whilst supporting children experiencing CP in school. Solé et al (2018) reported that teachers considered absenteeism and the negative effect of pain on the ability of students to engage in school activities as the most common pain-related challenges that prevented them supporting children’s school functioning. Teachers also reported problems with making adjustments for students with CP and promoting school policies that are adaptive and support the integration of these students. As noted above, a large survey of 10650 children and adolescents reported that CP was associated with poorer outcomes across all domains of school functioning. However, impaired school functioning was less pronounced when children perceived their teachers to be highly supportive (Vervoort et al., 2014).

In summary, the majority of studies report that CP negatively impacts general school functioning, including attendance, keeping up with schoolwork and the necessity for adaptations in school. Teachers also reported difficulty making the necessary adaptions to support school functioning for these students. Three studies however, reported no significant difference between student with CP and their peers in school functioning.

Qualitative studies (N= 12)

School attendance

Six qualitative studies reported the effects of CP on school attendance and performance. In focus group interviews, children and adolescents with juvenile idiopathic arthritis (JIA) reported that missing school was an important impact of JIA (Guzman et al., 2014). Similarly, children with uveitis associated with JIA reported feeling upset about missing their lessons and experiencing subsequent anxiety and pressure to catch up (Sen et al., 2017). In addition, Batthish et al (2005) found that of 14 children with JIA, 48% reported missing school and being unable to concentrate. A study of children aged 10- 14 diagnosed with arthritis reported that symptom flares, medication side effects and the necessity to attend hospital appointments caused regular disruption to their educational lives through repeated periods of absence (Farre, Ryan, McNiven, & McDonagh, 2019). Absence from school was also reported by 50 children with JIA and their families as a school related problem resulting from their condition (Konkol et al., 1989). Finally, a focus group comprised of school and mental health guidance staff found that high levels of absence were often cited as a challenge related to working with adolescents with CP in school (Logan & Curran, 2005).

Similarly to the quantitative review, the six qualitative studies report that CP negatively impacts school attendance, both for students and school staff who find high levels of absence challenging when supporting students with CP.

School performance

Six studies considered the impact of CP on school performance. A study comparing adolescents with juvenile chronic arthritis (JCA) and idiopathic musculoskeletal pain (IMP) found those with IMP reported more school stress, unrealistic worries about school performance and learning difficulties than those with JCA (Aasland, Flatö, & Vandvik, 1997). Similarly, children aged 10-14 reported impact on academic performance as a common disruption to their lives (Farre et al., 2019). Students experiencing CP also reported difficulties concentrating in school (Batthish et al., 2005).

Adolescents with CP conditions reported information needs relating to coping with the consequences and impact of a chronic condition on day-to-day life such as how to manage at school (Beresford & Sloper, 2003). A focus group of school staff reported that teachers perceived students with CP as good students who worked hard, however the academic content students missed due to absences caused frustration for teachers and they reported worrying about how the students would catch up (Logan & Curran, 2005). Similarly, students aged 6-18 reported feeling pressure to catch up with school work when they had been absent, and their parents reported inconsistent academic progress, as they felt their children became demotivated (Sen et al., 2017).

The six qualitative studies suggest CP negatively impacts students' school performance due to difficulties concentrating, high absence causing concerns about keeping up with school work, and students becoming demotivated and worried about their performance. This concern was shared by school staff who reported worrying that students with high absence would have difficulty catching up with school work.

Emotional Impact in school.

Three studies reported the emotional impact of CP on school functioning. Sen et al (2017) found that children reported feeling lonely and embarrassed about their CP. Children also felt embarrassed to inform teachers of their needs or necessary adaptations, in case this singled them out from their peers.

Another study found that 63 adolescents with chronic illness reported that managing at school, dealing with peers, coping with negative emotions, and maintaining a positive approach to life were considered equally as important as needing to know about their condition, yet health professionals were rarely mentioned as a resource for these information needs (Beresford & Sloper, 2003). Finally, sadness and loneliness were commonly reported by children with arthritis (Hackett, 2003).

In summary, all three studies reported a negative emotional impact of CP. Loneliness was commonly reported and children felt embarrassed about appearing different to their peers. Dealing with peers and maintaining a positive approach were also reported as important to adolescents. As peer relationships are a key factor in school life, it can be suggested that worries about appearing different or being excluded from the peer group due to CP significantly impacts emotional and in turn, school functioning.

Social Impact in school

The social impact of CP was reported in eight qualitative studies. In a focus group (Barlow et al., 1999) 10 children with JCA reported that peer belonging was their greatest concern. They worried about JCA making them appear different to their peers and being bullied due to their condition. In addition, parents reported frustration and anger at the number of social barriers that prevented normality in their children's lives.

Another study found that children aged 7-18 with JIA reported a number of social impacts in relation to their CP. Children did not speak to friends about their JIA, fearing it would make them appear different, they described not being able to keep up with their friends, or being held back from social activities to prevent pain flares. Children felt their friends were sympathetic but did not truly understand (Condon et al., 2017). Similarly, a study of children with JIA aged 7-11 reported that children felt their arthritis affected their friendships, due to not being able to play with friends and having to stay at home due to pain (Hackett, 2003).

Sen et al (2017) reported that children with juvenile arthritis described feeling left out and being directly bullied due to their condition. Adolescents spoke of feeling left out when the restrictions of their condition meant they had to self-exclude from activities. Psychosocial difficulties were the most highly reported difficulty by children with arthritis in another study, children reported fearing being laughed at and called names, and their parents felt concerned about peers being cruel (Konkol et al., 1989).

A UK study asked eight children with juvenile arthritis aged 10-18 what peer support meant to them, and the means by which it could best be provided. The children reported that social support reduced feelings of isolation, helped them to feel understood, reassured and provided a sense of self efficacy by helping others. However, peer contact was not always desired and varied access to peer support was required (Waite-Jones & Swallow, 2018).

Finally, when discussing the challenges CP posed to their education, 39 young people with arthritis reported disruptions associated with their symptoms, such as medication side-effects, regular hospital attendance and time off school. This impact was further accentuated when the adolescents compared themselves with their peers without chronic conditions (Farre et al., 2019).

In summary, CP negatively affects social functioning in school. Commonly due to CYP comparing themselves to their peer group, and worrying about social isolation, bullying and appearing different. Children reported that peer support was beneficial, however this type of support was not always desired and varied depending on the individual.

Limited activities

Eight studies reported the impact of CP on limiting activities in school, as a result of fatigue, physical limitations preventing children from joining in, and non-participation in various activities, most commonly physical education classes (Batthish et al., 2005; Hackett, 2003).

Hackett (2003) reported that 12 children with JIA spoke of difficulties joining in with leisure activities and decreased attendance at clubs, which they attributed to their arthritis. Fatigue was the most frequent symptom reported to interfere with these activities. A study of 50 children with juvenile arthritis reported that one of the children’s main concerns was their physical limitations impacting normal aspects of school life, for example sitting for too long being painful, being unable to carry heavy books and attending special classes (Konkol et al., 1989). Similarly, children reported practical issues such as taking longer to get changed as the main impact of their CP on activities such as PE classes (Sen et al., 2017).

Children reported their sadness at being left out of activities when parents and school staff restricted activity for safety reasons or to prevent symptom flares (Hackett, 2003). Children also reported sadness at being physically unable to keep up with their friends in school activities and in the playground (Condon et al., 2017).

In summary, CP negatively impacted CYP's engagement with physical activities due to fatigue, physical limitations preventing joining in, and school staff or parents restricting activities for health reasons.

School support

Finally, four studies explored school support for students with CP. Barlow et al (1999) reported that parents and children with juvenile chronic arthritis (JCA) reported a lack of support from school, particularly when their symptoms were less clear. Both parents and children reported problems at school, linked to teachers' lack of understanding regarding the fluctuating nature of JCA. Children found it difficult to assert their needs at school, and education about JCA was viewed by parents as a way to remediate this.

Similarly, Sen et al (2017) reported that young people felt teachers did not remember their difficulties, and they were reluctant to remind them. When support was provided, young people found it was not always successful, for example laptops were not always available. Some adolescents reported that recurrent pain in fact became a normal part of their education experience (Farre et al., 2019) which they accepted rather than seeking support.

Finally, a study of school teachers, school nurses and mental health staff (Logan & Curran, 2005) found all staff reported high absence rates and wide variation in the presentation of impairments as challenges when working with adolescents with CP. Teachers spoke of the need to balance accommodations made with school policies, the needs of other students, and dealing with parents. School staff also reported wanting more information about CP and guidance from healthcare professionals regarding how to manage pain symptoms and behaviours in school.

In summary, children reported a lack of successful support for their CP in school, and feeling reluctant to assert their needs. School staff reported challenges supporting CYP with CP and expressed wanting more information regarding managing CP in school.

2.4 Discussion

This systematic review explored the impact of CP on school aged children and young people including a wide age range (5-18), encompassing multiple domains of school functioning and identifying the various outcome measures used to determine the impact of CP on school functioning. Overall, the included studies suggested that CP negatively impacts numerous aspects of school functioning. The greatest impacts were found in the domains of school attendance, social functioning, emotional functioning and quality of life. Studies concerning general school functioning, academic self-efficacy, limited physical activities and school performance reported more mixed results. A wide range of outcome measures, including standardised and bespoke measures were used across the included studies to indicate the impact of CP in a wide range of school functioning domains. Collectively, this data is consistent with the existing literature regarding the significant impact of CP across the varying domains of school functioning (Alsaggaf & Coyne, 2020; Khan et al., 2015; Logan et al., 2012; Long et al., 2008), and the disparity of outcome measures used when considering school functioning (Gorodzinsky et al., 2011).

The wide ranging negative impact of CP on multiple aspects of children’s school functioning is concerning due to the broader implications for children’s subsequent education and achievement, future careers (Kashikar-zuck et al., 2010) future social relationships and social interactions (Dueñas, Ojeda, Salazar, Mico, & Failde, 2016), emotional wellbeing and mental health (Wager et al., 2021) and quality of life (Eccleston, Bruce, & Carter, 2006). For example, follow up research of youths with juvenile primary fibromyalgia (JPFS) found significantly lower scores on measures of physical functioning compared with healthy peers, as well as significantly greater symptoms of anxiety and depression. Youths with JPFS were also less likely to be enrolled in further education (Kashikar-zuck et al., 2010). Adults with CP are found to be less physically active, to lose employment opportunities due to the symptoms of their CP and to restrict their social contact and leisure activities (Dueñas et al., 2016).

Consistent with previous research (Evans et al., 2010; Groenewald et al., 2019; Logan et al., 2008; Nijhof et al., 2016; Sato et al., 2007) school attendance was greatly impacted in both qualitative and quantitative studies. School staff reported that high absence rates caused challenges when supporting students with CP, with teachers reporting that absenteeism and the negative effect of pain on ability to engage in school activities were the most common pain-related challenges they experienced when managing CP in the classroom (Solé et al., 2018). Poor attendance throughout school has significant implications for children's subsequent education, achievement and life outcomes (Stinson et al., 2013). Long term follow up research reports that the impact of CP on CYP's school attendance and performance is long lasting, impacting life outcomes, higher level education and employment (Kashikar-Zuck et al., 2010). Research finds that the negative impact of CP on school achievement in childhood impacts the likelihood of achieving higher education and employment goals in adulthood (Kashikar-Zuck et al., 2014).

Further, research suggests that levels of education are predictive of coping strategies. Individuals with higher levels of education are often more flexible in their thinking (Muyan-Yılık & Demir, 2020) and stick less rigidly to maladaptive coping strategies which are not helpful for adaptation (Noyman-Veksler et al., 2017); they are also more likely to draw upon multiple coping strategies (Muyan-Yılık & Demir, 2020). Use of adaptive coping strategies and focusing on returning to normal activities is key to recovering from the distress caused by CP and resuming 'normal life' (Eccleston et al., 2006; Vervoort, Goubert, Eccleston, Bijttebier, & Crombez, 2006) therefore, poor attendance has implications for CYP with CP being less likely to achieve higher levels of education. Of students with absence rates over 50% only 3% achieve 5 or more GCSE pass grades, and students with persistent absence are less likely to stay in education after the age of 16 years (Department for Education, 2012). This in turn influences subsequent ability to live a ‘normal life’ and engage in normal activities in the same way as their peers.

The majority of studies found CP impacts CYP’s participation in PE classes, classroom tasks and social activities. Exercise is important for children’s physical health, mental health and social inclusion, with involvement in curricular sport and PE lessons found to be related to positive physical and mental health as well as social inclusion by means of group sporting activities (Bailey, 2005). Exercise is also found to enhance aspects of children’s mental functioning that are central to cognitive development (Tomporowski, Davis, Miller, & Naglieri, 2007). Guidelines for children’s physical health suggest CYP aged 5-18 should aim for at least 60 minutes of moderate intensity physical activity a day to maintain good health (NHS, 2019). Engagement with activity also predicts lower depression rates in CP patients (Noyman-Veksler et al., 2017). Lack of engagement with activities throughout childhood can lead to social isolation, which continues to impact social interactions and engagement with activities later in life, as explored below.

The domain of social functioning was found to be greatly impacted by CP in both quantitative and qualitative studies. The impact of CP on school attendance and participation in activities is suggested to impact CYP’s social development into adulthood (Forgeron, Evans, McGrath, Stevens, & Finley, 2013). The impact of social isolation and lack of social participation due to CP in childhood for example, has implications for peer and romantic relationships in later life (Pietromonaco, Uchino, & Schetter, 2013). Research finds low levels of social participation continue into adulthood (Moulin, Clark, Speechley, & Morley-Forster, 2002) and individuals with CP have more negative experiences with relationships in adulthood, perhaps due to social isolation and lack of opportunities to build relationships earlier in life (Pietromonaco et al., 2013). Adults with CP describe their sense of self as profoundly changed by the negative impacts of CP on their psychological and social health, and it is suggested that CYP with CP experience these changes in self-identity also e.g. feeling different to their peers, which in turn influences social interactions and development of social skills (Smith & Osborn, 2007).

In this research, emotional functioning was closely linked to social functioning and was also greatly impacted in both the qualitative and quantitative studies. Children experienced higher rates of anxiety and depression which impacted school functioning in terms of absence, difficulty concentrating, reduced activities and school related anxiety. Unsupported, this emotional impact is found to continue to adulthood, with greater anxiety and depression found in adult individuals who experienced paediatric CP compared to their healthy peers (Kashikar-Zuck et al., 2014).

Finally, CP was also found to negatively impact CYP's self-efficacy, which is predictive of academic success, persistence and engagement (Freire et al., 2020). Again, the impact of CP on CYP's development of self-efficacy has implications for autonomy in later life. CYP that are less likely to achieve higher education due to limited academic success are less likely to develop autonomy and may find themselves to be more reliant on their families in adulthood. Limited development of self-efficacy and independence skills in children with CP is also found to predict poorer emotional wellbeing in adulthood (Sil et al., 2013).

Despite the wide ranging negative impact of CP on CYP's school functioning and the broader implications for life outcomes, an interesting aspect arising from this review is that support and positive perceptions from teachers and school staff often arose as a protective factor against the negative impact of CP. A number of the findings suggested important implications for the role school staff can play in supporting students with CP and adapting the school environment accordingly. One study reported that CP in fact motivated young people to succeed in school, with school staff observing them to be excellent students (Mandić et al., 2003). This is consistent with previous suggestions that school staff's support and positive perceptions of students with CP is greatly beneficial and is perhaps a factor in improving student's belief in themselves and subsequent achievement. These findings are consistent with the disability-stress-coping model, which posits that a child's adjustment is predicted by an interaction between stress and protective factors across various contexts (Wallander & Varni, 1992). Teacher support of competence was also found to be a protective factor against bullying, which has implications for supportive strategies individual school staff can use to support students. Impaired school functioning was also found to decrease when students felt their teachers were supportive, again suggesting an important role for school staff in providing a supportive role and improving outcomes for students with CP. However, children often reported a lack of support for their CP in school, and feeling reluctant to assert their needs. In addition, school staff reported challenges supporting students with CP and found making necessary adaptations challenging. Staff expressed wanting more information regarding managing CP in school. This has important implications for future research, considering the information and training needs of school staff to support them in effectively managing CP. Logan (2008) reported that students with more adaptations made in school showed poorer attendance and school performance. This could be due to the adaptations removing students from the classroom (e.g. being sent home or to the nurses office) and has useful implications when considering how to accommodate students with CP whilst ensuring they remain an active member of the class.

Given the wide ranging negative impact of CP, and the broader implications for this impact to continue into adulthood, interventions supporting the functioning of CYP with CP are important. Existing interventions discussed in this review found mixed results. School based manualised group interventions supporting the functioning of students with CP have been found to improve attendance (Simons et al., 2010) suggesting that supportive interventions aiming to improve school functioning can remediate some of the negative impact of CP on school attendance. Peer based social support is also found to be successful in reducing feelings of isolation (Waite-Jones & Swallow, 2018) therefore, interventions to support social relationships and inclusion may be beneficial. However, peer contact was not always desired by CYP therefore it is important that interventions of this nature are personalised. Self-help relaxation training was found not to impact social relationships or satisfaction with schoolwork in students with CP. Finally, an internet based intervention focused on improving participation and health related quality of life (HRQOL) (Armbrust et al., 2016) showed promising efficacy for improving school attendance and participation in activities, however the school subscale of the HRQOL measure did not maintain longitudinal improvement.

Interdisciplinary interventions are most commonly used successfully for CP and have been shown to improve coping strategies, emotional wellbeing, school attendance, school functioning and pain acceptance in CYP with CP (Liossi et al., 2019). However, difficulties with multidisciplinary communication are commonly reported e.g. between health care professionals and school staff (Logan & Curran, 2005) which creates a barrier to a multidisciplinary approach to intervention in schools. In addition, cognitive behavioural therapies, which increase the use of adaptive coping skills, are found to be efficacious in improving functioning for various CP conditions (Turner, Jensen, & Romano, 1999). Therefore, providing CYP with a range of adaptive coping strategies may remediate some of the difficulties discussed with CYP with lower education levels tending to rigidly use maladaptive coping strategies.

While the majority of the research in this review suggests that CP significantly impacts multiple domains of school functioning, it is important to note that there were mixed findings for a number of the domains. As the included studies ranged widely in participants age, CP condition, study characteristics and the outcome measure used to indicate the impact of CP it is not possible to generalise the findings. In addition, the findings in this research are compiled from widespread countries, and therefore cultural differences and differences in the educational systems of different countries should be considered. In the UK for example, some CYP may be almost a year older than others in their year group, meaning a significant difference in their developmental stage compared to countries such as the Netherlands, wherein CYP begin school aged 4 and are therefore developmentally more similar to the peers they will build relationships and develop learning skills alongside (Sharp, 2002).

Different cultures also place emphasis on different aspects of learning, therefore it is important to consider the differing school related pressures CYP may experience. Japanese education for example places emphasis on values such as diligence and endurance (Bossy, 2000; Ellington, 1990) Chinese schools favour rote learning and memorisation (Li & Cutting, 2011) whereas British schools favour developing critical thinking and promoting British values of democracy and mutual respect (Kim, 2019). The length of the school day also varies, meaning the hours at school that CYP with CP need to manage will differ. In Korea for example, a typical school day may last between 14-16 hours, and great emphasis is placed on academic achievement (Lee & Larson, 2000).

Strengths and limitations

This review raises awareness of the wide-ranging impact of CP on wide ranging domains of school functioning, and the importance of developing supportive interventions and necessary accommodations for these students in school. This review addressed the recommendations made in previous literature by exploring the impact of CP on the wide-ranging domains of school functioning, including a wide age range of school aged children and young people covering both primary, secondary and college educational settings. The review also determined and compared how the impact of CP on school functioning is measured using wide-ranging outcome measures. The review identifies that, consistent with previous literature, CP has a significant negative impact across each domain of school functioning. The review also suggests that teachers and other school staff play a crucial protective role in supporting students with CP which has promising implications.

This systematic review followed robust guidelines and assessed the quality of studies using validated tools. It was limited by the heterogeneity of the included studies, which varied in terms of groups of participants, measures used, educational setting and the country the research was conducted in which may have limited overall data synthesis. It is therefore difficult to generalise the findings of this review, as differences may be seen due to varying culture and education systems. In addition, the review included studies published in the English language only, which may have introduced a language bias. Finally, while a comprehensive search of the literature was conducted, it is possible that this review did not capture all relevant studies and domains of school functioning for CYP with CP.

Future Research

Given the clear impact of CP on all domains of school functioning, and the impact on student's subsequent education, future careers, social relationships and emotional well-being, as well as the important role of school staff's support and adaptations made in the school context that arose throughout this research. It would be beneficial for future research to explore the specific information and training needs of school staff to support them in effectively managing CP in school, thus hopefully improving outcomes. Children also reported a lack of support for their CP in school, and feeling reluctant to assert their needs. School staff reported challenges supporting students with CP and expressed wanting more information regarding managing CP in school. Therefore, future research could address these points by ascertaining the most and least effective strategies implemented in school settings to support CYP with their needs related to CP.

Implications for Educational Psychology Practice

The findings of this research suggest a number of practical implications that EP's are well placed to recommend and facilitate. Firstly, as school staff express a desire for more information about managing CP in school, EP's are well placed to deliver training to improve staff's knowledge and understanding of CP, using the biopsychosocial model as a frame to support the understanding of CP as a product of a complex interaction of factors which presents differently in different individuals and at different developmental stages. The finding that school staff's support and the adaptations they made for CYP with CP was important to CYP and had a positive impact on their school functioning is promising, therefore EP's could support school staff in beginning conversations with CYP about their

CP and the adaptations they feel are most helpful. Indeed the findings suggest that many CYP feel reluctant to approach school staff about their CP or to assert their needs in school, therefore facilitating school staff to begin these conversations may remediate this concern for CYP. EP's are also well placed to work collaboratively with schools to develop and implement supportive adaptations, taking the CYP's views and preferences into account. Given the wide ranging impact of CP on multiple aspects of school functioning, it is important that adaptations that make school more accessible for CYP are implemented early, taking the CYP's individual pain experience into account and understanding that a flexible approach will be necessary, as the impact of pain can vary. EP's are well placed to facilitate collaboration between medical professionals, school staff, parents and CYP themselves to support both understanding of the CYP's pain experience, and to suggest feasible supportive adaptations that can be arranged in the school setting. Finally, as the outcome measures for the impact of CP are so varied, as is an individual's pain experience, it is suggested that those working with CYP with CP should consult with the CYP themselves to understand the personal impact, and to develop interventions that are tailored to the individual and their changing level of need.

2.5 Conclusion

Overall, this review summarised that CP negatively impacts the school functioning of CYP in multiple domains. However, some studies reported mixed findings or no effect. The outcome measures used to determine the impact of CP varied widely between studies. Given the profound impact of CP on school functioning, it is important that CYP are supported by school staff who are knowledgeable about CP conditions, the adaptations required in a school setting, and have the necessary resources to provide such support.

Chapter 3 How can schools support the education of children and adolescents with chronic pain: Perspectives of teachers and other school staff.

Abstract

Chronic pain (CP) is a significant health problem in school aged children and young people. A body of evidence suggests it has a profound impact on many aspects of children's lives including in an academic context. CP is associated with poor school attendance, poor academic performance and overall school impairment. Given the wide ranging impact of CP on school functioning, it is important that children and young people experiencing CP are well supported in school by adults who feel competent in managing their symptoms and supporting their needs. However, despite the known impact of CP on school functioning, to date there has been limited research eliciting school staff's perspectives on managing CP in school. This study aimed to extend the current literature by conducting semi structured interviews with 12 members of primary and secondary school staff about their experiences supporting children and young people with CP at school. Through reflexive thematic analysis, four themes were developed concerning staff's perceived misunderstanding of chronic pain as a biopsychosocial phenomenon, the wide ranging impact of chronic pain, managing chronic pain in a school setting, and lessons learned from the Covid-19 pandemic. Promising implications were identified for supporting students with CP with greater flexibility and a blended learning approach in future. Further implications of the research are discussed.

3.1 Introduction

Chronic pain (CP) defined by the International Association for the Study of Pain (IASP) "an unpleasant sensory and emotional experience associated with, or resembling that associated with, actual or potential tissue damage" (Raja et al, 2020, p.1) is considered a significant health concern among children and young people (CYP) and is the leading cause of morbidity in CYP in the world today (World Health Organization (WHO), 2020). CP includes persistent and recurrent pain which may result from an underlying health condition (e.g., rheumatoid arthritis), or pain that is the disorder (e.g., headaches, musculoskeletal pain.) (Friedrichsdorf et al., 2016). Internationally comparable data from 42 countries suggests that self-reported CP among adolescents is highly prevalent, with an overall proportion of 44.2% of adolescents reporting weekly pain (Gobina et al., 2019). Prevalence varies according to the location of pain, chronic headache for example ranges in prevalence between 8 and 18% whereas musculoskeletal pain ranges between 4 and 40% (Hurley-wallace et al., 2019).

It is well documented that CP can have profound and concerning impacts on many aspects of CYP's lives including social, emotional and academic detriments. Long term follow up research reports that the impact of CP on CYP's school attendance and performance is long lasting- impacting life outcomes, higher level education and employment (Kashikar-Zuck et al., 2010). Managing CP as early in life as possible is vital, due to the harmful wide ranging impact it has on daily life and the poor long term outcomes seen when intervention is delayed (Rajapakse et al., 2014).

The impact of CP can vary widely between individuals. It is influenced by an interaction of biological, psychological and social factors (Rajapakse et al., 2014) meaning supportive interventions are most successful when tailored to the individual. However, CP is commonly misunderstood and takes time to identify, meaning opportunities for providing early intervention and individual support are often missed.

Worryingly, a fundamental system in CYP's lives that is negatively impacted by CP is school. A large body of research reports the wide ranging impact of CP on school functioning; a multi-dimensional concept comprising attendance, academic performance/achievement, academic competence, physical activities, and social relationships (Haraldstad, Sorum, Eide, Natvig, & Helseth, 2011; Khan et al., 2015). The school setting is a fundamental and influential system in CYP's lives (Bronfenbrenner & Mahoney, 1975). It provides important structure, developmental opportunities and relationships with key adults that are central to positive development (Brendtro, 2006). However, CYP with CP commonly experience high school absence rates. 68% of a large nationally representative sample of CYP with chronic school absence for example also experienced CP (Groenewald et al., 2019). This suggests that students with CP are therefore regularly missing out on the developmental opportunities and beneficial routine provided by school. Moreover, significantly poorer attendance rates are found for students with greater pain severity (Sturge et al., 1997) and teachers report absenteeism as one of the greatest challenges they face when supporting CYP with CP (Solé et al., 2018).

Absence rates are most widely used in the literature when considering the impact of CP on school functioning, with numerous studies reporting high absence rates for students with CP in comparison to their healthy peers (Evans et al., 2010; Nijhof et al., 2016) . However, the developmental skills and experiences that school provides reach beyond academic outcomes. School provides CYP with the opportunity to develop social skills, emotional wellbeing, identity, and sense of belonging (Korpershoek, Canrinus, Fokkens-Bruinsma, & De Boer, 2019; Osher et al., 2014). It provides a sense of routine and structure that is key to improved sleep cycles (Zhang, Fok, & Wing, 2010), positive peer relationships (Osher et al., 2014) and greater school success (Kearney & Graczyk, 2014).

Many CYP with CP who are regularly absent from school experience gaps in their knowledge, find it difficult to keep up with schoolwork and experience impacts on their functioning in multiple domains of health related quality of life. That is, physical, emotional and school functioning (Gold et al., 2009). CYP with CP are more likely to be socially isolated and subjected to bullying than their healthy peers (Forgeron et al., 2010). Sleep disturbances and fatigue (Yoon, Sturgeon, & Feinstein, 2019) are common in school age children with CP, and are associated with negative effects on daytime functioning (Long et al., 2008). Comorbid problems with depressive mood, anxiety and suicide ideation (Van Tilburg et al., 2011) are also reported in adolescents with CP. These comorbid difficulties exist within the complex, interlinked biopsychosocial experience of CP and all in turn influence CYP’s ability to function in daily life and attend school.

Without early intervention, the impact of CP on school functioning worsens, and barriers become more difficult to address. CYP can find themselves in vicious cycles of despair (Sørensen & Christiansen, 2017) in which their CP prevents attendance, yet extended periods of absence cause social isolation and anxieties about returning to school. Left unsupported, this may develop into emotionally based school avoidance and even school refusal (Kearney & Bensaheb, 2006). Early intervention and supportive accommodations made in the school setting are therefore key to supporting functioning. Indeed, school absence has been found to be lower when CYP perceive their teachers to be supportive (Vervoort et al., 2014).

Given the important role of school in CYP’s academic, emotional and social development and the concerning levels of school absence in CYP with CP, it is important that these CYP are supported to access school by adults who are knowledgeable about CP, and can implement the necessary adaptations to facilitate school functioning. However, limited research to date eliciting school staff’s perspectives regarding managing pain in an educational context suggests that staff feel they lack competence and are inadequately educated about managing CP in a school setting, meaning they often struggle to effectively manage CYP with CP in school (Logan & Curran, 2005). Staff also report having little understanding of CP conditions (Power, McGoey, Heathfield, & Blum, 1999), a lack of communication with healthcare professionals to aid this understanding (Logan & Curran, 2005), and both CYP and their families report a lack of necessary adaptations made in school as a result (Barlow et al., 1999; Sen et al., 2017). Further, research has found that the presence of medical evidence to support CP, and the extent to which parents work collaboratively or confrontationally with schools to address school functioning influences teachers responses to CP in the classroom, and their judgement of students with CP. However, this research was based upon hypothetical vignettes rather than teachers in vivo experiences (Logan, Coakley, & Scharff, 2007).

A more recent study eliciting the views of 40 teachers and 318 student teachers (Solé et al., 2018) found that absenteeism and the negative impact of CP on school activities were most challenging for teachers supporting students with CP. Teachers endorsed the use of coping and health promoting responses most often, but identified a need for guidelines for teachers supporting students with CP, and greater information about CP included in teacher training. Therefore, there is still work to be done improving teacher understanding and feelings of competence.

To date there is also limited research regarding how schools can support CYP with CP to attend school, perform to the best of their abilities and achieve their academic potential. Research exploring accommodating approaches employed by schools for CP found wide variations and inconsistency in the type of support offered (Logan, Coakley, & Scharff, 2007; Logan, Catanese, Coakley, & Scharff, 2007).When adaptations were in place, they commonly removed students further from the school setting by sending them home or to the nurse’s office, which is problematic for integrating students into school (Logan et al., 2008).

School staff misunderstanding CP is problematic as it can lead to responses that unintentionally reinforce symptoms (Logan & Curran, 2005). Indeed, parents and CYP report their concerns that their problems at school are linked to staff’s misunderstanding of CP symptoms (Barlow et al., 1999). The lack of communication between two central systems in the life of a child with CP- healthcare and school, creates a further barrier to supporting CYP to cope with their symptoms in school (Logan & Curran, 2005). In addition, supporting the management of CYP with CP is known to be challenging due to the complex and difficult to understand relationships between CP, illness and health which are misunderstood by both clinicians and those with CP themselves (Rajapakse et al., 2014).

A recent review of 14 studies considering school staff's responses to managing students CP reported both that staff responses and adaptations offered in school varied widely, and that research eliciting school staffs' views regarding managing CP remains limited, suggesting that future research should explore effective school staff responses to managing CP in order to further support students with CP in school (Alsaggaf & Coyne, 2020).

A profession that is uniquely qualified to support school staff with managing CP, but is not always widely utilised are Educational psychologists (EP's). EP's work closely with schools to apply psychological theory, research and techniques to support CYP, their families and school staff to promote the wellbeing of young people. EP's also have a role in assisting multidisciplinary teams to plan and implement appropriate accommodations to support vulnerable students. Therefore, there are implications for EP's to play a unique role in supporting CYP with CP by promoting collaboration between professionals, planning appropriate accommodations and supporting school staff to implement techniques. EP's are primarily concerned with accessing and promoting the voice of the child, therefore EP's are well placed to gain CYP's views concerning the support they desire, and to promote this in multidisciplinary meetings considering accommodating approaches. EP's may also advise local authority groups with regard to learning policies, therefore there are further implications for EP's to implement changes at a systemic level.

Previous research suggests the most effective support for CYP with CP requires professionals to have a biopsychosocial understanding of CP and its effects on quality of life, including school functioning (Gold et al., 2009). Research suggests that reintegrating CYP to school and providing caregivers with supportive coping strategies are the most effective treatment approaches for CP (Gold et al., 2009), both aspects that EP's are well placed to facilitate. To date, despite their involvement with such students and biopsychosocial understanding of CP, there is limited research eliciting the views of EP’s regarding the effective management of CP in schools. This research addresses this gap in the literature by including the perspectives of a wide range of school staff involved in the management of CP in school, including EP’s.

Much of the research discussed thus far concerning the impact of CP on school functioning and school staff’s management of CP in school applies to the school setting as we have known it for decades, in which children are required to physically attend. During the Covid-19 pandemic in 2020, national school closures were implemented in order to reduce transmission of the virus. During this unprecedented time with 8.8 million students in the UK not attending school (Lewis et al., 2021) the detrimental impact of not attending school on CYP’s general development, mental health and wellbeing was highlighted (Hazell, 2021; Williams, 2020) with the UK government implementing initiatives to support returning to school with great importance (Department for Education, 2020). In response to the school closures, school staff began to use virtual platforms to teach, assign learning tasks and to maintain a connection with students. For the first time, a vast majority of students experienced accessing their schoolwork in the same way as their peers with CP who regularly find it difficult to physically attend school, and many education staff further developed their skills in using virtual platforms to teach students that were unable to physically attend. It could be argued that CYP with CP benefitted from this situation, accessing their classwork in the same way as their peers for the first time, without physical attendance creating a barrier.

This unprecedented context provided a unique opportunity to discuss with school staff how virtual accommodations were made, and the potential for continuing their use for students with CP who will continue to find it difficult to access the school setting once the majority of their peers have returned due to the impact of their CP, hospital appointments, and treatment programmes.

Given that the important role of the school setting in CYP’s emotional, social and academic development and the widely negative impact of CP on school functioning is well documented, and the finding that a lack of early intervention and support for CP leads to unnecessary distress and poorer life outcomes (Rajapakse et al., 2014). It is concerning that CP remains poorly recognised and managed among professionals in key systems in the CYP's life, including their school setting. It is important that CYP experiencing CP are well supported to access school by adults who feel competent in managing their symptoms and supporting their needs. In order to support school staff to manage CYP's CP in school and to improve outcomes, it is necessary to understand the perspectives of school staff working with CYP with CP. Developing an understanding of how school staff can best understand and respond to the needs of CYP with CP would be beneficial in increasing CYP's school success, the ability to attend school and perform to the best of one's ability (Logan & Curran, 2005). Given the context of the pandemic and virtual working, it is also useful to explore the benefits and drawbacks of virtual working and to consider whether such methods could continue to be used for CYP with CP, to assist them in accessing school when they are unable to physically attend.

By developing an understanding of the experience of working with CYP with CP from the perspectives of school staff, and identifying the specific areas that school staff find more difficult to accommodate, it is hoped that specific supportive recommendations could be made to schools. It is recognised that school staff involved in the care of CYP with CP are not limited to teachers. Indeed, research has suggested that school psychologists are well placed to provide a link between healthcare recommendations for CP and school systems (Shriver, Matthews & Allen, 1999). Therefore, this research aimed to include the views of a wide range of staff involved in supporting the education of CYP with CP, including EP's, Learning Support Assistants (LSA's) and Special Educational Needs Coordinators (SENCO's). Moreover, much of the previous literature discussed eliciting school staff's views is conducted in the USA, therefore this research provides a unique perspective in considering the views of a wide range of school staff working in the British education system.

Accordingly, the aim of this research was to explore the perspectives of school staff regarding the ways schools and school staff can support the education of CYP experiencing CP.

3.2 Method

Participants

Participants were 12 members of school staff who held various roles in mainstream primary and secondary, special needs, and alternate educational settings. Sampling was purposive, determined by participants' professional roles as school staff working directly with CYP experiencing CP. Participants were selected on the basis they would provide rich data about supporting CYP with CP in a school setting (Patton, 2003). Participants ranged in age from 28- 65 years old and were geographically spread across the UK (Table 2). Years of experience working in education ranged from 4-38 years and all participants had experience working with at least one student with CP. CP conditions ranged from diagnosed, undiagnosed, unspecified and due to a pre-existing illness or condition. Therefore, participants had a range of experience working with school aged CYP with CP in various educational settings.

In consideration of saturation, or the point at which new information is not generated by interviews, in qualitative research studies have found that the majority of identified themes were gathered in between the first six to 12 interviews (Francis et al, 2010; Guest et al, 2006; Namey et al 2016) after which little new information was gathered (Morgan et al 2002.) In addition, Hagaman and Wuitch (2017) found data saturation to be reached in fewer than 16 interviews in cross cultural research. Therefore, 12 interviews were considered an adequate number to generate rich data and reoccurring themes, however it was acknowledged that more nuanced data may be missed and that saturation could not be confidently assumed with this number of participants.

Table 2

Table showing participant’s demographic information.

Table 2 Table showing participant's demographic information

Characteristic	Total N = 12 n	Percentage (%)
Gender		
Male	2	16.67
Female	10	83.33
Age		
25-30	3	25
31-35	5	41.7
36-40	1	8.33
41-50	0	0
51+	2	16.67
60+	1	8.33
Professional Role		
Teacher	4	33.33
Learning Support Assistant	1	8.33
Special Educational Needs Coordinator	2	16.67
School Physiotherapist	1	8.33
Educational Psychologist	2	16.67
Assistant Head teacher	1	8.33
Head teacher	1	8.33
Educational Background		
GCSE	1	8.33
Degree	5	4.17

Masters	4	33.33
Doctorate	2	16.67
Years of Experience		
1-10	8	66.67
11-20	2	16.67
21-30	1	8.33
31+	1	8.33
Educational Setting		
Mainstream Primary	3	25
Mainstream Secondary	3	25
Special Needs Primary	1	8.33
Special Needs Secondary	1	8.33
Alternate provision (Hospital School)	1	8.33
Through school (Primary and Secondary)	1	8.33
0-25 Settings (Pre-school to Post 16)	2	16.67
Region		
South East	8	66.67
London	1	8.33
East Midlands	1	8.33
North West	1	8.33
North East	1	8.33
Recruitment source		
Twitter	8	66.67
Email to schools	2	16.67
Word of mouth	1	8.33
Local authority website	1	8.33

Design

This study employed a qualitative approach using semi-structured virtual interviews and held a social constructivist epistemology. This position entailed an understanding that meanings are developed through subjective experience (Cresswell, 2003) and that knowledge can be best understood through the lens of the individual. Meanings were constructed and interpreted through the researchers interactions with participants (Burr, 1995).

Qualitative methodology was chosen as it facilitates gathering rich perspectives from participants about their experiences, which may be more difficult to access in the same detail in more formal methods (Pope & Mays, 1995)

In consideration of reflexivity, the researcher acknowledged that their position as a trainee EP might have influenced how data was collected and analysed; knowledge of the EP profession might have shaped the nature and content of their interactions and interpretations. Ethical approval was obtained from the University of Southampton's Ethics and Research Governance Committee.

Interview Guide

Questions were based on an interview topic guide, developed by the researchers (Appendix F). This was informed by existing literature and areas the researchers identified as informative given the context the research took place in (the Covid-19 pandemic meant that schools were closed and virtual learning was in place). The topic guide included core questions and associated prompts, and was used flexibly with supplementary questions to guide the interviews. In line with the epistemological position, the researcher was able to explore emerging ideas, facilitating a participant led process and rapport between researcher and participant.

Procedure

School settings that the researcher had pre-established links with through their work as a Trainee EP in the Local Authority were contacted by email with information about the project, a consent form (Appendix G) and an invitation to participate in an interview. An initial email was sent to senior staff in the identified schools to cascade to wider staff. The same information was presented on the researcher's local authority Educational Psychology website and twitter page. Consenting participants returned completed consent forms to the researcher via email. Interviews were conducted virtually on a one-to-one basis, lasting between 30 and 55 minutes, and were arranged at a time convenient to the participant.

Data was captured through audio and video recorded interviews using Microsoft Teams. All data was stored in compliance with General Data Protection Regulations (2018). Each interview was transcribed to a Microsoft Word document (Appendix H) and reviewed for accuracy. Personal identifiable information was excluded from the transcriptions and participants were assigned pseudonyms. Pseudonym information was stored separately from the transcript data. Following completion of transcriptions, the audio and video files were permanently deleted.

At the outset of each interview, the researcher reiterated the study's purpose with participants and clarified their consent. Participants were also reminded of their rights of participation detailed in the Information Sheet (Appendix I), including their right to withdraw or not answer questions, as well as the process of recording**.** Immediately after each interview, the researcher read the debrief information (Appendix J) aloud and also emailed it to participants. An opportunity was also provided for the participants to share any additional information the questions had not addressed, if they wished to.

Throughout the interviews, the researcher regularly summarised the main points of the discussion and checked the accuracy of this summary with participants to improve credibility and reiterate to participants that their views were validated (Harper & Cole, 2012). In addition, the data analysis and initial themes were discussed collaboratively with two other researchers (CL and DS) to clarify interpretations. CL is a Consultatnt Paediatric Psychologist at the Great Ormond Street Hospital's Chronic Pain Service, founder of the Pain Research Laboratory, University of Southampton, and world expert in paediatric pain. DS is a Lecturer in Health Psychology, Deputy Director of the Pain Research Laboratory, University of Southampton, and conducts a range of experimental pain research. The impact of these joint discussions resulted in refinement of the themes, for example to reflect that school staff perceived themselves to lack an understanding of chronic pain but in fact went on to discuss and demonstrate experiential knowledge of the wide ranging impact of chronic pain, as well as contributing well considered ideas for managing chronic pain in school. Theme one was therefore refined from "lack of knowledge about chronic pain as a biopsychosocial phenomenon" to "perceived misunderstanding of chronic pain as a biopsychosocial phenomenon." These discussions also influenced the categorising of the subsequent themes, for example the joint reflection that many of the school staff discussed their experiences of virtual learning promoted a discussion about the importance of including a theme to reflect the context school staff were working in at the time of the study, and also to reflect the lessons staff felt they had learned from this. Finally, an initially separate theme "collaboration" was discussed and considered to be connected as a subtheme within the wider theme "managing CP in a school setting". Through discussion it was suggested that participants felt collaboration was a key factor in successfully managing CP in school, and therefore collaboration became integrated as a subtheme.

Data Analysis

Thematic analysis was used following the phases described by Braun and Clarke (2006) (Table 3) which is appropriate for use with small samples (Willig, 2013). The researcher initially familiarised themselves with the data before coding (Langdridge, 2004). They then worked to reach an understanding of patterns of codes in order to identify themes using NVivo software to assist data analysis. Themes were constructed according to the researchers' decisions of how relevant the coded segments were in relation to the research questions, and were used within and between transcripts (Willig, 2013). In consideration of reflexivity and the researcher's position as a trainee EP, the themes reflect the researchers' collaborative interpretation of participants' experiences, attending to contrastive or shared experiences across the participant group.

An audit trail and reflective journal was kept throughout and referred to during thematic analysis which aided triangulation. This included field notes about the interview experience (Appendix K). Memos were also used to record developments of particular codes and themes in order to enhance dependability (Marks & Yardley, 2004).

When developing theme labels, the researcher considered the meaning of particular words to the participants, taking an interpretative position as opposed to being purely descriptive. Active regard was given to the impact of the research and interview questions in theme development, while being conscious to take an explorative approach. Participants' voice was captured by considering implicit meanings and latent content (Boyatzis, 1998). This allowed for themes to be developed in line with the researchers' epistemological position.

Table 3

Process of thematic analysis

Table 3 Process of thematic analysis

Phase	Process Description
1 - Familiarisation with the data	Transcripts were completed, read and re-read by the researcher and initial ideas were noted.
2 - Generating initial codes	Interesting features across the entire data set were coded using NVivo nodes for each transcript. Researchers were able to see developed nodes and could apply them in their own coding or create new ones. Related units of text were collated under the same code.
3 - Searching for themes	The developed codes were reviewed for similarities and collated into groups accordingly. Researchers considered how groups could be combined to form an overarching theme and ensured that all data relevant to each theme was gathered. No data was discarded at this stage, including ungrouped, isolated codes.

4 - Reviewing themes	Themes were reviewed in relation to the coded extracts within them. Refinement of themes and codes included: recoding; splicing; collapsing themes; and discarding themes or codes that did not reflect the data set as a whole.
5 - Defining and naming themes	Theme and subtheme names were developed and defined to reflect the researchers' interpretation of participants' experiences. Each theme was analysed by considering it individually and in relation to other themes, and the research questions. A thematic map was constructed to reflect this (See Figure 2).
6 – Producing report	Representative extract examples were selected for the final report.

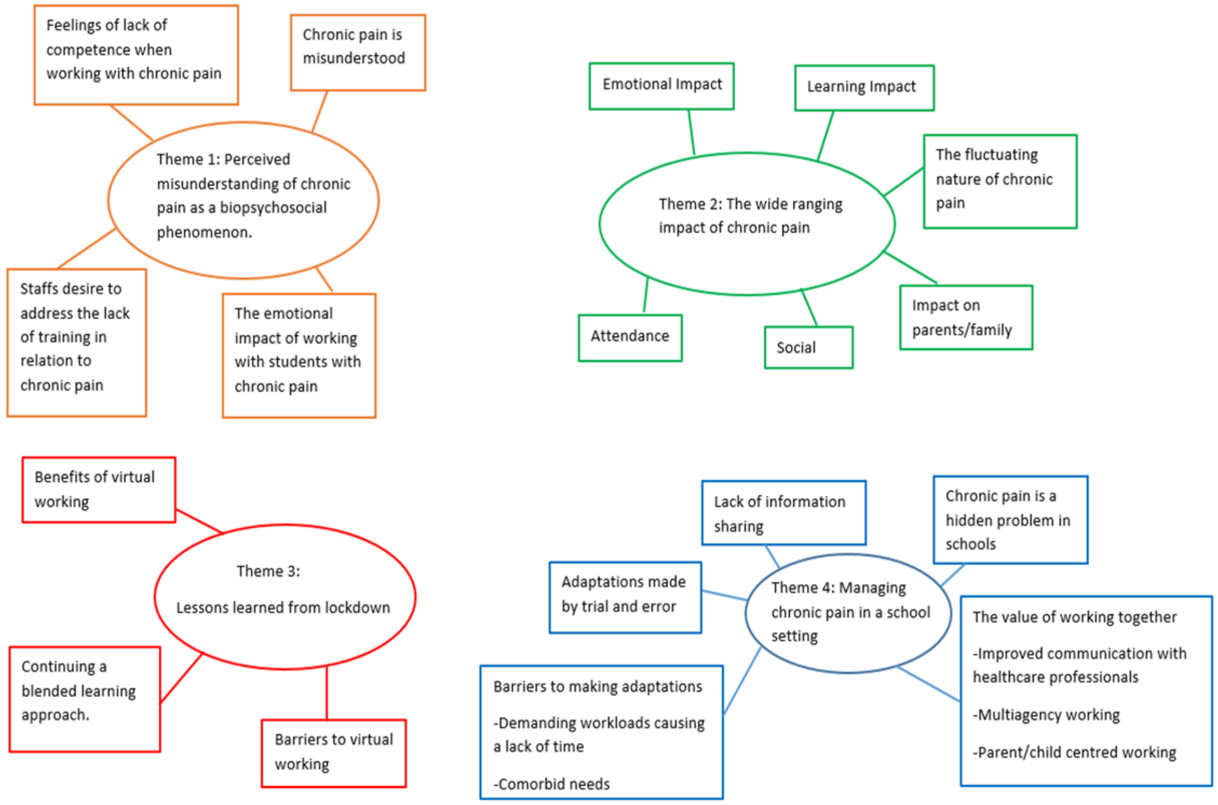
Note. Adapted from Braun & Clarke's (2006) six phases of thematic analysis.

3.3 Results

Four overarching themes and associated sub-themes were constructed through inductive thematic analysis, as detailed in the thematic map (Figure 2) and coding manual (Appendix L).

Figure 2

Figure 2 Thematic map



Theme 1: Perceived misunderstanding of chronic pain as a biopsychosocial phenomenon

While participants described CP as greatly misunderstood in schools, and felt that they lacked the knowledge and understanding of CP they felt was necessary to support CYP, all of the participants went on to describe their experiential understanding of the ways in which CP impacts every aspect of CYP’s lives, physically, psychologically, and socially. Participants therefore demonstrated an understanding of CP as a biopsychosocial phenomenon that perhaps they did not perceive themselves to have. Participants felt they lacked knowledge and understanding due to the lack of training they had received in relation to CP, which in turn led to the feeling that they lacked competence when working with CYP with CP. Participants also described the emotional impact of working with CYP with CP whilst feeling that they lacked the understanding or competence to support the CYP effectively, some participants found this emotional aspect particularly difficult to manage and felt they needed an outlet to discuss the way that feeling they lacked competence impacted them. Many participants felt that their perceived lack of knowledge and understanding of CP could be addressed by accessing training about CP in the same way as they would access training for other special educational needs. Some participants discussed also accessing supervision sessions to support their emotional needs. It was felt that improved access to training and supervision would help to remediate participants feelings that they lacked competence working with CYP with CP.

Chronic pain is misunderstood

Participants felt they and other school staff lacked knowledge about CP, particularly in comparison to other needs that were felt to be more common and thus better understood. “I think we still often still forget the health part, or it’s an afterthought…I don't think it's necessarily always given the same understanding or appreciation, as other areas of need.” (Line 627. P8, Educational Psychologist).

One participant noted “Staff still find those, those types of conditions like chronic fatigue, like chronic pain, fibromyalgia, those sort of things really difficult to get their head around.” (Line 73. P9, Headteacher, Hospital School)

Staff felt this misunderstanding could cause stigma towards CYP, such as doubting the legitimacy of the CP.

> It's not being seen in the same way. Like autism or ADHD or anything like that. That's been seen as a learning need that we need to support and have strategies about whereas chronic pain. It's almost is that kid making it up? (Line 476. P2, Mainstream secondary teacher)

In an attempt to aid their understanding, school staff often tried to unpick the causes and effects of CP. Staff appeared to be seeking a medical cause or rigid set of criteria that would comprise CP, and understanding that CP is a biopsychosocial phenomenon with cause and effect at many different levels was sometimes overlooked. Many participants felt that they did not have a good understanding of the definition, causes and impact of CP and therefore found it complicated to understand. “It becomes a chicken and the egg… and I think it's really hard to unpick with those children.” (Line 95. P6, Physiotherapist, Special Needs Provision). One participant summarised;

> It's hard to work out. What is chronic pain? What and what sort of level of chronic pain are we typically expecting?...And actually what's exacerbating the chronic pain, but also what the chronic pain is exacerbating in being able to concentrate in school and being able to focus…So it is, it's a web of things (Line 49. P8, Educational Psychologist)

When the condition was difficult to unpick, and therefore difficult to understand, CP was not always believed to be genuine, suggesting that misunderstanding of CP can lead to stigmatising beliefs. “Sometimes there's no organic reason which, which makes it hard for staff to deal with because it looks like it's made up.” (Line 16, P9, Hospital School Headteacher).

With experience, for some participants the cause of CP became less important. This allowed them to support the education of children with CP by working to support the current presentation regardless of the cause.

> I've worked with a wide number of young people with chronic pain. And I my, my philosophy is, is ignore the root cause of the pain, the child has got chronic pain, how can we devise a learning programme to enable them to access education? (Line 22. P9, Hospital School Headteacher)

Feelings of lack of competence when working with chronic pain

School staff largely described lacking feelings of competence when supporting CYP with CP at school. They displayed great empathy for the students, and wished to work in a child centred way to support, however, they did not always feel prepared or knowledgeable enough to do so. “We just kind of find ourselves in the thick of it. And we respond with our hearts.” (Line 577. P7, Educational Psychologist). Feeling unable to support students with CP effectively had an emotional impact on staff and they discussed the need for more training and formal supervision to support them in this respect.

Some staff discussed feelings of competence in relation to CP, due to their experience as a teacher or personal experiences with CP. Feeling knowledgeable about a condition appeared key to feeling competent. Participants who spoke about their feelings of competence discussed having knowledge and understanding of CP which helped them to feel prepared to support a student with the condition. “The medical condition that causes the chronic pain I have personal experience with so I actually know that condition, and I understand that condition.” (Line 144. P8, Educational Psychologist). “I think I'm competent enough because I'm experienced teacher. Yeah, I think I'm competent enough because my degrees’ in psychology, so I kind of got that understanding and that's my way in with kids.” (Line 57. P2, Mainstream Secondary Teacher)

For the majority of participants, however, working with students with CP despite feeling a lack of competence to do so was troubling, and feelings of competence did not improve with experience. “Not very [competent] at all, to be honest with you. And even by the end of that year, I don’t think I felt that competent at all.” (Line 202. P11, Mainstream Primary Teacher)

Participants spoke of feeling unsure within their role and worrying about getting things wrong when dealing with potentially serious conditions. “I’m just the class teacher, I don't know, I don't know the answer” (Line 561. P7, Educational Psychologist). “Yeah, like a chronic pain condition, like back or something else? Like? Yeah, I don't think I would feel super competent. In in handling that." (Line 254. P10, Mainstream Secondary Teacher). Overall, participants largely described feeling under pressure to manage conditions that they did not feel knowledgeable and therefore competent with.

Staff's desire to address the lack of training in relation to chronic pain

Many participants spoke about their lack of training in relation to CP, and felt that improved training opportunities would in turn improve understanding, feelings of competence and empathy towards students with CP. Few participants had experienced specific training for CP.

> For me, even when I when it was known that I was going into that class, there seemed to be no, you know, and no access to to sort of specialised or, or even just an expert telling us this is what these conditions can present like, or this is what a child who might be feeling pain, might, might present, like, I've never, never known that, and I've never heard of it, it's not really something that's kind of taught about I don't think in schools" (Line 458. P11, Mainstream Primary Teacher).

Participants questioned why this training was not delivered in the same way it would be to improve understanding of other needs.

> I've been in lots of kind of training sessions in in my seven years of teaching about sort of autism and about children with adverse childhood experiences, not once, not once, have I ever been in a training session where it's even been mentioned that children could have underlying medical conditions that could cause these symptoms? (Line 302. P11, Mainstream Primary Teacher)

Finally, participants felt that improved training opportunities would be greatly beneficial to their practice, both in developing staff confidence and increasing understanding and empathy for individual students. “I think there'd be a lot of teachers who would say, okay…that, like flicked a switch there that makes me think of this person. And that'll change my practice in this way.” (Line 317. P11, Mainstream Primary Teacher)

The emotional impact of working with children with chronic pain

When staff felt unable to support children with CP effectively, either due to gaps in their knowledge of CP, feelings of lack of competence or lack of training and appropriate understanding of CP, this had a notable emotional impact. “I find it frustrating and upsetting you know that somebody is in pain and you don't know what to do about it.” (Line 8. P1, Learning Support Assistant, Primary Special needs setting). Staff clearly had a great sense of empathy towards students with CP and spoke about finding it “very difficult not to become deeply, deeply, deeply involved.” (Line 564. P7, Educational Psychologist).

The emotional impact of working with students with CP led some participants to feel inadequate within their role, a subtheme that arose often. “The key thing really is it is very distressing for anybody to watch a child in pain…that can have emotional demands on staff, can leave them feeling like they're not doing their job, that they're not doing enough.” (Line 222. P9, Hospital School Headteacher)

Due to this emotional impact, many participants felt it important to have support, either through formal supervision sessions or opportunities for colleagues to support each other in group supervision. School staff do not routinely receive supervision, however many participants would appreciate this form of support. “The feeling inept, feeling incompetent, um to see them suffering and not know the best way to relieve it. And therefore, we need our own support network and support system as well.” (Line 528. P7, Educational Psychologist)

Staff felt supervision could be beneficial in many ways, including providing opportunities to reflect, problem solve and to reiterate important boundaries of the role.

> Supervision and the wider school network support can be really helpful…To both shoulder some of that, and but also to kind of help you to reflect on Okay, this is these are the- this is my remit. These are the boundaries of that remit, and that's hard to admit. But there they are. (Line 565. P7, Educational Psychologist)

Theme 2: The wide ranging impact of chronic pain

While school staff felt they lacked a full understanding of CP, an interesting contrast arose when they discussed their experiences working with CYP with CP. School staff discussed the wide ranging impact of CP they noticed in many aspects of CYP’s school life, how this differed between individuals, the wider impact on parents and families and the implications for supporting these students at school. It seemed that through peripheral knowledge and experience, staff did in fact have a rich understanding of CP-perhaps more so than they realised.

Attendance

Attendance was the most widely discussed impact, and staff felt poor attendance was a significant barrier to supporting students with CP. The academic gap in learning due to regular absence was a common concern, and staff felt it was difficult to remediate the impact of lost learning when students did attend. “They’ve already missed so much learning that you kind of fill in gaps and so they're already behind because of because of their pain.” (Line 623. P3, Special Needs Primary School SENCO)

Staff reported that when children were frequently absent, their academic aspirations also became poorer and they were not expected to achieve in the same way as their peers. “Unfortunately as well, these children tend to kind of find themselves in the lower sets because they're not going to be in.” (Line 36. P2, Mainstream Secondary School Teacher)

Staff acknowledged that school is so much more than learning alone “It’s not just about the learning, because school it's so much more than the physical learning. It's social, understanding the social engagement, those opportunities to connect with people. And also just opportunities to have downtime.” (Line 585. P8, Educational Psychologist). They noted that when children’s attendance is impacted by CP, they also miss out on developmental aspects of school, social connections and an important sense of belonging. “When he was unwell, he would disappear for weeks. And it could be months, and he would come back and almost the entire social landscape… of the year group have changed for him.” (Line 247. P12, Mainstream Secondary School Assistant Headteacher)

Staff also noted that when children were regularly absent, the impact of missing these essential connections became a vicious cycle, resulting in students feeling reluctant to attend when they were well enough. “Whatever cause- you have the chronic pain, then you can't go to school, then you become socially isolated from your peers, and everybody else, and then you get anxious because you're missing school.” (Line 142. P9, Hospital School Headteacher)

The fluctuating nature of chronic pain

Staff noted the wide ranging and fluctuating nature of CP, and discussed how the ebbs and flows made it difficult to fully understand the impact of CP for individual children and to pre-empt the support plans needed.

> So it’s the fluctuation and I think that's what schools struggle with the most, because they're used to putting in the same level of support across the board, but actually, for, a child with chronic pain, they might not need anything for two to three weeks. Then all of a sudden, need a really high level of support, because actually, their pain is so unmanageable that they aren't able to, to walk between lessons, they aren't able to sit on the chair for that period of time. (Line 227. P8, Educational Psychologist)

CYP with CP had in fact spoken to staff about their worries concerning the fluctuating impact of their condition and the impression this gave of their abilities. “They said, if they were able to do something one day, people think they can do it all the time.” (Line 212. P8, Educational psychologist).

Many participants described the discomfort they felt being unsure what type of support would be needed at what time, making it difficult to plan, and their frustrations when explaining the fluctuating nature of CP to fellow staff who were not always sympathetic.“They couldn't comprehend that his writing would go from being quite good when he when he was doing well, to being bad.” (Line 118. P12, Mainstream Secondary Headteacher).

Learning Impact

Further, school staff noticed that CP impacted CYP in multiple aspects of learning. Fatigue caused by lack of sleep due to pain meant that CYP struggled to maintain focus on their lessons and needed rest breaks throughout the day, which could not always be provided. Staff also noticed the impact of CP on student’s behaviour, causing them to become “Very short tempered and very intolerant. And that's when I used to think, oh, okay, we need to take a bit of a backseat here.” (Line 167. P11, Mainstream Primary School Teacher).

Behavioural difficulties in particular were difficult to manage using the regular procedures as staff empathised that the student was not choosing to behave this way, and they would likely feel the same if they were experiencing pain. One member of staff felt that their student was so affected by CP that they were simply not ready to learn. "It's not my priority at this moment in time. It's not Maths or English for you. My priority is getting you somewhere where you're comfortable." (Line 168 .P11, Mainstream Primary School Teacher).

This was reflected once more in staff's empathetic statements regarding how much they have struggled to focus when they have felt unwell themselves. Staff appeared to feel unsure how far they could prioritise learning tasks when a student was experiencing pain, sometimes looking to parents for guidance. "Mum says it's not… my priority is to keep her comfortable before I can get her to do any work, and I was like, I totally agree with that, like, that's fine." (Line 328. P5, Special Needs Primary School Teacher).

Emotional Impact

Finally, school staff recognised the overwhelming emotional impact of CP on CYP and their families. Staff witnessed their students feeling embarrassed, isolated, angry, and finding it difficult to come to terms with their condition "In their views, they told me I feel lonely, I feel isolated. I feel I can't talk to my friends. So they, for them, that's a big concern." (Line 105. P8, Educational Psychologist)

Impact on parents/family

In addition, staff sympathised that parents experience a high level of anxiety about their children's CP. "Your child is unwell. And you don't know why- that is terrifying…And you cannot help as a parent, your anxiety is transferring to your child." (Line 165. P9, Hospital School Headteacher).

Staff felt that in this instance, schools were in a good position to provide a supportive environment as respite from the highly emotional relationship between parents and children.

> So you've got to deal with that whole in meshed relationship and sometimes be able to facilitate the child to come into a more supportive environment for a couple of hours, is that two hours off for a coffee, or doing their shopping without, you know, and that's good for them both.(Line 167. P9, Hospital School Headteacher)

Theme 3: Lessons learned from lockdown

Interviews were conducted during the context of the Covid-19 pandemic, in which unprecedented school closures meant school staff were using virtual means to teach the vast majority of students. The lessons staff learned through virtual working, and reflections about using virtual working for students with CP in the near future were evident in all interviews. Staff spoke of their regrets that virtual learning was not used for these students previously, their wish to continue using virtual learning to support not just students with CP but any student in need of an adapted curriculum, and the potential barriers they felt needed to be overcome in order for virtual working to become commonplace in schools as they hoped it could be in future.

The benefits of virtual working

On reflection, a number of participants wondered why virtual working had not been used for students with CP before and felt regretful about the opportunities missed. “Thinking back we probably could have put things in place for her like if it was just a like, twice weekly zoom call with somebody doing reading” (Line 467. P3, Special Needs Primary SENCO).

> It wasn't in my mind or in the minds of anyone else…And now it would be the first thing you know, if if I was working with that young person now I'd be thinking oh, let's get her an iPad. (Line 411. P7, Educational Psychologist).

One participant described virtual resources as a "treasure trove". Staff felt the resources were always present but had only surfaced due to necessity in lockdown, when the ease at which virtual working could be implemented became evident.

Participants noticed the many benefits of virtual working for students with CP, most notably students improved attendance and engagement with virtual lessons that had become easier to access. This prompted a desire to continue working in this way once schools returned to in person learning and seemed to motivate school staff, perhaps because they felt more competent having seen the benefits first hand;

> I'm going to say that I've noticed a spike in sort of (names) attendance. And I'm wondering…when he has migraines, if you would like me to add him into the lesson via via teams online? Because if that, you know, if that helps him cope better? And if that helps him get these grades, then yeah, then yeah, I'll definitely do that. (Line 283. P10, Mainstream Secondary School Teacher)

Continuing a blended learning approach

Many participants felt that virtual working could continue to be used after lockdown, to benefit a wide range of students, including those with CP as part of a blended learning approach. It appeared as though thinking about CP had begun to shift from a misunderstood condition that was difficult to support to the same category as other needs, all of which could be successfully supported by virtual learning. "It'd be quite nice if we could get a system where we're doing tutoring from home. And with groups of kids online. I think a lot kids could benefit from that" (Line 260. P2, Mainstream Secondary School Teacher).

One participant explained that using virtual resources for those who could not attend school would and should "Become a way of working." Participants not only felt it would be a shame to lose the advances in technology they had developed during lockdown, but also reflected on the important psychosocial aspects virtual working provided to students that had perhaps been previously overlooked and were brought to light by the pandemic.

> I definitely think it could be really supportive for children with chronic pain. Because if they're able to access their lesson from say, home…or if they're in hospital or whatever, wherever they might be at that time, um, they're still then getting the same lessons from their teacher, they're still having that same connection to their school, they're still being able to possibly interact with their peers, because on a screen, you can just turn it and you can have that conversation. So they're, they're keeping up that really important connection with school. (Line 410. P8, Educational Psychologist).

The lessons learned from lockdown appeared to prompt a change in thinking for school staff, whereas it was previously felt too difficult and arduous to support children virtually, staff knew now how easily it could be done, and the vast benefits of implementing this type of support. "I think if we had that situation again, if any of our children were in a similar situation, we would rethink how we support them. Because of we've had this opportunity to learn how to advance- to access people." (Line 532. P3, Special Needs Primary SENCO).

Barriers to virtual working

In order to continue using virtual working, participants discussed various barriers that would need to be addressed. Notably, “One of the biggest barriers is just their access to technology.” (Line 404. P11, Mainstream Primary School Teacher).

Staff felt concerned that students with learning difficulties or limited access to technology would find it difficult to engage with virtual working. It was important that supportive measures were accessible to all, particularly the most vulnerable students. Equal access to resources seemed important to staff who worried about an already advantaged group (those that have access to technology and a quiet space to work in) being further advantaged by online learning whereas those of low socioeconomic status risked facing further disadvantage.

> I think it comes down to how we use these things carefully, where we expect them to do them and what, what we expect them to have at their disposal- both in terms of their own skills and areas of strength and weakness and technological capabilities and the sort of the social um, ability to get some space to do that at home. (Line 372. P4, Mainstream Secondary School SENCO).

Staff’s commitment to continuing to implement virtual working was evident in their consideration of ways to overcome these barriers, including liaising with parents regarding how to work virtual platforms and keeping in regular contact with the students, following up completed work with feedback and checking in with students informally to maintain a sense of connection. Staff considered these to be simple yet effective strategies that could reasonably be implemented upon the return to school, and this felt promising.

Theme 4: Managing chronic pain in a school setting

Many participants felt CP was a “hidden illness” in school. When participants were aware of students with CP they worked hard to support their needs, however a number of barriers were discussed which made it more difficult for staff to manage CP in school.

Chronic pain is a hidden issue due to lack of information sharing

A number of participants felt that CP was not a common issue in schools, however upon further reflection many felt that CP perhaps appeared to be less common due to a lack of information sharing. “I'm sure. There's, there's prevalence, but it's not really ever anything that's kind of been discussed, as far as I know.” (Line 86. P11, Mainstream Primary Teacher).

Staff felt they often had to seek information regarding these students, or that the onus was on parents to share information, causing them to become the link between healthcare and education which could be problematic. It was also recognised that children are not forthcoming about their needs due to embarrassment, not wishing to appear different to their peers and comorbid needs affecting their ability to express themselves fully.

> The head of year haven't has not informed me, his mother has not informed me, the boy himself has not informed me, it's just literally these notes. I see on the attendance register, that I know that this kid is having chronic migraines so bad that he cannot come to school. (Line 67. P10, Mainstream Secondary Teacher)

Further, participants commented that students with CP were “Sort of moved out of sight.” (Line 451. P12, Mainstream Assistant Headteacher). Students were commonly supported in smaller provisions within the school, meaning when they were able to attend, they were rarely in class.

> There was about four of them in an alternate unit within, within our school. And they were all in different year groups, all different abilities. And I went down to visit the, my one that was in year 11. And I realized… Actually, you know what, there's four other kids in here who should be doing GCSE. (Line 424. P12, Mainstream Assistant Headteacher)

With good intentions, CYP with CP seemed to be commonly supported outside of the classroom in smaller settings with support staff. This appeared to create a vicious cycle by which their teachers had even less contact and therefore less awareness of the necessary support to be implemented in the classroom.

Adaptations made by trial and error

In terms of managing CP in school, a strong subtheme was constructed concerning staffs efforts to make adaptations, and the barriers they encountered when doing so. Some staff felt that schools "Need to do better" (Line 421. P10, Mainstream Secondary Teacher). Others stated that the current adaptations were not sufficient.

> They are able to leave class early so they can get to avoid the crush, and they can they can get to their next lesson earlier. Hmm. But apart from that, where do we adapt ourselves? Like what do we provide them in the day? (Line 431. P2, Mainstream Secondary Teacher)

Participants discussed various ideas for accommodating the needs of students with CP, however they felt they were often using common sense when making supportive adaptations. "A lot of it for me was just trial and error" (Line 475. P11, Mainstream Primary Teacher). Staff also reported feeling unsure whether implementing strategies were "Within the power of my remit to decide." (Line 341. P7, Educational Psychologist).

When recommendations were suggested by a healthcare professional, school staff found themselves making further adaptations to help students maintain their dignity or not feel different to their peers. School staff also discussed how adaptations were difficult to implement as they worried about embarrassing the student or making the pain worse. Some staff had experienced students not wanting adaptations, and in this situation they felt unsure how far to enforce them.

Overall, the sense was that seemingly simple recommendations given in healthcare plans often became more difficult to implement in the complex school environment where many other factors needed to be taken into consideration. Competence and boundaries of the school staff role were raised again. Staff felt as though they were expected to implement and make judgements regarding adaptations created by healthcare professionals, which went beyond the remit of their role as school staff.

Barriers to making adaptations

Participants discussed a number of barriers to making adaptations in school. Most commonly not knowing where to source necessary resources, budget limitations and organising for additional support staff to be present in the classroom to implement support. Type of educational setting appeared to influence how flexibly staff could implement support, and the type of resources at their disposal. Special school and hospital school staff were aware of “The limitations that my [mainstream] colleagues have… they don't have the resources, they can't do the personalised stuff.” (Line 244. P9, Hospital School Headteacher). They discussed feeling lucky to have more autonomy in their settings to try different resources and ideas in order to find a good fit for the student.

Demanding workloads causing a lack of time

Time was a common subtheme arising within the theme of managing CP in school, underpinning many aspects discussed. School staff felt they were “Juggling all these plates.”

(Line 472. P2, Mainstream Secondary Teacher). Under pressure to deliver high quality lessons, to secure their students good grades and attendance figures, to meet a wide variety of needs and to manage liaising with parents, staff felt little time was left to read information about medical needs or to plan accommodating measures such as adapting the classroom or setting work virtually. One participant summarised “We’re really busy… people forget.”(Line 182. P10, Mainstream Secondary Teacher.)

Many participants discussed the desire for more training, supervision sessions and opportunities to share information to support them to better manage students with CP in school, however this was often followed by timetabling concerns for those who already felt time poor and at their workload capacity. “To find the time to get their training for those individuals…the logistics of that take time to set up, which then you think of some of these individuals that have chronic pain challenges. They need that support straightaway.” (Line 111. P3, Special School SENCO)

Comorbid needs

Staff reported that comorbid needs were common in students with CP and complicated supporting the students in terms of which need should be prioritised and the mediating effect of other needs. As mentioned in previous themes, school staff tried to unpick students’ needs in order to prioritise support, but found this to be confusing and ineffective. Sometimes the cause of the CP was unknown, and the relationship between CP and the impact on many aspects of a student’s life were too complex to reasonably unpick.

Language needs were a common barrier mentioned, and staff found it most difficult when students could not verbally express their pain.

> “I think I've mentioned a few times our biggest challenge is communicating with some of these children if they've got chronic pain, and also the Speech and Language communication

challenges that is, that is the biggest barrier that we face at the moment because you're not necessarily always aware of what their pain is." (Line 613. P3, Special Needs School SENCO)

The value of collaborative working

Many of the ideas participants discussed to improve supporting CYP with CP in school centred on collaborative working between school staff, healthcare professionals, parents and the child or young person. As one participant summarised "The key thing really is all working together to move things forward." (Line 47. P9, Hospital School Headteacher).

Improved communication with healthcare professionals

School staff felt that increased opportunities to liaise with healthcare professionals would be beneficial, as it would provide opportunities to clarify recommendations, ask questions and gain a clearer understanding of conditions. Receiving correspondence was not felt to be sufficient, as the medical terminology could be difficult to understand. "They often use quite a lot of difficult terminology, which is not in everyday language, it doesn't really explain the impact that the pain might have on the child, but it will explain, you know, they've got this diagnosis."(Line 347, P8, Educational psychologist)

> *It's not our lane. We have to try and do our best to figure it out…We Google it and we're like, still haven't got a clue. And, and sometimes the language that's used to communicate with schools can be a bit a bit difficult.* (Line 770, P12, Mainstream Secondary School Assistant Headteacher)

Multi agency working

Regular multidisciplinary meetings were also suggested to facilitate understanding and information/resource sharing between professionals, and school staff had found these types of meeting helpful in the past.

> I think liaising with other professionals in both roles, I think I’ve done quite well, because I've been very aware of where the gaps in my understanding are, and how important it is for me to have a deeper understanding. (Line 254 .P7, Educational Psychologist)

Parent/child centred working

Finally, it was felt to be key that parents and CYP were at the centre of collaborative discussions, as they have beneficial information to share. “Often the most top tip came from the parent…So respecting them as being experts in their child’s care.” (Line 400. P9, Hospital School Headteacher).

School staff recognised that parents may have experienced a difficult journey with their child’s CP, continuously advocating for their needs and battling to secure the appropriate support. Therefore, keeping the lines of communication open and showing willing to work collaboratively with parents was important to facilitate positive working relationships.

> They are already on the back foot, they're already defensive, they're coming in thinking, I'm going to another battle with the school, they're not going to believe anything, I say, What am I going to do, and they're like, from that hopeless position. (Line 420. P9, Hospital School Headteacher)

Ultimately, staff felt that listening, and working in a collaborative, person centred way were key to the support they could offer. “The best thing that we can do is listen, listen to the child, listen to the parent, about what the impact of their condition is.” (Line 150. P9, Hospital School Headteacher).

3.4 Discussion

This research aimed to explore the ways in which schools can support the education of CYP with CP, from the perspectives of 12 members of school staff including teachers, SENCO’s and EP’s. Four overarching themes and associated subthemes were constructed; perceived misunderstanding of CP as a biopsychosocial phenomenon, the wide ranging impact of CP, lessons learned from lockdown, and managing CP in a school setting.

School staff’s descriptions of their lack of knowledge and understanding of CP are consistent with the previous literature (Logan & Curran, 2005; Power et al., 1999). Staff in this research extended further by discussing how their misunderstanding of CP led to feelings of lack of competence, which in turn had an emotional impact. Opportunities for more in depth training about CP and supervision sessions to support staff’s emotional wellbeing were suggested as ways to address this. This is consistent with previous literature in which staff identified that there should be greater knowledge about CP included in teacher training (Solé et al., 2018) and has clear implications for EP’s, as EP’s are well placed to provide training and to deliver supervision (Dunsmuir & Leadbetter, 2010).

Interestingly, staff who did discuss feeling competent felt so due to their personal experiences with health issues. Staff also empathised with students e.g. discussing how difficult they found it to work when they had a migraine. While well intentioned, staff did not appear to acknowledge the difference between adults and children’s individual experiences of CP, which risks unintentionally minimising children’s symptoms. Indeed, research suggests that staff misunderstanding of CP can lead to responses which unintentionally reinforce symptoms (Logan & Curran, 2005). This was also consistent with staff’s discussions about misunderstanding of CP leading to stigmatising beliefs such as believing the CP is made up. Indeed, CYP with CP express their concerns that they will not be believed, or may be thought to be fabricating their impairment (Chomistek et al., 2019).

Staff's descriptions of CP as a hidden problem due to a lack of information sharing is consistent with the previous literature that describes a disconnect in communication between key professionals in a child's life (Logan & Curran, 2005). The current research extends our understanding of this communication difficulty to the language professionals' use specifically creating a barrier. This has implications for improving information sharing between professionals, particularly using multidisciplinary collaborative meetings.

Further, staff described not always being aware of students with CP as they are not forthcoming about their condition. This is consistent with previous literature that students with CP do not feel confident about asserting their needs in school (Barlow et al., 1999) and are reluctant to remind staff when they feel they may not be aware of their condition (Sen et al., 2017). In addition, staff described adaptations made in school for CP that placed students in lower class sets, or further removed them from mainstream teaching via teaching in small groups in alternate provisions within the school. This is in line with previous research which reports adaptations for CP commonly remove students further from the school setting (e.g. by sending students home) which is problematic for integrating students into school (Logan et al., 2008). This has important implications for developing policies and adaptations that promote integration of students to 'normal' school life. Research supports that the most successful interventions for CP involve reintegrating students to school (Gold et al., 2009) improving school attendance and resuming social and academic activities that were previously enjoyed (Rajapakse et al., 2014).

An interesting contrast arose when staff discussed the wide ranging impact of CP. While their descriptions of the impact of CP on CYP's attendance, learning, social skills and emotional wellbeing, as well as the impact on families were consistent with previous literature, it was interesting that staff felt they did not have a good understanding of CP as a biopsychosocial phenomenon. However, through their experience working with CYP with CP, staff did in fact develop anecdotal understanding of the wide ranging impact of CP on many aspects of students and their families lives. Staff also discussed the fluctuating nature of CP, further suggesting a deeper understanding of the way CP can have a changeable impact on individuals over time. This finding extends current knowledge as it could be suggested that school staff do understand CP as a biopsychosocial phenomenon, however in the absence of a framework to apply this knowledge to, their perception is that they are not knowledgeable and therefore not as competent as they feel they should be to support CP. This has implications for introducing a formal framework of understanding CP such as the biopsychosocial model, perhaps via training by EP's. Indeed, previous research suggests that supporting the management of CYP with CP is known to be challenging due to the complex relationships between CP, illness and health which are misunderstood by both clinicians and those with CP themselves (Rajapakse et al., 2014) and school staff identify a need for guidelines when supporting students with CP (Solé et al., 2018). Therefore, training in a model of CP such as the biopsychosocial model could be greatly beneficial in improving the management of CP in schools.

In contrast with the literature regarding bullying issues for students with CP (Greco et al., 2007), school staff suggested that while CYP with CP experienced social isolation as a result of their absence from school, which is consistent with the literature (Kashikar-Zuck et al., 2007) they felt they did not experience bullying. It is possible that bullying instances were not reported by students or not recognised by staff as previous literature suggests (Mishna, Scarcello, Pepler, & Wiener, 2005). However, it could also be suggested that recent government initiatives to improve mental health awareness and support (Department for Education, 2020) and lessons with a wellbeing focus regularly being delivered as part of the curriculum have improved students awareness and acceptance of other's needs. Participants commented that students were generally accepting of their peers and were at most curious, certainly without malicious intent. It should be considered however, that this was noted by primary school staff. Younger students are found to be generally more accepting of differences amongst their peers (Carter & McCloskey, 1984). Participants observed that students are generally more open about their own needs, particularly concerning mental health which may in part explain the more accepting culture reported in this study. Indeed, CYP report feeling that their peers disbelief of their CP is due to an inability to understand their experiences, rather than deliberate malice (Meldrum, Tsao, & Zeltzer, 2009). It should be considered however, that school staff may have been influenced by wishing to give desirable answers, and were therefore reluctant to acknowledge bullying, with its many negative connotations taking place in their school.

The findings regarding virtual working during the pandemic are unique and extend current knowledge about adaptations that can be made for CYP experiencing CP. To the author's knowledge, this is the only current study to consider the benefits of virtual working in the context of the pandemic for students with CP specifically. Staff noticed a number of benefits to using virtual learning, most notably improved attendance and engagement for students who would ordinarily be absent due to CP, but also maintaining an important connection with school through staying in touch with peers and school staff. Previous research has found that the sense of belonging provided by building relationships at school and being a member of a class group is important for children's self-esteem, happiness and school success (Korpershoek et al., 2020). The findings of this research suggest that virtual learning provided a much needed sense of connection in an otherwise isolating time.

Many staff described their regret that virtual learning had not been used for students with CP before and discussed how this would influence their practice upon the return to school. Staff discussed a change in thinking, whereas previously setting work was considered an arduous process, the pandemic caused staff to realise the ease and many benefits to a virtual learning approach for all students and not just those with CP. Staff felt these advances should be maintained in a blended virtual and in person learning approach going forward, as this would continue to benefit any student absent from school for a period of time.

In order to continue to use a blended virtual learning approach, staff identified key barriers that would need to be overcome. Specifically, staff felt concerned about vulnerable students being further disadvantaged by the increased use of virtual learning e.g. students with learning difficulties who require a high level of support in the classroom, and students of low socioeconomic status who may not have access to the appropriate environment or resources to benefit from virtual learning. Research suggests that digital disparity is a disadvantage to virtual learning and that learning in this way may detriment students social skills (Dung, 2020). In addition, research suggests that the pandemic will likely widen achievement gaps between students of high versus low socioeconomic status, with better access to technological resources, internet connection and parents' differing engagement with online resources. Research suggests that accounting for this gap and promoting equitable access to online learning is key to education policy responses to the pandemic (Bacher-Hicks, Goodman, & Mulhern, 2021). This introduces important considerations to be taken into account when considering implementing a blended virtual learning approach to support CYP with CP.

With regard to managing CP in school, staff's descriptions of the barriers they experienced when making adaptations were consistent with previous research which finds CYP and their families report a lack of necessary adaptations made in school as a result of staff misunderstanding CP, and CYP feeling reluctant to assert their needs (Barlow et al., 1999; Sen et al., 2017). Staff's descriptions of inconsistencies in the type of adaptations made and staff's responses to managing CP in school are also consistent (Alsaggaf & Coyne, 2020; Logan, Catanese, Coakley, & Scharff, 2007; Logan, Coakley, et al., 2007) However, this research extends the knowledge about why this is so. Staff described feeling that in the absence of full understanding of CP, they used trial and error to make adaptations. Staff also described the way in which comorbid needs complicated the management of

CP in school as they did not feel confident prioritising needs, and making decisions about CYP's readiness to learn when they were experiencing pain.

When discussing ways forward to support CYP with CP in school, staff empathised with parent's difficult position and discussed working collaboratively, with the child and parent's views at the centre of the work as a key step forward in supporting CP in school. Research suggests that reintegrating CYP to school and providing caregivers with supportive coping strategies are the most effective treatment approaches for CP (Gold et al., 2009) and that outcome goals should be negotiated with children and their families to ensure they are personally meaningful (Rajapakse et al., 2014). Again, this has implications for EP's who are well placed to support the development of appropriate, meaningful goals negotiated between school staff, CYP and families, and can provide supportive advice for both staff and caregivers regarding adaptive coping strategies.

Strengths of the research

The findings of this research address the gaps in the literature by eliciting the perspectives of a wide range of school staff, including EP's, LSA's and SENCO's. The research considers the unique position of school closures and using a virtual working approach for students who cannot attend school, and identifies a number of implications for school staff to continue supporting CYP with CP using a blended virtual and in person learning approach upon the return to school. Implications are also identified for supporting staff's training and supervision needs, and providing a framework for understanding and supporting CP to improve staff knowledge, understanding and feelings of competence.

The qualitative, inductive nature of this research is a significant strength. Conducting detailed, participant driven semi-structured interviews allowed the researchers to obtain a rich and complex account of school staff's perspectives (Braun and Clarke, 2006). By analysing this data thematically, the researchers were able to understand the views of the participants regarding their experiences supporting CYP with CP in detail, and derived new ideas from the themes. The use of semi structured interviews carried out online, although necessary due to the context of the pandemic wherein face to face interviews were not possible, is a methodological strength. This method of interviewing was accessible and convenient for participants, potentially allowing participants across a wide geographical spread and with busy schedules to take part when they may have been unavailable for an in person interview.

The semi structured nature of the interviews and the use of a topic guide allowed the researcher an element of control over the questions asked, therefore increasing the likelihood of generating useful data, whilst also allowing flexibility to explore certain aspects of participants answers further. Refining the topic guide following each interview in order to explore interesting points raised by the participants improved the likelihood of gaining the most useful responses. In addition, semi-structured interviews are well suited to small sample sizes in order to gather rich data. This methodology is also potentially more suited to sensitive topics in comparison to focus groups for example, as there is less social pressure, allowing a safe space to discuss potentially sensitive issues such as feelings of a lack of competence.

Finally, participants had experience across a wide range of settings and with various forms of CP (pain as the condition itself, CP due to illness, unspecified, diagnosed and undiagnosed) therefore, the participant group is considered a strength due to the wide range of experience in both careers and experience with CP.

Limitations of the research

While the methodology of this study was carefully considered in order to appropriately meet the research aims, this did result in limitations. Firstly, virtual interviews can be considered a poorer substitution to face to face interviews (Novick, 2008) however, they have particular strengths and weaknesses in their own right (Sturges & Hanrahan, 2004) virtual interviews are accessible and convenient for participants for example, and may provide a safe space to discuss sensitive topics. Virtual interviews could be considered not as accessible to participants that are not computer literate. However, in person interviews were not a possibility due to the context of the pandemic. Although accessibility has been raised as a possible limitation in general, the nature of the sample and aims of this study would however suggest this not to be an issue. School staff would be expected to be computer literate as using a computer is a standard aspect of their daily role, and more recently during the pandemic, using technology such as Microsoft teams has been required of school staff.

It is acknowledged that the sample size, and the fact that participants were predominantly female limits the generalisability of the findings in this research. Female teachers are found to have more positive attitudes towards inclusive education for example (Navarro-Mateu, Franco-Ochoa, Valero-Moreno, & Prado-Gascó, 2019; Tsakiridou & Polyzopoulou, 2014). The sample also impacts the transferability of the findings to other educational settings somewhat, as there will naturally be differences in practice (some school staff for example, may feel that they are provided with high quality training in relation to CP and therefore do not consider this a need.). The covid-19 pandemic unfortunately resulted in difficulties recruiting participants, as school staff found themselves extremely busy managing the pressures of delivering both in person and online teaching. Although the researchers noted the same themes arising throughout interviews, which could suggest the data was approaching thematic saturation it cannot be confidently posited that 12 participants were sufficient to assume saturation was achieved.

Finally, it is acknowledged that while constructing themes using inductive thematic analysis, the researcher’s role as a trainee EP, as well as the researchers theoretical and epistemological position would have been present and influential. It is possible that the researcher’s position as an EP may have influenced responses. School staff may have wanted to be seen as empathetic and trying to put support in place for example, and this may have resulted in more socially desirable answers. Joffe (2012) notes that a disadvantage of using a topic guide is that it imposes content on participants thinking. In order to remediate this influence as far as possible, transcripts and initial themes were considered by a second researcher to allow more than one interpretation to be discussed. While themes were discussed collaboratively, it is acknowledged that nuanced data may have been overlooked (Guest, 2012).

Future research

There is scope for future research to consider the implementation of blended virtual and in person learning for students with CP from the perspectives of both school staff and CYP. This research was conducted before the post pandemic return to school, therefore it would be useful to consider the advantages and barriers to this approach from both perspectives, once the approach has been used for a reasonable length of time to ascertain its effectiveness and suitability for students with CP.

Implications for educational psychology practice

The findings from this study have important implications for understanding how school staff support and manage the needs of CYP experiencing CP, and the advantages and barriers of using virtual learning approaches for these students. Implications were also identified for developing training, guidelines, and policies for facilitating school staff's understanding, and therefore support of CYP with CP's school functioning.

It was hoped that gathering the perspectives of school staff would identify their needs that should be met in order to support CP in school. The findings identified that school staff felt they needed a greater understanding of CP, and greater collaboration with parents and healthcare professionals in order to achieve this. The findings of this research have influenced the development of information leaflets for school staff and families supporting CYP with CP due to life limiting illness (Appendix M) to contribute to the PARAMOUNT project which explores pain management by carers and healthcare professionals in infants, children and young people in non-hospital settings. Thus implications for practice are taking shape and are currently under development.

A further finding was that school staff felt they did not have a good understanding of CP as a biopsychosocial phenomenon, and this led to feelings of a lack of competence. However, through their experiences working with CYP with CP staff demonstrated a rich understanding of the wide ranging impact of CP in multiple aspects of students and their family's lives. Staff were empathetic towards these issues and keen to support. This has implications for EP practice, in that psychoeducation about explicit frameworks such as the biopsychosocial model of CP and training about CP more generally would facilitate greater understanding and confidence for school staff. EP's are also well placed to inform procedures regarding adaptations for students with CP, and to provide supervision (Dunsmuir & Leadbetter, 2010). Both aspects that school staff expressed would be helpful in supporting CYP with CP e.g. procedures for blended virtual working, and guidance regarding the adaptations made in school.

3.5 Conclusion

This study has provided a unique contribution to the field of educational psychology and the literature on school staff's perspectives about managing CP. The perspectives of school staff regarding their experiences of supporting CYP with CP, and in particular the lessons learned from using a virtual learning approach during the pandemic supports the necessity of making informed adaptations for students with CP in order to improve their school functioning and success. The implications in applying this research to educational psychology practice is clear, providing frameworks and guidance to aid school staff's understanding of CP, as well as providing the training and supervision school staff identified as helpful. EP's are well placed to facilitate change at an organisational level, which has implications for advising learning policies e.g. a blended virtual learning policy for CYP with CP. Finally, EP's are able to facilitate collaborative working approaches, and multidisciplinary meetings, approaches that were also suggested to be helpful in improving the practice of school staff supporting CYP with CP.

Glossary of Terms

Biopsychosocial	The interconnection between biology, psychology, and socio-environmental factors. The biopsychosocial model specifically examines how these aspects play a role in health and disease.
Catastrophizing	Assuming that the worst will happen in a given situation.
Comorbid Need	A need or needs that co-occur with another need in an individual.
Competence	The ability to do something successfully or efficiently.
Demographics	The statistical characteristics of human populations.
Fibromyalgia	Fibromyalgia, also called fibromyalgia syndrome (FMS), is a long-term condition that causes pain all over the body.
Functional Disability	Acquired difficulty in performing basic everyday tasks or more complex tasks needed for independent living.
Hypermobility	The ability to move joints beyond the normal range of movement.
Musculoskeletal Pain	Refers to pain in the muscles, bones, ligaments, tendons, and nerves.
Paediatric	Relating to the branch of medicine dealing with children and their diseases.
Rheumatoid Arthritis	An autoimmune and inflammatory disease, in which the immune system attacks healthy cells in the body by mistake, causing inflammation (painful swelling) in the affected parts of the body.
School Functioning	Refers to a wide range of factors including school attendance, academic achievement and social relationships.

Self-Concept	An idea of the self, constructed from the beliefs one holds about oneself and the responses of others.
Self-Efficacy	Refers to an individual's belief in his or her capacity to execute behaviours necessary to produce specific performance attainments.
Sickle Cell Disease	A group of inherited health conditions that affect the red blood cells.
Social Functioning	An individual's interactions with their environment and the ability to fulfil their role within such environments as work, social activities, and relationships with partners and family.

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Appendix A Search strategy for systematic literature review.

Databases: MEDLINE, PsycINFO, CINHAL (title, abstract, subject terms) searched via EBSCOhost

1 pain*
2 ache*
3 abdominal pain
4 arthritis
5 headache*
6 musculoskeletal pain
7 fibromyalgia

8 1 OR 2 OR 3 OR 4 OR 5 OR 6 OR 7

11 boy*
12 girl*
13 child*
14 teen*
15 youth*

16	adolescen*
17	young*
18	schoolchild*
19	school child*
20	juvenil*
21	paediatric*
22	pediatric*
23	famil*
24	mother
25	father
26	caregiv*
27	guardian
28	parent*
29	teach*
30	educator
31	learning support assistant
32	SENCO
33	Special Educational Needs Coordinator
34	physician
35	nurse
36	psychologist
37	doctor
38	clinician
39	healthcare professional
40	counsellor
41	physiotherapist
42	occupational therapist

43 11 OR 12 OR 13 OR 14 OR 15 OR 16 OR 17 OR 18 OR 19 OR 20 OR 21 OR 22 OR 23 OR 24 OR 25 OR 26 OR 27 OR 28 OR 29 OR 30 OR 31 OR 32 OR 33 OR 34 OR 35 OR 36 OR 37 OR 38 OR 39 OR 40 OR 41 OR 42

44 school
45 education
46 institute
47 academi*
48 college
49 sixth form
50 GCSE*

51 44 OR 45 OR 46 OR 47 OR 48 OR 49 OR 50

8 AND 43 AND 51

Note: This search was repeated three times for title, abstract and subject terms separately. Each search was then combined with OR (e.g., Title search results OR Abstract search results OR Subject term results).

Database: Web of Science

Fields searched: Title

TI=(pain* OR ache* OR abdominal pain OR arthritis OR headache* OR musculoskeletal pain OR fibromyalgia) AND TI=(boy* OR girl*, OR child* OR teen* OR youth* OR adolescen* OR young* OR schoolchild* OR school child* OR juvenil* OR paediatric* OR pediatric* OR famil* OR mother OR father OR caregiv* OR guardian OR parent* OR teach* OR educator OR learning support assistant OR SENCO OR Special Educational Needs Coordinator OR physician OR nurse OR psychologist OR doctor OR clinician OR healthcare professional OR counsellor OR physiotherapist OR occupational therapist) AND TI=(school OR education OR institute OR academi* OR college OR sixth form OR GCSE*)

Database: Cochrane Library

Fields searched: Title, Abstract, Keywords

(pain*OR ache*OR abdominal pain OR arthritis OR headache*OR musculoskeletal pain OR fibromyalgia) AND (boy*OR girl*OR child* OR teen* OR youth* OR adolescen* OR young* OR schoolchild* OR school child* OR juvenil* OR paediatric* OR pediatric* OR famil* OR mother OR father OR caregiv* OR guardian OR parent* OR teach* OR educator OR learning support assistant OR SENCO OR Special Educational Needs Coordinator OR physician OR nurse OR psychologist OR doctor OR clinician OR healthcare professional OR counsellor OR physiotherapist OR occupational therapist) AND (school OR education OR institute OR academi* OR college OR sixth form OR GCSE*)

Database: OpenGrey

Field searched: Main search field

(pain*OR ache*OR abdominal pain OR arthritis OR headache*OR musculoskeletal pain OR fibromyalgia) AND (boy*OR girl*OR child* OR teen* OR youth* OR adolescen* OR young* OR schoolchild* OR school child* OR juvenil* OR paediatric* OR pediatric* OR famil* OR mother OR father OR caregiv* OR guardian OR parent* OR teach* OR educator OR learning support assistant OR SENCO OR Special Educational Needs Coordinator OR physician OR nurse OR psychologist OR doctor OR clinician OR healthcare professional OR counsellor OR physiotherapist OR occupational therapist) AND (school OR education OR institute OR academi* OR college OR sixth form OR GCSE*)

Appendix B Data extraction table

Study	Country	Study aims, design, and details	Paediatric sample demographics and medical characteristics	School functioning outcome measures	Person completing school functioning outcome variable	Additional outcome and outcome measures (if applicable)	Summary of school functioning results
Assa, Ish-Tov, Rinawi& Shamir.,(2015)	Israel	Design: Mixed methods Aim: To assess school-related quality of life and school absenteeism in children with Inflamatory bowel disease (IBD compared with functional abdominal pain (FAP) and healthy controls.	43 children aged (10-17) with Crohn disease 31 children (aged 10-17) with ulcerative colitis 42 children (aged 10-17) with FAP 30 age matched healthy children (control group).	A questionnaire addressing the impact of gastrointestinal symptoms on the child's school absenteeism and participation in school and after-school activities. The questionnaire was composed of 9 questions: 1.How many school days did	Self-report and proxy parent report.	Absenteeism data were cross-matched with patient's official school final annual report cards.	Children with FAP (17.6 (8.75–30) CD (24 (14–30), and UC (21 (12–25) missed significantly more school days than age-matched healthy controls (5.1 (3.75–6.25), *p* < 0.001). Absenteeism because of abdominal pain was similar in FAP, CD, and UC (10 [3–16.25], 10.5 [2–15], and 8.7 [2–10] days), significantly greater

		Method: School absenteeism and participation in school and after-school activities data were obtained for children with Crohn disease (CD), ulcerative colitis (UC), FAP, and age-matched healthy controls for the 2013–2014 school year. A semi-structured questionnaire for both children and parents was used.	Mean age in years: FAP: 13.1 CD 14.9 UC 14.8 Healthy controls 13.7 Disease severity at diagnosis: Mild (%) CD= 13 (30) UC= 8 (26) Moderate (%) CD= 17 (40) UC= 17 (55) Severe (%) CD= 13 (30) UC= 6 (19) Numbers of flares in the last year 0 (%) CD= 14 (33) UC=12 (39) 1 (%) CD=17 (40) UC=13 (42) 2 (%) CD= 10 (22) UC= 6 (19) 3 (%) CD=2 (5) UC= 0 (0)	your child/you miss during the last school year? 2.How many school days did your child/you miss because of abdominal symptoms? 3.How many days did your child/you miss because of hospitalizations? Clinic/ER visits? 4.How often did your child/you participate in gym classes? 5. Did your child/you participate in school trips? 6. How often did your child/you participate in extracurricular school activities?			than healthy controls (0.4 [0–1], $p < 0.001$). 64% of patients with IBD and 48% of patients with FAP had missed > 3 weeks of school, compared with 3% for healthy adolescents. Compared with children with FAP, absenteeism because of medical appointments and hospitalization was significantly greater in children with CD and UC compared with FAP/FAPS (8.8 [4–14] and 7.1 [3–10] vs 4.4 [2–6.25], $p < 0.001$). Absenteeism because of medical appointments/hospitalizations in the IBD group showed the greater part is attributed to outpatient clinic visits (CD 6/8.8 days [68%], UC 5.5/7.1

				7. How often did your child/you participate in after-school (excluding sport) programs? 8. How often did your child/you participate in after-school sport activities? 9. How often did your child/you participate in after-school social activities? The same questionnaire was introduced to the child as a measure to reduce recall bias.			days [77%]), whereas hospitalizations (CD 1.4/8.8 days [16%], UC 1.1/7.1 days [16%]) and infliximab infusions (CD 1.4/ 8.8 days [16%], UC 0.5/7.1 days [7%]) contribute only a small proportion. Participation of children with IBD and FAP in various school activities and after-school activities was significantly reduced compared with healthy controls: Participation in gym classes No–rarely (%) FAP= 10 (24) CD=15 (35) UC=10 (32) Healthy= 0 (0) FAP, CD < Healthy $p = < 0.001$ UC< Healthy $p = < 0.01$. Participation in after-school program No–rarely (%) FAP= 7 (64)

							CD=36 (84) UC= 24 (77) Healthy= 2 (8). FAP, CD, UC < Healthy *p* = 0.001. Participation in after-school sport activities No–rarely (%) FAP= 0 (48) CD=26 (60) UC= 15 (48) Healthy= 2 (8). FAP, CD, UC < Healthy *p* = 0.001. Social activities both during school (school trips) hours and after school (social meetings and parties) were not similarly affected. Participation in after-school social activities No–rarely (%) FAP=5 (12) CD=5 (12) UC= 2 (6) Healthy= 3(10) Not Significant. Participation in school trips (%) FAP= 33 (78) CD= 34 (79) UC= 27 (87) Healthy= 27

							(90) Not Significant. Participation in school activities No–rarely (%) FAP=6 (19) CD=3 (7) UC= 4 (14) Healthy= 0 (0). Not Significant. There was no significant difference in school attendance and participation in school and after-school activities between children with IBD and FAP.
Aasland & Diseth., (1999)	Norway	Design: Mixed methods Aim: To explore the Harter Self-Perception Profile for Adolescents (SPPA) as an indicator of psychosocial outcomes in adolescents with chronic physical disorders.	Adolescents (12-17 years old) with juvenile chronic arthritis (23) with good psychosocial adjustment. Mean age= 14 (2.0) Adolescents with anorectal anomalies (20) with a high level of psychosocial	Overall score of psychosocial functioning according to the Children's Global Assessment Scale (CGAS) taken from a psychiatric interview. The score reflects functioning in family, with friends, and at **school**.	Self report by adolescents	Psychiatric assessments: All patients were interviewed by the authors utilizing the semistructured Child Assessment Schedule (CAS) (15). The CAS covers important areas of the patient's life such as school, friends, family, worries and anxieties,	The adolescents with ARA had significantly lower scores of global self-worth, school competence, and social acceptance as compared to the adolescents with JCA. SPPA School Competence score: JCA= 3.2 (0.6) ARA= 2.8 (0.7), $p < 0.05$.

		Methods: Questionnaires and established measures of psychosocial outcome were administered (the semi-structured Child Assessment Schedule (CAS) interview, the Youth Self Report (YSR) and Child Behaviour Checklist (CBCL) questionnaires).	maladjustment. Mean age= 13.6 (1.7).	Interrater reliability, discriminant validity, and clinical usefulness of the CGAS have been well documented. Psychosocial functioning also assessed by the Youth Self Report (YSR) and Child Behaviour checklist (CBCL) questionnaires. A total score of social competence is given including participation in activities, relationships with friends and family, and **school performance**. Self-esteem: Self-Perception Profile for Adolescents (SPPA).		self-image, mood, behavior, and reality testing. A set of scores consists of symptom complexes analogous to psychiatric diagnoses in the Diagnostical and Statistical Manual of Mental Disorders (DSM-III-R) The adolescents completed the Youth Self Report (YSR) (2) and the parents completed the Child Behavior Checklist (CBCL) (3). These standardized questionnaires provide a total behaviour problem score, a score of internalizing behaviour (anxiety and depression, withdrawal, and somatic complaints), and a score of externalizing behaviour	Social acceptance score: JCA= ARA= *p* < 0.01. Adolescents with JCA scored significantly higher than the population on global self-worth (*p* < 0.001), school competence (p < 0.01), social acceptance (*p* < 0.001), close friends (*p* < 0.01).

				The SPPA inquires about the adolescents' self-concept in domains of competence considered to be of importance for a majority of adolescents, but in addition assesses global self-worth directly by asking the adolescents about their general evaluation of themselves. The revised version used contained seven subscales: **Scholastic Competence**, Social Acceptance, Athletic Competence, Physical Appearance, Romantic Appeal, Close		(aggression and delinquency). The YSR and CBCL have good test-retest reliability and construct validity.	

				Friends, and Global Self-Worth. Each subscale contains four items, each having four options: 1 Describes me very poorly), 2 (Describes me fairly poorly), 3 (Describes me fairly well), and 4 (Describes me very well), providing a mean score of perceived competence in that area, ranging from 1 (lowest level of self-esteem) to 4 (highest level of self-esteem)			
Aasland, Flatö, & Vandvik. (1997)	Norway	Design: Mixed methods Aim: To explore the role of psychosocial	23 children with IMP and 52 children with juvenile chronic arthritis (JCA)	Interview using the Child Assessment Schedule (CAS). Standardized questions	Self report by children via semi structured interview.	Pain: Visual analogue scale (VAS) the child is asked to indicate amount of present	At first admission, patients with IMP reported more school stress than those with JCA. More patients with persistent IMP

		factors in the development and persistence of idiopathic musculoskeletal pain (IMP) in children. Methods: Semi structured interviews were conducted with children with JCA and IMP at first admission to hospital and at 9 year follow-up.	IMP Median age= 12.0 (5-15) JCA Median age= 9.0 (1-16)	covering 11 areas: school, friends, activities, family, fears, worries and anxieties, self-image, mood, physical complaints, expression of anger and reality testing. Answers are coded and scores provide diagnoses according to diagnostic criteria in the Diagnostic and Statistical Manual of Mental Disorders, 3rd edition (DSM-III). The reliability and validity of the interview have been well established.		pain and the worst pain experienced. Endpoints on the scales were “no pain” (= 0) and “worst pain imagined” (= 10). Patients were also asked whether they experienced other recurrent aches and pains, such as head-ache and stomachache. Overall psychosocial functioning: Children’s Global Assessment Scale (CGAS). Measures severity of psychiatric disturbance and behavioural functioning across different life situations (e.g. in family, with friends, at school). The score ranges from 1 to 100, where 100 implies excellent functioning in all areas, 70 is the cut-off score between	had reported worries about school performance ($p < 0.05$). More patients with IMP had unrealistic worries about school performance or learning difficulties ($p < 0.01$ and $p < 0.05$, respectively).

						normal and impaired functioning and 1 implies extreme malfunctioning. The inter- rater reliability, discriminant validity and clinical usefulness of the scale are well established Chronic family difficulties: One of the parents of each child was interviewed by a child psychiatrist using a semistructured interview. The interview contained questions about employment and education, economy, housing conditions, marital or family discord, social network and physical and mental health of the family members. Based on this information, a global assessment of chronic family	

						difficulties was made. The score ranges from 0 to 6, where 0 implies no signs of chronic family difficulties and 6 implies severe family difficulties.	
Abdul-sattar, Abou El Magd & Negm,. (2014)	Egypt	Design: Cross Sectional Aim: To investigate the factors associated with school absenteeism and poor school functioning in Egyptian children and adolescents with juvenile idiopathic arthritis (JIA). Methods: Patients underwent assessment of socioeconomic and demographic characteristics, disease activity (JIDaS-27), functional ability (cHaQ), depressive	52 patients with JIA aged 7-17 years and with duration of disease ≥1year. The median age of the patients was 9.5 (7–17) years; the median disease duration was 4.9 (1–11) years. 90 Healthy children (control group)	Assessment of school functioning: (PedsQ 4.0) Health related quality of life scale. Well-established reliability and validity in children with both acute and chronic health conditions. Four subscales: physical functioning, emotional functioning, social functioning, and school functioning (addressing school	Self report by children and parent proxy report.	Assessment of disease activity: JIDaS (Juvenile arthritis disease activity) Score is based on 27 joints. 4 measures were included: physician global assessment of disease activity using a visual analog scale (VAS), parent global assessment of child's well-being determined by a VAS, count of joints with active disease (evaluating 27 joints), and eSR. eSR is normalized to a score ranging from 0 to 10. JaDaS-27 is calculated as the sum of the scores of its 4 components, which	69% of the sample missed 3 weeks or more of school during past academic year. The mean percentage of missed school days was 12.5% (equivalent to 25 absent days). A total of 46% of patients had poor school functioning (school functioning subscale score of HRQOl≥1 SD below the mean of healthy children). Self reported school functioning (Self report children with JIA): Mean= 65.79 (SD 18.23), Healthy children: Mean= 83.90 (SD 16.59), *p* < 0.001.

		symptoms (cDI score), and school functioning (PedsQl 4.0).		performance and the ability to be in school). All scales demonstrate high reliability. Each scale uses a likert 5-point scale to ask the child or parent how much of a problem each item has been over the past month: (0=never a problem, 1=almost never a problem, 2=sometimes a problem, 3=often a problem, and 4=almost always a problem). Higher scores indicate better health related quality of life.		yields a total score of 0–57: 0=no disease activity, higher scores associated with worse disease activity, and 57=maximum disease activity. The JaDaS-27 has adequate validity Functional ability: Childhood health assessment questionnaire (cHaQ). Describes the child's usual activities in 8 domains over the past week. It includes dressing and grooming, arising, eating, walking, with or without aids or assistive devices, hygiene, reach, grip, and activities. Each question is scored from 0 to 3, (0=no difficulty, 1=some difficulty, 2=much difficulty, and 3=unable to do).	Parent proxy reported school functioning: (Children with JIA): Mean= 66.65 (SD 19.24), Healthy children: Mean= 80.06 (SD 15.02), $p <$ 0.001. In multiple regression analyses, high cHaQ scores, disease activity, and depressive symptoms were independent predictors for both of school absenteeism and of poor school functioning. Living in rural regions was independently associated only with high school absenteeism in patients with JIA.

						The score for each of the 8 functional areas is averaged to calculate the disability index. The assessment has excellent internal reliability (cronbach's α=0.94) Depressive symptons: Children's depression inventory (cDI score). 27-item self-report inventory of a variety of depressive symptoms. Items assess negative mood, interpersonal difficulties, negative self-esteem, ineffectiveness, and anhedonia in children aged 7–17years. Each item is rated on a 3-point scale from 0 to 2 summed to obtain a total score. Total score ranges from 0 to 54 in which a higher score	

						indicates severe depression. The CDI has adequate factor reliability and validity (cronbach's α=0.84)	
Abdul-Sattar, Elewa, Enass, El-Shahawy &Waly. (2013)	Egypt	Design: Quant Descriptive Aim: To identify the possible determinants of impaired health-related quality of life (HRQOl) in Egyptian children and adolescents with juvenile idiopathic arthritis (JIA). Methods: Patients with JIA underwent assessment of socio-economic and demographic characteristics, the HRQOl using	58 patients with JIA (aged 8-18) Median age= 9.1 years. Disease duration, years, median= 4.7 years Schooling status [(%)] Continue 46 (79.3) Stop 12 (20.7) Subtypes of JIA [(%)] Systemic 13 (22.4) Oligoarthritis28 (48.3)	Assessment of school functioning: (PedsQ 4.0) Health related quality of life scale. Well-established reliability and validity in children with both acute and chronic health conditions. Four subscales: physical functioning, emotional functioning, social functioning, and school functioning	Self-report by children.	Assessment of disease activity: JIDaS (Juvenile arthritis disease activity) Score is based on 27 joints. 4 measures were included: physician global assessment of disease activity using a visual analog scale (VAS), parent global assessment of child's well-being determined by a VAS, count of joints with active disease (evaluating 27 joints), and eSR. eSR is normalized to a score ranging from 0 to 10. JaDaS-27 is calculated as the sum	55% of the patients (32 of 58) had impaired HRQOL. Stopping going to school (OR 3.9, 95% CI 2.0–7.3, *p* = 0.01) was a significant determinant for HRQOL impairment.

		Pediatric Quality of life Inventory 4.0 generic core Scale, disease activity using the Juvenile arthritis Disease activity Score, functional ability using the childhood health assessment questionnaire (cHaQ), pain score on visual analog scale and psychological symptoms using the children's Depression Inventory (cDI) score.	Polyarthritis17 (29.3)	(addressing school performance and the ability to be in school). All scales demonstrate high reliability. Each scale uses a likert 5-point scale to ask the child or parent how much of a problem each item has been over the past month: (0=never a problem, 1=almost never a prob-lem, 2=sometimes a problem, 3=often a problem, and 4=almost always a problem). Higher scores indicate better health related quality of life.		of the scores of its 4 components, which yields a total score of 0–57: 0=no disease activity, higher scores associated with worse disease activity, and 57=maximum disease activity. The JaDaS-27 has adequate validity Functional ability: Childhood health assessment questionnaire (cHaQ). Describes the child's usual activities in 8 domains over the past week. It includes dressing and grooming, arising, eating, walking, with or without aids or assistive devices, hygiene, reach, grip, and activities. Each question is scored from 0 to 3, (0=no difficulty, 1=some difficulty, 2=much	

						difficulty, and 3=unable to do). The score for each of the 8 functional areas is averaged to calculate the disability index. The assessment has excellent internal reliability (cronbach's α=0.94) Depressive symptons: Children's depression inventory (cDI score). 27-item self-report inventory of a variety of depressive symptoms. Items assess negative mood, interpersonal difficulties, negative self-esteem, ineffectiveness, and anhedonia in children aged 7–17years. Each item is rated on a 3-point scale from 0 to 2 summed to obtain a total score.	

						Total score ranges from 0 to 54 in which a higher score indicates severe depression.	
Aggarwal,Khubchandani et al., (2018)	India	Design: Cross Sectional Aim: To cross-culturally adapt and validate the Hindi parent, child/adult version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) in patients with juvenile idiopathic arthritis (JIA). Methods: Each participating centre was asked to collect demographic, clinical data and the JAMAR in consecutive JIA patients or all consecutive patients seen in a 6-month period	275 JIA patients 28.4% systemic arthritis 10.9% with oligoarthritis, 13.8% with RF negative polyarthritis, 6.9% with RF positive polyarthritis, 1.8% with psoriatic arthritis 32.0% with enthesitis-related arthritis 6.2% with undifferentiated arthritis Median age= 12.5 100 healthy children (control group) Two healthy children did not consent to their data being used.	School attendance Specific item used: JAMAR item 12: Report of school problems caused by JIA (list of items) More items chosen from the list= more problems with school functioning. The JAMAR consists of 15 sections intended to assess the broader construct of the most relevant parent/ patient-reported outcomes in JIA, including overall well-being, functional status, health-related quality of life	Self-report by child or proxy parent report. 99.2% of subjects had the parent version of the JAMAR completed by a parent (272 from parents of JIA patients and 98 from parents of healthy children) The child version of the JAMAR was	Assessment of health related quality of life using the Physical Health (PhH), and Psychosocial Health (PsH) subscales (five items each) and a total score. Likert response, 'never' (score=0), 'sometimes' (score=1), 'most of the time' (score=2) and 'all the time' (score=3). A 'not assessable' Rating of the intensity of the patient's pain on a 21-numbered circle Visual Analogue Scale Assessment of physical function using 15 items in which the ability of the child to perform	No significant difference between the healthy subjects and their affected peers in the school-related problems variable. JIA= 5.1% problems attending school compared to 1.2% Healthy controls.

		and to administer the JAMAR to 100 healthy children and their parents.	Median age= 12.8 Enrolled at three paediatric rheumatology centres.	(HRQoL), pain, morning stiffness, disease activity/status/ course, articular and extra-articular involvement, drug-related side effects/compliance and satisfaction with illness outcome. Three versions are available: -Parent proxy-report (child's age 2–18) -Child self-report (suggested age range of 7–18 years) -Adult	completed by 259/373 (69.4%) children aged five or older.	each task is scored: 0=without difficulty, 1=with some difficulty, 2=with much difficulty, 3=unable to do and not applicable	
Cagliyan-Turk & Sahin., (2020)	Turkey	Design: Cross Sectional Aim: To determine the frequency of juvenile fibromyalgia syndrome (JFMS) among children and adolescents in Turkey, and its impact by	Wider sample that the study participants were chosen from: 476 children and adolescents (245 boys, 231 girls; mean age 13.81±2.3 years; range, 9 to 17 years).	School Measure: Pediatric Quality of Life Inventory (PedsQL) Varni, 1999. Four subscales: physical functioning, emotional functioning,	Self report and parent proxy report.	Students were examined by evaluating sensitive points. TP examination was applied while the student was in sitting position. Approximately 4 kg force was applied using the index finger to	The number of minor JFMS diagnostic criteria, number of TPs, depression level and number of days the participants were absent from school were significantly higher in the JFMS group compared

		comparing the levels of academic success, depression and quality of life (QoL) in individuals with and without JFMS. Method: Participants' sociodemographic data, parental information, and school achievement in addition to data on chronic illness and drug use were collected via questionnaires (depression and QoL). A tender point (TP) examination was performed on each participant.	Thirty-five (7.35%) of the participants (girls, n=25; boys, n=10) were diagnosed with JFMS. The control group (non-JFMS group) 105 age and sex matched healthy participants (75 girls, 30 boys; mean age 14.1±1.8 years; range; 9 to 17 years)	social functioning, and school functioning (addressing school performance and the ability to be in school) All scales demonstrate high reliability. Each scale uses a likert 5-point scale to ask the child or parent how much of a problem each item has been over the past month: (0=never a problem, 1=almost never a prob-lem, 2=sometimes a problem, 3=often a problem, and 4=almost always a problem). Higher scores indicate better quality of life/ functioning in the subscale area.		the TP. The student was asked to say when she/he felt pain. The 18 TP regions (nine pairs) specified in the American College of Rheumatology criteria were evaluated. The Children's Depression Scale (CDS): Self-assessment scale to evaluate depression levels. For children and adolescents between the ages of 6 and 17. The scale contains 27 items, each with three options. The child chooses the most appropriate sentence based on the previous two weeks. Each item is scored as 0, 1 or 2 regarding the severity of symptoms. The maximum total score is 54, with	with the non-JFMS group (*p* = 0.001) . The mean school grade point scores of the JFMS group were significantly lower than those of the non-JFMS group (*p* < 0.05). The QoL subgroup scores as assessed by physical functioning, emotional functioning, social functioning and school-related problems of the JFMS group were significantly lower than the non-JFMS group (*p* = 0.001) However parental evaluation revealed that the JFMS group had significantly lower levels in the school-related problems subgroup compared to the control group (*p* = 0.011).

						a higher total score indicating a higher level of depression. The recommended cut-off point is 19. The reliability and validity of the Turkish version of the scale are confirmed. Quality of life was assessed using the Pediatric Quality of Life Inventory (PedsQL) Varni, 1999 23 item scale Items scored between 0 and 100. If the answer to a question is ‘never’, it receives a score of 100, whereas responses of ‘rarely’, ‘sometimes’, ‘often’ and ‘always’ receive scores of 75, 50, 25 and 0, respectively. Higher PedsQL total scores	Depression was negatively correlated with QoL and school-related problems (r= -0.672, r= -0.731; $p < 0.05$, respectively). There was a positive correlation between grade score means and QoL (r= 0.432, $p = 0.010$).

						indicate better health-related QoL.	
Armbrust, Bos et al., (2016)	Netherlands	Design: Multicenter randomized controlled trial Aim: To determine the effects of Rheumates@Work, an internet-based program supplemented with 4 group sessions, aimed at improving physical activity, exercise capacity, health-related quality of life (HRQoL), and participation in children with juvenile idiopathic arthritis. Method: Patients were recruited from 3 pediatric rheumatology centers in The	Intervention Group: 28 children who had been diagnosed with JIA according to the criteria established by the International League of Associations for Rheumatology. Aged 8–13 years, (median age 9.7 (8.7–11.3) Inclusion: Good comprehension of the Dutch language, a computer with access to the internet, and an exercise capacity below or equal to the 5th percentile for age and sex or	School Measure: Pediatric Quality of Life Inventory (PedsQL) Varni, 1999. Four subscales: physical functioning, emotional functioning, social functioning, and school functioning (addressing school performance and the ability to be in school) All scales demonstrate high reliability. Each scale uses a likert 5-point scale to ask the child or parent how much of a problem each	Self-report	Exercise capacity: expressed as maximum endurance time, measured with the Bruce Treadmill protocol. Presented as a Z score of the Dutch population norm, to evaluate the long-term effects of R@W. Z scores were calculated as patients' exercise capacity- population mean/population SD. An increase of endurance time of 10% or more was considered clinically relevant. Disease activity: assessed by a pediatric rheumatologist on a 0–10-cm VAS at commencement	In the intervention group, longitudinal followup showed that all scales of the HRQoL questionnaire improved, except the school subscale. Participation in school activities increased. The percentage of children in the intervention group who missed at least 1 day of school due to JIA during the preceding 3 months, decreased significantly from 43% to 14% ($p = 0.02$) at T1. In the control group this percentage increased from 24% to 29% ($p = 0.60$) The difference between groups was

		Netherlands for an observer-blinded, randomized controlled multicenter trial. Physical activity level, time spent in rest, light, and moderate-to-vigorous physical activity (MVPA) were recorded in a diary and with an accelerometer, before intervention, after intervention, and at followup after 3 and 12 months (intervention group only). Exercise capacity was assessed using the Bruce treadmill protocol, HRQoL was assessed with the Pediatric Quality of Life Inventory generic core scale, and participation in school and in physical education	had a sedentary lifestyle, (defined as 60 minutes of physical activity of moderate-to-vigorous intensity for at least 4 days in a 7-day period as recorded in an activity diary). Exclusion criteria: children who had a physical disability caused by a condition other than JIA and that limited motor and/or exercise performance, received cognitive behavioural therapy, and had a high disease activity as defined by a physician's	item has been over the past month: (0=never a problem, 1=almost never a prob-lem, 2=sometimes a problem, 3=often a problem, and 4=almost always a problem). Higher scores indicate better quality of life/ functioning in the subscale area. Participation in school and physical education classes: measured during 3 months prior to the test. School absenteeism was defined as being absent from school for 1 or more days as a consequence of JIA, and not as a result of		and during the intervention, to monitor exacerbations (0-5 no disease activity and 5-10 maximum disease activity). Functional ability: measured using the Dutch version of the Childhood Health Assessment Questionnaire, which measures functional impairment in 9 domains. Pain and well-being: measured on a 0–10-cm VAS (where 0 5 no pain or optimal well-being and 5-10 the maximum amount of pain possible or the worst well-being possible).	not statistically significant. Participation in physical education classes increased from 57% to 71% (*p* = 0.01) and from 62% to 67% (*p* = 0.01) in the intervention and control groups, respectively. The difference between the intervention and control groups was not statistically significant.

		classes were assessed by questionnaire.	score of 2 cm on a visual analog scale (VAS; range 0–10). Control Group: 21 children Median age 10.2 (9.0–10.8)	an infection or regular hospital visits. Participation in physical education classes was rated as full when children did not miss any classes due to JIA. Partial participation was defined as missing a class every now and then, or if the activities were adjusted because of the disease. No participation was defined as no participation whatsoever due to JIA.			
Armbrust, Lelieveld et al., (2016).	Netherlands	Design: Cross Sectional, descriptive. Aim: To assess the presence and severity of fatigue in patients with JIA, including	80 patients with JIA (age 8–13). Median age= 9.8 JIA classification: -Oligo-JIA, persistent 25	Participation in school and physical education class were queried, with a 3-month recall period. School attendance	Self report children	Fatigue: measured with the Pediatric-Quality-of Life-Inventory Multidimensional Fatigue Scale (PedsQl-MFS) for children aged 8–12 years.	Seventy percent of patients reported full school attendance without absenteeism due to the disease. Correlations of fatigue with full participation in

		factors presumed associated with fatigue (e.g., disease activity, disability, pain, physical activity, exercise capacity, and self-efficacy), and whether fatigue is related to participation in physical education classes, school attendance, and sports frequency. Method: Used baseline data of 80 patients with JIA who participated in an intervention aimed at promoting physical activity. Primary outcome measurements were fatigue, assessed using the Pediatric-Quality-of-Life-Inventory (PedsQl)-Fatigue-scale and energy level assessed using a VAS scale.	-Oligo-JIA, extended 11 -Poly-JIA, Rf- 25 -Poly-JIA, Rf+ 3 -Psoriasis related JIA 4 -Enthesitis related JIA 3 -S-JIA 9 Inclusion criteria: diagnosis of JIA according to the ILAR criteria, good comprehension of the Dutch language, availability of a computer with Internet connection. Exclusion criteria: a physical disability that was caused by a	was defined as no absence from school or absence for 1 or more days, related to the disease but not to infections or regular hospital visits. Participation in physical education class was rated as complete, when the lessons were not adapted or when the child did not miss a class for reasons related to the disease.		The PedsQl-MFS includes 3 subscales: general fatigue, sleep/rest fatigue, and cognitive fatigue. Patients rated how often a symptom occurred during the past month, using a 5-point Likert scale (0 = never a problem, 1 = almost never a problem, 2 = sometimes a problem, 3 = often a problem, 4 = always a problem). Scoring was performed according to the manual, resulting in subscale and total scores between 0–100. Higher scores indicate lower levels of fatigue Energy level: Estimated using a unidimensional VAS score from 0–10. Zero meant no energy (for the patients: an “empty	physical education class and school attendance approached significance but were not significant. (*p* = 0.07) The use of medication, disease activity, pain, and disability significantly correlated with both school attendance (*p* = < .01, *p* = 0.05, *p* = < .01, *p* = < .01 respectively) and participation in physical education class. (*p* = < .01). With respect to school attendance, pain predicted 46% of the variance. (*p* = < .01).

		Other outcome measurements were disease activity (VAS Physician Global Assessment Scale), disability (Childhood Health Assessment Questionnaire), physical activity (accelerometer), exercise capacity (Bruce treadmill test), self-efficacy (Childhood Arthritis Self-Efficacy Scale), and participation (self-report).	condition other than JIA and that limited motor and/or exercise performance (e.g. paralysis or heart conditions), receiving cognitive behavioral therapy, and a disease activity defined as a Physician Global Assessment >2 cm out of 0 to 10.			battery") and 10 meant maximum energy ("battery fully charged"). Patients rated their energy level 3 times a day for 7 days. Mean daily energy levels were calculated, as well as mean energy levels morning, afternoon, and evening. Low mean daily energy levels were defined as a VAS score of 8 and less, and very low energy as 5 and less. The number of days out of 7 days, with a low and very low mean daily energy level, was counted for each patient. Zero days meant a patient indicated no day with (very) low energy levels, whereas 7 meant the patient indicated a maximum number of days with (very)	

						low energy levels Pain: measured on a 0–10 cm VAS. Zero meant no pain, whereas 10 meant the maximum pain imaginable. Disease activity: Measured by a pediatric rheumatologist, expressed in a VAS Physician Global Assessment (VAS-PGA) anchored by 0–10 cm (0 = no disease activity to 10 = high disease activity). Disability: Dutch version of the Childhood Health Assessment Questionnaire (C-HAQ38), which measured functional impairment in 9 domains. Scores ranged from 0 to 3,	

						where 0 stands for no impairment and 3 for maximum impairment Physical activity: Measured using an accelerometer, which patients wore for seven consecutive days. It measures accelerations in any plane of movement, translates them into activity counts per time unit and to activity-related energy expenditure (AEE) in Kcal per day. The wearing-time of the Actical on a day during the week had to amount to at least 8 hours and on a weekend 6 hours in order to count as a valid measurement. Exercise capacity: measured on a treadmill by means of the Bruce	

						protocol, expressed as maximum endurance time. Participants were vigorously encouraged to reach maximum exertion (as measured with a polar chest-belt), defined as a maximum heartbeat of 180 or higher. The test was terminated at the patients request or at the observers discretion. Self- Efficacy: Childhood Arthritis Self-Efficacy Scale (CASE). Includes 11 questions concerning capacity to manage JIA, on 3 different subscales: symptoms, emotions, and activity. Patients were asked, on a 5-point Likert scale, how certain they were to be able to manage various	

						issues. One means very uncertain, and 5 very certain. Scores were standardized to compare the subscales. Higher score= higher self efficacy.	
Barlow, Shaw & Harrison,. (1999)	UK	Design: Qualitative Aim: To gain insight and understanding of the needs and preferences of children with JCA and their parents, and to examine how these may be more adequately addressed by future psycho-educational interventions. Method: Data were collected through focus group discussions with children, parents	Five focused group discussions were held with each of the following groups; Health professionals (7). Children designated as having 'mild' JCA (5) Children designated as having 'severe' JCA (5) Parents of the 'mild' children (6) Parents of the 'severe' children (7).	A set of questions was developed and used as a means of generating discussion around the topics of interest in the focus groups: Perceived needs, views on the availability, content and format of existing interventions, and views on future interventions in JCA.	Focus group discussion (children, parents and health professionals).	Questions asked in the focus groups to generate discussion around four topics of interest: -Perceived needs. -The experience of psycho-educational interventions: access, availability and content. -Thirst for knowledge. -Future psycho-educational interventions	Children felt that current interventions failed to explain how JCA may affect school life, friendships, social lives and family functioning. More specifically, children wanted to know in advance that they may not be able to participate in Physical Education (PE) or go cycling with friends, they wanted to know that they may be teased or bullied. They wanted to know how they could deal with these situations when they arose. Children were adamant that they

		and health professionals, respectively.	The children's group included 5 boys and 5 girls aged 8–15 years. The health professional group included a paediatric rheumatologist, and representatives from nursing, physiotherapy, occupational therapy and disease educators. The parents' group comprised 4 fathers and 9 mothers.				should not be shielded from the more negative aspects of JCA and its treatment. Most parents and children reported problems at school, often linked to teachers' lack of understanding regarding the fluctuating nature of JCA, which can result in a child being unable to walk into the classroom in the morning but able to run and play with classmates in the afternoon. This led to parents and children feeling discriminated against and marginalized. Children wanted others to understand their needs but did not feel able to explain the nature of JCA themselves. Asserting their needs at school was particularly difficult,

							therefore wider provision of education in society was viewed as a means of removing this burden from children. Several parents, who had attempted to take information into schools had met with disappointing responses. Children felt that every aspect of JCA and their health-care served to make them look, feel and behave differently from their peers. Consequently, their greatest concerns were for peer belonging and social acceptance. Parents expressed immense frustration and anger at the number of social barriers that thwarted attempts to achieve the goal of

							normality in their children's lives. They felt that their children were met with discrimination and criticized both in Health and Educational services for a perceived lack of support and assistance. When JCA was less visible, children and their families reported a lack of both institutional and personal support. A dominant theme across all focus groups concerned the failure of current psychoeducational interventions to address the wider aspects of JCA (e.g. psycho-social impact).

Barthel, Ravens-Siberer et al., (2018).	Germany	Design: Longitudinal Aim: Identifying predictors of generic health-related quality of life (HRQoL) in chronically ill children and adolescents over time. The newly developed computer-adaptive test Kids-CAT was used to assess five dimensions of HRQoL. Method: Longitudinal data from the Kids-CAT study on children and adolescents with asthma, diabetes and juvenile arthritis (n= 248; aged 7–17 years) were assessed at three measurement points over six months.	248 Children and adolescents with Asthma, Diabetes and Juvenile arthritis. Aged 7-17 years. Mean age= 12.61 (2.746)	The newly developed Kids-CAT tool was used to assess generic Health related quality of life (HRQoL) HRQoL dimension: School wellbeing over time. The Kids-CAT provides t-scores (M= 50, SD = 10) calculated based on age- and gender-specific reference scores for each dimension. The psychometric properties of the Kids-CAT were found to be good.	Self-report (children and adolescents)	The newly developed Kids-CAT tool was used to assess generic Health related quality of life (HRQoL) HRQoL dimensions over time: Physical Well-Being (WB) Psychological WB Parent Relations Social Support & Peers Sociodemographic factors: Besides age and gender, measured SES of participants at baseline using a parent-reported index. This SES index covers three dimensions (i.e., education, occupation and income) by means of overall seven items; higher index scores indicate better SES. Disease and health-related factors:	> 55% of the total variance in each dimension of HRQoL could be explained by differences between the subjects (Physical WB: ICC= 0.59; Psychological WB:ICC= 0.60; Parent Relations:ICC= 0.66; Social Support & Peers: ICC= 0.56; School WB: ICC= 0.67). Found higher scores in younger compared to older children and adolescents with girls reporting lower scores in younger, but higher scores in older participants compared to boys. Better School WB was related to higher SES. Moreover, School WB was negatively associated with subjective health complaints and with mental health problems over time.

						The clinical center was documented for each participant at baseline. Further, pediatrician-reported information gathered at baseline were used to allocate participants to disease groups (i.e. asthma, diabetes and JIA), and to determine the duration of the disease (in years) as well as the existence of severe comorbid diseases (0 =“none” 1=”at least one”). Disease control: assessed at each measurement point based on paediatrician reported data. In the Kids-CAT study, short sets of disease-specific items were developed by pediatric specialists using clinical	We found an average score of 51.87 for School WB at baseline.

						disease-specific guidelines. These item sets served to gather information on the current level of disease control with five to eight items focusing on disease-specific indicators of disease control. Sum scores were calculated over the disease-specific items and determined disease-specific cut offs for each sum score to identify participants with good disease control, partly uncontrolled or completely uncontrolled diseases. Subjective health complaints: Assessed at each measurement point using the self-reported German version of the Health Behaviour in School-aged Children	

						Symptom Checklist (HBSC-SCL). The HBSC-SCL includes eight items on subjective health complaints (i.e., headache, abdominal pain, backache, feeling low, irritability or bad mood, feeling nervous, sleeping difficulties, and dizziness) offered with five response options each: (1 = about every day ,2= more than once a week ,3= about once a week ,4= about once a month , and 5= rarely or never Good psychometric properties were reported for the measure. Mental health problems:	

						Measured using the parent-reported German version of the Strengths and Difficulties Questionnaire (SDQ). The SDQ includes four problem scales on emotional symptoms, conduct problems, hyperactivity/inattention, and peer-related problems with five items each. Response options (0 =not true 2 = certainly true. The total difficulties score of the SDQ is calculated gathering all 20 items of the four problem scales with higher total difficulties scores indicating more problems. Parental HRQoL: Reported by the parents and assessed at each measurement point using the	

						German version of the Short Form-12 Health Survey (SF-12). SF-12 items are offered with varying response options ranging from two categories to five-point Likert-scales. Metric summary scores were calculated for the scales physical and mental health using the standard scoring algorithms based on German norm data. Higher scores in SF-12 scales indicate better HRQoL. The SF-12 has been found to be a reliable and valid measure	
Bartholomew, Koenning, Dahlquist & Barron., (1994).	USA	Design: Mixed methods Aim: To describe the use of the	Children with juvenile rheumatoid arthritis.	Needs assessment data from several sources to define self-management behaviours and plan an	Self report by parents where relevant (survey and	No additional measures.	Two sets of interrelated behavioural factors were identified through the needs assessment: 1) those

		PRECEDE model (predisposing, reinforcing, and enabling causes in educational diagnosis and evaluation) to organize needs assessment data in order to define self-management behaviours and plan an educational intervention for children with juvenile rheumatoid arthritis (IRA) and their families. Method: Analysis of; needs assessment data collected from several sources: 1) literature review, 2) survey of parents of 51 children with IRA, 3) group interview of seven parents of children with IRA, 4) results of pilot	Pauciarticular: 10 Polyarticular: 16 Systemic: 9 School grades: K-5: 19 6-8: 8 9-12: 8	educational intervention for children with juvenile rheumatoid arthritis (IRA) and their families: 1) literature review, 2) survey of parents of 51 children with IRA, 3) group interview of seven parents of children with IRA, 4) results of pilot programs, and 5) clinical experience of an interdisciplinary paediatric rheumatology team.	group interview).		related to managing the school environment to facilitate optimal participation and to minimize school-related disability, and 2) those related to treating pain and stiffness, intervening in the disease process, and preserving joint function. The needs assessment suggested that JRA affects several aspects of quality of life, including the child's school attendance and participation. In behavioural and environmental diagnosis, two sets of interrelated factors for JRA were identified throughout the needs assessment process: 1) those related to managing the school environment to facilitate optimal participation and to

		programs, and 5) clinical experience of an interdisciplinary paediatric rheumatology team.					minimize school-related disability. Predisposing factors (characteristics of the target population that facilitate learning and performing the behaviour] and enabling factors (variables that determine whether the behaviour can be performed] in our analysis include knowledge, skills, and self-efficacy of the parent and the child regarding self-care, pain management, and communication with school personnel and the health care team. Reinforcing factors (elements of the environment that reward the performance of the behaviour] in the school-oriented model include school personnel's knowledge of JRA

							related to school functioning of the child and skills and self-efficacy in communicating with the health care team. The health care team must be knowledgeable about school services and have skills and self-efficacy for evaluating the child regarding school needs and communicating those needs to the school personnel. One goal is for both the school and the health care team to encourage the family's attempts to obtain appropriate school services for the child and to support those attempts with information and action.
Batthish et al., (2005)	Finland	Design: Qualitative Aim: Interviewed patients with systemic onset	Fourteen patients with systemic onset form of juvenile idiopathic	Open ended questions during interviews to elicit aspects of disease activity, which included	Self-report by children and proxy report parents	CHAQ scores measuring disease severity and disability Scores (from 0,	Decreased school attendance was a common item identified as a relevant aspect of disease activity.

		form of juvenile idiopathic arthritis (SO-JIA) and their parents in order to elicit specific items reflecting their perceptions of active disease that may be considered for inclusion in a disease activity measure for SO-JIA. Method: SO-JIA patients followed at The Hospital for Sick Children and their parents were chosen by purposive sampling. A trained research coordinator interviewed all participants using open-ended questions to elicit aspects of disease activity(defined as reversible manifestations of disease) of relevance to	arthritis (SO-JIA) (eight females) with a mean age of 11.8 years (mean disease duration 5.2 yr) and their parents.	generating the topic of school.	during interview.	representing no disability, to 3, representing very severe disability)	Activity level (‘decreased play/sports’, ‘couldn’t participate in physical education’) 56% of respondents School attendance (‘missed school’, ‘can’t concentrate in school’) 48% of respondents

		families. A list of these aspects was then generated and organized by categories to allow item reduction.					
Bessisso, Bener, Elsaid, Al-Khalaf & Huzaima., (2005)	Qatar	Design: Cross sectional survey Aim: To determine the prevalence rate and impact of headache in schoolchildren on school attendance with particular attention to migraine. Method: A cross sectional survey was conducted among the school children ranging from 6-17 years old over a period from March 2001 to April 2003. The study was carried out in 10 primary, preparatory and secondary schools. Subjects were selected by multi	851 children First- tenth year of school 72.3% of the respondents were females and 27.7% were male.	Survey: The information in the survey was based on a structured prospective questionnaire in Arabic by one of the researchers. (no additional description is given).	Self report (parent report if aged under 10)	No additional measures.	The impact of headache on children was frequent absence from school 80.1% students were affected in their school performance because headache caused frequent absence from school.

		stage stratified sampling procedure. This involved 851 children studying in the first to tenth year of school in the State of Qatar.					
Beresford & Sloper., (2003)	UK	Design: Qualitative Aim: To explore the experiences of chronically ill adolescents in communicating with health professionals, including the identification of factors which hinder or facilitate their use of health professionals as an information source. Method: adolescents were interviewed, and subsequently took part in two group discussion meetings with	63 adolescents: 27 boys and 36 girls. They fell into one of two age bands: 10-12 years (n= 29) 14-16 years (n=34) With one of five conditions: Juvenile chronic arthritis (17) Cystic fibrosis (11) Diabetes (12) Epilepsy (10) Duchenne muscular dystrophy (13).	Semi-structured interviews which collected background information about the adolescent's condition; their understanding of the condition; its impact on their day-to-day lives; and their experiences of communicating with health professionals. This latter included: asking participants about hospital staff they liked and disliked and the reasons behind those preferences;	Self report through interview and discussion.	Facilatory techniques were used in the group meetings to explore communication with health professionals: Role play was used to explore participants experiences of communicating with doctors. Each group planned and acted out a nightmare/ideal outpatient appointment The data came from the debriefing of the role play and a subsequent discussion of what the participants wanted in terms of promoting communication with	Information needs relating to coping with the consequences and impact of a chronic condition on day-to-day life(for example, how to manage at school, dealing with peers, coping with negative emotions, and maintaining a positive approach to life) were considered by participants to be as important as needing to know about their condition and its management. However, health professionals were rarely mentioned by participants as a resource in terms of these sorts of information needs.

		other adolescents of a similar age with the same condition. Data were analyzed using the framework method involving data reduction, data display, and conclusion-drawing and verification.		and their feelings about putting a question to a doctor and/or other health professional and the perceived factors which hindered or supported that process.		their doctor.	
Berrin, Malcarne et al., (2006)	USA	Design: Quant descriptive. Aim: To test a model of how pain and fatigue, independently or in combination, relate to school functioning in paediatric cerebral palsy (CP) Method: Parents of children with CP completed the Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales and the	73 children with a spastic CP diagnosis aged 5–18 (27 with hemiplegia, 34 with diplegia, 12 with quadriplegia) Mean age of children who self reported= 10.3 years (SD= 3.9)	Pediatric Quality of Life Inventory (PedsQL) Varni, 1999. Four subscales: physical functioning, emotional functioning, social functioning, and **school functioning (addressing school performance and the ability to be in school)** All scales demonstrate high	Child self-report and parent proxy report	No additional measures	Results supported the existence of an indirect relationship between diagnostic subtypes and school functioning that was partially mediated by both pain and fatigue. Parents reported poorer school functioning than their children (lower scores indicating poorer school functioning). Parent proxy report of school functioning mean= 52.47 (21.39) Children's self-report mean= 65.61 (22.18)

		PedsQL™ 3.0 Cerebral Palsy Module. Children with CP completed the PedsQL™. Path-analytic and mediational techniques were utilized to test the a priori model.		reliability. Each scale uses a likert 5-point scale to ask the child or parent how much of a problem each item has been over the past month: (0=never a problem, 1=almost never a prob-lem, 2=sometimes a problem, 3=often a problem, and 4=almost always a problem). Higher scores indicate better quality of life/ functioning in the subscale area. Additionally, there are two summary scores: a Psychosocial Health Summary Score (derived from the Social, School, and Emotional Functioning subscales) and a Total Scale Score			There were no significant differences in proxy ratings between parents of children who completed a self-report and parents of children who did not with regard to reports of children's pain, fatigue, or school functioning. The parent proxy path-analytic model variables explained 9% of the variance for pain, 42% for fatigue, and 31% for school functioning. These results suggest that diagnostic severity and pain explain large amounts of reported fatigue in CP, as do pain and fatigue for school functioning. The child self-report model explained 9% of the variance for pain, 20% for fatigue, and 14% for school functioning, which

				(from all sub-scales). Previous validation research with the PedsQL™ 4.0 Generic Core Scales has shown internal consistency reliabilities that generally exceed the .70 standard for group comparisons among children with CP The PedsQL™ 3.0 Cerebral Palsy Module was developed as a condition-specific HRQOL instrument (Varni, Burwinkle, Berrin, et al., 2006). It includes 35 items divided into seven subscales: Daily Activities (9 items),**School Activities (4**			suggests similar conclusions for pain variability. However, children’s self-reported diagnostic severity and pain comprised a smaller role in fatigue presence than did the reports from their parents; additionally, less variance in children’s reports of school functioning was explained by pain and fatigue. Pain as a mediator between diagnostic severity and school functioning: Diagnostic severity was significantly associated with school functioning ($\beta = -.232$, $p = .001$;R2 = .054, $p = .001$). Pain and school functioning were significantly associated ($\beta = .403$,$p < .001$; R2 = .163, $p < .001$).

				items), Movement and Balance (5items), Pain and Hurt (4 items), Fatigue (4 items), EatingActivities (5 items), and Speech and Hearing (4 items). Like the Generic Core Scales, responses are given on the same 5-point response scale, with the self-report scale for children aged 5–7 years previously modified to reflect developmental ability. Previous validation research with the PedsQL™ 3.0 Cerebral Palsy Module Scales has shown internal consistency reliabilities that			Both diagnostic severity ($\beta = -.154$, $p < .05$) and pain ($\beta = .366$, $p < .001$) were significantly associated with school functioning (R2 = .185, $p < .001$). Fatigue as a mediator between diagnostic severity and school functioning: Diagnostic severity was significantly associated with school functioning($\beta = -.232$, p = .001; R2 = .054, $p = .001$). Fatigue and school functioning were significantly associated ($\beta = .420$, p < .001; R2 = .163, $p < .001$). Both diagnostic severity ($\beta = -.137$, p < .05) and pain($\beta = .385$, $p < .001$) were significantly associated with school functioning (R2 = .185, $p < .001$).

				generally exceed the .70 standard for group comparisons.			Fatigue mediating pain and school functioning: Pain was significantly associated with school functioning (β = .403, p < .001; R2 = .163, *p* < .001). Fatigue was significantly associated with school functioning (β = .420, *p* < .001; R2 = .176, *p* < .001). Both pain (β = .233, p < .001) and fatigue (β = 280, *p* < .001) were significantly associated with school functioning (R2 = .212, *p* < .001). Fatigue was not found to be a mediator between pain and school functioning for the child self-report. Pain was significantly associated with fatigue (β = .407, *p* = .001; R2 = .166, *p* = .001). Pain was significantly associated with school functioning (β

							= .379, $p < .01$;R2 = .144, $p < .01$). The relationship between fatigue and school functioning, was not found to be significant, although there was a trend toward significance (β = .230, $p = .061$; R2 = .053, $p = .061$)
Boey, Omar & Phillips (2003)	Malaysia	Design: Cross sectional survey Aim: To investigate the extent to which recurrent abdominal pain and other factors were associated with academic achievement among Year-6 (12 years of age) schoolchildren. Method: A cross-sectional survey was conducted from September to November 2001. Schoolchildren were recruited	1971 primary school children in year 6 (12 years old) randomly selected from all primary schools in Petaling Jaya, Malaysia. 958 boys and 1013 girls: 1047 Malays, 513 Chinese and 411 Indians. (The three major ethnic groups in Malaysia are Malaysian, Chinese and Indian) 456 (23.1%) fulfilled the	Academic achievement: Assessed using a score based on the Malaysian Primary School Achievement Examination. (Sat by all Year-6 primary-school children throughout Malaysia.) There are five subjects in this examination: Malay language (comprehension); Malay language (written); English language;	Self-report (questionnaire and interview)	Information concerning recurrent abdominal pain, socio-economic status, life events, demographic and other details was obtained using a combination of questionnaires and interviews. The children were first given the questionnaires to fill in, and this was followed by an interview with the children on the same day. During the interview, the same questions as in the questionnaire were asked to	Using the method of binary logistic regression analysis, the following factors were found to be independently associated with poor academic performance: -A low socio-economic status (odds ratio (OR) 1.30; 95% confidence interval (CI) 1.25–1.35) 60.8% children of low socio-economic status had below average examination scores compared with 21.4% children of high socio-economic status ($p < 0.001$

		from primary schools that were selected randomly from a list of all primary schools in Petaling Jaya, Malaysia, using random sampling. Information concerning recurrent abdominal pain, socio-economic status, life events, demographic and other details was obtained using a combination of questionnaires and interviews. Academic achievement was assessed using a score based on the Malaysian Primary School Achievement Examination.	criteria for recurrent abdominal pain.	mathematics; and science. The results of these are released in five Grades: A (very good);B (good); C (moderate); D (weak); and E (extremely weak). For the purpose of the present study, Grade A was given a score of 4, Grade B a score of 3, Grade C a score of 2, Grade D a score of 1 and Grade E a score of 0. The scores obtained for each of the five subjects were added together to give an overall score (mean = 14.6; SD = 5.1; range = 0–20). An overall score at or above the mean was taken to indicate high		ensure that there was no misunderstanding, and also to establish consistency of response. Recurrent abdominal pain in children was defined based on Apley's criteria as 'at least three episodes of abdominal pain severe enough to affect daily activities, over a period of at least 3 months' A score was given for each parent for educational attainment(1–4) and occupation (1–5) with a higher score denoting a higher educational attainment or occupation. In scoring educational attainment, primary education was given a score of 1,lower secondary	-Male sex (OR 1.61; 95% CI 1.26–2.05) Compared with girls, boys achieved lower examination scores (45.7% of boys vs 36.6% of girls; $p < 0.001$ -The death of a close relative (OR 2.22; 95% CI 1.73–2.85) $p < 0.001$ -The divorce or separation of parents (OR 3.05; 95% CI 1.73–5.40) $p < 0.001$ -The commencement of work by the mother (OR 1.34; 95% CI 1.02–1.76) $p = 0.04$ -Hospitalization of the child in the 12 months prior to the study (OR 1.83; 95% CI 1.12–3.01) There was a higher prevalence of below average examination scores among those children who had been hospitalized in

				academic achievement, whereas a score below the mean indicated poor academic achievement.		education a score of 2, upper secondary education a score of 3 and college or university education a score of 4. Occupation was classified and scored according to the scoring system of the Dictionary of Occupational Classification. In this system, manual jobs had the lowest score, administrative jobs were given higher scores, while professional jobs like medicine and law had the highest score. The final score for socio-economic status was obtained by adding up individual scores obtained by both parents for educational background and occupation (mean = 10.9; standard	the year prior to the study (59.7 vs 39.7%; *p* < 0.001) -Lack of health-care consultation (OR 1.80; 95% CI 1.36–2.36) If, apart from the hospitalization, the child had a tendency to consult a doctor when ill, there was also a lower chance of performing poorly in the examination compared with those who did not consult a doctor (35.6 vs 54.2%; *p* < 0.001) -Missing breakfast(OR 1.47; 95% CI 1.07–2.02) There was a significantly higher prevalence of below average examination scores among children who missed their breakfast compared with those who never missed breakfast (44.4 vs 29.6%; *p* < 0.001)

						deviation (SD) = 3.7; range 4.0–18.0). A score that was above or equal to the mean was taken to indicate a high socio-economic status, while a score below the mean indicated a low socioeconomic status. Life events: the child was asked whether he or she had experienced any of the following during the 12 months prior to the study: divorce/separation of parents; father losing his job; mother starting work; death of a close relative; or hospitalization of a close relative. Close relatives were defined as parents, siblings, grandparents or any other relative whom the child loved and missed.	-Lack of kindergarten education (OR 1.35; 95% CI 1.04–1.75). Compared with children who had attended 2–3 years of kindergarten, there was a significantly higher prevalence of low academic achievement among those who had not been to kindergarten or who had only attended kindergarten for 1 year(58.9 vs 31.0%; $p < 0.001$) Recurrent abdominal pain did not correlate directly to academic performance. However 23.1% children who fulfilled the criteria for recurrent abdominal pain and the presence of this complaint was associated with an increased prevalence of below average performance in examination (47.6 vs 39.1%; $p = 0.001$;

							OR 1.42; 95% CI 1.15–1.75). Similarly, those with recurrent headaches also tended not to perform as well (47.6 vs 33.0%; *p* < 0.001; OR 1.85; 95% CI1.54–2.22)
Breuner, Smith & Womack (2004)	USA	Design: Retrospective Aim: To examine possible risk and protective factors for school absenteeism among adolescents referred to a hospital-based behavioural treatment program. Method: Data obtained from intake interviews, screening questionnaires, and baseline headache diaries of 283 consecutive adolescents referred for behavioural	233 adolescents, aged 11 to 18 years, seen consecutively for behavioural treatment of recurrent headache in the Headache and Stress Management Clinic at Children's Hospital and Regional Medical Center. Classed as low absenteeism (those who missed 2 or less days of school due to headache) and high absenteeism (those who	School absenteeism was measured by averaging parent and student estimation of the number of schooldays missed due to illness within the previous 6 months that school was in session. The intake interview in the Headache and Stress Management Clinic includes a thorough assessment of psychosocial status including school attendance, performance, and	Self report	Anxiety: measured using the Trait form of the Spielberger State-Trait Anxiety Inventory (STAI-T). The STAI-T consists of 20 statements on 4-point Likert-type scales that assess the generally characteristic level of anxiety a person experiences. The STAI has been found to have acceptable validity, internal reliability, and test-retest reliability. Symptoms of depression over the 2 weeks before the appointment: evaluated using the Children's	Compared with the low absenteeism group, the high absenteeism group had lower academic performance (2.1±1.0versus 1.7±0.8, *p* <.0001). There was a significant difference (*p* <.0002) in school performance between the high absenteeism group (2.1±1.0) and the low absenteeism group (1.7±0.8). The 2 groups were not statistically different in age, sex, length of headache history, type of headache, current headache frequency or intensity scores,

		treatment of recurrent headache were reviewed for demographics, length of headache history, headache type, current headache activity, symptoms of anxiety and depression, perceived self-efficacy regarding headache control, school performance, participation in extracurricular activities, and school absenteeism. The study population was divided into 2 groups at the median number of days missed due to headache in the previous 6 months that school was in session. Adolescents who missed 2 or less	missed more than 2 days). Low absenteeism group: (n= 147) Sex: Female- 63% Male- 35% Mean age: 13.6 (1.9) Headache history mean: 46.6 (34.2) Headache type: Migraine- 106 Tension- 40 Unclassified- 1 Headache frequency mean: 3.0 (2.7) Headache intensity mean: 5.6 (2.3) High absenteeism group: (n= 123) Sex: Female- 57% Male- 42% Mean age: 13.7 (1.7) Headache history mean: 46.6 (39.0) Headache type:	participation in extracurricular activities. The study evaluator reviewed this information in order to assess students' school performance and involvement in extracurricular activities. School performance for each student was graded on a 1-to-5 scale (1=mostly A's, 2=mostlyB's and C's, 3=mostly C's, 4=mostly D's, 5=mostlyF's). Involvement in extracurricular activities was also determined by review of the intake history. A yes score was recorded if the student was		Depression Inventory (CDI), which consists of 27 items rated on a 3-point scale. The CDI has been found to have adequate reliability and validity. Headache type: classified using the International Headache Society (IHS) diagnostic criteria as migraine with or without aura, migrainous disorder not fulfilling all IHS criteria, tension-type headache, tension-type headache not fulfilling all IHS criteria, or unclassified headache. Headache frequency was assessed at intake by asking the students how many headaches they experienced over	anxiety scores, self-efficacy ratings, or participation in extracurricular activities.

		days of school due to headache (low absenteeism) were compared with those who missed more than 2 days (high absenteeism). Data were reviewed from standard intake-screening tools and clinical interviews.	Migraine- 75 Tension- 45 Unclassified- 2 Headache frequency mean: 3.4 (2.8) Headache intensity mean: 5.8 (2.3)	involved in extracurricular activities such as sports, drama, music, art, computer skills, tutoring, sewing, debate club, etc. A no score was recorded for lack of involvement. For each extracurricular activity noted in the chart, a separate yes score was recorded		the past 2 weeks. Headache intensity was determined by asking the students to respond to a 0-to-10 (none to most severe)scale rating average individual head pain intensity over the past 2 weeks. Students were asked to rate the perceived control they had over headache frequency, intensity, and duration using a 10-point visual analog scale for each measure. The average of these estimates was a self-efficacy score with a total maximum score of 10.	
Castro, Rockett et al., (2013)	Brazil	Design: Cross sectional study Aim: To evaluate the prevalence of headache in school-aged children and its relationship to	750 students aged 7 to 14 years. Mean age was 10.4 ± 1.7 years ,and 56.1% were female.	Quality of life: assessed using the Pediatric Quality of Life Inventory (PedsQL™) version 4.0 (in Brazilian language).	Self-report	Information was collected through interviews on; sociodemographic characteristics (age, sex, socioeconomic status, educational system, and class schedule),clinical	Regarding measurement of quality of life, patients without headache had higher total PedsQL™ mean scores (73.9 ± 10.8) when compared to the group with headache

		anthropometric characteristics, lifestyle, and quality of life. Methods: A cross-sectional study was conducted in six schools located in two cities in southern Brazil. Information was collected on sociodemographic characteristics, clinical variables (presence of headache and menarche), anthropometric data, lifestyle, and quality of life.	Attending three public and three private schools in 2012. The schools were located in two different cities in southern Brazil.	It consists of 23 questions that result in scores in four domains related to paediatric health (Physical, Emotional, Social, and **School Functioning**)		variables (presence of headache and menarche),anthropometric data, and lifestyle variables (alcohol consumption, smoking, and extracurricular activities –activities such as sports, dancing classes, language classes, or private lessons). The socioeconomic status of the participants was defined based on their responses to a questionnaire designed and validated by the Brazilian Association of Market Research Agencies, namely Economic Classification Criterion-Brazil. This questionnaire is used to estimate the purchasing power of individuals and	(69.9 ± 11.8) (*p* = 0.017). When analysing quality of life scores per domain (Physical, Emotional, Social, and School Functioning), the group without headache had higher scores in the Social domain (88.9± 14.3vs.85.2 ± 16.4, *p* = 0.001). The school functioning domain is not reported as significant.

						families and categorizes the Brazilian population into five socioeconomic levels: A to E – with A being the highest and E the lowest level. Children who reported having headaches answered a questionnaire on the characteristics of headache. The responses were then evaluated by a neurologist according to the diagnostic criteria defined by the International Headache Society. Anthropometric variables included weight (kg), height (cm), and Body Mass Index (BMI). The nutritional status was classified according to z-score reference ranges (BMI-for-age),14	

						which were calculated using the World Health Organization (WHO) AnthroPlus v. 1.0.4 software. The participants were weighed according to the WHO guidelines using a portable electronic digital scale. Height was measured using a vertical stadio meter with a length of 2.10 m to the nearest 0.1 cm.	
Charuvanij & Chaiyadech (2018)	Thailand	Design: Cross sectional Aim: To measure the Health related quality of life (HRQOL) and identify factors influencing the HRQOL in Thai children with Juvenile Idiopathic Arthritis (JIA)	Sixty-five children (33 girls and 32 boys) diagnosed with JIA. The median age of the children was 9.6 (interquartile range 6.4–12.3) years and the median disease duration was 1.1	The PedsQL 4.0 generic core scale is a questionnaire consisting of 23 items, categorized into four subscales: physical, emotional, social and school functioning. The responses ranged from 0	Self-report and parent proxy report.	Data, including age, sex, age at disease onset, age at diagnosis, JIA subtype, current clinical status, active joint count, limited joint count ,physician global assessment (PGA) of disease activity, patient/parent global assessment of well-being (PGW),	The school functioning subscale had the lowest score, at 60 (25– 100) reported by parents. HRQOL median (range) scores for school functioning subscale: Child reported: 80 (25–100) Parent reported: 60 (25–100)

		Method: Conducted a cross sectional study in Thai children with JIA and their parents between January and December 2015, using the Thai version of the Pediatrics Quality of Life (PedsQL) 4.0 generic core scale.	(IQR 0.2–2.2) years. 26 (40%) children had systemic JIA; 14 (21.5%) had enthesitis-related arthritis (ERA); 12 (18.5%) had oligoarticular JIA; 6 (9.2%) had RF-negative polyarticular JIA; 5(7.7%) had RF-positive polyarticular JIA; 2 (2.1%) had undifferentiated JIA. Six (9.2%) and three (4.6%) patients had joint contracture and joint deformities, respectively.	(never a problem) to 4 (almost always a problem). All items were linearly converted and transformed into 0– 100 scales. Higher scores represented better HRQOL. Suboptimal HRQOL was defined as a PedsQL 4.0 generic core scale total mean score of <78.6.		medications and complications of JIA (including joint contracture, joint deformity and uveitis),were collected at enrolment. An active joint count was defined as swelling within the joint or at least two of the following symptoms: limited range of movement, tenderness, warmth or pain during joint movement. Limited joint count was defined as a joint with a reduced range of motion. PGA was measured on a 0–10 visual analogue scale (VAS; 0 = no activity and 10 = maximum activity) and PGW was measured on a 0–10 VAS (0 = very well and 10 = very poor).	

						The Juvenile Arthritis Disease Activity Score-71 (JADAS-71) was used to evaluate disease activity. JADAS-71 is composed of four scoring systems: active joint count (71 joints), 0–10 VAS for PGA, 0–10 VAS for PGW, and adjusted ESR. The ESR was standardized to a 0–10-point scale. Inactive disease was defined as a JADAS-71 score of≤1. High disease activity (HDA) was defined asa JADAS-71 score of >4.2 for oligoarthritis and 10.5 for polyarthritis. In the present study, HDA was applied as a JADAS-71 score of >10.5, regardless of the JIA subtypes.	

						Disability was evaluated by the Thai version of the Childhood Health Assessment Questionnaire (CHAQ). The CHAQ was completed by parents and consisted of 30 questions, in eight domains—namely, dressing and grooming; arising; eating; walking; hygiene; reach; grip; and activities. Responses ranged from 0 (without difficulty) to 3 (unable to do).If the child was unable to perform a task owing to developmental incapability, a response of “not applicable” was indicated. The use of any device for aiding the child, or assistance from others was assigned at least a	

						score of 2 for the aspect if rated lower. The highest score in each aspect was averaged into the CHAQ score, ranging from 0 to3. Higher scores indicated higher functional impairment. A patient with a CHAQ score≥1 was regarded as having severe disability	
Chomistek, & Johnson et al (2019)	USA	Design: Cross sectional observational study Aim: To identify patient-reported school barriers and their associated impact in juvenile idiopathic arthritis (JIA) Method: A cross-sectional observational study of children diagnosed with JIA, and followed	98 children with JIA aged between 8-17 The median age of participants was 13 years (interquartile range 11-15). The JIA subtypes in this cohort reflected the normal JIA distribution.	A questionnaire was administered to the child to assess the barriers experienced by JIA patients at school. The questionnaire collected information about school attendance/performance, impact of JIA symptoms (e.g, pain and fatigue), physical challenges and accommodations,	Self-report	Demographics, diagnosis, and disease course were obtained from health records.	Physical challenges at school (e.g, gym, writing, and sitting for long periods of time) were reported by 42.1% of patients. Accommodations (e.g, modified gym, accommodation letter, and computer access) were used by 23% of patients. The inability to participate in activities in class or outside with their peers occurred for

		in the rheumatology clinic/Alberta Children's Hospital was performed. Demographics, diagnosis, and disease course were obtained from health records. A questionnaire was administered to the child to assess the barriers experienced by JIA patients at school. The questionnaire collected information about school attendance/performance, impact of JIA symptoms (eg, pain and fatigue), physical challenges and accommodations, communication, participation and peers, and school support. Descriptive		communication, participation and peers, and school support.			32.2% of patients and in gym for 40.7% of patients. Social concerns included embarrassment from talking about their illness, worry regarding being treated differently, and being told they were fabricating their illness.

		statistics were used to analyze the data.					
Claar, Kaczynski, Minster, McDonald, Nolan & LeBel (2012)	USA	Design: Quant descriptive Aim: To examine whether school functioning and attendance improved after a multidisciplinary evaluation focusing on a return to functioning despite headaches. Method: Adolescents completed the PedsQL School Functioning Scale at evaluation, 2-3months later, and again 6 months after evaluation. Information regarding headache frequency, severity and duration, and school attendance was obtained from medical records. Repeated measures	47 adolescents ages 12-17, diagnosed by their neurologist with chronic tension-type headache who underwent a multidisciplinary evaluation at a tertiary headache clinic. Most of whom had not responded to past neurological treatment. All patients with tension-type headache who completed an initial evaluation and both follow-up assessments were included. The sample was predominantly Caucasian (93.0%) and female (76.6%).	Adolescents completed the PedsQL School Functioning Scale at evaluation, 2-3 months later, and again 6 months after evaluation. The Paediatric Quality of Life School Functioning Scale is a 5-item child self-report subscale of the Paediatric Quality of Life Inventory that assesses school functioning in the past month. The timeframe covered by the questionnaire was modified to 3 months to assess patients' school functioning during the current school term. Thus, in the current study the	Parent and child self-report	Children underwent a multidisciplinary evaluation by a neurologist and clinical psychologist. The neurological evaluation (approximately 1 hour) included a medical history, neurological examination, and treatment recommendations including medication, pursuit of psychological treatment, return to school, and additional tests (electrocardiography, magnetic resonance imaging) when indicated. Ratings of headache frequency, duration, and severity were collected from a review of participants' medical records.	Using repeated measures analyses of variance, the authors found that school functioning and attendance improved significantly from evaluation to follow-up, as did headache frequency and duration. School functioning Mean and SD: Time 1: 9.50 (4.86) Time 2: 8.36 (4.49) Time 3: 7.80 (4.68) School attendance Mean and SD: Time 1: 1.60 (.65) Time 2: 1.57 (.65) Time 3: 1.92 (.28)

		analyses of variance were used to examine whether school functioning and attendance, and headache frequency/duration improved significantly from evaluation to follow-up.		stem for each item was, ‘‘In the past 3 months, how much of a problem have you had with....’’ Items on the School Functioning Scale assess difficulty paying attention in class, forgetting things, keeping up with school, missing school because of not feeling well, and missing school because of medical appointments and hospitalizations. Responses are rated on a 5-point scale ranging from never(0) to almost always(4). A total score is computed by calculating the mean rating. Higher scores indicate greater		Headache frequency was coded from never (0) to daily(7).Headache duration was coded from none(0) to constant(8). Headache severity was coded from no pain(0) to worst pain experienced(10)	

				difficulty with school functioning. Adolescents completed this measure at the initial evaluation and the 2 follow-up appointments. Alpha reliability in this study was .87for the initial assessment .75 at the first follow-up assessment and.85 at the second follow-up assessment. School attendance: A trained research assistant reviewed the patients' medical records and rated adolescents' school attendance for the past 3 months on a 3-point scale with 0 indicating not attending school (when patients missed greater			

				than 75% of school days), 1 indicating partially attending school (when patients missed between 20% and 75% of school days), and 2 indicating attending school fully (when patients missed less than 20% of school days). School breaks and summer vacations also were factored into the number of possible school days used to compute these percentages. The psychological evaluation (approximately 1 hour) included a review of patient and parent standardized psychological measures as well as a semi-structured			

				evaluation assessing patients' headaches, impact of headaches on functioning and activities (including school), patient's school attendance and performance, patient's current psychological functioning and psychosocial stressors, and family psychiatric history. Approximately 2-3 months after their initial evaluation and again 6 months after their initial evaluation, patients returned for follow-up appointments with their neurologist and again completed questionnaire measures			

				regarding school functioning. School functioning was also emphasized as an important component of treatment at follow-up appointments. Patients' headache diagnoses, school attendance, and information regarding headache frequency, severity, and duration at both the evaluation and each follow-up appointment were obtained from a review of patients' medical records.			
Clementi, Chang, Gambhir, Lebel & Logan (2019)	USA	Design: Retrospective cohort study Aim: To examine the impact of sleep	109 youth aged 7 to 17 years (Mean age= 14.01, SD= 2.36) with persistent	Functional disability was assessed using the youth-reported Functional	Self-report and parent proxy report.	Headache frequency: was rated on a 6-point scale between 0 (less than once per week) and 5 (daily). Head-ache severity	At 6-month follow-up, patients demonstrated improvements in functional disability, t(96) = 6.46, *p* < .001,

		on functional outcomes and to explore pain-related fear as a mediator of the association between sleep problems and functioning Method: Youth with persistent headache presenting to a tertiary pediatric headache center (and their parents) completed measures of sleep problems, fear of pain, functional disability, and school functioning at the time of an initial evaluation and 6 months later.	headache evaluated in a multidisciplinary paediatric tertiary headache program. Patients were included if they had complete data on clinic questionnaires at initial evaluation and returned for a follow-up appointment approximately 6 months later (+1 month). The sample was predominately Caucasian (84%) and female (72%).	Disability Inventory. 15-item self-report measure assessing difficulty with performing daily activities within the home, school, recreational, and social domains and is frequently used with paediatric headache populations. Youth reported how often they had difficultly completing these activities over "the past few days" on a 5-point Likert-type scale, ranging from 0 (no trouble) to 4 (impossible). Items are summed to create a total score between 0 and 60, with higher scores indicating greater		was rated on an 11-point scale between 0 (no pain) and10 (worst pain experienced). International Headache Classification (ICHD-3) diagnosis was also obtained from review of medical record. Sleep: Assessed using the parent-reported Sleep Hygiene Inventory for Paediatrics (SHIP), which was developed for clinical purposes in a tertiary care paediatric headache clinic. The SHIP is a15-item parent report measure assessing child sleep problems, including difficulties with sleep onset and morning awakening, sleep duration, night time awakenings, and daytime sleepiness.	and school functioning, t(95) = 4.37, *p* < .001, from baseline Linear regression analyses indicated that increased sleep problems at baseline were associated with increased functional disability and poorer school functioning at baseline (b= 0.28, *p*= 0.1, b= 0.42, *p* < .001, respectively). Poor sleep at baseline was associated with poorer school functioning (but not functional disability) at follow-up (b= 0.25, *p* = .02). Mediation models demonstrated an indirect mediating effect of pain-related fear on the association between baseline sleep problems and follow-up functional disability (b= 0.06, 95% confidence

				functional disability. The Functional Disability Inventory has demonstrated high internal consistency, moderate to high test-retest reliability, and good predictive validity. Internal consistency in the current study was excellent (Cronbach a= 0.93). School functioning was assessed using the parent proxy Pediatric Quality of Life Inventory (PedsQL) School Functioning subscale, a 5-item measure of school functioning (e.g., paying attention in class, keeping up with		Items are rated on a 3-point scale corresponding to the frequency of the child's sleep behaviour. Parents are asked to recall sleep behaviours occurring during a typical recent week. Higher scores indicate greater sleep disturbance. The SHIP has been validated in a paediatric headache sample (aged7-17years) and demonstrated good criterion and construct validity. Fear of pain: Assessed using the youth-reported Fear of Pain Questionnaire for Children (FOPQ-C). The FOPQ-C is a 24-item self-report measure of child pain-related fears and avoidance	interval 0.01 - 0.15) and between baseline sleep problems and follow-up school functioning (b= 0.06, 95% confidence interval –0.13, –0.004)

				schoolwork, attendance). Items begin with the stem "In the past one month, how much of a problem has your child had with..." and are rated on a 5-point Likert-type scale ranging from 0 (never) to 4 (almost always). Items are reverse-scored and linearly transformed to a 0 to 100 scale so that higher scores indicate better school functioning (less impairment). Scale scores are computed as the sum of the items divided by the number of items answered. Internal consistency for the 5-item subscale in the		behaviours. This measure has been validated in children aged 8 to 17 years and has demonstrated good construct, discriminate, and criterion-related validity, in addition to acceptable 1-month stability estimates.	

				current study was good(Cronbach a= 0.85).			
Condon, O'Regan, MacDermott & Killeen, (2017)	Ireland	Design: Qualitative survey Aim: To explore the self-management needs and coping activities of children with Juvenile Idiopathic Arthritis (JIA) and their parents. Method: Twenty-six face-to-face interviews were conducted at an outpatient tertiary hospital in Ireland using a semi-structured format.	Children with a confirmed diagnosis of JIA, who were attending an out-patient department at one tertiary hospital. Male: (n= 7) Mean age= 12 Age range= 7-15 Female: (n=19) Mean age= 10 Age range= 3–18	The interview began with broad questions about the person's conditions, time since diagnosis and then focussed on elements around what they wanted to know about the conditions, what they did to assist themselves, what problems they experienced with managing the conditions and what sources of information they used to manage the condition.	Self- report	No additional measures	Friends in particular were sympathetic, but 'don't really get it' although on the whole friends make adaptations to facilitate their friend with JIA. For the most part, young people did not talk to their friends about having JIA as it adds to the concept of being different. ll children described the condition in terms of loss of function, in particular loss of social function: "Can't run, can't keep up with friends in schoolyard" "Makes me sad" (if held back from activity by parent to prevent flare up)

Connelly (2003)	USA	Design: Descriptive correlational study (Thesis) Aim: Measuring how school-age children with Juvenile Rheumatoid Arthritis (JRA) live with this chronic pediatric disease and its impact on psychosocial development and family functioning, to examine the relationship between family functioning, hope, and quality of life in school-age children with JRA. Method: The Disability-Stress-Coping model of Wallander and Vami (1992) was used to examine the factors that may be particularly	Sixty-eight children, eight to twelve years of age, with a diagnosis of JRA and their parents were recruited for the study. Shriners Hospital for Children (Springfield, MA) and Connecticut Children's Medical Center (Hartford, CT) served as the two recruitment sites. Children ranged in age from 8 to 12 years (M = 9.8, SD = 1.72)	The children completed three survey instruments that included: The Children's Hope Scale (CHS) A 6-item self-report measure. Three of the six items reflect agency thinking (e.g., "I think I am doing pretty well"), and three reflect pathways thinking (e.g., "When 1 have a problem, I can come up with lots of ways to solve it"). The agency subscale (odd-numbered items) taps an active orientation about goals and the future; the pathways subscale (even-numbered items) measures a discovery perspective about	Child and parent self-report.	Parents completed three survey instruments that included the Feetham Family Functioning Survey (FFFS) The FFFS is a 25 item scale designed to assess three major areas of family functions as relationships: (1) the relationship between the family and the broader social units, including the family and the community, the family and economy, such as with schools and work outside the home; (2) the relationships between the family and the subsystems, including the division of labour such as housework; and (3) the relationships between the family and the individual focusing on the reciprocal	The research question examined the relationship between the parent report for children and child report on the Pediatric Quality of Life Inventory (PedsQL) and Rheumatology Module. A paired t-test was preformed, indicating no statistical significance difference between groups (PedsQL t = -.235, p >.01; PedsQL Rheumatology Module t = .237, p >.01). A low correlation was reported between the FFFS score and the Children’s Hope Scale (CHS) score, (r=-.35*, p <.05). No significant correlations were noted between the FFFS score and the Pediatric Quality of Life Inventory (PedsQL), parent report (r=.03, p <.05),

		relevant to the outcomes of children with JRA and their families.		finding ways to reach one’s goals under ordinary and extraordinary circumstances. The total CHS score is achieved by adding the responses to the six items, with "None of the time = 1; "A little of the time" = 2; "Some of the time" = 3; "A lot of the time" = 4; "Most of the time" = 5; and, "All of the time" = 6. The agency and pathways subscale scores range from a low of 3 to a high of 18; total scores can range from a low of 6 to a high of 36; higher scores represent a higher level of agency and pathways		relationships between husband and wife, and parents and children. The Parent Report for Children Pediatric Quality of Life Inventory (PedsQL) The Parent Report for Children PedsQL Rheumatology Module.	PedsQL child report (r=02, p <.05), the PedsQL Rheumatology Module parent report (r=.02, p .<05) or PedsQL Rheumatology Module child report (r=.04, p <.05).

				thoughts to reach goals perceived by children. The CHS has been validated for use with children ages 7 to 16. Internal reliabilities using Chronbach alphas for the CHS total score ranged from 0.72 to 0.86 The Child Report Pediatric Quality of Life Inventory (PedsQL) The 23-item PedsQL Generic Core Scales encompass the essential core domains for pediatric HRQOL measurement: 1) Physical Functioning (8 items), 2) Emotional Functioning (5 items), 3) Social Functioning (5 items), and 4)			

				School Functioning (5 items). Response choices range from "Never" = 0; "Almost never" = 1; "Sometimes" = 2; "Often" = 3; and, "Almost always" = 4. On the PedsQL 4.0 Generic Core Scales items are reversed scored and linearly transformed to a 0-100 scale, so that higher scores indicate better HRQOL. Internal consistency reliability of the PedsQL 4.0 is excellent with an alpha coefficient reaching 0.90 for child self-report and parent proxy-report.			

				Content validity and reliability of the PedsQL 4.0 has been reported (Vami, Seid, & Rhode, 1999) The Child Report PedsQL Rheumatology Module. A 22-item questionnaire that measures problems associated with rheumatic illness: 1) Pain and hurt (4 items), 2) Daily activities (5 items), 3) Treatment (7 items), 4) Worry (3 items), and 5) Communication (3 items). Response choices range from "Never" = 0; "Almost never"= 1; "Sometimes" = 2; "Often" = 3; and "Almost always" = 4.			

				Items are reversed scored and linearly transformed to a 0-100 scale, so that higher scores indicate better HRQOL with a rheumatic illness. Content validity and reliability has been reported.			
Doležalová, Bohm et al., (2018)	Czech Republic	Design: Cross sectional study. Aim: Cross-culturally adapt and validate the Czech parent, child/adult version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) in patients with juvenile idiopathic arthritis (JIA). Method: Collected demographic and clinical data along the JAMAR questionnaire in JIA patients and	103 children with JIA. (5.8% systemic, 35.9% oligoarticular, 37.9% RF-negative polyarthritis, 20.4% other categories). Median age = 11.6. 100 healthy children (control group). Median age = 10.4.	School attendance Specific item used: JAMAR item 12: Report of school problems caused by JIA (list of items) More items chosen from the list equals more problems with school functioning. The JAMAR consists of 15 sections intended to assess the broader construct of the most relevant parent/	Self-report by either child or parent. 99.5% of participants had the parent version of the JAMAR completed by a parent (103 from parents of JIA patients and 99 from parents of healthy children).	Assessment of health related quality of life using the Physical Health (PhH), and Psychosocial Health (PsH) subscales of the JAMAR (five items each) and a total score. Likert response, ‘never’ (score = 0), ‘sometimes’ (score = 1), ‘most of the time’ (score = 2) and ‘all the time’ (score = 3). Patient pain intensity rated on a 21-numbered circle Visual Analogue Scale	No significant difference between healthy participants and their affected peers in the school-related problems variable. Problems attending school for patients with JIA (3.3%) compared to healthy peers (1%).

		administered the JAMAR to healthy children and their parents.		patient-reported outcomes in JIA, including overall well-being, functional status, health-related quality of life, pain, morning stiffness, disease activity/status/course, articular and extra-articular involvement, drug-related side effects/compliance and satisfaction with illness outcome. Three versions are available: -Parent proxy-report (child's age 2–18) -Child self-report (suggested age range of 7–18 years) -Adult.	The child version of the JAMAR was completed by 163/203 (80.3%) children aged five or older.	Assessment of physical function using 15 items in which the ability of the child to perform each task is scored: 0=without difficulty, 1=with some difficulty, 2=with much difficulty, 3=unable to do and not applicable	
Durmaz & Alayli et al (2013)	Turkey	Design: Cross Sectional Aim: To determine the prevalence of	1109 children (mean age (14.8±2.0) years old).	Pediatric Quality of Life Inventory 4.0 (PedsQL4.0). The 23-item PedsQL™ 4.0 Generic Core	Self-report.	Depression: Children's Depression Inventory (CDI) a validated and widely used	PedsQL scores of children with JFMS were lower than the non-JFMS group for physical, emotional, social, school

		JFMS in the urban population of Samsun and to determine the impact of JFMS on depression symptoms, school performance and quality of life (QOL). Method: A questionnaire was applied to the children and a medical examination including TP was performed. Yunus and Masi's criteria were used for diagnosis of JFMS. The children with JFMS were compared with an age and sex matched non-JFMS group. Depression was assessed with Children's Depression Inventory (CDI)	Age and sex matched non JFMS group.	Scales encompass; (1) Physical Functioning (8 items), (2) Emotional Functioning (5 items), (3) Social Functioning (5 items), and (4) School Functioning (5 items). A 5-point Likert scale was used across self-reports for ages 8–18 years (0: never a problem; 1: almost never a problem; 2: sometimes a problem; 3: often a problem; 4: almost always a problem). Items were reverse-scored and linearly transformed to a scale from 0 to 100 points such that higher scores indicate better QOL		measure of depression symptoms in children and adolescents frequently used to assess depression symptoms in paediatric populations with pain. Items on the CDI are categorized into five scales; negative mood, interpersonal problems, ineffectiveness, anhedonia, and negative self-esteem. For each item, adolescents choose 1/3 responses, representing varying symptom levels that best describe their symptoms for the past two weeks. Total score ranges from 0 to 54. Higher scores represent more severe depression. CDI scores of ≥19	functioning and total score (*p* = 0.001) The JFMS group reported more school absences (*p* = 0.001) and the average school grade was lower in the JFMS group than in the non-JFMS group (*p* = 0.03)

		and QOL was evaluated with Pediatric Quality of Life Inventory 4.0 (PedsQL4.0).		School absences: The number of days absent from school as a result of pain during the one month prior to the date of the assessment was obtained directly from each child. School success: The average grade of the previous year for each child was obtained from the school administration.		are considered as clinically meaningful to identify significant depression symptomatology. Diagnosis of JFMS: Yunus and Masi's criteria were used for diagnosis of JFMS. Criteria include the presence of diffuse musculoskeletal pain in at least three areas of the body that persists for at least three months. In addition to five or more typical TP, the Yunus and Masi criteria also require that three of 10 minor criteria or associated symptoms be present for diagnosis. These include fatigue, sleep disturbance, chronic anxiety or tension, chronic headaches, irritable bowel	

						syndrome, subjective soft tissue swelling, numbness of tingling of the extremities, pain modulated by stress or anxiety, weather and physical activity. Pain: The global pain of the children was assessed by visual analogue scale (VAS) pain score; 0–10 cm, with higher scores indicating more pain.	
Evans & Taub et al (2010)	USA	Design: Observational Aim: To describe sociodemographic, pain and health characteristics of a cohort of children presenting to an urban tertiary paediatric chronic pain clinic; and to document the role of sociodemographic factors, including	219 paediatric chronic pain patients (70.8% female (n=155) Mean age= 14.34 years (range = 7 years 9 months – 18 years 3 months, SD=2.49) Presenting for treatment at a multidisciplinary, tertiary clinic	Demographic Information Questionnaire: An author developed demographic information questionnaire was completed by parents, assessing information such as child age, sex, and race/ethnicity. Parents were asked about their level of education and their child's	Self- report and parent proxy report.	A sub set of parents completed the Functional Disability Inventory (FDI), as well as items about the child's sleep, and current level of pain. Child Health Questionnaire, Parent Report (CHQ PF-28): The CHQ PF-28 is designed to assess parents' measurement of their child's physical and	Less than half of children attended full time school, significantly less than the national rate of 91% (US Department of Education, 2003, 2005) (Chi square = 453.5, *p* = .00). The rate of home schooling was 22%, ten times higher than the national rate of 2.2%.

		child sex, age and the impact of minority status, on pain and health outcomes in patients. Method: Questionnaires were mailed to the home. Questionnaires assessed demographic and health information including measures of the child's pain and functioning. A subset of 78 parents were administered additional measures, including the Functional Disability Inventory (FDI), as well as items about the child's sleep, and current level of pain.	specializing in paediatric chronic pain. Presenting pain diagnoses: (percentages add to more than 100% due to multiple diagnoses) 44.7% headaches (n=98) (migraines;myofascial, vascular, tension, stress-related or any other type), 37% functional neuro visceral pain disorder (n=81) (functional bowel, uterine, or bladder disorder), 35.2% myofascial pain(n=77) (excluding headaches),	current schooling situation, including whether the child is in regular full-time school. Responses were categorized according to levels (no high school, some high school, completed high school, some college, college degree and post-graduate degree), and were transformed to continuous variables for regression analyses. Parents also reported on the number of hours their child had slept the previous night. Clinical Information: Information regarding duration of pain		psychosocial well-being. It has acceptable reliability and validity. The CHQ parent form is comprised of a number of sub-scales. For the purposes of assessing children's pain and health status, we focused on the bodily pain and global health sub-scales. The bodily pain sub-scale asks about intensity and frequency of child general pain and discomfort. Higher scores indicate better functioning, i.e. less pain. The global health sub-scale assesses the parent's report of the child's general health status, ranging from excellent to poor, with higher scores indicating better health.	Children and teens did not differ except for type of school program attended (Chi square = 18.9, $p < .01$), with teens more likely to be home schooled than children.

			10% fibromyalgia (n=22), 7.3% complex regional pain syndrome (CRPS) (n=16), 9% arthritis (n = 2). Average duration of pain symptoms was 45 months (SD=48.32). Almost a third of patients (29.7%, n=65) presented with multiple pain diagnoses.	symptoms, number and type of pain diagnoses, and psychological diagnoses were obtained from patients' medical records via chart review. Additionally, information was obtained about school absenteeism and type of schooling (e.g. home or at school, independent study, etc.). These items were obtained from the child and parent during clinic intake interviews and recorded in the assessment portion of the initial evaluation report by the evaluating physician. A standard evaluation form was used to assess		Children's Somatization Inventory (CSI) Parent Report: The CSI contains 35 psychophysiological symptoms rated on 5-point scales: 0= not at all; 1= a little; 2=somewhat; 3= pretty much; and 4= very much. Parents indicated the extent to which their children experienced each symptom over the past two weeks. Symptoms include gastrointestinal (e.g. "nausea/upset stomach"), pseudo neurological (e.g. "seizures"),cardiovascular (e.g. "heart beats too fast"), and pain (e.g. "pain in arms or legs") complaints. Total score can be computed by summing the score across all items.	

				all new patients, so that the same group of questions was asked of each patient.		Higher scores indicate higher levels of somatic complaints. Good internal consistency and test-retest reliability have been reported (*p* =.001). Functional Disability Inventory (FDI) Parent report: The FDI is a 14-item questionnaire measuring children’s difficulty in physical and psychosocial functioning due to their physical health during the past two weeks. Parents rated the severity of their child’s functional disability in daily activities including walking, chores, social activities, eating and sleeping. Respondents rate the level of difficulty their child has performing each of the items and total	

						scores are computed by summing the ratings for each item. Higher scores indicate greater disability. The FDI has been documented as valid, stable, and sensitive to change. This measure was completed by the subset of 78 parents. Pain intensity: Children were asked to rate their pain on a 10-cm Visual Analogue Scale (VAS) representing a continuum from no pain to worst pain possible. The VAS has been established and widely used as a reliable and valid measure of pain intensity with children. This method measured the amount of pain currently experienced by the	

						child and was completed by the subset of 78 patients.	
Farre, Ryan, McNiven & McDonagh (2019)	UK	Design: Qualitative Aim: To further explore the education and employment related aspects of the overall experiences of young people living with arthritis during early adolescence through to young adulthood, who had been sampled and recruited using different methods from those of previous qualitative studies specifically addressing education and employment issues in young people with arthritis. Method: A supplementary	39 young people who had been diagnosed with arthritis in childhood, adolescence or young adulthood. Age at interview 10– 14 years (20.5%). Age at diagnosis: <5 years: 23.1% 5–9 years:15.4% 10–14 years: 43.6%	Narrative and semi-structured interviews included a focus on educational experiences and outcomes.	Self-report	No additional measures	The findings illustrate how young people living with arthritis are faced with a range of added disruptions and challenges in their educational/vocational lives: Young people living with inflammatory arthritis are faced with the challenge of adjusting their lives to irregular periods when their condition becomes active, involving symptoms such as painful, swollen or stiff joints, increased tiredness and/or fever during the active phases of the condition. These will therefore involve a range of disruptions in young peoples everyday life, which can often

		secondary analysis of a qualitative dataset comprising narrative and semi-structured interviews of 39 young people who had been diagnosed with arthritis in childhood, adolescence or young adulthood.					coexist with disruptions associated with medication side-effects as well as other difficulties such as regular hospital attendance for blood tests and treatment monitoring. For young people, this also means that such disruptions will take place at a time where key developmental tasks and stages occur, including the educational and vocational aspects of their development. This impact can be further accentuated when young people with arthritis compare themselves with their peers without chronic conditions. Side-effects and other complications associated with the medication can translate into spells of recurrent time off,

							which can add to such disruptions for those in education. And vice versa, the challenges and pressures associated with academic performance can also translate in the worsening of some symptoms. Commonly cited disruptions suggested an indirect impact on one’s academic performance. Participation in education and work are demanding on physical activity and energy levels, both of which are impacted by the presence of arthritis. Examples included the negative impact of pain on appropriate sleep. Despite such various disruptions, the participants’ accounts also illustrate that experiencing

							recurrent pain can become an integral part of one's normal experience of, and relationship with, formal education. In addition, the cyclic nature of arthritis means that young people with inflammatory arthritis can engage in periods of 'normal' academic activities, particularly when the condition can be controlled with effective treatment and there is sustained adherence to medication.
Fatoye (2008)	Scotland	Design: Cross Sectional (Thesis) Aim: To identify the range of neuromuscular performance, functional range of motion (ROM) and QoL indices, and investigate the relationships	Twenty nine children with HMS (aged 8-15 years) 8 boys and 21 girls diagnosed with HMS based on the Beighton scores Mean age= 11.9	Paediatric Quality of life Inventory. The 23-item Core Scales encompass; (1) Physical Functioning (8 items), (2) Emotional Functioning (5 items), (3) Social	Self-report	Knee joint kinaesthesia (JK) and position sense (JPS) were examined using a motorised device. Muscle torque was tested with a digital myometer.	The overall QoL perception and all the domains were significantly poorer (p range < 0.001 to 0.008) in children with HMS than the controls. There were significant differences (all $p < 0.05$) in all

		between these features in children with Hypermobility Syndrome (HMS). Method: Children with HMS and healthy children were investigated for neuromuscular indices, functional ROM and QoL. Knee joint kinaesthesia (JK) and position sense (JPS) were examined using a motorised device, muscle torque was tested with a digital myometer, passive ROM was measured with a universal goniometer and functional ROM was assessed using the VICON camera system. Pain intensity and QoL were measured using the Coloured Analogue Scale	Control group: 37 healthy children (aged 8 – 15 years) Mean age= 11.5	Functioning (5 items), and (4) School Functioning (5 items). A 5-point Likert scale is used: (0: never a problem; 1: almost never a problem; 2: sometimes a problem; 3: often a problem; 4: almost always a problem). Items are reverse-scored and linearly transformed to a scale from 0 to 100 points such that higher scores indicate better QOL.		Passive ROM was measured with a universal goniometer and functional ROM was assessed using the VICON camera system. Pain intensity was measured using the Coloured Analogue Scale. The CAS has been shown to be a valid pain measurement tool for use in children aged 5 years and older, but its reliability has not been established. The CAS resembles a ruler, with one side showing a wedge-shaped figure filled with color that gradually progresses from white to red as the figure widens and the other side showing corresponding numerical ratings from 1 to 10 cm,	the domains of QoL between the two groups. These findings show that healthy children had better QoL perception in physical functioning, emotional functioning, social functioning and school functioning than the HMS cohort. School functioning: Healthy children= 100.0 (0.0), HMS children= 90.0 (45.0) $p = 0.008$.

		and the Paediatric Quality of life Inventory respectively. Mann-Whitney U tests and independent t-tests were performed to determine the differences between the two groups. The relationships between pain and each of the following: neuromuscular impairments, functional ROM and QoL were examined in children with HMS. The correlation between Beighton scores and each outcome was also evaluated in children with HMS.				divided into 0.25-cm increments.	
Fischer & Barthel et al (2019)	Germany	Design: Cross sectional	309 children and adolescents aged 7–17 years.	Self-reported HRQoL: assessed using the Kids-CAT. It is based	Self-report	Paediatricians were asked to complete a form for all participating	T scores reported for parent relations, social support and peers, and school

		Aim: examines HRQoL of children and adolescents with three different chronic conditions (i.e., diabetes mellitus, asthma, juvenile arthritis) using the computer-adaptive test Kids-CAT, comprising five HRQoL domains: physical well-being, psychological well-being, parent relations, social support and peers, and school well-being. Further, associations between HRQoL and distinct clinical data and medical assessments are investigated to explore how much variability of the five domains can	Age was grouped into the two categories children (7–11 years) and adolescents (12–17 years). Of these, 18.8% (n=58) were diagnosed with asthma, 65.4% (n=202) with diabetes mellitus (type 1),and 15.9% (n=49) with juvenile arthritis. Mean disease duration was M=5.44 (SD=3.73) years. At least one additional diagnosed health condition was reported for 32.5% (n=100) of the participants.	on the domain structure of the KIDSCREEN-27 and covers the five domains physical well-being, psychological well-being, parent relations, social support and peers, and school well-being. The Kids-CAT is constructed on the basis of item response theory. Each domain consists of an underlying item bank, including various items to measures a wide range of the respective domain. The Kids-CAT comprises in total 155 items. The item bank physical well-being consists of 26 items, 46 items are included in		children and adolescents within or after patient consultation, including the following items: year of diagnosis, co-morbidity, disease control, and paediatricians' assessment of patients' overall health status. Further, we asked paediatricians to rate the overall health status of their patients by use of a 5-point Likert scale ranging from very good to very poor.	well-being were slightly higher than mean scores of the reference population. Domain scores were 36.86 for social support and peers (M=54.10; SD=8.22), and 46.09 for school well-being (M=52.25; SD=9.54). For social support and peers, 6.5% of the variance could be explained (R2=0.065, adjusted R2=0.036), with age and SES being a statistically significant predictor. Finally, for school well-being, 6.3% of the variance could be explained (R2=0.063, adjusted R2=0.034), with SES as statistically significant predictor.

		be explained by these variables. Method: Cross-sectional data of the Kids-CAT study was analysed. The Kids-CAT was used in two outpatient clinics in northern Germany gathering data on self-reported HRQoL in=309 children and adolescents aged 7–17 years. Additionally, general patient information, clinical data, and paediatrician-reported medical assessments were measured. Multiple regression analyses were conducted to explore associations between HRQoL and selected variables (i.e., disease duration,		the psychological well-being item bank, the item banks parent relations and social support and peers comprises 26 items, and 31 items are included in the item bank to assess school well-being of children and adolescents.			

		co-morbidity, disease control, overall health status).					
Fichtel & Larsson (2002)	Sweden	Design: Quant descriptive Aim: To examine the prevalence of headache, its comorbidity with other pains and psychosocial impact among adolescents Method: 793 adolescents in a sample recruited from 8 schools in the middle of Sweden were assessed via administration of questionnaires.	793 adolescents 13 to 19 years old (mean=15.8, SD=1.6) and the sample consisted of 49% girls (n=385) and 51% boys (n=407) The pupils attended four secondary schools (n=423, grade 7-9) and four high schools (n=370, grades 10-12) representing 53% and 47% of the whole sample, respectively.	The Functional Disability Inventory (FDI): Walker and Greene (1991) assesses functional disability in children and adolescents when they are ill. It covers several domains of consequences of illness related to physical and psychosocial functioning in everyday activities. Functional disability is defined as troubles in age-appropriate physical and psychosocial functioning due to physical health status. The	Self-report	Frequency and Severity of Pain.: Participants were asked whether they experienced pain at the time of assessment, and if positively endorsed, they were further asked to specify their type of pain. Students also rated the frequency of headache and 6 other pain complaints: abdominal, muscle, back, and joint pain, in addition to tooth ache and ear pain, on the following 1-5 scale: 1, seldom or never; 2, one to three times a month; 3, once a week; 4, several times a week; and 5, daily. A rating of 3 or more was de-fined as a frequent pain problem, and a rating	Out of the various pains, headache frequency showed the highest positive correlations to medication usage $p < 0.001$, leaving school $p < 0.01$ and school absence $p < 0.001$ The correlations between headache, school absence, and medication use was higher for boys. However, girls reported significantly more school absence than boys, (n= 792) = 6.03, $p < 0.001$, as well as leaving school more often due to pain, (n= 792) = 6.35, $p < 0.001$.

				original items were rephrased to address students' pain experience by changing "feeling sick or not well" to "when being in pain or having ache." The FDI consists of 15 items and each item is scored on a 5-pointscale, where 0 represents "no problem" in performing the activity and 4 is "impossible to perform" the activity. A total sum score is calculated varying between 0 and 60. The 3-week test-retest correlation was r = 0.75, *p* < 0.05. Cronbach's alpha and split-half reliability were 0.91 and 0.90, respectively.		of 2 or less was considered an infrequent pain problem. The students also rated the pain problems according to how troublesome they were experienced by the subjects on the following scale: 1, no problem at all; 2,minor problem; 3, fairly problematic; 4, quite a lot problematic; and 5, extremely problematic. Frequency and perceived problems with pain were summarized into a composite measure pain index. Center of Epidemiologic Studies-Depression Child (CES-DC): The CES-DC is an instrument for self-rating of depressive	

				School Absence, and Leave: School absence: was estimated by asking students about the number of school hours they had been absent due to pain, and their responses were rated on the following scale: “0 hours,” “1 to 5 hours,” “6 to 10hours,” or “more than 10 hours.” In addition school leave: was estimated by asking the students about the number of times during previous month they had left school due to pain and to grade their responses on the following scale: “never,” “1 to 3 times,” “4 to		symptoms. It was originally developed for adults (CES-D)26 and has been adapted for children. It consists of 20 statements on which subjects are asked to rate the frequency of their symptoms during the previous week, where 0 is not at all, 1 is few times, 2 is now and then, and 3 is of-ten. All ratings are summarized into a total score varying between 0 and 60. The 3-week test-retest correlation was r = 0.78, *p* < 0.05. Cronbach’s alpha and split-half reliability were 0.86 and 0.87, respectively. Revised Children’s Manifest Anxiety Scale (RCMAS): The RCMAS is one of the most widely used instruments to	

				6 times," or "more than 6 times."		measure anxiety symptoms in children and adolescents. Excluding the social desirability items, it consists of 28 items to be answered by subjects with a "No" (0) or "Yes" (1), and the responses are summarized into a total score ranging from 0 to 28. Examples of questions are: "I get nervous when things do not go the right way," and "I of-ten worry about something bad happening to me" The RCMAS has been found to have good psycho-metric properties with an internal reliability estimate of 0.85.29 The 3-week test-retest correlation was r = 0.88, *p* < 0.05. Cronbach's alpha	

						and split-half reliability were 0.88 and 0.88, respectively. Illness Behavior Encouragement Scale (IBES): The IBES consists of 12 questions concerning what adolescents perceive their parents do when they are having a cold or gastrointestinal symptoms.30 The questionnaire is based on social learning theory and assesses how parent-child interactions may contribute to the development of a child’s illness behaviour. For example, a child does not have to do regular household chores or gets more attention from the parents. For this study, the questions were asked in regard	

						to the adolescent’s pain experiences, and the responses were rated on a 5-point scale, where 0 is “never” and 4 is “very often.” A total sum score was calculated with a higher score indicating more positive consequences for the subject when being in pain. The 3-week test-retest correlation was r= 0.85, $p < 0.05$. Cronbach’s alpha and split-half reliability were 0.66 and 0.46, respectively. Medication use: The students were also asked to estimate their usage of painkilling medication on the following scale: “never/seldom,” “1 to 3 times a month,” “1 to 3 times a	

						week,” “almost every day,” and “every day.”	
Fujita, Fujiwara,Maki, Shibasaki & Shigeta (2009)	Japan	Design: Retrospective Aim: To investigate the headache types, the clinical features, the treatments and the prognoses of chronic daily headache (CDH) associated with school phobia in a paediatric headache specialty clinic. To examine whether CDH with school phobia is different in characteristics compared to CDH without school phobia. Method: Retrospectively reviewed all charts of children aged 3–16 years presenting with chronic and/or	24 children with CDH and school phobia. 26 children with CDH but without school phobia. CDH was defined as the occurrence of headache for at least 15 days per month for more than 3 months.	All children with CDH were encouraged to record their headaches and life events, such as troubles at school and/or home, in their headache diaries, which were a modified version of the diary invented by Sakai et al. Their diagnoses of headaches and psychiatric disorders, if probable, were confirmed using the diaries at every interview at the clinic according to ICHD-II and DSM-IV-TR. Definition of effect in treatment and prognosis was measured by the	Self-report	Headaches were diagnosed according to the International Criteria of Headache Disorders second Edition (ICHD-II). The criteria describe a migraine as an attack of pulsating and unilateral or bilateral(frontotemporal) headache with nausea and/or vomiting, and with photophobia and phonophobia, lasting 1–72 h in children. The criteria of tension-type headache(TTH) is defined as bilateral pressing/tightening (non-pulsating)headache without nausea or vomiting, lasting 30 min to 7 days; the same as for adults. Psychiatric disorders were diagnosed	There were significantly more children with CDH in junior high school or above than those in elementary school (*p* < 0.0001). Of 50 children with CDH, 24 (48%) had school phobia: 19 of 35 (54%) girls aged 12.5 +1.5 years and 5 of 15 (33%) boys aged 12.0 +0.7 years. There was no significant difference in children with CDH but without school phobia between elementary school and junior high school or above. There was a significantly higher rate of CTTH (chronic tension type headache) and both CTTH and migraine in children with CDH

		recurrent headaches to a paediatric headache specialty clinic. Twenty-four children with CDH and school phobia were studied regarding their headache types, psychosocial factors, psychiatric disorders, treatments, and prognoses, compared with 26 children with CDH but without school phobia.		reduction of intensity of headache and frequency, and days of attending school.		according to the DSM-IV-Text Revision.	and school phobia than in children with CDH but without school phobia ($p <$ 0.0001) Psychosocial problems were reported in all of the 24 children with CDH and school phobia. Problems were differentiated into school problems (n=15, 63%), family problems (n=11, 46%),and patients' problems (n=4, 17%). School problems included stress in school with peers (n=11), with teachers (n=1), and at club activities (n=3). Bullying was identified in two cases of those who had stress with peers. In prognoses for school when treated with psychotropic medications and/or counselling, nine (37%) have attended

							school again regularly, 10 (42%) have attended school irregularly(such as in the nurse's office or from the afternoon), and two(8%) have still been absent. Psychotropic medications and/or counselling were useful for mental stability and incentives to attend school again in 19 (79%) children.
Garralda & Rangel (2004)	UK	Design: Mixed methods Aim: To compare impairment, illness attitudes and coping mechanisms in childhood chronic fatigue syndrome CFS and in other paediatric disorders. Method: The measures used were: interviews with children with various conditions	28 children and adolescents with chronic fatigue syndrome CFS 30 with juvenile idiopathic arthritis (JIA) 27 with emotional disorders (ED). Patients with medically and psychiatrically unexplained fatigue fulfilling the Oxford research criteria for a diagnosis	Socio-demographic and illness impairment data: A semi-structured interview was developed for the study and given to both parents and children, separately. It provided information on socio-demographic data, present physical status, current degree of impairment in all	Self-report and parent proxy report	Functional Disability Inventory, FDI (Walker & Greene, 1991). This is a 14-item questionnaire of documented validity, stability and sensitivity to change. It scores the presence and severity of functional disability in areas such as walking, travelling, daily chores, social and leisure activities, sleeping and eating.	Children with CFS reported significantly more illness impairment, especially in school attendance, than those with JIA and ED. On the Kidcope they named school issues (work, expectations, attendance) as illness- or disability-related problems more than the other two groups. Significantly more children in the CFS than in the other two groups were having

		and their parents, with detailed enquiry on impairment, including the Functional Disability Inventory (FDI), Illness Attitudes Scales (IAS), and Kidcope to measure coping styles in relation to common problems, illness and disability.	of Chronic Fatigue Syndrome (CFS, Sharpe et al., 1991),were selected. Mean age= 15.0 (2.1) They were group matched for age and gender with children suffering from Juvenile Idiopathic Arthritis (JIA). Mean age= 5.2 (2.4) attending a regional unit in the outskirts of London, and with a group of children suffering from emotional disorders (ED) Mean age= 13.9 (2.3) who had been referred to two child psychiatric clinics linked to the two specialist	areas of children's life, history and characteristics of illness and degree of impairment during the most severe episode of illness. Children and parents defined the worst episode of illness as the time when symptoms of the studied conditions were most severe and impairing. The socioeconomic status of the family was defined by the occupation of the main breadwinner. The degree of associated impairment at the time of the research interview (current) and during the worst episode of illness		The children's version of the Illness Attitude Scale (Kellner, 1986; Eminson et al., 1996). Consists of questions addressing attitudes and degree of concern about illness and health, with each question being rated on a 5-point scale. Scores are derived on 9sub-scales (i.e., worry about illness, concern about pain, health habits, hypochondriacal beliefs (which explore disease conviction), tanatophobia (or fear of death), disease phobia, bodily preoccupation, treatment experience and effect of symptoms). The scales have satisfactory internal reliability. The Kidcope (Spirito et al., 1988):	home tuition as an alternative to school education and more JIA children had had their special educational needs officially recognised over the years. These needs were medically related, involving mobility and physical strength, for example help or allowances for carrying books or walking between classrooms and buildings.

			paediatric clinics from which CFS participants were recruited.	was assessed through direct questioning on **school attendance**, stress or problems in interactions with family members or in peer relationships, and ability to perform usual age-appropriate household chores and activities at home. Impairment in school attendance (current or during worst episode of illness) was scored as: none (none or only odd days off school); mild (attending at least 85% of the time); marked (attending between 50 and 85% of the time);severe (less than 50% attendance), and extreme (has not		Checklist designed to assess cognitive, emotional and social coping strategies in children and adolescents. The checklist fo rolder adolescents version (13 years old and above) is composed of 10 items, tackling the use of the following coping strategies: distraction, social withdrawal, wishful thinking, self-criticism, blaming others, problem solving, emotional regulation, cognitive restructuring, social support and resignation. These strategies can be grouped into active coping strategies (i.e., problem solving, cognitive restructuring, emotional regulation, social support); avoidant coping	

				attended school at all for at least one academic term).		strategies (i.e., distraction, social withdrawal, wishful thinking, resignation) and negative coping strategies (i.e., self-criticism and blaming others). Children are asked about problems in different areas encountered in the month prior to the interview, and to rate each of the 10 coping strategies according to the frequency with which they are used (frequency scale: 4-point Likert-type rating scale ranging from not at all to almost all the time. For adolescents; it is rated as present or absent for pre-adolescents under 13 years of age).The Kidcope has moderate test–retest reliability for short	

						periods of time ranging from 3 days to 2 weeks and concurrent validity has been demonstrated by moderate to high correlations with other coping scales.	
Garmy, Hansson, Vilhjalmsson & Kristjansdottir (2019)	Iceland	Design: Cross sectional survey. Aim: Examine whether self-reported use of analgesics is associated with being a victim of bullying. Method: Students completed an anonymous standardised questionnaire: the Icelandic Contribution to the International Health Behaviour in School-Aged Children (HBSC) exploring self-reported pain, use of analgesics and bullying	161 schools with 11,018 students participated. The response rate was 84%. The mean age in each grade was 11 (6th grade) 13(8th grade) and 15 years (10th grade). Some students (n = 628) chose not to answer the questions on bullying, therefore response for this study = 10 390 students. 50% of the respondents	The Icelandic Contribution to the International Health Behaviour in School-Aged Children (HBSC) Survey. The following question regarding bullying was included: 'How often have you been bullied in school during the last months?' Five response options ranging from 'never' to 'several times a week'. Responses dichotomized:	Self-report by children.	Pain: Students were asked how often they had experienced the following symptoms in the last six months: Headache, Stomach ache, backache, and neck and shoulder pain. Responses coded: 1= if the student had at least one of the pains on a weekly basis and 0 = if the student had pain less frequently. Students were asked if they took medication for headache, stomach-ache, backache, or neck/shoulder pain.	Bullied students used more analgesics compared to non-bullied peers even when controlling for pain, gender, age and socioeconomic status. The use of analgesics for easing pain was significantly higher among bullied students than among non-bullied peers: <u>Medicine use weekly (%)</u> Headache (Bullied = 45.5%, Not bullied= 29.5 p = < 0.001) Stomach pain (Bullied= 30.8% , Not bullied= 14.2% p = < 0.001)

		This study used the Icelandic dataset from the WHO International Research Network HBSC.	were female- 32.1% were 6th graders (11-year-olds), 34.9% were 8th graders (13-year-olds), and 33.0% were 10th graders (15-year-olds).	‘two times or less’ = 0, and other options (ranging from ‘2-3 times a month’ to ‘several times a week’) = 1.		Responses: ‘not taking medication last week’ = 0 and ‘taking medication last week’ = 1.	Back pain (Bullied= 17.9% Not bullied= 8.1%, *p* = <0.001) Neck and shoulder pain (Bullied= 21.5% Not bullied= 9.3% *p* = <0.001)
Gil, Carson et al (2003)	USA	Design: Quant descriptive Aim: To determine the extent to which daily stress and mood are associated with pain, health-care use, and school activity in adolescents with sickle cell disease (SCD) Method: Adolescents with SCD completed daily diaries assessing pain, stress, mood, activity, and health-care use for up to 6 months.	Adolescents with SCD (n= 37) (24 girls, 13 boys) in the age range of 13 to 17 (M= 14.8, SD= 1.4). Twenty-eight had sickle cell anaemia, 6 had haemoglobin SC disease, and 3 had sickle beta thalassemia syndromes.	School and Other Activities: To assess daily activity, adolescents were asked whether, on that day, they (1) stayed home from school, (2) participated in extracurricular or after-school activities, and (3) completed household chores.	Self-report	Daily Diary of Pain, Health-Care Use, Activity, Stress, and Mood: The daily diary was a simple form that adolescents completed each day. It was modelled after the diary used in our prior study of adults (Porter et al., 2000). Adolescents were trained in how to complete the diary by an investigator in person who helped them to complete sample diaries. Sickle Cell Disease Pain, Other Pain, and Health-Care Use:	Daily increases in stress and negative mood were associated with increases in same-day pain, health-care use, and reductions in school and social activity. Increases in positive mood were associated with decreases in pain, less health-care use, and more activity participation. Regarding activity, adolescents stayed home from school on 13% of pain days and eliminated extracurricular activities on 10% of pain days and household chores on

		Multilevel modelling was used to analyze the data.				The first section of the diary. These questions were modified from the Structured Pain Interview and Daily Self-Monitoring Record developed by Gil (1994). Participants were asked if they had SCD pain today that was located anywhere in the body and that had no known cause other than SCD. They then rated their average pain level for the day on a100 mm visual analogue scale (VAS). A pain day was de-fined for the analyses as any day on which the child re-ported “yes” to the question “Are you having an episode of sickle cell pain today?” Adolescents were also asked to indicate pain duration, whether	18% of pain days. Thus, for a large proportion of days when adolescents had pain, they managed pain on their own without a health-care contact. Regarding activity reduction, increases in stress and negative mood were associated with more school absences and reductions in activities, whereas increases in positive mood were associated with fewer school absences and less reduction in activities. As expected, adolescents’ ratings of SCD pain were significantly and positively associated with all same-day activity and health-care use variables such that increases in pain were related to more school absences and reductions in

						they called or visited their doctor, went to the emergency room (ER), were admitted to the hospital, or took prescription medication. Reliability and validity of the items have been reported in studies of children and adolescents with SCD. Stress: The second section contained an assessment of daily stress based upon the approach used by Stone and colleagues(Stone & Neale, 1982, 1984; Stone et al., 1997). As part of the initial diary completion training session, adolescents were given a list of daily stressors. However, rather than complete the checklist each day, they were asked to use it as a guide for the range of	extracurricular activities and household chores.

						potential stressors. Each day, they were asked to rate the perceived level of overall stress of the day on a 100 mm VAS anchored at not at all stressful and as stressful as I can imagine. They were asked to describe what situations they were dealing with that day, to identify the most stressful situation, and to select one of six categories that best de-scribed it: school, family, boyfriend/girlfriend, other friends or other relationships, sickle cell disease, or other. Mood: The final section of the diary consisted of the daily mood scale developed by Diener and Emmons (Diener & Emmons,	

						1985; Emmons & Diener, 1985). The mood scale assessed two dimensions of affect positive affect (PA) and negative affect (NA) by asking participants to rate the degree to which they felt various mood states that sampled these two overall domains of affect (PA = happy, enjoyment/fun, joyful, pleased; NA = depressed /blue, unhappy, angry/ hostile, frustrated, worried/anxious). Adolescents rated each mood each day on a 6-point scale from not at all to extremely. Composite scores for PA and NA were obtained using the sum score of PA items which was computed creating the positive mood	

						variable and the sum score for the NA items was computed creating the negative mood variable. This mood scale has shown adequate reliability and validity in daily diary studies with college students. To examine the internal consistency of the scale with the adolescents in this study, we calculated alpha coefficients and found that reliability for each mood scale was high (alpha for PA = .92 and for NA = .88). Daily Hassles: The Adolescent Daily Hassles Scale (Seidman et al., 1995) was used as a baseline measure of daily hassles.	

						This is a 28-item scale examining daily hassles in areas including family, peers, school, neighbourhood, and resources. Adolescents rate each stressor on a 4-point rating scale (not a hassle/ hasn't happened in the past month to a very big hassle. The daily hassles' cumulative severity score is the sum of the ratings. The coefficient alpha for the 28-item measure was .89. Psychological Distress: Symptoms of psychological distress were assessed in adolescents using the Symptom Checklist-90 –Revised (SCL-90 –R; Derogatis, 1983).	

						The SCL-90 –R measures psychological distress along nine dimensions: somatization, obsessive compulsive, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation, psychoticism, and other dimensions of distress. The Global Severity Index (GSI) was used as the summary score of psychological distress.	
Greco, Freeman & Dufton (2006)	USA	Design: Case-control Aim: This study compared children with frequent abdominal pain with a pain-free control group on measures of overt	60 children with frequent abdominal pain Mean age of 12.22 years (SD = 1.19) 60 gender- and age-matched peers.	Use of School Medical Services: Children were asked to estimate the number of times they used school medical services or visited the school nurse since the	Child self-report, peer and teacher reports.	Abdominal Pain Index: The Abdominal Pain Index (API; Walker, Smith, Garber,& Van Slyke, 1997) is a five-item scale used to assess the frequency, duration, and intensity of	Children with frequent abdominal pain experienced higher levels of victimization than their pain-free peers, with boys in the pain group rated highest in overt victimization.

		and relational victimization and examined the link between abdominal pain and school-related functioning. Method: Child, peer, and teacher reports were used to assess abdominal pain, peer victimization, use of school medical services, social skills, and academic competence.	Mean age of 12.30 years (SD = 1.35) In grades 5–10 who participated in a larger project on children's health and friendship. Children in the pain group reported (a) a minimum of 3–4 episodes of abdominal pain over the past 2 weeks; (b) pain episodes lasting at least 30 min; and (c) pain rated as moderate to severe in intensity.	beginning of school. A research assistant specified the month children should refer to when answering this question. Teacher report: Academic competence scale: Items on the Academic Competence Scale assess children's academic performance across multiple domains with a possible range in scores from 7 to 35. Higher scores= higher academic competence.		abdominal pain episodes occurring over the previous 2 weeks. Responses on the API were used to create the pain and control groups. Cronbach's alpha in this sample was 0.93. The API has good concurrent and predictive validity as well as acceptable internal consistency and test–retest reliability. Children's Social Experiences Questionnaire-Peer Report: The Children's Social Experiences Questionnaire-Peer Report (CSEQ-PR; Crick & Bigbee, 1998) is a measure of overt and relational victimization that has been well validated by prior	For children in the pain group, overt and relational victimization made incremental contributions to outcomes and moderated the link between pain- and school-related functioning. A significant positive correlation was found between abdominal pain symptoms and overt and relational victimization and use of school medical services. Conversely, a significant negative correlation was found between levels of abdominal pain and social skills and academic competence. After entering covariates and abdominal pain, overt victimization made a significant incremental contribution to

						research (Crick & Bigbee, 1998). Items on the CSEQ-PR ask children to identify class-mates who are the targets of overt victimization (e.g., gets beat up, is picked on by bullies) and relational victimization (e.g., is left out, has lies and rumours told about him/her). Using a class roster and number identification procedure, children nominated up to three classmates who fit each of nine descriptors. Overt and relational victimization scores were then computed for each child by summing the items within each category and standardizing scores by gender within each class-room.	teacher-reported social skills ($\Delta R2 = .17$, $p = .004$), academic competence ($\Delta R2 = .08$, $p = .042$), and self-reported use of school medical services ($\Delta R2 = .19$, $p = .000$). In addition, overt victimization moderated the relation between children's abdominal pain and (a) academic competence ($t = 3.43$, $p = .001$) and (b) use of school medical services ($t = 3.05$, $p = .004$). Among children experiencing low rates of overt victimization, academic competence was higher and appeared to be influenced by level of abdominal pain ($t = -4.51$, $p = .000$). Finally, high abdominal pain was

						Teacher-Report Measure: Social Skills Rating Scale Homeroom teachers completed the Social Skills Rating Scale (SSRS; Gresham & Elliot, 1990) for elementary school students, and English teachers completed the SSRS for middle- and high-school students. The SSRS is a teacher-report measure that includes 30 items assessing Social Skills and 9 items assessing Academic Competence. Items on the Social Skills Scale measure cooperation, assertion, and self-control in peer and classroom settings, with a possible range in scores from0 to 60. Scales on the SSRS have been found to have good	associated with more frequent use of school medical services when overt victimization was also high (t = 3.84, *p* = .000).

						internal consistency, test–retest reliability, and concurrent validity.	
Groenewald, Giles & Palermo, (2019)	USA	Design: secondary cross sectional analysis Aim: To estimate the national burden of school absenteeism associated with pain among 6 to17-year-old children in the United States. Method: Data were analysed from a large, nationally representative sample from the 2012 National Health Interview Survey. Associations between pain and school absence were analysed using multivariate negative binomial models controlling for sociodemographic	For each family included in the NHIS, 1 child (aged 17 or younger) and 1 adult (18 or older) were randomly selected for additional, more extensive questionnaires collecting information on the presence or absence of health conditions and health behaviours. The final sample contained 8641 school-aged children (6 to 17 y). Mean age of children in the sample was 11.5 years. The sample contained	School Absenteeism: Defined as the number of days of school days missed because of illness or injury as reported by parents over the preceding12 months (continuous variable; range, 0 to 240 d). Specifically, parents were asked "During the past 12 months, about how many days did (name of their child) miss school because of illness or injury?" Chronic absenteeism was defined as missing>15 days of school during the past 12	Parent proxy report	Pain: Childhood pain was identified by parental responses to 10 questions in the 2012 NHIS Sample Child file, consistent with previous studies. Specifically, parents were asked "During the past 12 months, has (name of their child) had any of the following conditions...(1) frequent headaches or migraines; (2) recurrent headaches other than migraines; (3) abdominal pain; (4) pain in/around a joint over the past 30 d; (5) neck pain; (6) lower back pain; (7) other muscle or bone pain; (8) severe sprains or strains;(9) dental pain; or (10) other chronic pain."	Compared with children without pain, parents of children with pain reported an additional 1.5 days (95% CI,1.1-1.9 d ;$p < 0.0001$) of missed school annually after controlling for other sociodemographic and clinical covariates (on average children with pain missed 4.0 d of school while children without pain missed 2.5 d of school). This translates to an additional 61% sick days annually (incidence rate ratio=1.61; 95% CI, 1.45-1.78;$p < 0.001$) We found that number of comorbid conditions was also strongly associated with school absenteeism: children with ≥ 4

		and clinical characteristics.	slightly more males (52%) than females (48%). In the overall sample 2698 children were identified with pain (30.3%).	months, which is consistent with the definition used by the United States Department of Education.		Because the 2012 NHIS did not specify pain intensity, frequency, duration, or interference, we were unable to classify these pain-related conditions as either recurrent or chronic according to the International Association for the Study of Pain (IASP) taxonomy. Sociodemographic Variables: Information captured included age group (6 to 10, 11 to 13, 14 to 17 y), sex (male/female), race and ethnicity (white non-Hispanic, black non-Hispanic, Hispanic, American Indian/Native Alaskan, Asian, and other/multiracial group), family income (<$34,999, $35,000to $74,999, $75,000 to $99,999, $100,000 and over), insurance status	comorbidities missed significantly more school as children without any comorbidities. Chronic absenteeism was reported in 2.75% (n=247) of children. However, the percentage of children with pain who were chronically absent were almost 5 times that of children without pain (6.1% vs. 1.3%). Amongst children who were chronically absent, 68% had pain ($p <$ 0.0001).

						(uninsured, some private, public only), parent educational status (bachelor’s or higher, some college, high school or less) and United States census region (Northeast, Midwest, South, and West). Comorbid Conditions: NHIS gathers data on several priority chronic child health conditions including: depression, anxiety, asthma, attention deficit and hyperactivity disorder (ADHD), allergies, infections ,autism, muscular dystrophy, diabetes mellitus, neurodevelopmental delay, Down’s syndrome, cystic fibrosis, seizures, and hypertension. We decided a priori to control for the co morbid conditions	

						by assigning participants to 1 of 4 categories representing number of comorbidities (0, 1, 2-3, and 4+ comorbid conditions) excluding pain, asthma, and ADHD. Asthma and ADHD were included as separate comorbid conditions in order to directly compare school absenteeism associated with each to school absenteeism associated with childhood pain.	
Guzman,Gómez-Ramírez et al.,(2014)	Canada	Design: Qualitative. Aim: Assess which clinical features are most important for patients, parents, and clinicians in the course of juvenile idiopathic arthritis (JIA).	Youth with JIA. (Varied subtypes of JIA, disease severity, and disease duration). Experienced parents. Novice parents (< 6 months since diagnosis).	Participants were provided with a list of definitions for 34 JIA clinical features (Extracted from published literature by the authors). Participants reviewed all the definitions, added any additional	Self-report/ discussion by children and young people with JIA, parents, paediatric rheumatologists and allied health professionals through	No additional measures.	Children with JIA stated that quality of life included needing help, symptom difficulties, and missing school. All groups agreed that the medications required for controlling JIA and the side effects were high priority features.

		Method: 6 focus group discussions and 112 reciprocal interviews. Participants discussed the importance of 34 JIA clinical features extracted from medical literature. Transcripts and interview reports were qualitatively analysed to establish relative priorities for each group of participants.	Paediatric rheumatologists. Allied health professionals.	items considered important, and discussed what items were most important to them. High-priority items were those explicitly chosen by participants as top priority; medium priority were those initially identified by participants as important, but after discussion were thought less important than those in the top priority list; low priority were those that were not addressed in the discussion or did not draw enough supporting arguments in analysis. Very low priority were those that were not discussed to any extent.	interview or focus group discussion.		Most participants considered medication requirements, medication side effects, pain, participant-defined quality of life, and active joints as high priority clinical features of JIA. Children with JIA felt their experiences did not fit well on a scale. They expressed dissatisfaction with scales and questionnaires assessing their experience and wanted to use their own words to describe their situation.

Haberfehlner & Visser et al (2011)	Netherlands	Design: Cross sectional case-control Aim: To describe handwriting difficulties of primary school children with juvenile idiopathic arthritis (JIA), and to investigate possible correlations with hand function and writing performance Method: In a cross-sectional approach, 15 children with JIA and reported handwriting difficulties were included together with 15 healthy matched controls. Impairments (signs of arthritis or tenosynovitis, reduced grip force and limited range of motion of the wrist (wrist-	15 children with JIA and reported handwriting difficulties 15 matched healthy controls. Matched with regard to age, gender, writing left or right-handed, and school level. The JIA group had a mean age ± SD of 10.8±1.5 (range 8.0-13.1) years and did not differ from the control group, which had a mean age ± SD of 10.7±1.5 (range 7.9-12.9) years. The inclusion criteria were: 1) diagnosis of JIA, according to the International League of	Questionnaire: The children were asked in a structured way about handwriting difficulties at school, and their use of handwriting aids (e.g. a laptop or an adapted pencil). The questions were designed following the formulation used in the Dutch version of the Childhood Health Assessment Questionnaire (CHAQ), which is available as a child-administered version from 8 years on (16). Children were asked to rate their answers on a 100 mm VAS. Questions considered the following	Self-report	Disease history and clinical characteristics, including data on disease duration, age at onset of the disease, disease activity, current active joint count, medication, and ILAR classification, were collected from the medical charts. Disease activity was assessed on a 100 mm Visual Analogue Scale (VAS-doctor) (0 mm=inactive, 100 mm=extremely active), and a 5-point Likert scale (Likert-doctor) (0=none, 1=mild, 2=moderate, 3=severe, 4=extremely severe). We assessed 0–71 joints for clinical active arthritis (9), and previous involvement of joints of the dominant upper	The majority of the JIA children (73%) had no active arthritis of the writing hand, and only minor hand impairments were found. Overall, the JIA children performed well during the short handwriting test, but the number of letters they wrote per minute decreased significantly during the 5-minute test, compared to the healthy controls. The actual presence of arthritis, and limitation in grip force and wrist-ROM did not correlate with reported participation restrictions with regard to handwriting at school. The JIA children reported pain during handwriting, and inability to sustain

		ROM)), activity limitations (reduced quality and speed of handwriting, pain during handwriting), and participation restrictions (perceived handwriting difficulties at school) were assessed and analysed	Associations for Rheumatology (ILAR) criteria (4), 2) self-reported handwriting difficulties, 3) at least one year learning to write at school, and 4) attending a regular Dutch primary school. The exclusion criteria were: other medical conditions which can interfere with handwriting	handwriting features: 1) frequency of their handwriting difficulties, 2) severity of their handwriting difficulties 3) frequency of difficulties in finishing handwriting tasks on time, 4) severity of their difficulties in finishing handwriting tasks on time, 5) appearance of their handwriting, 6) frequency of pain during handwriting, 7) severity of pain during handwriting, and 8) frequency of their difficulties with sustaining handwriting throughout the day. A higher score indicated a worse		limb, including tenosynovitis, was recorded Assessment of hand function: In the JIA children, the hand and wrist of the writing hand were assessed for signs of active arthritis or tenosynovitis (i.e. swelling and pain). The range of motion of the wrist (wrist-ROM) was measured on the dorsal side of the hand with a hand-held goniometer (E-LINK R500 Range of Motion Kit, Biometrics Ltd). Manual goniometry has shown high intrarater reliability. Maximal isometric grip force was measured with a JAMAR-dynamometer (E-LINK H500 Hand Kit, Biometrics Ltd),	handwriting for a longer period of time. The JIA children rated almost all restrictions in participation as high (mean ± SD: 57.5±19 mm), and significantly higher than their controls, except for ‘finishing handwriting tasks on time’ and ‘appearance of their handwriting’.

				situation. End-points were marked with a happy smiley face and a sad face. The values of the second question, about the severity of handwriting difficulties at school were used for the analyses of correlations between reported hand-writing difficulties and hand function (arthritis, ROM and grip force) Handwriting assessment: A Dutch method for the assessment of children’s handwriting (“Beknopte beoordelings method voor kinderhandschriften = BHK) was applied.		and counted in Newtons (N). The children were asked to grip as strongly as possible three times. The average of the three grips and the maximum value per child were used for further analysis. The average value was compared with published norm data, a score was considered abnormal if is this was below the mean norm value, minus two standard deviation (SD) Pain assessment: The children were asked to rate the upper extremity pain they experienced on a 100 mm VAS-pain (0 mm = no pain, 100 mm = extremely severe pain). End-points were a happy smiley face and a sad face. Pain was rated before and after the	

				The BHK is used to identify handwriting problems in primary school children. The writing task consisted of copying a standard text that was printed on a card, within five minutes. For the assessment, 13 handwriting characteristics, such as insufficient word-spacing, acute turns in connecting letters, irregularities in connections, or their absence, and collisions of letters, were scored with the BHK. The total BHK score was used to determine		handwriting task, and also after the grip force measurements	

				whether the child was 1) not dysgraphic (score 0-21), 2) at risk (score 22–28), or 3) dysgraphic (score 29 or higher). Writing in print was also scored, Writing speed was determined by counting the number of letters produced in exactly five minutes. The scores were then converted into decile scores related to norm values, corrected for the children's grades. Scores falling within the lower two deciles were considered to reflect slow writers, and within the upper two deciles, fast writers.			

				Interrater reliability of the BHK has been reported to vary between r=0.71 and r=0.89; intra rater reliability was r=0.79 to r=0.94 (12).			
Hackett (2003)	UK	Design: Qualitative Aim: To explore the perceptions of play and leisure in junior school aged children with juvenile idiopathic arthritis Method: A phenomenological approach was used to investigate the experience of play and leisure gaining information directly from the participant.	Twelve children between the ages of 7 years and 11 years. Mean age= 9 years. Attending a major children's hospital, who fulfilled the International League Against Rheumatism criteria for JIA. There were three boys and nine girls. Three children had oligoarthritis (that is, affecting less than five joints), one had	Semi structured interviews focused on the effect of arthritis on play and leisure activities.	Self-report via semi structured interview	No additional measures	Four major themes were evident from the data: play and leisure as a phenomenon, barriers to play and leisure, coping strategies and feelings. All the children reported some difficulty with play and leisure activities, which they felt was directly attributed to their arthritis. The difficulties varied from being only a minor inconvenience to having a more profound effect on play. Attendance at clubs and participation in

			psoriatic arthritis, two had systemic arthritis, and six had either polyarthritis (five or more joints involved) or extended oligoarthritis (oligoarthritis-onset disease extending to five or more joints).				household chores and in indoor and outdoor games were also viewed as problematic. Friendships were also seen to be affected by arthritis. Not being able to play with who they wanted to on a consistent basis was an issue for many of the children. They perceived that this was the result of a number of factors, including the location of a friend' s house and being confined to their home as a result of disease symptoms. Fatigue was mentioned more frequently than any other symptom as interfering with play and leisure activities. This was featured in the reports of children with varying degrees of arthritis as well as those with quiescent disease. Fatigue was

							reported to affect games, sports and attendance at clubs. Overprotection and constraints imposed by parents, relatives, friends and school personnel were all seen to limit the activities that the children themselves felt able to do. These constraints ranged from simple prompts to more limiting dictates, which appeared to restrict activities and trips as well as spontaneity. The most common theme to emerge from the data was an overwhelming feeling of being ‘ left out’ of certain play and leisure activities. Feelings of sadness and loneliness were commonly reported by children with mild, moderate and severe arthritis.

Haraldstad, Sorum, Eide, Natvig & Helseth (2011)	Norway	Design: Descriptive Aim: The specific aims of the study were to study the prevalence of pain, its association with age, gender, and socio-demographics, its frequency, duration, and type. A further aim is to describe the impact of pain on daily living, perceived triggers of pain, and correspondence between parents' and children's perceptions of pain. Method: Data were collected using a structured self-report questionnaire, the Lübeck Pain-Screening Questionnaire (LPQ). The children filled in	A cluster sample of children and adolescents (age 8–18 years N = 1238) 60% of the children and adolescents reported pain within the previous 3 months.	The Lubeck Pain-Screening Questionnaire (LPQ) questions about the self-perceived impact of pain on daily living and a list of possible choices (disturbed sleep, problems with eating, missed school days, hobbies, social contacts, and health-care utilization). The respondents were asked to rate the impact of pain as never, sometimes, often, or always. Responses using more than one alternative could be provided for each of these questions. The LPQ has been used in several European studies for which it was considered	Self-report by both children and parents.	Demographic variables: The first part of the questionnaire concerned demographic details such as nationality, date of birth, gender, cohabitant status, parental marital status, and school year. For analysis, age was classed as8–11 years, 12–15 years, and 16–18 years. The parental marital status was dichotomized as two parents (married or cohabiting) or single parent (unmarried, divorced, or widowed). Whether the respondent had moved during the previous 5 years was dichotomized as a 'yes' or 'no' response. Pain questionnaire: The Lübeck Pain-Screening Questionnaire (LPQ) is a structured self-	Children reported impact on social life; inability to pursue hobbies, disturbed sleep, absence from school, and inability to meet friends because of pain. The most common impact on daily activities according to both genders was disturbed sleep and being unable to pursue hobbies. More than half of the girls (59%) and 45%of the boys reported disturbed sleep because of pain. Girls reported significantly more sleep disturbances than boys($p < 0.001$

		the questionnaires at school, while the parents completed the questionnaires at home.		an appropriate instrument.		report questionnaire, which evaluates the prevalence of pain during the preceding 3 months. The questionnaire addresses the prevalence and consequences of pain and describes self-perceived factors for evaluating the development and maintenance of pain and its impact on daily living. The questionnaire has three versions for children, depending on age, and one version for parents. We only analysed responses to the following item of the parent version: ‘‘Did your child have pain within the past3 months?’’ The questionnaire contains 13 questions about pain, the first of which is	

						‘‘Did you have pain within the past 3 months?’’ If the answer was negative, no other question about pain needed to be answered. If the answer was ‘‘yes’’, the respondents were asked to describe where they had experienced pain during the preceding 3 months, and a list of choices was supplied (head, back, abdomen, arm leg, ear, throat, chest, and tooth). The children were asked about the duration of the type of pain that troubled them the most (answer categories: only once, <1, 1–3, >6, and >12 months) and its frequency (answer categories: less than once a month, once a month, two to three times a month, once	

						a week, two times a week to every day). The questionnaire also contained a visual analogue scale to assess pain intensity, questions about self-perceived triggers of pain, and requested an explanation for the first occurrence of pain. A list of possible causes was given (change of weather, lack of sleep, annoyance/conflicts, school tests, cold, common cold, school situation, sports/physical efforts, family situation, light, noise, computer use, consumption of sweets, nutrition, sadness, excitement, and nonspecific factors).The respondents were asked to tick all possible causes.	

						The participants were also asked whether their pain had been medically diagnosed, whether a family member had experienced recurrent or chronic pain, and whether they had visited a doctor because of pain.	
Haverman & Grootenhuis et al (2012)	Netherlands	Design: Aim: To assess health-related quality of life (HRQOL) and its predictors in a group of children and adolescents with Juvenile Idiopathic Arthritis (JIA). Method: HRQOL was measured using the Paediatric Quality of Life Inventory 4.0 (ages 6–18 years). Functional ability was measured using the Childhood Health	All JIA patients (ages 6–18 years) who consulted a paediatric rheumatologist in Amsterdam, The Netherlands, between February 2009 and March 2010. 152 patients included in the final analysis. Mean age= 13.03 A Dutch youth norm population including children with other chronic	HRQO: Paediatric Quality of Life Inventory 4.0 (PedsQL). The proxy-report (ages 6 or 7 years)and self-report versions (ages 8–18 years) were used. The 23 PedsQL items are divided into 4 subscales (including 5-point Likert scales): physical functioning (8items), emotional functioning (5 items), social functioning (5	Self-report	Sociodemographic: Collected using the online baseline questionnaires completed by the mother or father. The following information concerning the child was obtained: age, age at onset of disease, school absence (missed days at school in the last 3 months), sex, participation in sports, and subjective burden of medication use. Data were obtained from the parents on their age, sex,	Both children (ages 6–12 years) and adolescents (ages13–18 years) with JIA reported a significantly lower HRQOL in almost all domains compared to either healthy controls or children with other chronic health conditions. Approximately half of the children with JIA showed an impaired HRQOL. The main predictors of HRQOL were functional ability, pain, subjective burden of medication use, and school absence.

		Assessment Questionnaire, and medical and sociodemographic parameters were assessed. The study sample was compared to a Dutch youth norm population including children with other chronic health conditions. The proportion of children with JIA with an impaired HRQOL (<1 SD) was evaluated and multivariate regression analyses were performed to predict HRQOL outcome.	health conditions (n= 62) Including: asthma (36.4%), congenital defect (13.6%), skin disease (6.1%),and migraine (6.1%). Mean age= 14.04	items), and school functioning (5 items). The Dutch PedsQL version differentiates between children with and without a chronic condition. In rheumatology, the PedsQL generic scale has shown excellent reliability, validity, and responsiveness.		country of birth, education (where low indicates no education, primary school, or primary vocational education; middle indicates secondary school or secondary vocational education; and high indicates higher vocational education or university), and employment status. Information on the child's age, sex, and parental country of birth in the non-participants group was retrieved from medical files. Medical data and assessment of JIA severity: The participants' medical data were assessed by the paediatrician during the consultation. The nonparticipants' medical data were collected retrospectively,	The HRQOL of children ages 6 and 7 years, based on proxy reporting, was significantly lower compared to the Dutch healthy norm population ($p < 0.05$) in all the domains except emotional functioning. Large effect sizes were found for the total score, physical health, and school functioning. Children (ages 8–12 years) reported significantly lower HRQOL scores in all domains compared to the Dutch norm ($p < 0.05$). Large effect sizes were found for the total score and physical health. Adolescents (ages13–18 years), in line with the group ages 6 and 7 years ,reported significantly lower HRQOL scores on all

						based on the reports in the medical files. All patients were classified according to the International League of Associations for Rheumatology criteria. During the consultation, the physician assessed the disease activity on the 100-mm visual analog scale (VAS; where 0=no disease activity and 100=very severe activity) and the number of active joints. These were classified as follows: no active joints, monarthritis (1joint), oligoarthritis (2–4 joints), polyarthritis (5–10joints), and severe polyarthritis (11 active joints). The patient’s medication at the	scales compared to the Dutch healthy norm population, except for emotional functioning. School functioning mean for: JIA:72.86 Norm group:86.31 Chronic health condition:79.55

						time of the consultation was recorded. Current or previous presence of uveitis was noted. The time between disease onset and diagnosis was calculated, as well as disease duration (time from disease onset to the date of the consultation) Functional ability and discomfort: Childhood Health Assessment Questionnaire (C-HAQ).The Dutch version of the C-HAQ was used to measure functional ability. The disability index is a summarized score ranging from 0 to 3, with higher scores indicating higher disability. The C-HAQ can be used as a self-report, as well as a parent-proxy report. Both	

						versions, the proxy report (ages 6 or 7 years) and the self-report (ages 8–18 years), were used in this study. Discomfort was assessed by the completion of a 100-mm VAS for the evaluation of pain (where 0=no pain and 100=very severe pain) and a VAS for the evaluation of overall well-being (where 0= very well and100=very poor) by the parent or patient, depending on the age of the child.	
Ho, Bennett, Cox & Poole (2009)	USA	Design: Retrospective descriptive study Aim: To examine the patterns of cognitive functioning and academic achievement in children and adolescents with chronic pain	57 children and adolescents with chronic pain. The participants' age at the time of assessment ranged from 8 to 18 (M=14.64, SD=2.39). The majority (n=46, 81%) were females.	General Cognitive Ability: Participants aged 8–15 who completed psychoeducational assessment between 1998 and 2003 were assessed using the Wechsler Intelligence Scale for Children-	Retrospective review of academic achievement.	No additional measures	On average, participants scored higher in general intelligence, verbal ability, nonverbal reasoning, word reading, and math reasoning than the general population. The level of academic achievement for most participants was

		attending a tertiary-care interdisciplinary pain service. Method: The standardized psychoeducational testing results of 57 children and adolescents with chronic pain aged 8–18 were retrospectively reviewed	Diagnoses included headache (n=17), back pain (n=6), abdominal pain (n=6), leg pain (n=2), diffuse idiopathic musculoskeletal pain(n¼7), localized idiopathic musculoskeletal pain (n=6),and multiple pains (e.g., headache and back pain)(n=13). On average, participants had been experiencing pain for 46.98 months. Most reported being in pain on a daily basis (n=48, 84%), and their mean pain intensity rating on a 10-point scale was 6.26.	Third Edition (WISC-III; Wechsler, 1991). The Wechsler Adult Intelligence Scale-Third Edition (WAIS-III; Wechsler, 1997) was used for 12 participants aged 16 or above. Academic Achievement: (Measured using a range of measures due to the 6 year span of the review). The Wide Range Achievement Test-Third Edition (WRAT-3; Wilkinson,1993), the Gray Oral Reading Test-Third Edition (GORT-3; Wiederholt & Bryant, 1992), and the Test of Written Language-Third			consistent with their intellectual ability. In the sample with complex, disabling pain, the group mean data did not indicate overall cognitive impairment, or a single atypical achievement pattern. School absence (known from a previous sample of CPS patients studied: Bennett, Huntsman et al., 2000) showed that the majority of children and adolescents (91% ,n=39) reported school absence due to pain, with 26% (n=11) missing more than 1 month of school within a school year

				Edition (TOWL-3; Hammill & Larsen,1996) were administered to patients seen prior to 2001. After 2001, the Wechsler Individual Achievement Test-Second Edition (WIAT-II: The Psychological Corporation,2001) and the Gray Oral Reading Test-Fourth Edition(GORT-4; Wiederholt & Bryant, 2001) were used. The six core academic areas assessed were:(1)Word reading. Twenty-seven participants completed the WIAT-II Word Reading subtest and 24 completed the WRAT-3			

				Reading subtest.(2)Reading comprehension. Reading comprehension was assessed using the WIAT-II Reading Comprehension subtest, or the GORT-4. Arithmetic: Participants completed either the WIAT-II Numerical Operations subtest or the WRAT-3 Arithmetic subtest. Mathematical reasoning: The WIAT-II Math Reasoning subtest was used to assess the participants' ability to reason mathematically and to apply mathematical concepts.			

				Spelling: Participants' single-word spelling was assessed using either the WIAT-II Spelling subtest or the WRAT-3 Spelling subtest. Written expression: Writing skills were assessed either with the WIAT-II Written Expression subtest or the TOWL-3 Story Construction subtest.			
Jones, Stratton, Reilly & Unnithan, (2004)	UK	Design: Cross sectional survey Aim: To provide evidence of the prevalence and consequences of recurrent low-back pain in children from Northwest England.	A cross-sectional sample of 500 children and adolescents. Boys (n= 249) and girls (n= 251) Subjects were aged between 10 and 16 years [Mean age= 13.5 (2.0) years]	The questionnaire used to assess low- back pain history also examined the consequences of the low-back pain experience. Questions were asked relating to absence from school, medical treatment and	Self-report	Low-back pain evaluation: Subjects were required to complete a questionnaire to assess for low-back pain history. The questionnaire was designed to identify lifetime prevalence, point prevalence, recurrent prevalence and	13.1% of children (95% CI = 12.5±13.7) experienced recurrent low-back pain that led to disabling consequences; 23.1% visited a medical practitioner, 30.8% experienced loss of physical activity/sports and 26.2% had been absent from school

		Method: A cross-sectional survey was conducted involving a standardized questionnaire with established reliability and validity.		limitation of activity. The questionnaire approach has been found to be both reliable and valid.		duration of the low-back pain. Lifetime prevalence was defined as the proportion of the population that had experienced an episode at some point in their lifetime. Point prevalence was defined as the proportion of the population that had been cases within the previous week. Recurrent low-back pain was identified by the question `do you get back pain regularly'; this question referred to the previous 12 months and was classified by repeated acute episodes. An anatomical drawing was used to identify the localization of the back pain.	because of low-back pain.

Kaczynski, Claar & LeBel (2012)	USA	Design: Retrospective review. Cross sectional. Aim: To assess for differences in headache characteristics and psychosocial factors based on headache diagnosis, and to evaluate whether headache diagnosis moderates relations between psychosocial factors and school difficulties. Method: Retrospective chart review was conducted. Adolescents completed measures of anxiety, depression, and pain coping. Parents completed a measure of parental protective	262 adolescents with chronic tension-type headache (CTTH) (n=153) and migraine (n=109) evaluated at a paediatric headache clinic 11–17 years (mean= 14.7 years, SD= 1.6) Patients attending regular school full-time (69.9%),part-time (24.9), or receiving home-schooling or home-bound education (5.6%) were included to represent the full range of educational circumstances encountered in our clinic population.	PedsQL School Functioning Scale: (Varni, Seid, &Kurtin, 2001) is a 5-item subscale of the PedsQL that assesses school functioning in the past month. Parents completed this measure to report on their child’s school functioning. The timeframe was modified to assess patients’ school functioning during the current school term. Thus, the stem for each item was, ‘‘In the past 3 months, how much of a problem have you had with...’’ Items on the school	Parent proxy report	Demographics: Basic demographic (e.g., age, gender) and medical information (e.g., diagnosis) were collected from a review of patients’ medical records. Headache Characteristics: Patient-reported ratings of headache frequency, duration, and intensity were obtained during the evaluation with the psychologist. Headache frequency was coded from 0 (never) to 7(daily). Headache duration was coded from 0(none) to 8(constant). Headache intensity was coded from 0(no pain) to 10 (worst pain experienced).	Adolescents with CTTH reported greater depression symptoms, and their parents endorsed greater school difficulties, whereas parents of adolescents with migraine reported more protective parenting. Protective parenting was positively associated with school difficulties in both groups, but the relation was significantly stronger in adolescents with CTTH. In the TTH group, there was a significant covariance between headache severity and protective parenting ($p < .05$). The relation between protective parenting and school difficulties was significant in both groups; however,

		behaviour and school functioning.		functioning scale assess difficulty paying attention in class, forgetting things, keeping up with school, missing school because of not feeling well, and missing school because of medical appointments and hospitalizations. Responses are rated on a 5-point scale ranging from 0 (never) to 4 (almost always). A total score is computed by calculating the mean rating. Higher scores indicate greater difficulty with school functioning. (Reliability in this study was 87).		Revised Children's Manifest Anxiety Scale: The Revised Children's Manifest Anxiety Scale (RCMAS)(Reynolds & Richmond, 1978; Reynolds & Bigler 1997) is a 37-item yes/no self-report questionnaire that assesses symptoms of anxiety. Total anxiety scores are calculated by summing all items to which the child responds ''yes'' with the exception of the seven lie scale items. Total raw scores range from 0 to 28, with higher scores indicating higher levels of anxiety. The RCMAS is a well-validated and reliable measure of anxiety for children aged 7–17years.	it was significantly stronger in patients with TTH (r=46, *p* < .001) than in patients with migraine (r=17, *p* < .05) There was not a significant interaction between depression symptoms and protective parenting in predicting school difficulties for either group, suggesting depression symptoms and protective parenting are linked to school difficulties independently. Headache duration and depression symptoms were significant predictors of school functioning in both groups. There was a significant difference in school functioning (t(283)= 2.37, *p* < .05; d=28) with adolescents with TTH reporting

						The Children's Depression Inventory: Contains 27 self-report items that assess depressive symptoms (Kovacs,1981, 1992). Items are rated on a 3-point scale and summed to obtain a total score. Total raw scores range from 0 to 54, with higher scores indicating higher levels of depressive symptoms. The Children's Depression Inventory has been found to have adequate reliability and validity for children aged 7–17 years. Pain Response Inventory: (Walker, Smith, Garber, &Van Slyke, 1997) A child-report measure of pain	more difficulties in school functioning than adolescents with migraine.

						coping strategies that comprises three higher-order composite scales: passive coping (15 items), active coping (16items), and accommodative coping (16 items). Only the passive coping subscale was used for this study. Passive coping strategies include self-isolation, activity restriction, and catastrophizing. Children report the frequency with which they use different coping strategies on a 5-pointscale ranging from 0 (never)to4(always). A total score is computed by taking the average of the item scores, and higher scores indicate higher levels of passive coping.	

						The Pain Response Inventory has demonstrated adequate validity and reliability. Adult Responses to Children's Symptoms: (ARCS) (VanSlyke & Walker, 2006) is a parent-report measure that includes three subscales assessing parents' responses to their children's pain: parental protectiveness, minimization of pain, and encouraging and monitoring responses. Only the protect scale was used in this study. Items on the protect scale include giving the child special attention and limiting the child's normal activities.	

						Responses are rated on a 5-point scale ranging from 0 (never)to 4 (always). A total score is computed by taking the average of the item scores, and higher scores indicated greater levels of protective parenting. The ARCS has been developed and validated in parents of children aged 8–18 years.	
Kashikar-Zuck & Johnston et al (2010)	USA	Design: Descriptive Aim: To describe school absences in adolescents with Juvenile Primary Fibromyalgia Syndrome (JPFS) and examine the relationship between school absenteeism, pain, psychiatric symptoms, and	Adolescents with JPFS (N=102; mean age 14.96 years) Patients were eligible if they met Yunus and Masi criteria (Yunus & Masi, 1985) for juvenile fibromyalgia and had no other rheumatic disease.	School Attendance and Type of Schooling: School attendance data were obtained by parent report and directly from school records. All school absences were counted (including days missed for doctor's visits or	Self-report and parent proxy report.	Demographic Information: Parents completed a demographic information form. Items on the form included: child's gender, age, race/ethnicity, current grade in school, parents' education levels, and socioeconomic status including annual household income and	Over 12% of adolescents with JPFS were home schooled. Those enrolled in regular school missed 2.9 days per month on average, with one-third of participants missing more than 3 days per month. School absences per month (days missed): School report: Regular school: mean= 2.88

		maternal pain history. Method: Adolescents with JPFS (N=102; mean age 14.96 years) completed measures of pain and depressive symptoms, and completed a psychiatric interview. Parents provided information about the adolescents' school absences, type of schooling, and parental pain history. School attendance reports were obtained directly from schools.		for reasons unrelated to JPFS symptoms). Late starts were not included unless they were denoted as a ''half-day absence'' on school reports. Average number of school days missed per month was calculated by dividing the total number of days missed since the first day of school by the number of months the child had been in school for the academic year. School attendance records were obtained directly from the school. Parents reported on the type of schooling: regular school or home schooled (defined as full-time home schooling,		parents' occupations. An index of socioeconomic status based upon occupational prestige was calculated for mothers and fathers. Pain Intensity: Daily pain diaries. Diaries consisted of a 10-cm visual analog scale (VAS) anchored on the ends by ''no pain'' and ''worst possible pain.'' VAS scales have been validated for use in school age children. Average pain intensity score based upon one week of daily diaries was calculated. Depressive Symptoms: Children's Depression Inventory (CDI):	Home schooled: No data Parent report: Regular school: mean= 2.90 Home schooled: mean= 2.52 Pain and maternal pain history were not related to school absenteeism. However, depressive symptoms were significantly associated with school absences (t=2.11;*p* = 03).

				home-bound, or internet-based home program) and reason for home schooling.		A 24-item index of depressive symptoms that has been validated for use in children ages7–17 years (Kovacs, 1992). Respondents select one of three statements for each item. A total raw score and age- and gender-normed T-scores can be calculated. Psychiatric Diagnoses: The Kiddie schedule for affective disorders and schizophrenia (K-SADS-PL) (Chambers et al., 1985; Kaufman et al.,1997) A semi-structured psychiatric interview, was used to determine diagnoses according to the Diagnostic and Statistical	

						Manual of Mental Disorders – Fourth Edition(DSM-IV). Assessment of DSM-IV psychiatric disorders: adolescents were categorized into whether or not they had a current anxiety disorder (panic disorder, agoraphobia, specific phobia, social phobia, obsessive–compulsive disorder, post-traumatic stress disorder, generalized anxiety disorder, or separation anxiety disorder), a depressive disorder (major depressive disorder, dysthymic disorder, depressive disorder NOS), or an attentional disorder [attention deficit hyperactive disorder (ADHD) inattentive type, ADHD hyperactive type,	

						ADHD combined type, or ADHD NOS] Maternal Pain History: The parent pain history questionnaire was used to obtain maternal pain history. The measure contains a list of pain conditions on which the respondent indicates whether or not they suffered from each type of pain and whether or not they received treatment for that condition. Total number of pain conditions was calculated.	
Kashikar-Zuck & Zafar et al (2007)	USA	Design: Case-control Aim: To assess peer relationships of adolescents with juvenile primary fibromyalgia syndrome (JPFS)	55 adolescents with JPFS (ages 12–18 years) from a paediatric outpatient rheumatology clinic	Social reputation: Revised Class Play (RCP) A 30-item measure to measure 4 dimensions of social reputation. Popularity/leadership, prosocial	Self-report (peer and teacher report)	No additional measures	Adolescents with JPFS were perceived (by peer and self-reports) as being more isolated and withdrawn and less popular.

		compared with matched classroom comparison peers (MCCPs) without a chronic illness. Method: Participants were 55 adolescents with JPFS (ages 12–18 years) from a paediatric outpatient rheumatology clinic and 55 MCCPs. Data on peer reputation and peer acceptance were collected from teachers, peers, and self-report in a classroom setting with no focus on JPFS.	55 matched classroom comparison peers (MCCPs) selected from the classroom of each target adolescent with JPFS.	aggressive/ disruptive and sensitive/isolated. Ratings were obtained from teachers and peers, and self-ratings were obtained from the adolescents. Participants were instructed to imagine that they were “casting” members of the class into a variety of roles. Each participant was provided a list of children in the class who were the same sex as the adolescent with JPFS. Participants were asked to nominate 1 adolescent from the list for each role. Adolescents also rated the roles that they thought would be			Adolescents with JPFS were less well liked, were selected less often as a best friend, and had fewer reciprocated friendships. Teachers tended to nominate adolescents with JPFS for the sensitive/isolated dimension more frequently, but the difference did not reach statistical significance. Unlike peer and self-ratings, teachers did not nominate adolescents with JPFS less frequently on popularity/leadership. Adolescents with JPFS were seen by teachers as significantly less aggressive/disruptive than MCCPs. Adolescents with JPFS were significantly less well liked (p = 0.026) were

				appropriate for themselves. The RCP has been shown to be both internally consistent and stable and have documented predictive validity. Scoring for the RCP assigns each adolescent an item score based upon the number of times they were nominated for each role. Item scores are summed for each source to create subscale scores on each of the 4 dimensions and 4 non-social attributes. Social acceptance: Three Best Friends. A measure of social acceptance and mutual			selected less often as a best friend (*p* = 0.051) and had fewer reciprocated friendships than MCCPs (*p* = 0.020). The JIA sample showed no differences from MCCPs in social acceptance ratings. Adolescents with JPFS were more likely to be seen as being sick a lot (*p* = .000), less athletically competent (*p* = .000), and less physically attractive (*p* = .003) by their peers. They were not perceived as being different from MCCPs in terms of their academic competence.

				friendships. Adolescents were asked to choose the 3 peers in their class whom they thought of as their best friends. Each adolescent was given 1) a social acceptance score based upon the number of times he or she was chosen as a friend by peers, and 2) a mutual friendship score indicating how many of their friendship selections were reciprocated. Like Rating Scale: Measure of social acceptance providing a measure of overall popularity. It has been shown to be a reliable and stable measure of likeability.			

				Adolescents were asked to rate all of their classmates on a 5-point scale (where 1=someone you do not like and 5=someone you like a lot). An average liking score was computed for each adolescent based on the ratings they received from peers. Non-social attribute: 9 additional roles were added to the end of the RCP relating to non-social attributes that may be affected by chronic illness such as being sick a lot (3 roles), academic competence (2 roles),athletic ability (2 roles),			

				and physical appearance (2 roles). The items were identical in format and scored in the same way as the other items on the RCP.			
Kashikar-Zuck & Zafar et al (2013)	USA	Design: Case control Aim: To compare pain characteristics, quality of life, and emotional functioning among youth with paediatric chronic migraine (CM) and juvenile fibromyalgia (JFM) Method: Combined data obtained during screening of patients for two intervention studies of youth (ages 10-18) with CM (N = 153) and	Youth (ages 10-18) with Chronic migraine CM (N = 153) and juvenile fibromyalgia JFM (N = 151) At least 15 headaches per month were required for a classification of CM and this was confirmed by a prospective 4-week daily headache diary completed by participants. Participants with JFM were diagnosed by a paediatric	Paediatric Quality of Life Inventory (PedsQL) – Generic Core Scales: Each item has four response options - never, sometimes, often, and always. Self-report and parent-proxy versions of the PedsQL™ were administered. Participants were asked to rate their own (or their child's) quality of life in the 4 domains of physical, social, emotional and school	Self-report	Demographic Information: Families completed forms detailing background and demographic information including race, ethnicity, age, gender, and socioeconomic status. Pain Characteristics: Participants with JFM completed daily diaries with 0-10 centimetre daily Visual Analog Scales (VAS) to assess pain intensity over one week, and participants with CM completed daily 0-10 Numeric Pain Rating	Youth with JFM had significantly higher anxiety and depressive symptoms, and lower quality of life in all domains. Among children with CM, overall functioning was higher but school functioning was a specific area of concern When the individual dependent measures were considered separately, children and adolescents with CM evidenced significantly higher functioning across all domains of the PedsQL (emotional,

		JFM (N = 151). Measures of pain intensity, quality of life (Pediatric Quality of Life; PedsQL™, child and parent-proxy), depressive symptoms (Children's Depression Inventory; CDI), and anxiety symptoms (Adolescent Symptom Inventory-4 - Anxiety subscale) were completed by youth and their parent. A multivariate analysis of co-variance (MANCOVA) controlling for effects of age and gender was performed to examine differences in quality of life and emotional functioning	rheumatologist based on the 1985 Yunus and Masi criteria for JFM classification (generalized musculoskeletal pain in at least 3 sites for at least 3 months; 5 or more painful tender points upon palpation; associated symptoms such as sleep disturbance, fatigue, headaches, irritable bowel syndrome)	functioning over the last month. The PedsQL™ is reverse-scored with scores ranging from 0-100, with higher scores indicative of better functioning. Scores on the PedsQL™ scales range from about78-91 (for child and parent-proxy report) among healthy children.		Scales for four weeks (28 days). Average pain intensity was defined as average pain over seven days (for the CM group, this was the average pain intensity of headaches they experienced in the last 7 days of their 4–week diary). The VAS and numeric pain ratings are reliable, valid instruments used to measure pain in both adult and paediatric populations. For patients with CM, headache frequency and average duration of pain was also calculated from diaries. Children's Depression Inventory (CDI): A 27-item self-report	social, physical, and school). Mean quality of life scores of both JFM and CM groups were lower than those reported for healthy children. The MANCOVA showed significant differences between the two groups on the combined dependent variables, F (11, 284) =19.56, $p < 0.001$ after controlling for age and gender effects.

		between the CM and JFM groups.				measure that assesses cognitive, behavioural, and affective symptoms of depression in children and adolescents. Each question has three response choices related to the individual's feelings during the past two weeks. Total scores range from 0-54 and normative scores based on age and gender are available. CDI total raw scores > 10 indicate at least mild depression. Adolescent Symptom Inventory-4 (ASI-4) – Generalized Anxiety Sub-scale: Used to measure caregiver ratings of a child's emotional functioning. Consists of eight questions which ask parents to rate how	

						often their child displays a symptom (never, sometimes, often, or always). Items are then scored either 0 or 1 (0-never and sometimes; 1-often and always) to get a symptom criterion score. Scores of greater than or equal to five on the Generalized Anxiety Sub-scale of the ASI is an indication that the participant exhibits significant symptoms consistent with Generalized Anxiety	
Kernick, Reinhold & Campbell (2009)	UK	Design: Descriptive Aim: To quantify the impact of headache in a school population. Method: 1037 school children were surveyed. Main outcome measures were	1037 school children aged between 12-15. The average age was 13.5 years. 49% were female	Paediatric Migraine Disability Assessment Score (Ped MIDAS): A validated instrument measuring the impact of headache-related quality of life in terms of days in the previous 3	Self-report	No additional measures	10% of the population had a PedMIDAS score of 16.8 and a PedsQL4 generic quality of life score of 70.1, indicating a poorer quality of life than that of children with asthma, diabetes, or cancer. For the 31% of participants that had

		headache frequency, disease specific impact, and quality of life impact.		month period where headache has had a total or partial impact on school or home life. Pediatric Quality of Life Inventory (PedsQL4): The 23-item Core Scales encompass; (1) Physical Functioning (8 items), (2) Emotional Functioning (5 items), (3) Social Functioning (5 items), and (4) School Functioning (5 items). A 5-point Likert scale is used: (0: never a problem; 1: almost never a problem; 2: sometimes a problem; 3: often a problem;			no headache the PedsQL4 score matched the UK population norm. PedMIDAS increased and PedsQL4 decreased with frequency of headache. An average of 0.6 days of school was lost in a 3-month period across all schoolchildren.

				4: almost always a problem). Items are reverse-scored and linearly transformed to a scale from 0 to 100 points such that higher scores indicate better QOL.			
Khan & Tran et al (2015)	USA	Design: Descriptive Aim: To empirically test a model of associations between constructs predicting school functioning in youth with chronic pain to examine the direct effect of anxiety on school attendance and other indicators of school-related disability Method: Youth, mothers, fathers, and clinicians completed	349 youth and their parents (311 mothers and 162 fathers) who attended a multi-disciplinary pain clinic.	Parent School Functioning Questionnaire: Mothers completed a questionnaire regarding the effect of pain on their child's school attendance and ability to keep up with school-work. Mothers reported the number of school days their child missed in the past 30 days (0 to 30) and a subjective rating score of the extent to which their	Self-report and parent proxy report.	Pain Ratings: Youth provided a rating of their usual pain intensity on a scale of 0 (no pain) to 10 (worst pain), pain frequency (number of days with pain in the past 2 weeks, 0 to 14), and duration of the pain in months. SCARED: completed by youth and parents. A commonly used and well-established 41-item child-reported and parent-reported measure of child anxiety. It has been validated for	Anxiety was directly related to problems with school attendance and avoidance, concentration, and keeping up with schoolwork. Mothers reported children missing 7.88 days of school over the last 30 days, and that pain moderately affected children's attendance and ability to keep up with schoolwork. According to clinician report, 24% of youth demonstrated symptoms of SA,

		assessments of clinical outcomes important to family and clinician perceptions of school functioning; youth, mothers, and fathers completed an assessment of youth anxiety. Structural equation modelling was used to examine interrelations among predictors.		child’s pain affected his or her attendance at school on a scale of 0 (unable to attend) to 10 (attends daily). Mothers also reported the extent to which their child was able to keep up with missed schoolwork over the past 30 days on a scale of 0 (behind in work) to 10 (completely caught up) Past research has demonstrated that parent, youth, and school reports of school absence are fairly consistent and should be considered valid. Clinician-rated School Avoidance:		use with a wide age range of ages and includes 4 sub-scales that map directly onto DSM-IV-TR anxiety disorder criteria, and 1 subscale pertaining to anxiety in the context of school. The SCARED yields a total anxiety score and several subscales: panic or somatic symptoms, generalized anxiety, separation anxiety, social anxiety, and school phobia. The total score ranges from 0 to 82 with a clinical cut off score of 25	59% were rated as not school avoidant, and ratings were missing for approximately 18% of youth. For all significant relationships, increased anxiety was related to poorer school functioning. T tests were conducted to examine the relationships between anxiety and the clinician rating of SA. The youth classified as school avoidant had higher anxiety as reported by the child, mother, and father compared with those who were not school avoidant (M=22.57, SD = 14.95 and M= 18.23, SD = 12.61,t284= 2.50, $p < 0.05$; M= 20.95, SD = 14.30 and M= 13.21, SD = 11.18,t255= 4.62, $p < 0.001$; and M= 18.13, SD = 12.22 and M= 12.28, SD = 10.09,t131=

				At the end of each intake appointment, mental health providers at the pain clinic reported whether the child demonstrated SA based on their global clinical impression of the criteria outlined by Khan and Ladwig: (1) high rates of absenteeism; (2)unexpected treatment responses (including shifting symptoms, multi-"failed" medical interventions, and medical work-ups); (3) escalating symptom severity; (4) escalating functional disability; and (5) dramatic presentation (eg,			2.69,$p < 0.01$, respectively). Results support the hypothesis that anxiety has a stronger relationship with school functioning relative to pain severity among youth with chronic pain.

				cry, scream, or refuse to get out of bed or leave the house). Children were classified as “school avoidant” if any 4 of these 5 criteria were present. PedsQL School Functioning subscale: A 23-itemmeasure which has been validated for use with children ages 8 to 18 in both community and paediatric settings. (For this study, the 5-item school functioning subscale was used) PedsQL total scores have demonstrated good internal			

				consistency. The 4 subscales (physical, emotional, social, and school) have also evidenced good reliability and validity. Higher scores indicate better functioning.			
Konkol & Lineberry et al (1989)	USA	Design: Qualitative Aim: To undertake an educational needs assessment of 50 children with juvenile arthritis (JA) and their families. Method: Through utilization of a grounded theory methodology, open-ended questionnaires were completed by	50 children with JA and their families. Polyarticular arthritis= 21 (Median age 12) Pauciarticular arthritis= 12 (Median age 6) Systemic Rheumatic disease= 9 (Median age 6) Other=8 (Median age 14)	Separate questionnaires for JA children, parents, and siblings were used. Each contained seven open-ended questions, which covered: (1) perceptions about JA, (2) knowledge about JA, (3) perceived impact of JA on social functioning (family and	Self-report	No additional measures	Percentage response to the question "Has arthritis caused your child/ you any problems at school?" Physical limitations: Parent (69) Child (64) Psychosocial difficulties: Parent (37) Child (67) Absence: Parent (21) Child (5) None: Parent (21) Child (12) JA children themes: Not being able to play

		JA children, their parents, and their siblings.		school), (4) future concerns about the child with JA, (5) identification of factors most helpful in understanding and adapting to arthritis in the family, and (6) personal advice that may help other families deal with arthritis.			and run. I had to crawl. Falling down and hurting myself. Kids laughing at me. Being called names. Special classes. Heavy books. Sitting too long. Getting out of the little desks. Parent themes: Child afraid of attending extracurricular activities. Cruelty of peers. Ignorance of teachers concerning disease. With regard to school functioning: Parents were primarily concerned about physical limitations (69%), while JA children were equally concerned about psychosocial difficulties (peer reaction/acceptance) (67%) and physical limitations (64%). Most parents and children reported at least one problem at

							school because of arthritis.
Kuburovic, Pasic et al., (2014)	Serbia	Design: Cross sectional. Aim: Evaluate levels of health-related quality of life (HRQOL) and anxiety and depressive symptoms in children with primary immunodeficiency disease (PID). Method: Self and parent rated data from 25 children with PID were available. Data from 50 children with juvenile idiopathic arthritis (JIA) and 89 healthy children were included as controls.	50 children with JIA (control group) aged < 18. Mean age= 11.4 (4.3). 89 healthy children (control group) aged <18. Mean age= 12.4 (4.2). 25 children with PID aged <18. Mean age=11.3 (4.2).	HRQOL: The Paediatric Quality of Life Inventory (Varni, Seid & Kurtin, 2001) Self-rated and proxy-rated questionnaire including 23 item scales: physical functioning (eight items), emotional functioning (five items), social functioning (five items), and school functioning (five items). All items are a 5-point response-scale format (0 = never a problem, 1= almost never a problem, 2 = sometimes a problem, 3 = often a problem,	Self and proxy parent rated data.	Anxiety symptoms: Screen for Child Anxiety-Related Emotional Disorders questionnaire (Birmaher, Brent et al., 1999) Self-rated and proxy-rated 41-item questionnaire. Items are scored on a 3-point scale (0 = not true or hardly ever true, 1 = somewhat true or sometimes true, 2 = very true or often true). The sum of all answered items gives the total SCARED score (0–82). Higher SCARED score equals higher levels of anxiety symptoms.	School functioning was significantly lower among children with PID (parent-rated only) compared to children with JIA. Proxy report school functioning: PID= 61.0 (27.3) JIA= 84.2 (15.3) Healthy controls= 83.7 (15.8) p = <0.001. Self-report school functioning: PID= 72.4 (23.4) JIA= 84.7 (14.9) Healthy children= 82.3 (16.0) p = 0.07. Not significant. No other significant school functioning differences.

		The Paediatric Quality of Life Inventory was used for HRQOL assessments. Anxiety symptoms were identified using the Screen for Child Anxiety-Related Emotional Disorders questionnaire, while depressive symptoms were identified using the Mood and Feeling Questionnaire.		4= almost always a problem). Scoring: Items are reverse scored and linearly transformed to a 0–100 scale. Higher scores indicate better HRQOL.		Depressive Symptoms: Mood and Feeling Questionnaire (Wood, Kroll, Moore & Harrington,1995). Self-rated and proxy-rated questionnaire. The self-rated version has 33 items, and the proxy-rated version 34 items. Scored on a 3-point scale (0 = not true, 1 = sometimes, 2 = true) Higher total MFQ score equals higher levels of depression.	
Larsson, Melin, Lamminen & Ullstedt (1987)	Sweden	Design: Repeated measures Aim: To examine whether a self-help relaxation training (SHR) approach dealing with headache per se would more effectively reduce	34 students 16-18 years of age, recruited from three Swedish high schools. SHR: 12 PDC: 10 SM: 12	Satisfaction with school work and social relationships, self-confidence, and assertiveness: The Social Relationship-Competence Questionnaire	Self-report	Headache Diagnosis: Based on criteria suggested by Vahlqvist (1955). Information obtained from a standardised Swedish headache questionnaire (Ekbom, 1976) completed with a medical-neurological	Due to a low medication school absence report (four subjects reported sporadic nonattendance) prior to treatment and minor changes post treatment, no statistical analysis was performed.

		headache than a problem-discussion condition (PDC), focusing on common psychological stressors or headache elicitors. Method: 3(Group) x 3 (Phase) repeated measures design. The three experimental groups were SHR, PDC, and self-monitoring SM, and the three phases were baseline (4 weeks), post-treatment, and 5-month follow-up.	Tension Headache: SHR: 11 PDC: 8 SM: 10 Mixed Headache: SHR:1 PDC: 2 SM: 2 Headache duration (years): 1-2 (SHR n=3 PDC n=6 SM n=3) >2-5 (SHR n=4 PDC n=4 SM n= 6) >5 (SHR n=3 PDC n= 2 SM n=3)	(SRCQ) comprising 53 items scored on a 0-8 scale, was developed particularly for the purpose of the study. School absences were recorded in daily diaries as the number of hours absent per week.		examination constituted the basis for final headache diagnosis. Psychological Assessment: Students took several psychological tests aimed at assessing their degrees of anxiety-depression (a Swedish translation of Children's Manifest Anxiety Scale (Reynolds & Richmond, 1978), and a slightly modified Depression Scale for Female Adolescents (Achenbach & Edelbrock, 1983). The two scales yielded a total score based on 35 items rated on a 1-4 scale. In addition, students' experience of stress (11 items rated on a 1-4 scale), the number of psychosomatic	Social Relationships (SRCQ): pre-post treatment scores revealed no significant difference between groups on this measure.

						symptoms endorsed (21 items rated on both frequency and intensity of complaints) were assessed. Headache Diary: Daily headache recordings, performed during a 4-week period. Participants rated their headache activity at a fixed schedule four times a day, using a 6-point scale ranging from 0 = no headache to 5 = intense, incapacitating headache. Total measure of headache activity was calculated by summing the values of the 28 weekly ratings. Headache frequency: The number of discrete headaches per week.	

						Scored as one headache period if there was a rating of zero before and after each headache for that day. Headache-free days= number of days when no headache at all was scored. Headache duration: average length of discrete headaches per week. Peak headache intensity: The highest single headache rating per week. Medication consumption: recorded as the number of tablets per week. Treatment Credibility: At the end of the first session in both PD and SHR groups, the students rated their expectancies for	

						treatment improvement on a 10-point scale (1 = no confidence and 10 = very high confidence). Students' Satisfaction: The students' satisfaction with the two active treatment approaches was measured at the final session on a 5-point scale (1 = treatment didn't help at all; 5 = helped very much). Headache Annoyance: The subjects rated their degree of annoyance due to headache activity on a visual analog scale. Social Validation: 1 month after treatment, a significant other person was asked to rate on a visual analog scale a noticeable change in	

						the student's headache activity, coinciding with the student's headache recordings post treatment.	
Logan & Curran (2004)	USA	Design: Qualitative (focus group) Aim: To systematically analyse school personnel's understanding of adolescent chronic pain problems and to learn how healthcare and school systems can collaborate more effectively to address these problems. Method: Focus groups were conducted in middle- and high-school settings. Five groups, comprised of 38 schoolteachers,	Not a paediatric sample: Five groups, comprised of 38 schoolteachers, administrators, school nurses, and guidance/mental health staff.	Key questions delivered in the focus group included: (1) What do you know about chronic pain problems in teenagers? (2) Is there a "typical" student who develops chronic pain? Do these students tend to have other difficulties? (3) What are the biggest frustrations or challenges that you face when working with a student with chronic pain?	Self-report (focus group)	No additional measures	Focus group members cited many challenges related to working with adolescents with pain in school (high absence rates, wide individual variation in presentation of symptoms and impairment, the need to balance accommodations with school policies, attending to the needs of other students, and dealing with parents). The groups identified needs for more information about chronic pain problems and more guidance from healthcare professionals regarding how to

		administrators, school nurses, and guidance/mental health staff participated.		(4) Do pain behaviours tend to arise in certain contexts? (5)What is your usual approach to dealing with pain problems in school? What strategies have you used successfully or unsuccessfully? (6) What challenges have you encountered in working with medical teams around students' chronic pain problems? (7) What do you see as your role in helping a student cope with a chronic pain problem in school? What is the parents' role? What is the role of the medical team?			manage pain symptoms and pain-related behaviours in the school setting. Theme 1: Aspects of chronic pain disorders that make these problems difficult for teachers to understand and manage in school. -Teachers observed that many students with chronic pain were good students who worked hard in school - Group participants commented on social issues among students who developed pain problems. "The[se]kids are somewhat socially not in the centre of things—not ostracized, just not quite in the mix." - Participants repeatedly emphasized the wide variability in how families respond to pain and suggested

							that this variability in coping affects the degree of functional disability that accompanies pain - Participants viewed the context in which pain occurs as a strong influence on pain behaviours. Contextual aspects of the school setting included attention ("Every time there was an audience, the pain behaviours increased"); motivation to participate in a task ("She said she needed her crutches but if there was something she really wanted to do, she'd set them down and run down the hallway"); avoidance of classroom activities ("It's more than coincidental that she is always having stomach problems the day before or the day of a test "); and potential social gain

							(“The tears would come whenever her friends were there”). Such patterns of increased pain behaviours in particular contexts de-legitimized pain as a medical problem. Theme 2: Challenges to successful management of chronic pain in school include high absenteeism, the rarity and individual variability of pain, need to adhere to school policies, responding to needs of other students, and dealing with parents. - The importance of missed academic content and the frustration this caused for teachers “Work can be made up, sure, but when you don’t understand what’s going on . . .”

							-Student anxiety stemming from missed class time “They’re very bright and they come back to school after being out and they have no clue what’s going on, so that adds to the stress and frustration and the feeling that they are never going to climb out of that hole . . .” -Participants expressed frustration related to seeing teens functioning in other realms of their lives but unable to attend school. -Participants gave examples of schools working out plans for students with pain to reintegrate gradually back to a full schedule, but there was general consensus that students and their families must be motivated to return to school in order for such plans to succeed.

							- As school personnel struggled to understand and manage pain problems, they experienced confusion, concern, and isolation. “We don’t know what it is and we’re scared from a safety standpoint” and “It’s difficult in a regular classroom dealing with some of these problems on your own.” They expressed uncertainty about how to respond appropriately to pain behaviours. “How far should we push?” - School staff: “You want to accommodate, but you have to uphold certain standards,” “We want to be flexible but we need deadlines.” “They [public schools] have more money, there are more services that

							they can offer. I believe we [parochial schools] are more flexible.” Another added, “Every year we have kids who need special supports, and we are short on the resources we can offer them here.” -Participants expressed concerns about the effects of a student with chronic pain on classmates. And having to respond to perceived injustices, e.g., “Other kids ask us, ‘Why can she do that and I can’t?’” - Participants acknowledged that their views of appropriate accommodations differed at times from the parents of students with pain, leading to frustration.

							Theme 3: Almost every participant felt under-informed about the specifics of some of the pain problems they have seen in students. The school nurses in the groups reported slightly more familiarity with pain issues, but also expressed needs for more information. - School personnel want to be provided with definitions and descriptions of chronic pain disorders and knowledge of what to expect - Increased communication would help school personnel feel more qualified to manage pain in school - Specific guidance and directives from the medical team are crucial - Greater involvement by the healthcare team could foster a

							general collaborative approach.
Logan, Gray, Iversen & Kim (2017)	USA	Design: Case-control Aim: To investigate school self-efficacy and sense of school membership (collectively "school self-concept") as potential influences on impaired school function among adolescents with chronic pain, including comparison of adolescents with primary pain to those with disease-based pain and pain-free peers. Method: 264 adolescents (12–17 years old) with primary pain conditions, juvenile idiopathic arthritis, or no pain completed	264 adolescents (12–17 years old) with primary pain conditions, juvenile idiopathic arthritis, or no pain. Adolescents presenting to a tertiary care multidisciplinary chronic pain clinic with : Complex primary pain disorders (n=129) Adolescents with established diagnosis of JIA seen in a hospital-based Rheumatology clinic (n= 60). Adolescents with no chronic medical issues recruited from	Self-Report of School Functioning: The Pediatric Quality of Life inventory (Peds-QL;Varni, Seid, & Rode, 1999) School functioning sub-scale: A five-item rating scale assessing subjective impressions of school attendance and performance. ThePeds-QL is a well-validated instrument for use with children and adolescents with a variety of chronic medical conditions. Internal consistency for the measure within this sample was found to be good; alpha= .80	Self-report and parent proxy report.	Demographic and Medical Information: Parents of all participants provided basic demographic information including adolescent age, gender and ethnicity, and parent education levels. Parents also reported time since pain onset. Adolescents in the primary pain and JIA groups rated typical and worst pain intensity on a 0–10 numeric rating scale (NRS)where 0=no pain and 10= worst pain possible. Pain frequency was indicated on a multiple-choice item with options ranging from "daily" or "almost daily" to "never." Adolescents also estimated the	Adolescents with primary pain conditions reported poorer school self-concept. School self-efficacy, but not school belongingness or predicted school functioning later in the school year. School attendance rates: mean days missed in the primary pain group was 11.87 (SD=14.0) over the past 3 months. The JIA group reported a mean of 2.23 (SD=4.52) days missed, and the healthy group reported 0.53 (SD=1.13) days missed in the past 3 months. The primary pain group reported significantly higher school absence compared with either of the other

		measures of functional disability, school functioning, pain characteristics, and school self-concept, the Self-Efficacy Questionnaire for School Situations (SEQ-SS), and Psychological Sense of School Membership(PSSM).	the community (n= 74)	Self-Report of Social Functioning: The Peds-QL social functioning subscale: A five-item rating scale assessing social functioning. Internal consistency for the measure within this sample was found to be acceptable; alpha= .71 School Self-Concept: The Self-Efficacy Questionnaire for School Situations. (Heyne, 2006; Heyne et al.,1998) Contains 25 items rated on a 5-point response scale. Comprises four subscales:		frequency of visits to the school nurse's office in the previous month. Diagnosis for the presenting problem and location of pain were extracted from medical records. Pain Self-Efficacy: The Child Pain Self-Efficacy Scale (Bursch, Tsao ,Meldrum, & Zeltzer, 2006) A seven-item measure assessing youth's self-efficacy for functioning normally when in pain. Items include "How sure are you that you can take care of yourself when you have pain?" and "How sure are you that you can do well in school when you have pain?"	groups (F(df=2, 245)=35.61, *p* < .001). There was a significant between-groups difference on both the Self-Efficacy Questionnaire for School Situations and the Psychological sense of school membership: (SEQ-SS,F(2,244)= 11.45, *p* < .001; for PSSM, F(2, 244)= 8.88, *p* < .001). The primary pain group scored significantly lower on both the SEQ-SS (Tukey Honest Significant Difference(HSD)= 8.59, *p* < .001; effect size= 0.61) and the PSSM (Tukey HSD= 3.05, *p* <.05; effect size= 0.42) compared with the JIA group. Differences between the primary pain

				dealing with special school situations, dealing with normal school situations, dealing with authority/not liking school, and dealing with uncertainty (in yourself or with others without parents). The measure has been shown to be reliable and valid in a normative sample of youth aged 10–18 years. The Psychological Sense of School Membership Questionnaire. The PSSM (Goodenow, 1993): The 18-item questionnaire uses a 5-point response scale and has		Items are scored on a 5-point Likert scale, with lower scores indicating higher self-efficacy. Internal consistency for the measure within this sample was found to be excellent; alpha=.92 Pain Self-Efficacy, Parent Report: Seven-item pain self-efficacy measure (parent report version). Global Functional Disability: The Functional Disability Inventory (Walker &Greene, 1991) A self-report measure of perceived difficulty in performing activities in school, home, physical, and social contexts. Has been validated for ages 8–17 years.	group and healthy comparison group were also significant for both the SEQ-SS (Tukey HSD= 9.55, *p* < .001; effect size= 0.75) and PSSM (Tukey HSD= 4.17,*p* < .01; effect size= 0.49). There were no statistically significant differences between the JIA and healthy comparison groups.

				demonstrated reliability and validity. School Attendance: Parents reported the number of days that the participant missed school in the previous 3 months. Days the participant arrived at school late or left early owing to pain= 0.5 of a missed day.		Cronbach's alpha for this sample was .94. Pain Catastrophizing: The Pain Catastrophizing Scale for Children (Vervoort, Goubert, Eccleston, Bijttebier, & Crombez,2006) A validated 13-item self-report measure of negative thoughts and behaviours related to pain. Higher scores indicate more catastrophizing. Cronbach's alpha for this sample was .85.	
Logan & Simons (2010)	USA	Design: Descriptive Aim: To establish feasibility and preliminary efficacy of ''Coping with Pain in School'' (CPS), an intervention to improve school functioning in	40 adolescents aged 12–17 years who presented for evaluation at an outpatient paediatric chronic pain clinic. Mean age= 14.7 years.	School Attendance: Information on full days absent, late arrivals, and early dismissals was collected. Academic Performance: Parent reports of adolescents'	Self-report and parent/teacher proxy report.	Pain: A 10-cmvisual analogue scale (VAS) rating of ''worst pain'' over the previous week was obtained at baseline and again at post-treatment follow-up. VAS pain ratings have been shown to	School attendance improved after treatment. Participants were missing an average of almost 8 school days per month (i.e., out of 20 school days), which significantly decreased to approximately 4 days

		adolescents with chronic pain and depressive symptoms Method: Participants completed measures of pain severity, depression, and school attendance at baseline and one month after participating in a manualized group intervention. Several other indicators of school functioning were explored.	Inclusion criteria were 3-month or greater history of pain complaints; a physician assigned diagnosis of a chronic or recurrent pain syndrome without clear organic etiology (e.g., headache, recurrent abdominal pain, Complex Regional Pain Syndrome); absence of severe cognitive impairment by history; and current enrolment in a structured school setting (i.e., not permanently home schooled, but students receiving temporary home-bound instruction were eligible)	average grades in the year prior to onset of the pain problem and average current grades (in 9-point multiple choice format from ‘‘Mostly A’s’’ to ‘‘Mostly F’s’’) Perceived Pain Interference: Two single item ratings completed by adolescents and parents: The first worded, ‘‘How much has pain interfered with your [your child’s] attendance at school?’’ and the second, ‘‘How much has pain interfered with your [your child’s] performance at school?’’ Responses were recorded in 10 cm visual analogue format with 0=		be a reliable and valid measure of pain severity in adolescents Adolescents also completed 3-week pain diaries daily prior to the intervention and again beginning immediately after treatment completion. They rated pain intensity four times daily using a 5-point numeric rating from 0‘‘no pain’’ to 4‘‘very severe pain.’’ These ratings were averaged to develop a pain index representing both frequency and intensity of pain. Depressive symptoms: The Children’s Depression Inventory (CDI; Kovacs, 1985)	per month after treatment *p* = .001

				‘‘did not interfere at all’’ to 10= ‘‘interfered extremely.’’ The two items were averaged to form one score representing the extent to which pain interferes with school functioning. Higher score= higher interference. Self-perceived Academic Competence: 6-item ‘‘Scholastic’’ subscale from the Harter Self-Perception Profile for Adolescents (SPPA; Harter,1988). Higher scores indicate higher self-perceived competence.		A 27-item self-report measure of current depressive symptoms. Items are rated on a 3-point scale from 0–2 and summed to obtain a total score and five subscale scores: Negative Mood, Interpersonal Problems, Ineffectiveness, Anhedonia, and Negative Self Esteem. Higher scores indicate higher depressive symptoms. The CDI has adequate reliability and validity (Kovacs, 1985). Cronbach’s alpha for this sample was excellent (0.96). Acceptability and Satisfaction with Intervention: Adolescents and parents responded to	

				Cronbach’s alpha scores for the current sample were .80. Teacher Perceptions of Academic Competence: The Walker-McConnell Scales of Social Competence and School Adjustment, Adolescent Version (WMS; Walker & McConnell, 1995). A 53-item scale assessing teacher perceptions of the student’s academic and social skills in the classroom setting. The sub-scale score for School Adjustment contains items assessing		multiple choice and open-ended items adapted from the Helpfulness Questionnaire (Beardslee, 1990) Sample items on the adolescent version include, ‘‘I have made changes in how I think and act as a result of this treatment,’’ and ‘‘I would recommend thi streatment to other adolescents with chronic pain.’’ Sample items on the parent version include, ‘‘This treatment was a good way to handle my adolescent’s problem,’’ and ‘‘I would recommend this treatment to parents of other adolescents with chronic pain.’’ Items were rated on a 5-point scale from ‘‘Strongly	

				academic competence (e.g., ‘‘has good work habits’’, ‘‘is personally well organized,’’) Items are answered on a 5-point scale from 1‘‘Never’’ to 5‘‘Frequently,’’ with high scores indicating better adjustment. Cronbach’s alpha for the School Adjustment subscale was .97		Disagree’’ to ‘‘Strongly Agree.’’	
Logan, Simons & Carpino (2011)	USA	Design: Descriptive Aim: To test the hypothesis that parental pain catastrophizing and parental protective responses to child pain influence the extent of school impairment in children with chronic pain.	A clinical sample of 350 children ages 8–17 years with chronic pain and their parents. The mean age of children was 13.7 years.	School functioning: Attendance rates: Number of school days missed in the past 3 months due to pain (including for doctors’ appointments) was obtained by parent report. Reports of days when the	Self-report	Parental pain catastrophizing: The Pain Catastrophizing Scale for Parents (PCS-P) A validated 13-item self-report measure of parents’ negative thinking related to their child’s chronic pain (e.g., ‘‘When my child is in pain, I can’t keep it out of my mind.’’).	Controlling for the known influences of pain intensity and child depressive symptoms, parental pain catastrophizing and parental protective responses to child pain each independently predicted child school attendance rates and reports of overall school impairment.

		Method: Measures of pain characteristics, demographic characteristics, child depressive symptoms, school attendance rates, overall school functioning, parental pain catastrophizing, and parental protective responses to pain were collected and a mediational model was used.		participant arrived to school late or left school early due to pain were incorporated into the count of missed days as half days missed. Raw responses were reduced into a 6-point scale with categories representing 0 days missed, 1–5 days missed, 6–10 days missed, 11–20 days missed, 21–35 days missed, and more than 35 days missed. Global school functioning: The Pediatric Quality of Life Inventory (PedsQL) school functioning subscale. A 5-item measure of school functioning. Items all begin with the		This measure has been shown to be psychometrically sound. Higher scores indicate greater levels of catastrophizing. Parental protective responses to pain: The Adult Responses to Children's Symptoms scale Assesses parents' responses to their children's pain in 3 subscales; parent protectiveness, minimization of pain, and encouraging and monitoring. The 13-item protective responses subscale was used. Responses are rated on a 5-point scale ranging from never (0) to always (4), and subscale scores are computed by	

				stem, ‘‘In the past one month, how much of a problem has your child had with...’’ and response options range from never (0) to always (4).Example items are ‘‘Paying attention in class’’ and ‘‘Keeping up with schoolwork.’’ Raw scores are transformed into standard scores on a scale of 0–100, with higher scores indicating better functioning (less impairment).		calculating the mean rating for items on each subscale. Higher scores indicate higher levels of parent protective responses. The internal consistency for the protectiveness scale in this sample was .74. Pain intensity: Children provided pain intensity ratings for their average or usual pain using a numeric rating scale of 0–10, a reliable and valid method for obtaining children’s self-report of pain in this age group. Time since pain onset: Length of time since the initial onset of the current pain problem was measured in months based on parent report.	

						Child depressive symptoms: The Children’s Depression Inventory (CDI) A well-validated 27-item self-report measure of children’s depressive symptoms.	
Logan, Simons & Kaczynski (2009)	USA	Design: Descriptive Aim: To explore associations between depressive symptoms and school functioning, including school attendance, academic performance, self-perceived academic competence, and teacher-rated school adjustment among adolescent	217 clinically referred adolescents (aged 12–17 years). Mean age= 14.7 years.	School attendance: Attendance records were collected from schools to track school attendance for the month prior to the date on which families completed questionnaires. This information was used to create a variable indicating percentage of days on which the adolescent was absent, arrived	Self-report, parent proxy report	Pain characteristics: Time since pain onset was recorded in months since onset of current pain problem, by parent report. Pain intensity over the past week was measured at a single time point on a standard 11-point numeric rating scale with 0‘‘no pain’’ and 10‘‘worst pain possible.’’ Adolescents provided ratings for both their current and average pain.	Depressive symptoms strongly correlated with school functioning indicators. In linear regression analyses, higher levels of depressive symptoms predicted more school impairment.

		chronic pain patients. Method: 217 clinically referred adolescents (aged 12–17 years) and their parents completed measures of pain characteristics, depression, and school functioning. Additional data were collected from school records and teacher reports.		late, and/or was dismissed early. Perceived effects of pain on school attendance: Measured with a single item worded, ‘‘How much has pain interfered with your attendance at school?’’ Responses were recorded on 10-cm visual analogue scale (VAS) lines where 0= did not interfere at all’’ to 10= ‘‘interfered extremely.’’ Academic performance: Parents reported the average grades their adolescent received in the year prior to onset of the pain problem and grades currently received, using a		Depressive symptoms: The Children’s Depression Inventory (CDI; Kovacs,1985). The CDI contains 27 self-report items rated on a 3-point scale from 0 to 2, summed to obtain a total score. Higher scores indicate higher levels of depressive symptoms. The CDI has been found to have adequate reliability and validity (Kovacs,1985). Alpha reliability in this sample was .85	

				multiple-choice format with options including ‘‘mostly A’s,’’ ‘‘A’s and B’s,’ ’‘‘mostly B’s,’’ ‘‘B’s and C’s,’’ ‘‘mostly C’s,’ ’‘‘C’s and D’s,’’ ‘‘mostly D’s,’’ ‘‘D’s and F’s,’’ and ‘‘mostly F’s.’’ Responses were used to derive an indicator of change in grades since onset of pain based on the extent of decline or improvement. Higher scores indicate larger declines in performance since pain onset). Perceived effects of pain on school performance: The question, ‘‘How much has pain interfered			

				with your performance at school?'' Responses were recorded on a 10-cm VAS with points identical to the item assessing effects of pain on school attendance. Self-perceived academic competence: The six-item Scholastic subscale from the Harter Self-Perception Profile for Adolescents (SPPA; Harter, 1988). Adolescents first determine which of two statements is more like them and then rate how true the statement is (i.e., ''sort of true for me'' vs .''really true for me'').			

				Participants recruited in the final 9 months of the study received the measure in an alternative format. In this format, participants were given the initial statement from each of the items and asked to rate how true that statement is for them (from ‘‘not at all true’’ to ‘‘really true’’). Both formats use a 4-point scale with item scores averaged to yield the subscale score. Higher scores indicate higher self-perceived competence(i.e., less impairment). Cronbach’s alpha scores for the current sample are .79 for the			

				original version and .82 for the revised format version. Teacher perceptions of school adjustment: Walker–McConnell scales of social competence and school adjustment, adolescent version (WMS;Walker & McConnell, 1995). The WMS is a 53-item scale assessing teacher perceptions of how frequently students display various academic and social skills in the classroom setting. It includes the domains of self-			

				control (e.g., ‘‘copes effectively with being upset’’), peer relations (e.g., ‘‘interacts wit ha number of different peers’’), school adjustment,(e.g., ‘‘is personally well organized’’), and empathy(e.g., ‘‘is sensitive to the needs of others’’). Items are answered on a 5-point scale from 1¼‘‘never’’to 5¼‘‘frequently,’’ with higher scores indicating better adjustment. Cronbach’s alpha for the total scale score was = .95			
Logan, Simons, Stein & Chastain (2008)	USA	Design: Descriptive Aim: To assess and describe school functioning among adolescents	Adolescents aged 12 to 17 presenting for evaluation at a tertiary care chronic pain clinic within a	School Attendance: Attendance information for 1 month was obtained through official school	Self-report and parent proxy report	Pain duration: Recorded in months since onset of current pain problem by parent report. Pain intensity for the past week was	Adolescents with chronic pain miss a significant amount of school, experience a decline in grades, and perceive pain to

		presenting for evaluation in a tertiary care paediatric chronic pain clinic Method: Adolescents and their parents participated in the study, providing self-reported data on school attendance, school performance, and perceived academic competence. Participants' schools provided official attendance records, descriptions of accommodations implemented to address the student's pain problems in the school setting, and teacher ratings of academic competence.	large, urban paediatric hospital. Mean age= 14.7	attendance records. In addition, adolescents and parents reported days absent, late arrivals, and early dismissals due to pain over the previous month. For each type of absence parents and adolescents were presented with multiple choice categories including none, 1 to 3 days, 4 to 7 days, 8 to 10 days, 11 to15 days, and 16 to 20 days. Parents and adolescents also provided subjective reports of the perceived effects of pain on school attendance. This was elicited with the question, "How much has pain interfered		recorded through 10-cm visual analog scale (VAS) ratings, ranging from 0=no pain to 10=worst pain possible. Adolescents were asked to mark the point on the line representing their current, worst, and usual pain ratings. The VAS has been shown to be a valid and reliable measure of pain intensity among children over 5 years of age.	interfere with their school success. Various indicators of school impairment are highly intercorrelated ,suggesting that impairment or success in 1 domain is typically associated with similar patterns in other domains of school functioning. Adolescents with pain are viewed by themselves and their teachers as academically competent.

				with your/your child’s attendance at school?” Responses were recorded on a 10-cm VAS with “Pain has not interfered at all” to “Pain has interfered extremely.” Academic Performance: Parents reported adolescents’ average grades before the onset of their pain problem and their current average grades in multiple choice format (“mostly A’s, “A’s and B’s,” “mostly B’s,” “B’s and C’s,” “mostly C’s,” “C’s and D’s,” “mostly D’s,” “D’s and F’s,” “mostly F’s”).			

				Parents and adolescents also provided subjective reports of the effects of pain on academic performance by responding to the question, “How much has pain interfered with your/your child’s performance (e.g., grades) at school?” Responses were recorded on a 10-cm VAS with the same points as the attendance-interference item. Self-Perceived Academic Competence: Adolescents rated their own perceptions of their academic competence on the Scholastic subscale of the Harter Self-Perception Profile			

				for Adolescents (SPPA). TheSPPA is a 45-item measure of adolescents' perceptions of competence in 9 areas. Adolescents first determine which of 2 statements is more like them (e.g., "Some teenagers find it hard to make friends, but for other teenagers it's pretty easy") and then rate how true that statement is for them (eg, "Sort of true for me" vs "Really true for me"). Participants recruited in the final 9 months of the study (n=84) received the measure in an alternative format, participants are			

				given the initial statement and then rate how true that statement is for them (eg,“Not at all true” to “Really true”). Across formats, the items are rated on a 4-point scale (1– 4) and averaged to yield the subscale score. Teacher Perceptions of Academic Competence: The Walker-McConnell Scale of Social Competence and School Adjustment (WMS) Assesses teachers’ perceptions of how frequently students display various academic and social skills			

				in the classroom setting. The “School Adjustment” subscale measures behavioural competencies with items such as “is well organized,” “has good work habits,” and “listens while others are speaking.” WMS raw subscale scores correspond to standardized scores. For the current sample, Cronbach’s a for the School Adjustment subscale = .93 Accommodations Provided Due to Pain: School personnel completed a			

				checklist reporting all accommodations implemented for the student in response to their pain problem. Examples include extensions on assignment deadlines, modified schedule, and individual tutoring. School personnel also indicated whether an official written education plan for students with disabilities was in place.			
Mandic, Baraban & Boranic (2003)	Croatia	Design: case-control Aim: To assess basic personality traits and specific behaviour characteristics in adolescents with chronic tension type headache.	39 children 12-15 years old Mean age= 13.7 years. All children fulfilled criteria for chronic tension type headache CTTH	School achievement: Ascertained by interviewing parents and official school grades ranging from 1 (fail) and 5 (excellent).	Self-report	Eysenck personality questionnaire: 81 items with 4 measurement scales: Psychoticism, neuroticism, extroversion and lying. Total scores on each scale were compared	CTTH patients strived to achieve superior marks at school $p = < 0.01$ and to succeed in life $p = < 0.05$. 46.1% of CTTH patients were excellent students (grade 5) and 33.3%

		Method: The Eysenck personality questionnaire and DAIA measures were applied for testing.	Age matched healthy controls			to corresponding healthy controls. Questionnaire of domination, aggression, introversion, and ambition (DAIA): 4 measurement scales with 24 items with statements at opposite ends of the scale (10cm long scale). The child marks their opinion on the scale and this is converted to a numerical value. Wechsler intelligence scale for children: Verbal, non verbal and 10 subtests. Global intelligence quotient was used as a score, placing children in intelligence categories.	were very good (grade 4).
Mihaylova & Varbanova et al (2018)	Bulgaria	Design: Case control Aim: To assess the results of the	83 JIA patients (12% systemic, 53.6% oligoarticular, 23.5% RF	School attendance Specific item used: JAMAR item 12: Report of	Self-report	No additional measures	There was no significant difference between the healthy subjects and their affected peers in the

		cross-cultural adaptation and validation of the parent and patient versions of the JAMAR in the Bulgarian language Method: The reading comprehension of the questionnaire was tested in 10 JIA parents and patients. Each participating centre was asked to collect demographic, clinical data, and the JAMAR in 100 consecutive JIA patients or all consecutive patients seen in a 6-month period and to administer the JAMAR to 100 healthy children and their parents. The statistical validation phase explored descriptive	negative polyarthritis, 10.9% other categories) Median age= 11.9 100 healthy children were enrolled in two centres. Median age= 9.7	school problems caused by JIA (list of items) More items chosen from the list= more problems with school functioning. The JAMAR consists of 15 sections intended to assess the broader construct of the most relevant parent/ patient-reported outcomes in JIA, including overall well-being, functional status, health-related quality of life (HRQoL), pain, morning stiffness, disease activity/status/ course, articular and extra-articular involvement, drug-related side effects/compliance and satisfaction			school-related problems variable. Problems attending school reported for 6/82 (7.3%) of JIA patients and 0 (0%) of healthy controls.

		statistics and the psychometric issues of the JAMAR: the 3 Likert assumptions, floor/ceiling effects, internal consistency, Cronbach's alpha, interscale correlations, test–retest reliability, and construct validity (convergent and discriminant validity)		with illness outcome. Three versions are available: -Parent proxy-report (child's age 2–18) -Child self-report (suggested age range of 7–18 years) -Adult			
Milatz & Klotsche et al (2019)	Germany	Design: Cross sectional Aim: to (1) estimate the prevalence of participation in school sports among patients with JIA; (2) determine the correlates associated with school sports absenteeism; and(3) investigate whether attendance	Schoolchildren with JIA (n=5879) (Mean age 13.1 ± 3.3 years, female 65%, disease duration 5.9 ± 4.0 years, persistent oligoarthritis 37%)	School sports attendance: Participation in school sports was reported by the patients aged≥13 years or the parents of patients aged < 13 years) on a four-point Likert scale ranging from 'almost always' to 'sometimes not', 'often not' ,and 'exempt from school sports'.	Self-report, parent proxy report	Sociodemographic and clinical characteristics reported by the paediatric rheumatologist include the patient's age, sex, diagnosis, age at disease onset, disease duration, and laboratory values, such as erythrocyte sedimentation rate (ESR), body height and weight. Disease activity:	The proportion of patients who participated in school sports almost always steadily increased from 31% in 2000 to 64% in 2015 (β= 0.017, 95% confidence interval (CI) 0.015, 0.020) The exemption rate simultaneously decreased from 44% in 2000 to 16% in 2015 [β=−0.009, 95% CI -0.011,−0.007].

		in school sports has changed in the era of biologics Method: Data from schoolchildren with JIA recorded in the German National Paediatric Rheumatologic Database (NPRD) in the years 2000 to 2015 were considered for the analyses. Data from the year 2015 were inspected toanalyze correlates of school sports absenteeism. Whether school sports participation had changed between 2000and 2015 was determined using linear mixed models.				Physician's global assessment, PGA: on a numerical rating scale (from 0 = no disease activity to 10 = very severe disease activity). Inactive disease was defined as a physician's global assessment of disease activity score of 0. The patient-reported outcomes on an NRS included an evaluation of pain, fatigue, coping and overall well-being. The patients aged ≥13 years or the parents of patients aged < 13 years reported on their functional ability using the German version of the Childhood Health Assessment Questionnaire (C-HAQ). The resulting disability index	In 2015, the data from 5879 patients were available for evaluation. Full exemption from school sports (in 16.1% of cases) was associated with functional limitations, disease activity and any use of DMARDs, intra-articular glucocorticoid injections or physiotherapy.

						ranges from 0 to 3, whereby a value of zero indicates no functional disability and higher scores indicate light, moderate or severe level of disability. The clinical Juvenile Arthritis Disease Activity Score in 10joints (cJADAS-10): Considers the number of joints with active disease and the physician's and patient's/parent's global assessment without considering the ESR. Child acceptable symptom states were defined as minimal disease activity. The JADAS classification of minimal disease activity was 2 for oligoarticular JIA	

						and 3.8 for polyarticular JIA. The frequency of physical activity in leisure time: Patient-reported variable on a five-point Likert scale, ranging from‘daily’to‘3-5 times a week’,‘1-2 times a week’,‘more seldom’, and ‘never’. The patients aged≥13years or the parents of patients aged < 13 years also re-ported parental vocational training ranging from ‘academic degree’ to ‘apprenticeship’ and ‘no training’	
Mohseni, Pei,Bagheri-Nesami, & Shayesteh-Azar (2007)	Iran	Design: Cross sectional Survey. Aim: Determine the prevalence of nonspecific lower back pain (LBP) and associated risk factors in school-age children.	5000 State Secondary schoolchildren aged 11-14 were randomly recruited. Mean age = 13.1 (0.85).	Question item regarding position and duration of time spent doing homework. A self-completed structured questionnaire was designed to determine point,	Self-report. A response rate of 96.2% (n = 4813) was obtained.	Structured questionnaire with items concerning: -Lifestyle data. -Prevalence of LBP. -Characteristics of LBP.	LBP was significantly correlated with age (*p* = 0.000), position and duration of homework (*p* = 0.021 and *p* = 0.012, respectively). 43.4% of participants stated they do their homework in a lying position, and 32.5%

		Method: A cross-sectional study was conducted on randomly recruited secondary aged schoolchildren. A structured questionnaire including questions concerning demographic, mechanical and lifestyle data, and the prevalence/characteristics of LBP was used.	52.3% of the sample were female.	last month, last 6-month period, and annual prevalence of LBP. Point prevalence defined as experiencing LBP at the time of completing questionnaire. Last-month, last 6-month, and annual prevalence were defined as experiencing an episode of LBP within last month, last 6 month, and last year, respectively. The questionnaire was found to be reliable with Cronbach a = 0.84.			spent more than 2 hours a day doing homework.
Neder, & Van Weelden et al (2015)	Brazil	Design: Cross sectional	47 leprosy patients and 45 healthy subjects.	Paediatric Quality of Life Inventory (PedsQL4):	Self-report	No additional measures	The domain school activities was significantly lower in leprosy patients

		Aim: To evaluate the health-related quality of life (HRQL)in paediatric leprosy patients. Method: The HRQL was measured by Pediatric Quality of Life Inventory 4.0(PedsQL4.0) ,and evaluated physical,emotional ,social and school domains. The leprosy patients were classified by Ridley and Jopling classification criteria and assessed according to clinical musculoskeletal manifestations, laboratory and radiographic examinations.	Median age 12 (6-18) vs. 15 (5-18) years.	The 23-item Core Scales encompass; (1) Physical Functioning (8 items), (2) Emotional Functioning (5 items), (3) Social Functioning (5 items), and (4) School Functioning (5 items). A 5-point Likert scale is used: (0: never a problem; 1: almost never a problem; 2: sometimes a problem; 3: often a problem; 4: almost always a problem). Items are reverse-scored and linearly transformed to a scale from 0 to 100 points such that higher scores indicate better QOL.			compared to controls in the age group of 13-18years: 75(45-100) vs.90 (45-100), *p* = 0.021.

Nijhof, Van de Putte, Wulffraat & Nijhof (2016)	Netherlands	Design: Case-control. Cross sectional Aim: To determine the prevalence of severe fatigue and fatigue-related limitations among adolescents with juvenile idiopathic arthritis (JIA) and other paediatric rheumatic diseases (PRDs). In addition, to assess the effect of disease activity and pain on the severity of fatigue. Method: Patients completed validated questionnaires regarding fatigue, physical functioning, and school attendance. Disease activity in JIA patients was measured using the Juvenile Arthritis Disease Activity Score including 27	175 patients (ages10–18years) mean age= 14.5 who visited the paediatric rheumatology and immunology outpatient clinic at Wilhelmina Children's Hospital. Healthy control group. (n= 144) with a mean age of 15.3	School attendance: Measured retrospectively as the percentage of classes attended during the 6 months prior to completing the questionnaire.	Self-report	Fatigue: The fatigue severity subscale of the Checklist Individual Strength-20 (CIS; range 8–56, higher values indicate increased severity). The CIS has good reliability and discriminative validity. Physical functioning: Measured using the validated Dutch translation of the Child Health Questionnaire, physical functioning subscale: (range 0–100%, lower values indicate decreased function). The physical functioning subscale measures limitations in physical activities due to health-related issues in the previous 4 weeks. The cut-off value for impaired	The prevalence of severe fatigue among patients with PRDs was 25.1%, significantly higher than among the healthy control group (*p* < 0.001). Fatigued patients had significantly lower levels of physical functioning compared to non-fatigued patients (62.1% versus 89.0%, respectively; *p* < 0.001) and a significantly higher percentage of school absences (21.2% versus 11.6%, respectively; *p* = 0.005).

		joints. The results were compared against a healthy control group.				physical functioning was set at <85%	
Norgaard & Herlin (2019)	Denmark	Design: Case-control Aim: To investigate the habits of patients with JIA regarding participation in club sports, leisure-time physical activity, and school-educational physical activity and relate this to objectively measured physical activity using accelerometry and to compare the findings with those in healthy controls. Method: Consecutive patients from the Aarhus University Hospital outpatient clinic were included. Clinical characteristics,	Children ages 10–16 years who met the 2001 revised International League of Associations for Rheumatology classification of juvenile idiopathic criteria. Mean age 12.7 JIA subcategory (%) Polyarticular, RF positive 6 Polyarticular, RF negative 10 Systemic 11 Oligoarticular, persistent 19 Oligoarticular, extended 16 Psoriatic 4 Enthesitis-related 2	The Physical Activity and Sport Questionnaire [PASQ]): 31 questions on specific club sport habits and leisure-time and school-educational physical activities, including type of specific activity or sport, frequency, consistency, and intensity including type of specific activity of sport; frequency, consistency and intensity of participation; barriers to participation (e.g. disease related symptoms, adherence, competency, satisfaction with	Self-report	Functional impairment: Assessed using the revised Childhood Health Assessment Questionnaire including 38 items (C-HAQ38) Daily physical activity: Monitored with a hip-worn ActiGraph GT1M accelerometer measuring acceleration of the body. Children were instructed to complete an activity log indicating when the monitor was put on/removed, as well as activities performed while not wearing the monitor or those that are difficult to measure with the monitor. Only children providing a minimum of 3	The proportion of patients spending >3 hours/week participating in club sports was significantly lower than the proportion of controls. (*p* = 0.025) No difference in time spent engaging in physical activity during leisure-time was observed. (96% of patients and 94% of controls) Participation in compulsory school-educational physical activity was equally high in patients and controls, although participation by patients was significantly less consistent than that by controls. 51.5% participating always compared with 76.3% of controls *p* = 0.001.

		functional ability, and exploration of specific habits in club sports, leisure-time physical activity, and school-educational physical activity (based on a standardized questionnaire) in patients were recorded and compared with those in healthy controls. The intensity and frequency of physical activity were measured by accelerometer monitoring, using ActiGraph GT1M	118 healthy controls ages 10–16 years were recruited from a public school. Mean age 12.4	own effort); and strategy for those having difficulties during physical activity.		separate days of at least 8 hours of valid recording were included.	Patient reports of time spent with club sport and leisure-time physical activity was significantly related to accelerometry measures, whereas this was not observed for school-educational physical activity.
Nyame & Ambrosy et al (2010)	USA	Design: Longitudinal survey Aim: To longitudinally evaluate the epidemiological characteristics of headaches in a school-based, community setting	237 3rd- 8th grade students at two Chicago Public Schools.	Pediatric Quality of Life Inventory: Measures physical, emotional, social, and school functioning. A total of 23 items are rated on a scale of 0 to 4 and converted to a reverse score of 0	Self-report	Headache and pain symptoms: weekly questionnaires recorded the prevalence and severity of headaches. The students rated each pain symptom on a5-point scale from 0 (“not at all”) to 4 (“a whole lot”). The	Children reporting headaches had a significantly increased risk of experiencing other troubling somatic symptoms ($p < 0.05$). Headache severity showed a moderate correlation with increased feelings of

		and to determine the impact of headache symptoms on the health of children Method: A prospective cohort study was conducted at two Chicago public schools for a period of 6 months. Both schools were surveyed weekly for headache and other pain symptoms. The students rated each pain symptom on a5-point scale from 0 (“not at all”) to 4 (“a whole lot”). Demographic information was collected at the time of enrolment, and all participants were asked to complete age-appropriate and validated paediatric surveys		to 100 where 0=100, 1=75, 2=50, 3=25, and 4=0. On the 100-point scale, higher numbers correspond to a greater quality of life. The total scale score was computed by averaging the rating for each survey item.		total number of headaches and a pain score were determined for the entire study period. The pain score was the average of all headache scores reported during the study period. CSI: To assess the severity of somatic symptoms (ie, “faintness or dizziness,” “sore muscles,”etc.) that do not require an organic disease etiology. Participants rated each of 31 symptoms on a scale ranging from 0 (“not at all”) to 4 (“a whole lot”). The number of reported somatic symptoms irrespective of the severity (range 0 to 31) and a total score taking into account both the number and the severity of symptoms (range 0	anxiety, functional disability, and a diminished quality of life ($p < 0.05$)

		to assess the severity of concurrent somatic complaints, anxiety symptoms, functional limitations, and quality of life issues.				to 124) were calculated. STAIC: Consists of two scales: the S-anxiety scale and the T-anxiety scale, each comprised of 20 statements designed to measure the Diagnostic and Statistical Manual of Mental Disorders defined symptoms of anxiety. The S-anxiety scale is designed to measure transitory anxiety states that fluctuate over time, while the T-anxiety scale is intended to measure stable differences in anxiety that are fixed overtime. For both scales, each statement was rated from1 to 4, with higher scores indicating higher levels of anxiety.	

						Responses were summed for total values for both scales for each participant. The Pearson correlation coefficient between the S-anxiety and T-anxiety scales and headache pain scores was calculated. Paediatric Functional Disability Inventory: Assesses health-related difficulties in physical and psychosocial functioning in children. The survey consists of 15 potential activity limitations rated on a scale of 0 to 4. Total scores were calculated by summing the rating for each item. The total score had a potential range of 0 to 60 with higher values indicating greater functional disability.	

Offenbächer & Kohls et al (2016)	Germany	Design: Descriptive Aim: To translate the Functional Disability Inventory (FDI) into German, to evaluate its validity and to assess functional limitation in a large cohort of children and adolescents with juvenile fibromyalgia syndrome (jFMS). Method: Several questions (e.g., sociodemographic, school-related issues) and questionnaires were administered to 329 patients and one parent. The questionnaires included, among others, a German version of the FDI, the CHAQ (parent report), KIDSCREEN,	329 patients with juvenile fibromyalgia Mean age= 13.9 years	One parent provided data on age, gender, education, current job and duration of the child’s pain problem as well as information on school-related issues (e.g., number of days missed at school). The child provided also information concerning school-related matters (number of days missed at school this year and last year, ability to participate at school sports). The KIDSCREEN-27: A generic health-related quality-of-life (HRQOL) questionnaire for children and adolescents. It measures 5	Self-report	Functional Disability Inventory (FDI): Assesses children’s self-reported difficulty in physical and psychosocial functioning. The questionnaire consists of 15 items concerning perceptions of activity limitations during the past 2weeks measured with a 5-point Likert scale (no problems—not possible). Higher scores indicate greater disability. Pain: Assessed with a numerical rating scale (NRS) of current pain severity and pain severity during the last 3months as well as a tender point score (TPS, Lautenschlager et al) adapted for use in children, consisting of a body image illustrating 24	School-related variables [school absenteeism (parent report) and ability to participate at sports (child report)] were weakly correlated with the FDI ($p < 0.01$)

		tender point score (TPS), Depression Inventory for Children and Adolescents (DIKJ) and others. Patients were asked about the severity of pain today (NRS=numerical rating scale) and other symptoms.		HRQOL dimensions: physical and psychological well-being, autonomy and parent relation, peers and social support as well as school environment. Scores can be calculated for each of the ten dimensions. Higher scores indicate less limitations in HRQOL.		regions on the back and front, which are commonly indicated as painful by adult FMS patients. The patient has to rate each region on a scale from 0 to 5 (no pain—extreme pain). A total score is calculated by adding all regions. Highest possible score is 120. Childhood Health Assessment Questionnaire (CHAQ): parent version. Consists of 32 items. The subscale functional limitations assesses functioning in 8 areas such as dressing and grooming, arising, eating, walking, hygiene, reach, grip and activities. These are rated by the degree to which daily functions are difficult to perform	

						on a 4-point Likert scale (no problems—not possible), the reported use of special devices or aids as well as activities in which assistance of another is required. The patients' discomfort is determined by the presence of pain and its severity in the last week measured by a 100-mm visual analog scale (VAS). Higher scores denote more limitations. Depression Inventory for Children and Adolescents (DIKJ): A 27-item measure which assesses with a 3-point Likert scale different symptoms: emotional and somatic discomfort, loneliness, guilt, negative self-esteem, appraisal of social environment, feelings of failure und deficits in	

						school and others. A sum score above 18 is indicative of depressive symptomatology. Pain-Related Cognitions Questionnaire for Children (PRCQ-C): 3 subscales assessing catastrophizing (5 items), problem solving (4 items) and coping self-statements (4 items). Participants record how frequently they use coping strategies on a 5-point Likert scale (never—very often). Pain Experience Questionnaire (PEQ) and the Pain-related Parent Behaviour Inventory (PPBI): Four subscales in children [pain severity, pain-related interference in everyday life, affective distress (i.e., child’s mood,	

						irritability and coping efficacy with regard to everyday stressors) and social support] and three subscales in one parent (pain severity and pain-related interference in everyday life of youth as well as pain-related affective distress of parent). Responses to the items were measured with a 7-point Likert scale. Higher scores denote higher degree of symptomatology and functional limitations or greater support.	
Palermo,Witherspoon, Valenzuela & Drotar (2004)	USA	Design: Comparative Aim: To develop and validate a new measure, the Child Activity Limitations Interview (CALI), to improve the assessment of functional	89 children, aged 8 – 16 years (Mean age = 12:4; SD 2.5), 60% female, who were part of a longitudinal study of recurrent pain in children with headaches, juvenile	Functional disability. The FDI (Walker and Greene, 1991): Administered to children and their parents. The FDI describes the extent of restriction in performing 15 daily activities in	Self-report	Caregiver information form: Caregivers provided the child's age, race, gender, family income level, and parent marital and work status. Race was categorized as minority (African-American, Hispanic or other) versus non-	All items on the CALI were equally endorsed by both younger children and adolescents with the exceptions of 'going to school' which was chosen more often by adolescents, *p* < 0.05 and 'playing with friends' *p* < 0.003 which was

		impairment due to recurrent pain in school-age children and adolescents, and to compare this measure to the Functional Disability Inventory. Method: Measures of socio-demographics, pain, anxiety and depression, and functional disability were completed. A subset of participants (47%) were re-administered the CALI 1 month later and completed prospective ratings of pain and activity limitations using the CALI in daily diaries.	idiopathic arthritis, and sickle cell disease. recurrent headaches n = 84 juvenile idiopathic arthritis n= 60 Sickle cell disease n= 45	the domains of school, home, recreation, and social interaction due to physical health. Acceptable internal consistency and test – retest reliability coefficients have been reported. School absences: Parents completed the School Report Form to identify absences during the current and last school year. Parents indicated the number of absences on a 5-point categorical scale, where 1= 0 – 5 days, 2= 6 – 10 days, 3= 11 – 15 days, 4= 16 – 20 days, and 5=20 or more days.		minority (Caucasian). Child Activity Limitations Interview: In interview format, children and parents identified 8 out of 21 activities that were the most difficult to perform due to pain Each dyad rated the level of difficulty and personal importance of each activity on 5-point Likert type scales. Anxiety and depressive symptoms: Children and adolescents completed the Revised Child Anxiety and Depression Scale (RCADS; Chorpita et al., 2000), a self-report measure of depression and six anxiety disorders. Two subscales, major depressive	endorsed more often as being difficult by children than adolescents.

						disorder (MDD) and generalized anxiety disorder (GAD), were used in the data analyses to characterize child psychosocial distress. Pain: Children and parents completed parallel questionnaires to assess child pain symptoms over the previous 4weeks including pain intensity, frequency, duration, and emotional distress due to pain. Pain intensity was measured using the validated Faces Pain Scale (Bieri et al., 1990),which consists of a series of seven faces with anchors at the two ends representing ‘no pain’ to ‘worst pain.’ Adequate reliability and validity of the	

						measure have been reported Pain frequency was measured using a Likert-type rating scale with six response options ranging from ‘less than once a month’ to ‘daily’. Pain duration was also measured using a Likert-type rating scale with four response options ranging from ‘less than 1 hour’ to ‘all day’. Emotional upset due to pain was assessed using an adapted scale (McGrath, 1990) with five response options ranging from ‘not at all’ to ‘very much’ bothered by pain. Physician rating of illness severity and limitations: The subspecialty	

						physician for each child completed an assessment form that included a section on his/her rating of the child's illness severity and expectation of limitations due to the child's health condition. Illness severity was assessed via a 10 cm visual analogue scale with anchors at the two ends representing 'not severe at all' to 'extremely severe.' Expectation of the child's limitations due to his or her health condition was also assessed via a 10 cm visual analogue scale with anchors at the two ends representing 'I expect no limitations' to 'I expect extreme limitations.'	

						Daily diary: completed by a subgroup of children n= 88 to examine responsiveness of the CALI to changes in children’s pain symptoms. Children completed diaries either in a paper diary form or in an electronic diary form. Both diaries were identical in content and included 19 items that were to be completed using a daily recall procedure (at the end of each day). These items corresponded to (a) pain and distress ratings; (b) somatic symptoms; and (c) difficulty ratings on the eight items chosen from the CALI	
Powers, Patton, Hommel & Hershey (2003)	USA	Design: Comparative	572 consecutive patients (mean age, 11.4 + 3.6	Paediatric Quality of Life Inventory: Measures	Self-report	Headache Centre intake questionnaire:	Most patients (99%) had a clinical diagnosis of migraine:

		Aim: To examine quality of life (QOL) in a clinical sample of children with headaches and compared with children with other chronic diseases. Method: A survey study was conducted of 572 consecutive patients who presented with headaches to a children's headache centre. Children and parents completed the Paediatric Quality of Life Inventory, Version 4.0 and a standardized headache assessment.	years) who presented with headaches to a children's headache centre.	physical, emotional, social, and school functioning. A total of 23 items are rated on a scale of 0 to 4 and converted to a reverse score of 0 to 100 where 0=100, 1=75, 2=50, 3=25, and 4=0. On the 100-point scale, higher numbers correspond to a greater quality of life. The total scale score was computed by averaging the rating for each survey item.		Patients indicated the average severity of their headaches using a 10-point scale (10 most severe pain). Duration of headache pain was reported according to the duration of their shortest, longest, and average headaches. Headache frequency was reported as the average number of headache days that occurred per month during the past 3 months. Diagnosis was made using both clinical impression and the IHS criteria. The IHS criteria for migraine without aura are having at least 5 headaches that last untreated between 2 and 48 hours for children younger than 15 years or 4 to 72 hours if older than	85% met the International Headache Society migraine criteria, and 40% had chronic daily headaches. Total Paediatric Quality of Life Inventory score was lower for the entire group (73.1 + 14.4) compared with healthy norms (83.0 + 14.8) and lowest for children with chronic daily headaches (70.5+ 15.5). The impact on QOL of children with migraine was similar to that of children with arthritis and cancer. Children with migraine headaches reported lower QOL than children in the healthy comparison sample (PedsQL 4.0 Total Score) (t[1,554] 16.15, *p* = .01).

						15 years, having 2 of 4 features (pulsatile quality, focal location, aggravated by physical activity, and moderate to severe pain), having associated symptoms of nausea and/or vomiting or photophobia and phonophobia, and having abnormal neurologic examination and the headache not associated with a secondary cause.	
Pratsidou-Gertsi & Trachana et al (2018)	Greece	Design: Cross sectional Aim: To cross-culturally adapt and validate the Greek parent, child/adult version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) in patients with	272 JIA patients (5.9% systemic, 57.7% oligoarticular, 21.3% RF negative poly-arthritis, 15.1% other categories) Median age= 9.3 100 healthy children Median age= 11.7	The JAMAR is available in three versions, one for parent proxy-report (child's age 2–18), one for child self-report, with the suggested age range of 7–18 years, and one for adults. Item on the JAMAR: Report	Self-report/ parent proxy report	Assessment of physical function (PF): Using 15 items in which the ability of the child to perform each task is scored: 0=without difficulty, 1=with some difficulty, 2=with much difficulty, and 3=unable to do and not applicable if it was not possible to answer the question	There was no significant difference between healthy subjects and their affected peers in Psychosocial quality of life and school-related items on the JAMAR.

		juvenile idiopathic arthritis (JIA). Method: The reading comprehension of the questionnaire was tested in 10 JIA parents and patients. Each participating centre was asked to collect demographics, clinical data, and the JAMAR from 100 consecutive JIA patients or all consecutive patients seen in a 6-month period and to administer the JAMAR to 100 healthy children and their parents.		of school/university/ work problems caused by the disease: (list of items).		or the child was unable to perform the task due to their young age or to reasons other than JIA. The total PF score ranges from 0 to 45 with three components: PF-lower limbs (PF-LL); PF-hand and wrist (PF-HW); and PF-upper segment (PF-US) each scoring from 0 to 15. Higher scores indicating higher degree of disability. Rating of the intensity of the patient’s pain: on a 21-numbered circle visual analogue scale (VAS) Assessment of the presence of joint pain or swelling (present/absent for each joint)	

						Assessment of morning stiffness (present/absent) Assessment of extra-articular symptoms: (fever and rash) (present/absent) Rating of the level of disease activity: on a 21-circle VAS. Rating of disease status at the time of the visit: (categorical scale) Rating of disease course from previous visit: (categorical scale). Checklist of the medications the patient is taking: (list of choices) Checklist of side effects of medications. Report of difficulties with medication administration: (list of items).	

						Assessment of HRQoL: Physical Health (PhH), and Psychosocial Health (PsH) sub-scales (five items each) and a total score. The four-point Likert response, referring to the prior month, are ‘never’ (score=0), ‘sometimes’ (score=1), ‘most of the time’ (score=2) and ‘all the time’ (score=3). ‘not assessable’ column was included in the parent version of the questionnaire to designate questions that cannot be answered because of developmental immaturity. The total HRQoL score ranges from 0 to 30, with higher scores indicating worse HRQoL.	

						A separate score for PhH and PsH (range 0–15) can be calculated. Rating of the patient’s overall well-being: 21-numbered circle VAS. A question about satisfaction with the outcome of the illness: (yes/no).	
Ragnarsson, Johansson, Bergstrom, Sjoberg, Hurtig & Petersen (2019)	Sweden	Design: Longitudinal Aim: To explore the relationship between recurrent pain and perceived problems with academic achievement among boys and girls in middle and late elementary school. Method: 3-year follow-up study based on data from	1524 children attending elementary school in Sweden. (Those providing complete answers to the main variables regarding recurrent pain and PPAA in grade 6 as well as in grade 9 at follow up)	Perceived problems with academic achievement PPAA: Measured by a question capturing whether the child had experienced ‘problems keeping up with schoolwork’ during the last month. The question had five response alternatives,	Self-report	Recurrent pain: Measured by three child-rated questions concerning the frequency of headaches, stomach aches and backache during the past 6 months. 5 response alternatives ranging from ‘seldom or never’ to ‘daily’ pain. Pain occurring at least once a month during the past 6 months was defined	Recurrent pain (head, stomach or back) at least doubled the odds of concurrent- and subsequent perceived problems with academic achievement. In grades 6 and 9, recurrent pain among boys and girls (at least monthly, any site) increased the odds of PPAA two- to threefold (odds ratios (ORs) 2.6 in boys and 2.9 in girls)

		the Study of Health in School-aged Children from umeå (Sweden). Included children attending grade 6 in years 2003 and 2006, and a follow-up 3 years later in grade 9 (n= 1524, participation rate 90%).		ranging from ‘never’ to ‘almost always’. Problems occurring almost always, often, or sometimes were labelled PPAA. This question was derived from the Paediatric Quality of Life Inventory (PedsQL), which has verified reliability. Cohort explanatory variables: Measured by three child-rated questions capturing problems with sleep, concentration and absenteeism. The questions had five response alternatives from ‘never’ to ‘almost always’ during the last month. Problems occurring almost		as ‘recurrent’. Pain from one site was named ‘single pain’ and from several sites ‘multiple pain’. The questions were derived from the international survey Health Behaviour of School-aged Children (HBSC), which has acceptable levels of validity and reliability. Background variables: Child-rated information about sex, migration status instead of ethnicity and family structure. Parents gave information on parental education and other chronic diseases suffered by the children.	The odds of PPAA was two to three times higher in children experiencing pain once a week, and four to five times higher amongst those feeling pain more than once a week, as compared to children without recurrent pain. An exception to the pattern was boys in grade 6 for whom monthly pain doubled the odds of PPAA. Problems with sleep, concentration or school absenteeism did not explain the association.

				always, often, or sometimes for the three explanatory variables were labelled impaired sleep, impaired concentration and high school absenteeism respectively. These questions were also from the PedsQL.			
Rousseau-Salvador, Amouroux,Annequin, Salvador, Tourniaire& Rusinek (2014)	France	Design: Comparative Aim: To examine anxiety and depression, associated risk factors and school outcomes in a clinical population of youth with chronic daily headache CDH compared with youth with episodic headache (EH) Method: Data regarding headache characteristics,	368 consecutive patients presenting with primary headache at a paediatric headache centre. Aged 8-17 years. Mean age of total sample 11.9 years.	Sociodemographic information was recorded including age, sex, grade, and school absenteeism. Parents were asked to report absenteeism as the number of school days missed in the preceding year due to headache. The data was categorised into none, >7 days and >1 month	Self-report and parent proxy report.	The Revised Children's Manifest Anxiety Scale (R-CMAS): The R-CMAS has good reliability and validity. It is composed of 37 yes/no items that assess the level of generalized anxiety and four subtypes: physiological anxiety, worry/hypersensitivity, social preoccupation/concentration and deceit. The Multiscore Depression Inventory for	Twice as many children with CDH compared with children with EH (46.5% versus 20.5%) had missed at least seven days of school because of their headaches during the academic year preceding the medical consultation ($\chi2=18.39$; $p <$ 0.001). Children who had missed >1month of school were four times as likely to be in the CDH group compared with the EH group (16.9%

		anxiety, depression, and missed school days were collected from 368 consecutive patients eight to 17 years of age, who presented with primary headache at a specialized paediatric headache centre.				Children (MDI-C): Evaluates levels of depressive symptoms. The MDI-C includes 79 yes/no items that sum to a total score corresponding to a general measure of the severity of depression. The items are grouped into eight subscales including low energy, anxiety, self-esteem, sad mood, hopelessness, social introversion, pessimism and provocation. The MDI-C has been standardized and validated in the French population for children eight to 17 years of age.	versus 4.0%; $\chi 2=15.86$; $p < 0.001$.
Rusoniene,& Panaviene et al (2017)	Lithuania	Design: Cross Sectional Aim: To cross-culturally adapt and validate the Lithuanian parent, child/adult version	100 patients with JIA Median age= 12 100 healthy children Median age= 15.8	The JAMAR is available in three versions, one for parent proxy-report (child's age 2–18), one for child self-report, with the	Self-report and parent proxy report	Assessment of physical function (PF): Using 15 items in which the ability of the child to perform each task is scored: 0=without difficulty,	There was no significant difference found between healthy subjects and their affected peers in the school-related problems variable.

		of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) in patients with juvenile idiopathic arthritis (JIA) Method: The reading comprehension of the questionnaire was tested in ten JIA parents and patients. Each participating centre was asked to collect demographic, clinical data and the JAMAR in 100 consecutive JIA patients or all consecutive patients seen in a 6-month period and to administer the JAMAR to 100 healthy children and their parents.		suggested age range of 7–18 years, and one for adults. Item on the JAMAR: Report of school/university/ work problems caused by the disease: (list of items).		1=with some difficulty, 2=with much difficulty, and 3=unable to do and not applicable if it was not possible to answer the question or the child was unable to perform the task due to their young age or to reasons other than JIA. The total PF score ranges from 0 to 45 with three components: PF-lower limbs (PF-LL); PF-hand and wrist (PF-HW); and PF-upper segment (PF-US) each scoring from 0 to 15. Higher scores indicating higher degree of disability. Rating of the intensity of the patient’s pain: on a 21-numbered circle visual analogue scale (VAS)	

						Assessment of the presence of joint pain or swelling (present/absent for each joint) Assessment of morning stiffness (present/absent) Assessment of extra-articular symptoms: (fever and rash) (present/absent) Rating of the level of disease activity: on a 21-circle VAS. Rating of disease status at the time of the visit: (categorical scale) Rating of disease course from previous visit: (categorical scale). Checklist of the medications the patient is taking: (list of choices)	

						Checklist of side effects of medications. Report of difficulties with medication administration: (list of items). Assessment of HRQoL: Physical Health (PhH), and Psychosocial Health (PsH) sub-scales (five items each) and a total score. The four-point Likert response, referring to the prior month, are ‘never’ (score=0), ‘sometimes’ (score=1), ‘most of the time’ (score=2) and ‘all the time’ (score=3). ‘not assessable’ column was included in the parent version of the questionnaire to designate questions that cannot be answered because of developmental immaturity.	

						The total HRQoL score ranges from 0 to 30, with higher scores indicating worse HRQoL. Rating of the patient’s overall well-being: 21-numbered circle VAS. A question about satisfaction with the outcome of the illness: (yes/no).	
Salathe, Kalin, Zilse & Elfering (2019)	Switzerland	Design: Longitudinal Aim: To investigate the effects of juvenile musculoskeletal (MSK) pain and psychosocial risk factors on future pain. Method: The baseline sample comprised 189 adolescents, and 5-year follow-up	The baseline sample comprised 189 adolescents, and 5-year follow-up resulted in 107 15- to 18-year-old adolescents (M=16.3 years±.7, 66% females)	School variables: Satchel weight was measured with a digital scale to an accuracy of 100 g. Recommended school type was derived from the fact that, at the end of primary school (International Standard Classification of Education: ISCED level 1;	Self-report	Pain assessment: At follow-up, total MSK pain was assessed using blank-faced, genderless pain mannequins on which participants were asked to mark all current pain sites and all pain sites in which they had experienced pain for at least a day during the last 4 weeks by ticking a labelled radio button. Scores	The relationship between follow-up school pressure and current MSK pain was mediated by sleep quality at follow-up (B=.17, SEB=.07, 95% CI .06–.34) when baseline MSK pain was controlled.

		resulted in 107 15- to 18-year-old adolescents. Adolescents responded to an online questionnaire about psychosocial stressors, MSK pain, school achievement and leisure activities. A longitudinal hierarchic linear regression including all significant baseline predictors was run to assess their impact on MSK pain 5 years later. Mediation analysis was used to investigate sleep quality as a potential mediator of the relationship between school pressure and MSK pain at follow-up		12–13 years) pupils are recommended to enrol in one of three different performance-based secondary schools (ISCED level 2): basic, expanded lower-secondary or expanded higher-secondary, based on their grades and performance in achievement tests School pressure at follow-up: Participants evaluated the amount of pressure they felt to achieve good school grades (five-point Likert scale ranging from 1=no pressure to 5=very intense pressure.		from all pain sites were summed. Pupils were asked about parental back pain at baseline. Daily media consumption: Participants reported the total daily media consumption (six-point scale ranging from 0: none to 5:>3 h/day). Psychosocial strain: Psychosocial problems were assessed with the German version of the Strengths and Difficulties Questionnaire for 11- to 16-year-olds (SDQ), with 20 items using a three-point scale (0=no, 1=sometimes, 2=yes). Mean scores were calculated for each dimension. Cronbach’s alpha was satisfactory (α=.74).	

						The mediation analysis used follow-up data on the variables school pressure and sleep quality, with MSK pain as the outcome variable. Sleep quality at follow-up: Participants reported subjective short-term sleep quality using a five-point Likert scale ranging from 1=very poor to 5=very high	
Schanberg, Anthony,Gil & Maurin (2003)	USA	Design: Descriptive Aim: To analyse patterns of daily pain, stiff-ness, and fatigue related to juvenile arthritis; to examine the relationships of demographics, disease severity, and psychological adjustment to daily disease symptoms;	41 children with polyarticular arthritis: 24 = polyarticular juvenile rheumatoid arthritis (JRA; 5 were rheumatoid factor positive), 11= systemic-onset JRA, 3= psoriatic arthritis 3= spondyl arthropathy.	Daily activity reduction: In the daily diaries, children were also asked to indicate the amount they reduced school and social activities each day. Ratings were on a 4-point Likert scale anchored by “not at all” and “a	Self-report and parent proxy report	Daily symptoms: The daily diary included measures of daily symptoms and daily function. The daily self-report booklet: included items in which children rated daily symptoms, including pain intensity, painful locations, level of fatigue, and stiffness. Pain, fatigue, and stiffness	Multilevel random-effects analyses indicated that increased daily symptoms of pain, stiffness, and fatigue were significant predictors of reduced participation in school and social activities. Daily school activity reduction for the minimal disease activity group (mean= 0.1) and ongoing

		and to examine daily disease symptoms as predictors of reduced participation in school and social activity Method: For a 2-month period, 41 children with polyarticular juvenile arthritis completed daily diaries that included measures of symptoms and function. Children also underwent an initial evaluation and 4 follow up evaluations that included a joint count, laboratory testing, and completion of questionnaires assessing physical and psychosocial functioning.	Mean age= 12.3 years (range 8–17 years), and 59% were female.	lot," with higher values indicating greater reduction.		were measured using a 100-mm visual analog scale (VAS). The pain scale from the Pediatric Pain Questionnaire (PPQ) was used: The PPQ pain VAS is anchored at the endpoints by "no hurting, no discomfort, no pain" and "hurting a whole lot, very uncomfortable, severe pain." In addition to rating their daily pain intensity, children were asked to colour in or mark a body map showing painful locations. The pain location body map was adapted from the PPQ. Both the VAS and the body map have been shown to have adequate reliability and validity in the assessment of pain in children with	disease activity (mean= 0.2) not significant.

						rheumatic disease The 100-mm visual analog scales for fatigue and stiffness were modelled after the VAS for pain. The words “not tired” and “very tired” anchored the endpoints of the VAS for fatigue, and the VAS for stiffness was anchored by “no stiffness” and “very stiff.” Baseline functional status: Parents and children rated the child’s disease-related functional status using the parent-report and the child-report versions, respectively, of the Child-hood Health Assessment Questionnaire (C-HAQ) Both versions of the C-HAQ yield a disability index score and a discomfort index score. The	

						reliability and validity of this instrument in polyarticular JRA were previously established. Baseline disease severity: Disease severity was assessed at the initial evaluation using a variety of sources, including the physician’s rating, active joint count, and laboratory parameters. The paediatric rheumatologist provided a global assessment of the child’s disease severity, using a 100-mm VAS anchored by the end points “asymptomatic” and “very severe.” The joint count was recorded, and consisted of the number of swollen and tender joints, as	

						well as the number of joints in which range of motion was limited. From this information, the number of active joints for each child was determined. A joint was defined as active if it met the following criteria: 1) swelling alone, or 2) a combination of joint tenderness and limitation of movement. A laboratory measure of disease activity, the erythrocyte sedimentation rate (ESR), was obtained at the initial and follow up evaluations. Baseline psychological adjustment: The Children's Depression Inventory (CDI) and	

						the Revised Children's Manifest Anxiety Scale (RCMAS) were used to assess the psychological adjustment of the child. The CDI is a 27-itemself-report scale based on the Beck Depression Inventory, it assesses a variety of depressive symptoms including sleep disturbance, appetite loss, and dysphoria. A total scale score can be derived as a standard T score with a mean of 50 and a standard deviation of 10. The CDI is the most widely used and validated measure of childhood depression in children ages 8 to 17 years.	

						The RCMAS is a 37-item self-report scale designed to assess the level and nature of anxiety in children and adolescents ages 6 to 19 years across 4 areas: physiologic anxiety (e.g., difficulty breathing, difficulty sleeping, and abdominal pain),worry (e.g., anticipatory anxiety), social concerns/concentration (e.g., worries about the expectations of significant others), and total anxiety. Raw scores are converted to scaled scores based on children’s age and sex. For the total anxiety score, the scale score is a standard T score with a mea nof 50 and a standard deviation of 10; for the subscales, the	

						scaled scores have a mean of 10 and a standard deviation of 3. Higher scores are indicative of increased anxiety	
Schanberg, & Gil et al (2005)	USA	Design: Descriptive Aim: To analyse patterns of stress, mood, disease symptoms, and activity reduction in children with polyarticular arthritis, using a prospective daily diary method. Method: For a 2-month period, 51 children with polyarticular arthritis completed daily diaries that included measures of symptoms of pain, stiffness, and fatigue, as well as stress, mood, and activity reduction. Functional status and disease	51 children with polyarticular arthritis (mean age 12.4 years, 65% female)	Daily activity reduction: In the daily diaries, children were also asked to indicate the amount they reduced school and social activities each day. Ratings were on a 4-point Likert scale anchored by “not at all” and “a lot,” with higher values indicating greater reduction	Self-report	Daily measures: The daily diary included measures of daily symptoms, stress, mood, and function. Daily symptoms: The daily self-report booklet included items for which children rated daily symptoms, including pain intensity, painful locations, level of fatigue, and stiffness. Pain, fatigue, and stiffness were measured using a 100-mm visual analog scale (VAS), as reported previously. Daily stress:	Increases in daily stress, mood, and disease symptoms were significantly related to decreased participation in social activities on a day-to-day basis. Only mood and stiffness were predictors of a decrease in school attendance.

		activity were assessed at the initial and follow up evaluations with use of the Childhood Health Assessment Questionnaire, physician global assessment, joint count, and laboratory testing.				The Daily Events Inventory was used as a measure of children's daily stress level. The 17-item inventory was modified from instruments developed by Gil et al and Grant and Compas. The items include negative daily events such as "argued with parents or brothers and sisters, ""was made fun of," and "got in trouble." Children were asked to indicate whether each event occurred that day. A score is derived by adding the number of events endorsed. The scales Cronbach's alpha coefficient is 0.70. Daily mood: Daily mood was assessed using the Facial Affective	

						Scale (FAS) (McGrath) The FAS consists of 9 faces that vary in levels of overt distress expressed. Children were instructed: “Please mark the face that looks like how you felt deep down inside today—not just how your face looked, but how you really felt inside.” The numeric values for this facial scale have been determined experimentally and transformed to a 0–1 scale, where 1=maximum negative affect and 0=maximum positive affect. This scale has been shown to be a reliable and valid measure of mood in children.	

						Values <0.5 were considered to be positive, and values < 0.5 were considered to be negative. Baseline measures: Functional status: Children rated their disease-related functional status using the child-report version of the Childhood Health Assessment Questionnaire (C-HAQ). The C-HAQ yields a disability index score and a discomfort index score. The reliability and validity of this instrument in polyarticular juvenile rheumatoid arthritis are previously established. Disease activity: Assessed at the initial evaluation	

						using a variety of sources, including physician rating of disease severity, active joint count, and laboratory parameters. Paediatric rheumatologists provided a global assessment of the child's disease severity using a100-mm VAS anchored by the end points "asymptomatic" and "very severe." The joint count was recorded and consisted of the number of swollen and tender joints, as well as the number of joints in which range of motion was limited. Laboratory measures of disease activity were obtained at the initial and follow up evaluations and included the erythrocyte	

						sedimentation rate (ESR), platelet count, hematocrit, and hemoglobin concentration.	
Sen & Morgan et al (2017)	UK	Design: Qualitative Aim: To explore the subjective experience of children and young people being treated for chronic, non-infectious uveitis associated with a systemic disease such as juvenile idiopathic arthritis. Method: A semi-structured interview was conducted with 10 children and young people aged between 6 and 18 years of age and their parents.	10 children and young people aged between 6 and 18 years with uveitis.	Semi-structured interviews covered six principal domains and a general section with each participant. The six domains included: treatment received, ocular complications, impact on school activities, impact on out-of-school activities, social impact and emotional reactions.	Self-report via interview	No additional measures	The indirect effects of receiving treatment, such as missing school for appointments and treatment were import-ant to both children and young people. Themes identified in the “impact on school” domain: - Upset at missing lessons and subsequent anxiety “I usually miss out on the understanding of some of the lessons because I wasn’t there for it– it makes you feel worried because I don’t know what I am doing”. - The pressure to catch up with missed schoolwork is an additional

							stress and parents are aware that progress can be patchy, often in relation to the child's interests and motivation. - There were practical issues e.g. not being able to participate fully in Physical Education (PE):"I'm always the last one to get ready for PE and everyone else is waiting on the carpet for me. I feel embarrassed and lonely". - Even when adaptations are made by the school, they are not always successful, with young people commenting on laptop computers not being available - Young people felt that teachers did not always remember the

							difficulties they had and they were reluctant to inform or remind teaching staff as they did not wish to appear different from their peers :“I don’t really tell the teachers about my medical stuff........I don’t want to sit in another place to other people because that can be embarrassing”. In the “social factors” domain, the impact of both the treatment and complications of uveitis ranged from not feeling included or being the last person selected for a team or activity, to being actively bullied: “I was bullied every day in Year 9 [age 13-14years]... They said I was diseased or contagious and wouldn’t go near me”.

							Self-exclusion from activities was also reported. In older teenagers, restrictions imposed by treatment also led to feelings of being left out, especially when medication contraindicated alcohol consumption.
Simons, Logan, Chastain & Stein (2010)	USA	Design: Aim: To further understanding of social functioning in children with chronic pain, and particularly how social functioning relates to school impairment in this population. Method: 126 adolescents (12 to 17 y) evaluated at a multidisciplinary pain clinic. Adolescents completed measures assessing social functioning, pain, physical limitations,	126 patients with chronic pain between the ages of 12-17. Mean age= 15.0 years Diagnoses included: Musculoskeletal pain (25.4%), neuropathic pain (17.5%), headache (chronic daily, tension-type; 16.7%), back/neck pain (14.3%), recurrent abdominal pain (11.9%), migraine (7.9%),	School Impairment: Several measures were used to assess school attendance, academic performance, and academic competence. School attendance: adolescents and parents reported days absent because of pain over the previous month. Parents and adolescent were presented with multiple choice categories of days missed,	Self-report and parent proxy report	Basic Demographic Information: Parents provided basic demographic information (eg, child's age and sex, parents' occupations, education, and marital status) on the pain treatment service demo-graphic information form. Pain Experience: Pain, physical limitations, and somatic symptoms were assessed to measures each child's pain experience. For pain ratings, during the pain evaluation,	Lower social functioning scores were significantly associated with pain ($p < 0.01$) physical limitations ($p <0.01$) somatic symptoms ($p < 0.01$) , and school impairment ($p < 0.01$) Social functioning mediated the relations between adolescents' pain experience (i.e., pain, physical symptoms, and physical limitations) and school impairment.

		somatic symptoms, and school impairment.	and gynaecologic or genitourinary pain (6.3%). Duration of pain varied from 3 months to 167 months, with a median duration of pain of 15.5 months.	including ‘‘None,’’ ‘‘1 to 3 days,’’ ‘‘4 to 7 days,’’ ‘‘8 to 10 days,’’ ‘‘11to 15 days,’’ and ‘‘16 to 20 days.’’ Parents and adolescents also provided subjective reports of the perceived effects of pain on school attendance. This was elicited with the question, ‘‘How much has pain interfered with your/your child’s attendance at school?’’ Responses were recorded on a 10 cm visual analog scale (VAS) with anchor points of ‘‘Pain has not interfered at all’’ to ‘‘Pain has interfered extremely’’. Academic performance:		children were asked to provide their current pain rating on a standard 11-Point Numeric Rating Scale from 0 (no pain) to 10 (most pain possible). Physical limitations: Assessed using the Functional Disability Inventory (FDI) is a 15-item measure for assessing the perceptions of activity limitations owing to physical health in the past 2 weeks; total scores are computed by summing the items. 4 items from the FDI were omitted from the total score: 2 items referring to school (i.e., ‘‘Being at school all day,’’ ‘‘Reading or doing homework’’); 1 item referring to friends (ie, ‘‘Doing something with a friend’’); and 1 item	

				Parents reported adolescents' average grades before the onset of their pain problem and their current average grades in multiple choice format (‘‘Mostly As, ‘‘As and Bs,’’ ‘‘MostlyBs,’’ ‘‘Bs and Cs,’’ ‘‘Mostly Cs,’’ ‘‘Cs and Ds,’’ ‘‘Mostly Ds,’’ ‘‘Ds and Fs,’’ and ‘‘Mostly Fs’’). Parents and adolescents also provided subjective reports of the effects of pain on academic performance by responding to the question, ‘‘How much has pain interfered with your/your child’s performance (eg grades) at school?’’ Responses were		referring to watching television (ie, ‘‘Watching TV’’). Higher scores indicate greater physical limitations. The FDI has demonstrated reliability and validity. Somatic symptoms: Reported on the Child Somatization Inventory to assess the severity of nonspecific somatic symptoms (e.g.,‘‘weakness’’ and ‘‘dizziness’’) that need not have organic disease etiology. Adolescents rate the extent to which they have experienced each of 35 symptoms during the last 2 weeks using a 5-Point Scale ranging from ‘‘not at all’’ (0) to ‘‘a whole lot’’.	

				recorded on a 10 cm VAS with the same anchor points as the attendance-interference item. Self-perceived academic competence: Assessed with the Scholastic subscale of the Harter SPPA: 45-item measure of adolescents' perceptions of competence in 9 areas. Participants are given the initial statement (e.g., ''Some teenagers have trouble figuring out the answers in school'') and then rate how true that statement is for them (e.g., ''Not at all true'' to ''Really true''). The items are rated on a 4-point		Higher scores indicate higher levels of somatic symptoms; total scores are computed by summing the items. The CSI has been found to have adequate reliability and validity. Social Functioning: A broad measure of social functioning, a measure of self-perceived social competence, and of peer victimization were administered. To broadly assess the social functioning, the Social Functioning Scale of the PedsQL was administered. It consists of 5 items assessing social difficulties (eg, ''Other teens tease me,'' ''I have trouble getting along with other teens'').	

				scale (1 to 4) and averaged to yield the subscale score. Cronbach's a for this sample was 0.83. Parent and Adolescent School Functioning Index scores: Consisted of parent reported absence rates, perceived interference of pain with attendance and performance, and reports of grade changes as the pain onset. Adolescent School Functioning Index scores: Consisted of adolescent reported absence rates, degree to which adolescents		Parent and adolescent respondents answered each question on a 5-point Likert-type scale. Higher scores equal better functioning. Internal consistency estimates for the social functioning scale for parents (a= 0.73) and adolescents (a= 0.79) in this sample were acceptable. Self-perceived social competence and peer victimization: adolescents rated themselves on the Harter Self-Perception Profile for Adolescents (SPPA) Social Competence Scale and the Peer Victimization Scale (PVS). The SPPA is a widely used 45-item measure of	

				perceive pain to interfere with attendance and performance, and self-perceived academic competence ratings.		adolescents' perceptions of competence in 9 areas and the PVS was developed to be administered among SPPA items in the same format. Both subscales contain 6 items. The SPPA and PVS were administered in an alternative format in which participants are given the initial statement (eg,''Some teenagers are popular with others their age'') and then rate how true that statement is for them (eg, ''Not at all true'' to ''Really true''). The items are rated on a 4-PointScale (1-4) and averaged to yield the subscale score. Cronbach's a for this sample is 0.82.	
Shapiro & Dinges et al (1995)	USA	Design: Descriptive	18 children and adolescents with a diagnosis of	School absence was recorded in a daily self-report	Self-report	Sickle cell disease related pain: A pain diary (developed	Patients were absent from school on 21% of 3186 school days,

		Aim: To gain information about the natural history of pain associated with sickle cell disease and its impact on sleep and school attendance Method: Eighteen children and adolescents completed 4756 diary days of a home- based diary system to record information about pain, sleep and school attendance.	sickle cell disease 8-17 years of age (average: 13 years).	diary on weekdays.		from a self-report system used for research on sleep and circadian rhythms; Shapiro et al. 1990). Patients were asked to complete 2 pages each day, 1 in the morning as soon after awakening from sleep as convenient, and 1 in the evening before going to bed. On the morning page, patients indicated the presence of any SCD-related pain by circling 'yes' or 'no'. If 'yes' was circled, they indicated the pain intensity on a 10-cm linear analogue scale. Sleep: Patients also indicated by circling 'yes' or 'no' whether they slept well, and rated their perceived sleep length on a 5-cm linear analogue scale. At night,	with half of the absenteeisms on days with reported pain. Of the pain-associated absenteeisms, two-thirds occurred when pain was managed at home, and one-third when patients were hospitalized. The average consecutive number of school days missed was 2.7.

						children were again asked about the presence and intensity of SCD-related pain, school attendance on weekdays, and medication use.	
Sherry, McGuire, Mellins, Salmonson, Wallace & Nepom (1991)	USA	Design: Mixed methods. Aim: Report the clinical and psychological findings for children with psychosomatic musculoskeletal pain. Method: Clinical and psychological analysis using psychological scales and inventories.	100 children with diagnosed psychosomatic musculoskeletal pain. Psychosomatic pain defined as chronic or recurrent musculoskeletal pain in the absence of organic disease. Median age= 13 years. Median duration of symptoms= 1 year. Other symptoms: Abdominal pain (39)	School achievement: Wide Range Achievement Test Revised (25 children). Woodcock-Johnson Psychoeducational Battery (34 children). < 20th percentile on any sub score within each test was considered to be low school achievement.	Self-report.	The Family Environment Scale (232 individuals completed). Assesses family cohesion (interfamily psychological support), expression of affect, conflict, independence, achievement, orientation, intellectual-cultural orientation, moral religious emphasis, organization, and the extent to which rules control family life). The Brief Symptom Inventory (182 individuals). Measures perceived distress related to somatization,	The children were viewed as bright, however most children had normal intelligence and some unrecognised academic difficulty. These children had a significantly lower global wellbeing score compared to those with arthritis. 39% of children were incapacitated after physical activity. Most limited their activities and stopped playing sport. Most participants made considerable effort to please others, especially those in authority (teachers and parents).

			Ulcers (4) Headaches (37) Sleep disturbance (50) Monocular diplopia (4) Prior trauma (41) Excelled academically or socially (66) Described as bright (39) School problems (17) Identifiable pain role model (68) Recent move (25) Absence of father (28) Severe illness in family (20) Death in family (19) Major psychological trauma (5) Sexual abuse (9) Physical abuse (9) Marital discord (58)			obsessive-compulsiveness, interpersonal sensitivity, depression, anxiety, hostility, phobic anxiety, paranoid ideation and psychoticism. Global severity index rating of overall distress (T score of 63 < on global index or two subtests indicates significant distress. The Childhood Depression Inventory (50 individuals completed) to assess depression. Total score of 11-16 indicates mild depression and 17< indicates clinical depression. The Weschler Intelligence Scale for children revised: used to measure	IQ testing (62 patients) revealed a mean Full-Scale IQ score of 102 (range 69 to 126). The mean Verbal IQ score was 100 compared with a mean Performance IQ score of 105 ($p = .014$). 42% had a significant difference between their Verbal and Performance IQ scores at the $p < .05$ level and 31% had a difference significant at the $p < .01$ level. Children described as especially bright or gifted (27 of 39 tested) did not differ from the group in average Full-Scale IQ (mean 104, range 92 to 123). 7 (19%) of 37 patients with normal intelligence (Full-Scale IQ of 90 or greater) had

			Prior psychotherapy in the family (47). Multiple painful sites were common (66%) The pain was constant (63%) or intermittent (37%), 45% had hyperesthesia.			intelligence quotient (IQ in 62 children). Global wellbeing (completed by 80 children and their mothers) using a visual analog scale (0 = worst 100 = perfect) All inpatients (n = 51 and outpatients n = 31) had psychological interviews to assess depression, parental enmeshment and marital discord.	previously unknown low school achievement scores.
Sole & Castarlenas et al (2017)	Spain	Design: Descriptive Aim: To (1) examine the reactions of teachers and student teachers to children experiencing pain, (2) identify the most common challenges and potential resources	40 teachers and 318 student teachers teaching in secondary schools in Spain.	Teachers' responses to a student experiencing pain: Teacher Response to Children's Pain Inventory (Catalan measure named IRPEDNA-P) Consists of 24 statements that describe different	Self-report	Resources that teachers believed might help when dealing with students who have chronic pain: A list of resources that could potentially help teachers provide more effective responses to the needs of students experiencing chronic pain was developed	Experienced teachers endorsed solicitous responses significantly more often than student teachers. Absenteeism and the negative effect of pain on the ability of students to engage in school activities were the most common pain-related

		that are associated to dealing with them, and (3) examine whether their responses differed as a function of their experience or sex Method: Forty teachers and 318 student teachers completed a survey which included descriptive information, a questionnaire that assesses different responses of participants to children who experience pain, and provides a list of problems and resources that participants might encounter and implement, respectively, when dealing with these children.		reactions to children’s pain behaviours and actions, and the respondent is asked to indicate how often he or she enacts each one on a 5-point Likert rating scale (never, hardly ever, sometimes, often, or always). The items can be scored into 3 scales: Solicitousness, e.g., ‘‘I allow a student in pain to skip difficult school activities,’’ Discouraging, e.g., ‘‘I do not think his/her pain is something important because I think he/she is exaggerating a bit,’’ and Promotion of Well-Behaviours and Coping, e.g., ‘‘I try to distract him/her to avoid		by the researchers based on the results of a study by Logan and Curran who had interviewed a group of experienced school personnel. The list included the following resources: (1) having suitable knowledge about the definition and effect of chronic pain, (2) having clear instructions (guidelines) regarding how to help students who experience chronic pain, (3) how to effectively collaborate with and elicit support from health care professionals, and(4) how to effectively collaborate with the student’s families. Participants could choose 1 or more among these options.	challenges mentioned by the study participants overall. Responses reflecting solicitous responses were more frequent than discouraging responses (t(323)=26.93, $p <$ .001 Absenteeism was among the most common pain-related problems that teachers and student teachers endorsed (68% and 58%, respectively). Also common was the negative effect of pain on the ability of students to engage in certain activities (53%vs 60%). Four problems that were also commonly endorsed were the lack of knowledge about diseases that may cause chronic pain (43% vs 52%), the lack of knowledge

				his/her paying attention to the pain problem.'' Each scale score is computed as an average of the items associated with each scale; higher scores indicate a greater tendency to give solicitous, discouraging, or coping responses. Problems when dealing with students with chronic pain: Based on the results of a focus group made up of school personnel and the researchers clinical experience with young people with chronic pain, the researchers developed a list of 11 potential problems to assess the			about what is and what means having chronic pain (38% vs 47%), problems with making adjustments for chronic pain students (47% of students) and problems promoting a school policy that facilitates the integration and adaptation of children with chronic pain (43% vs 34%). The resource endorsed most often by teachers was having specific guidelines to learn what to do with a chronic pain student (80%). For the student teachers, having suitable knowledge about what chronic pain is and its effect on the school child was the most frequently indicated resource (89%).

				difficulties that teachers might have when trying to help students experiencing chronic pain: (1) students' absenteeism,(2) difficulties in helping students perform activities related to school work, (3) students demanding they be treated differently due to their pain condition, (4)a teacher's lack of knowledge about diseases that may cause chronic pain, (5) a teacher's lack of knowledge about the definition of chronic pain and its effect, (6) problems with making needed accommodations for students with chronic pain; for example, adapt certain gym			Developing better collaboration with families was the second most commonly indicated resource for both groups (78% of teachers, 84% of student teachers).Even though collaboration and support from healthcare professionals was among the least frequently indicated resource by both groups, it was still selected by a majority in both groups (70% and 75% of teachers and student teachers, respectively).

				activities or exercises, (7) difficulties in facilitating interactions with peers; (8) difficulties in being able to provide suitable information to other students,(9) problems with balancing the needs of a student with chronic pain with the needs of the students without chronic pain, (10) difficulties associated with developing a shared understanding of the problem with parents, and (11) problems with promoting a school policy that facilitates the integration and adaptation of children with chronic pain. Participants were			

				asked to indicate which of these problems they had encountered; they could indicate as many problems as they thought might be present.			
Stoff, Bacon & White (1989)	USA	Design: Descriptive Aim: To investigate the relationship between the effects of a rheumatic disease (RD) and school functioning in children with RD. Method: Parents, teachers, and Students responded to questionnaires investigating fatigue, distractibility, and absenteeism	46 children with rheumatic disease aged 5-18 years. Mean age= 12 years	The Child Activity and Health Questionnaire for Teachers (designed for this study): Teachers were asked to respond to questions about the child's classroom participation, level of fatigue and mobility limitations in school and the teacher's knowledge of disease. Absenteeism was also reported by teachers.	Self-report	The reading and math sub-tests of the Woodcock Johnson Psychoeducational Battery (WJ) were administered on an individual basis. The WJ is a commonly used battery, normed on a national stratified sample. Reliability coefficients for the achievement sub-tests are all at or above 0.89. The Swanson, Pelham and Nolan Checklist (SNAP): Questionnaire checklist developed to measure impulsivity, concentration, and peer aggression in	Inattention and distractibility were highly related to school achievement $p < 0.05$. Lower levels of school achievement were predicted by ratings of greater inattention and distractibility. A minimal relationship between fatigue and absenteeism and school performance was noted $p < 0.10$ Ratings of mobility used by physicians were unrelated to success on mathematics and reading achievement testing.

						school-aged children. Teacher input and parent input were obtained. A composite index was constructed by combining the inattention and distractibility components to form one score (I/D). Functional Class status: (Stein-brocker, Traieger & Batterman), describes the extent to which the diagnosis permits daily activities. The Chronic Activity Limitations Scale: Measure of mobility. The Child Activity and Health Questionnaire for Parents (designed for this study): Obtained input from parents about their child's level of	

						fatigue and mobility at home, and parents’ knowledge of the child’s disease.	
Sturge, Garralda,Boissin, Doré & Woo (1997)	UK	Design: Descriptive Aim: To examine school attendance in children with chronic arthritis in relation to illness severity or type of illness as well as in relation to a child's psychiatric adjustment and compliance with treatment. Method: Children and adolescents completed questionnaires to assess duration of illness, compliance with treatment and psychological adjustment. Teachers were also asked to complete questionnaires on the children's	13 children and adolescents (mean age 11 years) with juvenile chronic arthritis (73 with pauci- arthritis and 40 with polyarthritis).	School attendance: parents indicated the number of days their child was absent from school for any reason over the previous three terms (one academic year). School attendance was measured as percentage attendance out of expected attendances over the previous year.	Self-report	Illness severity was established according to illness type. The more severe form of juvenile chronic arthritis= polyarticular arthritis. It affects 30-40% of juvenile chronic arthritis groups and is defined as widespread arthritis affecting five or more joints during the first 6 months of illness. Compliance with treatment: Parents indicated on a four-point rating scale the child's co-operation with wearing splints, taking medication and physiotherapy. A score of four indicated full co-operation and a score	The mean attendance rate for the group was 92% (equivalent to 15 absent days a year) with a median of 97%. Attendance was significantly lower in the more severely affected poly group (90% vs 98% in the pauciarticular group; $p = 0.03$). Associations of school absence were found with (i) decreased compliance with physical treatments (r=ˇ0.35, $p < 0.05$, compliance with physiotherapy in the poly group and (ii) with child psychological deviance (r= 0.36 for parentally rated and r= 0.42 for teacher-

		education and behaviour.				of one lack of co-operation. Psychiatric adjustment: Rutter Behavioural Parental and Teacher Questionnaires. Scales consist of a list of symptoms covering emotions (i.e. misery, worry), behaviour (i.e. aggression, restlessness), relationship with peers and physical symptoms (i.e. wheezing, wetting). The relative incidence and severity of which during the previous year are rated on a three-point scale. Scores of 13 or more (parental scale) and of nine or more (teacher scale) indicate that the child has psychological	rated psychological deviance; both $p < 0.05$) in the pauciarticular group.

						problems or deviance, and is at high risk for psychiatric disorder.	
Ungerer, Horgan, Chaitow & Champion (1987)	Australia	Design: Questionnaire Aim: To assess the relations among disease severity, psychosocial functioning, and adjustment in three age groups—primary school, high school, and young adults with juvenile arthritis. Method: A questionnaire survey of 363 children and young adults with juvenile arthritis was conducted to assess the relations described. Parents were surveyed separately to determine which characteristics of the ill child at different ages most	363 children, adolescents and young adults with juvenile arthritis. Primary aged= 109 mean age= 10.6 High school aged= 163 mean age= 15.3 Young adult= 91 mean age= 21.7	Separate questionnaires were developed for each age group and covered topics including the number, frequency, and intimacy of social contacts, problems with social relationships, type of leisure activities, employment experience, ratings of physical health, illness related concerns, and the consequences of having JIA. The questions varied from multiple choice to open ended format.	Self-report and parent proxy report.	The Piers-Harris Children's Self-Concept Scale: Primary and high school groups. The scale consists of 80 statements about the self, the child responds using yes or no format. Total score is calculated by summing yes= 0 and no= 1 responses. The validity and reliability of this scale is established. Rating of disease severity: Parents rated on a scale from 1 (not present) to 5 (very severe) the extent to which each of five items were evident: pain, swelling, disability with upper limbs, difficulty	Primary age group: Associations between social functioning and self-concept were not found. Children in the lowest self-concept group within the primary aged group reported feeling lonely more often (p = 0.001) and experiencing more frequent teasing about their arthritis (p = 0.001) Those with low self-concept scores were also less likely to report liking most people in their class at school when compared with those with higher self-concept scores (p = 0.001) High school age group: Social

		significantly impact the well-being of the family.				walking, and difficulty dressing. Ratings were summed to produce a total score ranging from 5-25 with higher scores indicating higher disease severity.	functioning was associated with overall adjustment. Those with the lowest self-concept in the group were more likely to spend leisure time with family rather than friends (*p* = 0.02), they reported having fewer close friends (*p* = 0.001), and belonged to fewer school clubs (*p* = 0.005) These children also reported feeling lonely more often (*p* = 0.001) and being teased more frequently about their arthritis (*p* = 0.007) Those with a self-concept below the median score reported feeling discriminated against more often in social situations (*p* = 0.04). They were more likely to believe arthritis hindered their relationships (*p* =

							0.04) due to restrictions on activity, impaired appearance, and feeling different to healthy children. Those in the low self-concept group were more likely to plan to leave school at grade 10 rather than 12 (*p* = 0.001) But did not differ significantly from children with high self-concept on plans for future employment upon leaving school.
Vervoort, Logan, Goubert, De Clercq & Hublet (2014)	Belgium	Design: Cross sectional Aim: To examine child and adolescent pain severity in relation to various domains of school functioning and, in line with self-determination theory, the potentially protective role of	10650 children and adolescents. Equal distribution of boys (50.8%) and girls (49.2%). Mean age= 14.33 years	Child and adolescent school-related functioning: Several measures were used to assess school-related functioning including school attendance, academic performance, school-related pressure, school-	Self-report/ parent proxy report	Sociodemographic measures: Information about age, sex, school grade, family situation, and socioeconomic status was collected at the time of questionnaire administration. Family situation was coded as 'classic family unit,' 'one-parent family,' 'parent and	Higher pain grades were associated with poorer outcomes across all indices of school functioning (ie, school absenteeism, school-related pressure and satisfaction, and bullying experiences), with the exception of academic performance.

		perceived teacher support of child/adolescent autonomy and competence Method: Data from a large representative sample of Flemish school children and adolescents was collected as part of the World Health Organization (WHO) collaborative Health Behaviour in School-Aged Children (HBSC) survey. Child/adolescent pain severity was graded based on a paediatric pain classification system. The current study explored prevalence of pain among Flemish children/adolescents and examined		related satisfaction and peer victimization (i.e., being bullied at school). The majority of these measures, except school attendance, were mandatory or optional questions in the cross-national 2009/2010 HBSC survey. School attendance: Children and adolescents were requested to indicate the number of days that they had been absent from school because of pain problems in the past 6 months. Academic performance: Children and adolescents provided subjective reports		stepparent,' or 'other'. Family affluence was used as an indicator for individual socioeconomic status. The Family Affluence scale (FAS) is a composite indicator of self-reported socioeconomic status comprising 4 items that address family assets or conditions that indicate wealth, as follows: 'Does your family own a car, van or truck?' (0 = no; 1 = yes, one;2 = yes, two or more); 'Do you have your own bedroom for your-self?' (0 = no; 1 = yes); 'During the past 12 months, how many times did you travel away on holiday with your family?' (0 = not at all; 1 = once; 2 = twice, 3 = more than twice); How many computers does your family own? (0 =	The association between pain grade and school absenteeism was less pronounced when children perceived their teachers to be highly supportive of competence and autonomy. Teacher support of competence also appeared to buffer against the harmful effects of severe pain upon instances of bullying experiences at school.

		the specific role of pain severity across various domains of school functioning.		on how the teacher(s) evaluated their academic performance. This was elicited with the question ‘In your opinion, what does your class teacher(s) think about your school performance compared to your classmates’?’ This item was rated on a4-point scale with the endpoints ‘below average’ to ‘very good.’ School-related pressure: Child/adolescent perceived school-related effort was measured by means of 4 items (e.g., ‘I have too much school work,’ ‘I have more school work than I can handle’) rated on		none; 1 = one; 2 = two, 3 = more than two). Responses are summed on a scale of 1 to 10, with higher scores indicating greater affluence. The score (0–9) was divided into low, medium, high FAS score. Pain characteristics: Several measures were used to assess pain-related characteristics including pain intensity, frequency, health care use because of pain, pain location, and most troublesome pain. Most of these measures were added to the mandatory 2009/2010 HBSC survey, which included assessment only of the frequency of headache, stomach ache and back-ache during the past 6 months.	

				a 5-point scale with the endpoints ‘almost never’ to ‘very often.’ Cronbach’s alpha in the current study was 0.83. School-related satisfaction: Measured by means of 1 item. Specifically, children and adolescents were re-quested to indicate ‘how they felt about school at present’ using a 4-point scale with the endpoints ‘I don’t like it at all’ to ‘I like it a lot.’ Bully victimization at school: Children and adolescents were requested to indicate how much they had been bullied at school during the past couple of		Pain intensity: Children’s and adolescents’ experienced pain intensity was assessed by means of 3 items. Child and adolescent participants rated their current, worst, and average pain intensity during the past 6 months on a numeric rating scale (NRS) of 0 to10, with the end points ‘no pain’ and a ‘lot of pain.’ Mean pain intensity was calculated as the mean of current pain intensity, and worst and average pain intensity during the past 6 months. General pain frequency: Children and adolescents were also requested to indicate the number of days that they had experienced pain	

				months using a 5-point scale with the end points 'I have not been bullied at school in the past couple of weeks' to 'several times a week.' Teacher support: Child/adolescent perceived teacher support was indexed by 8 items reflecting 2 different dimensions derived from self-determination theory, competence and autonomy support. Participants were requested to rate each item on a 5-pointscale, with the endpoints 'strongly disagree' to 'strongly agree'(e.g., autonomy support: 'my		during the past 6 months. Health care use: Health care use because of a pain problem was assessed by asking children and adolescents to indicate the number of times that they had consulted their general practitioner or specialist in the past 6 months because of their pain. Specific pain location, frequency, and most troublesome pain: Specific pain location(s) and its frequency were assessed by means of 9 items referring to different pain locations (ie, headache, stomach ache, back pain, neck pain, ear pain, sore throat, chest pain, musculoskeletal pain	

				teachers try to understand how I see things before suggesting a new way to do things; competence support: ‘My teachers encourage me when I do school work’). Cronbach’s alpha values in the current study were 0.84 and 0.78, respectively.		[referred to as pain in the arms or hand, legs, or feet], and other pain); for each pain location, children were required to indicate the frequency of pain in the last 6 months on a5-point scale, as follows: about every day, more than once a week, about every week, about every month, or rarely or never. In addition, children were also requested to report on their most troublesome pain location: Children had to indicate which pain complaint (i.e., headache, stomach ache, back pain, neck pain, ear pain, sore throat, chest pain, and musculoskeletal pain or other) had troubled them the most in the past 6 months.	

						Pain severity: The severity of a child's pain problem was graded based on the Graded Chronic Pain Scale. The GCPS consists of 7 items and classifies participants into 1 of 5 categories according to characteristic pain intensity and disability indexed by disability days and pain interference. Pain intensity was categorized into low (<5) vs high (>5) pain according to the original GCPS. The number of disability days was indexed by 1 item assessing the number of days in the last 6 months the child/adolescent had been kept from doing his/her usual activities. Number of disability days (0–180) were classified in	

						disability points as follows: 0 to 6 days, 0 points; 7 to 14 days, 1 point;15 to 30 days, 2 points; and >31 days, 3 points. Only the item assessing interference with daily/usual activities was used; that is, children/adolescents were requested to rate the degree to which pain interfered with their daily/usual activities in the past 6 months using an NRS of 0 to 10 with the endpoints ranging from 'no interference' to 'unable to carry on any activities'. Degree of interference was classified into disability points; <3 interference score, 0 points;>3 and <5 interference score, 1 points;P5 and <7 interference score, 2 points; and >7	

						interference score, 3 points. Based on characteristic pain intensity and total disability points, pain severity was classified into 5 grades as follows: grade 0, no pain problem in the prior 6 months; grade I, low pain intensity (intensity index<5/10) and low disability (<3 disability points); grade II, high pain intensity (intensity index >5/10) and low disability (<3 disability points); grade III, moderate disability (3 or 4 disability points), and grade IV, high disability (5 or 6 disability points).	
Waite-Jones & Swallow (2018)	UK	Design: Qualitative	8 young people diagnosed with JA aged 10-18 years old.	Interviews and focus groups relating to peer	Self-report	No additional measures	6 major themes and sub-themes emerged from the views of young people,

		Aim: To gain a deeper understanding of what peer-based social support means to young people with juvenile arthritis within the UK and ways in which it could be best provided Method: A secondary analysis of underused, descriptively rich data relating to peer-based support contributed by young people with juvenile arthritis, their parents/carers and healthcare professionals from a qualitative study (seeking their views on a potential self-management mobile-app) was carried out using methods suggested by Interpretive		based support for children with JIA.			parents/carers and healthcare professionals on peer-based contact for young people with juvenile arthritis: 1. A new kind of normality: Reduced feelings of isolation, Shared similarities, Identification based on shared experience of condition rather than physical effects, Impact of young person's age 2. Understanding: Feeling understood, acceptance 3. Relief and Reassurance 4. Shared learning: Learning from each other, Increased self-efficacy through helping others 5. Ambivalence towards peer contact: Peer contact not always desired,

		Phenomenological Analysis.					Potential price paid for belonging 6. No one-size fits all: varied access to peer support required, Not all forms of peer contact provision acceptable, Varied types of access to peer support required.
Whitehouse, Shope, Sullivan, Kulik & Chen-lin (1989)	USA	Design: Descriptive Aim: To explore parent reported problems at school for children with juvenile rheumatoid arthritis (JRA). To determine parent knowledge of the PL94-142 law. Method: A pre-coded questionnaire containing 67 items, the majority of which required parents to select a categorical response, with the remainder	135 children and adolescents with JRA 68 percent (92) girls and 32 percent (43) boys with ages ranging from 4 to 18 (mean = 11.5) years. Grade level: preschool 5 percent, elementary 39 percent, junior high 24 percent, senior high 19 percent, and unclassified 1 percent. Systemic arthritis: 8%	A pre-coded questionnaire containing 67 items, the majority of which required parents to select a categorical response, with the remainder requiring scaled or narrative responses were sent to 135 parents of children with arthritis. The 67 items explored school problems. Eleven activities commonly performed in the school setting	Parent proxy report	A pre-coded questionnaire containing 67 items, the majority of which required parents to select a categorical response, with the remainder requiring scaled or narrative responses were sent to 135 parents of children with arthritis. To determine parent knowledge about PL 94-142, parents were asked what PL94-142 meant for their child. They were considered to have knowledge of the law if their answer included at least one of four key points:	With few exceptions, the 135 children were able to attend their regular public or private school. Only six children were in an alternative school because of JRA and/or the need for special services not avail-able through the regular school. Arthritis-related school absences occurred for 31 percent (42) of the children. The average was 3.6 days per year and the range was from 1 to 45 days. Children with systemic JRA were

		requiring scaled or narrative responses were sent to 135 parents of children with arthritis. To determine parent knowledge about PL 94-142, parents were asked what PL94-142 meant for their child.	Polyarticular: 39% Pauci articular: 53%	were listed on the questionnaire as well as another problem category. Parents indicated if their child currently, or in the past, had experienced problems with each of these activities.		equal opportunity to learn; access to help; education in the least restrictive environment; and a right to as full participation as possible. Medical records and physician's reports were used to classify children by arthritis type (systemic, polyarticular, and pauciarticular)	more likely to miss school ($X2 = 10.6$, $p < 0.05$), averaging 8.6 days per year, than children with polyarticular disease (averaging 2.6 days) or children with pauciarticular disease (averaging 1.6 days). The number of problems experienced with activities commonly performed in school per child ranged from 0 to 10 with a mean of 1.4 problems. Of the 63 children who experienced problems, 18 children had one problem, 17 had two, and 28 had three or more problems. Writing represented the most frequent single problem. Problems were categorised into four themes: hand activities, mobility activities, upper-extremity activities,

							and blackboard activities. Hand activities were the most frequently reported problems (81), followed by: mobility activities (61); upper extremity activities (29); and blackboard activities (6). Ninety-six percent (129) of the children were enrolled in schools that had a physical education program. Fifty-two percent (67) of these children attended physical education and participated fully, 21 percent (27) attended but did not participate fully, 8 percent (10) attended only irregularly and 19 percent (25) did not attend at all. Older children were less likely to participate fully (r = 0.42, *p* < 0.01), as

							were children with systemic/polyarticular JRA (F= 11.14, *p* < 0.01), and children for whom an IEP had been developed (t = 2.95, *p* < 0.01).
Yadav & Yadav (2013)	India	Design: Case-control Aim: To assess school adjustment, self-concept, self-esteem, general wellbeing and parent–child relationship in children with Juvenile Idiopathic Arthritis (JIA) and to study the correlation of these parameters with chronicity of disease, number of active joints, laboratory parameters of disease activity and JIA subtypes. Method: 64 children were recruited for	64 children (32 children with juvenile idiopathic arthritis 32 age and sex matched control healthy children) Mean age for cases= 12.75 Controls= 12.73 Thirteen patients had poly-articular JIA; eight had Enthesitis related arthritis and systemic onset JIA and three had Oligoarticular JIA.	Adjustment Inventory for School Students (AISS): Measures emotional, social and educational adjustment. All three domains have 20 questions each. Each question is scored as zero or one and added to give a final score for each domain. Final scores for each domain are summarized into 5 groups. Scores of <2 indicates excellent adjustment, score 3–4 indicates good, 5–7 average, 8–10 unsatisfactory and a score of >11	Self-report	PGI General Well Being Measure: Measures subjective wellbeing in terms of positive mental health. It comprises of 20 questions which measure freedom from disease, concern, worry, distress, energy level, satisfaction, cheerfulness, relaxation, emotional and behaviour control. The answer to each question is either yes or no. Each yes is scored as one and no as zero. The summation of scores give the total score (ranging from minimum 0 to maximum 20)	Adjustment of school students: JIA cases were poorly adjusted socially (*p* = 0.002) and educationally (*p* = 0.002) compared to healthy controls. Overall adjustment was also significantly lower for cases when compared to healthy controls (*p* = 0.006)

		analysis. Self-report questionnaires which included PGI General Wellbeing Measure, Adjustment Inventory for School Students, Parent Child Relationship Scale, Self Esteem Inventory and Self Concept Questionnaires were used.		indicates poor adjustment.		Higher scores indicate better general wellbeing. Parent Child Relationship Scale (PCRS): A 100 item questionnaire with 5 point graded answers to each question. It measures ten dimensions of parent–child relation (separately for father and mother) namely: protecting, symbolic punishment, rejecting, object punishment, demanding, indifference, symbolic reward, loving, object reward and neglect. Each question is scored 1–5 and summated to give 10 separate scores (one for each dimension minimum 5 to maximum 50) for each parent.	

						Self-Concept Questionnaire (SCQ): Evaluates six domains of self-concept: physical, social, temperamental, educational, moral and intellectual. The inventory contains 48 questions, 8 for each domain. Each question has 5 responses, scored 1-5 and added to sum individual score for each domain. Higher scores indicate higher self-concept. Scores between 33 and 40 implies high:, 25–32 above average,17–24 average, 9–16 below average and scores up to 8 implies low self-concept. Self-Esteem inventory (SEIS): Two parts with 30 questions in each.	

						Part 1(personally-perceived self-esteem) pertains to what the patient feels about himself/herself and part 2 (socially-perceived self-esteem) to what others feel about the patient. In both parts, each question has seven responses with scores from 1 to 7. Total score ranges from minimum 30 to maximum 210. If part 1's score is higher than the socially-perceived score, then the subject has positive self; if both scores are equal, then the subject has a balanced self-esteem.	
Zhang & Deng et al (2015)	China	Design: Cross sectional Aim: To investigate the prevalence of four types of chronic	3000 high school students aged 16-18. 2849 questionnaires (95 %) were	Learning burden: The questionnaire asked questions about "extracurricular learning tasks," "average daily	Self-report	A questionnaire developed for the study asked: in the last 3 months, how often did you feel frequent or continuous pain in	Prolonged study time, heavy learning burden, and pressure from parents, teachers and classmates were found to be closely associated with the

		pain (headache, abdominal pain, neck and shoulder pain (NSP), and low back pain (LBP)) and to explore the relationship between the prevalence of chronic pain and self-reported academic pressure in high school students in Shanghai, China Method: Three thousand students were randomly surveyed on related issues using a questionnaire, and the results were analysed using a multivariate logistic regression model.	returned and 2587 questionnaires (86.2 %) were considered valid.	sitting time" and "academic ranking". Self-reported feelings of the adolescents, such as "very tired after every day learning" were also gathered.		neck/shoulder, low back, head and abdomen" The onset frequency of pain was classified into the following four levels: "almost never", less than once per month; "occasionally",1–3times per month; "often",1–3 times per week; and "always", more than 3 times per week.	prevalence of chronic pain. Learning burden: 60.7 % of the high school students frequently felt tired after every day learning, and 32.2 % of students received academic pressure from parents and teachers.

Appendix C Quality assessment tables

C.1 Quality assessment of included qualitative studies

Table C1

Quality Assessment of Included Qualitative Studies.

Reference	Study Design	Clear statement of aims?	Qualitative methodology appropriate?	Appropriate design to address aims?	Appropriate recruitment strategy?	Data collected to address research issue?	Relationship between researcher and participant's adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Clear statement of findings?	How valuable is the research?
Aasland, Flatö, & Vik., (1997)	Qualitative Semi Structured Interviews	Yes	Yes	Can't tell	Yes	Yes	No	Yes	Yes	Yes	Valuable

Reference	Study Design	Clear statement of aims?	Qualitative methodology appropriate?	Appropriate design to address aims?	Appropriate recruitment strategy?	Data collected to address research issue?	Relationship between researcher and participant's adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Clear statement of findings?	How valuable is the research?
Barlow, Shaw & Harrison., (1999)	Qualitative Focus Groups	Yes	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Valuable
Batthish et al., (2005)	Qualitative Interviews	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Valuable
Beresford & Sloper., (2003)	Qualitative Semi Structured Interviews	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable
Condon, O'Regan, MacDermott & Killeen, (2017)	Qualitative Semi Structured Interviews	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Farre, Ryan, McNiven & McDonagh (2019)	Qualitative Narrative and Semi Structured Interviews	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Valuable

Reference	Study Design	Clear statement of aims?	Qualitative methodology appropriate?	Appropriate design to address aims?	Appropriate recruitment strategy?	Data collected to address research issue?	Relationship between researcher and participant's adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Clear statement of findings?	How valuable is the research?
Guzman, Gómez-Ramírez et al.,(2014)	Qualitative Focus Groups	Yes	Yes	Yes	Yes	Yes	No	Can't tell	Yes	Yes	Valuable
Hackett (2003)	Qualitative Semi Structured Interviews	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable
Konkol & Lineberry et al (1989)	Qualitative Questionnaire	Yes	Yes	Yes	Yes	Yes	Can't tell	Can't tell	Yes	Yes	Valuable
Logan & Curran (2004)	Qualitative Focus Group	Yes	Yes	Yes	Yes	Yes	Can't tell	Yes	Yes	Yes	Valuable
Sen & Morgan et al (2017)	Qualitative Semi Structured Interviews	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Valuable

Reference	Study Design	Clear statement of aims?	Qualitative methodology appropriate?	Appropriate design to address aims?	Appropriate recruitment strategy?	Data collected to address research issue?	Relationship between researcher and participant's adequately considered?	Ethical issues considered?	Data analysis sufficiently rigorous?	Clear statement of findings?	How valuable is the research?
Waite-Jones & Swallow (2018)	Qualitative Semi Structured Interviews and Focus Groups	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Valuable

C.2 Quality assessment of included studies using MMAT Mixed Methods Tool

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Assa, Ish-Tov, Rinawi& Shamir.,(2015)	Case- control	Yes- To assess school-related quality of life and school absenteeism in children with Inflamatory bowel disease (IBD compared with functional	Yes- data collected via semi structured questionnaire addressing the impact of gastrointestinal symptoms on the child's school absenteeism and participation in school and after-school activities.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
		abdominal pain (FAP) and healthy controls.	
Aasland & Diseth., (1999)	Mixed methods using semi structured interview, questionnaires and established measures of psychosocial outcomes	Yes-To explore the Harter Self-Perception Profile for Adolescents (SPPA) as an indicator of psychosocial outcomes in adolescents with chronic physical disorders.	Yes- data collected on psychosocial outcome using established measures (the semi-structured Child Assessment Schedule (CAS) interview, the Youth Self Report (YSR) and Child Behaviour Checklist (CBCL) questionnaires).
Abdul-sattar, Abou El Magd & Negm,. (2014)	Cross sectional	Yes- To investigate the factors associated with school absenteeism and poor school functioning in Egyptian children and adolescents with juvenile idiopathic arthritis (JIA).	Yes- data collected via assessment of socioeconomic and demographic characteristics, disease activity (JIDaS-27), functional ability (cHaQ), depressive symptoms (cDI score), and school functioning (PedsQl 4.0).

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Abdul-Sattar, Elewa, Enass, El-Shahawy &Waly. (2013)	Quant descriptive	Yes- To identify the possible determinants of impaired health-related quality of life (HRQOl) in Egyptian children and adolescents with juvenile idiopathic arthritis (JIA).	Yes- data collected on socio-economic and demographic characteristics, the HRQOl using Pediatric Quality of life Inventory 4.0 generic core Scale, disease activity using the Juvenile arthritis Disease activity Score, functional ability using the childhood health assessment questionnaire (cHaQ), pain score on visual analog scale and psychological symptoms using the children’s Depression Inventory (cDI) score.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Aggarwal,Khubchandani et al., (2018)	Cross sectional (case-control)	Yes- To cross-culturally adapt and validate the Hindi parent, child/adult version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) in patients with juvenile idiopathic arthritis (JIA).	Yes- data collected on pain, health related quality of life and constructs on the JAMAR (including overall well-being, functional status, health-related quality of life (HRQoL), pain, morning stiffness, disease activity/status/ course, articular and extra-articular involvement, drug-related side effects/compliance and satisfaction with illness outcome.)
Cagliyan-Turk & Sahin., (2020)	Cross sectional (case-control)	Yes-To determine the frequency of juvenile fibromyalgia syndrome (JFMS) among children and adolescents in Turkey, and its impact by comparing the levels of academic success, depression and quality of life (QoL) in individuals with and without JFMS.	Yes- data collected on levels of academic success, depression and quality of life (QoL) in individuals with and without JFMS.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Armbrust, Bos et al., (2016)	Randomised control trial	Yes- To determine the effects of Rheumates@Work, an internet-based program supplemented with 4 group ses- sions, aimed at improving physical activity, exercise capacity, health-related quality of life (HRQoL), and participation in children with juvenile idiopathic arthritis.	Yes- data collected on physical activity, exercise capacity, health-related quality of life (HRQoL), and participation in children with juvenile idiopathic arthritis.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Armbrust, Lelieveld et al., (2016).	Cross sectional, descriptive	Yes- To assess the presence and severity of fatigue in patients with JIA, including factors presumed associated with fatigue (e.g., disease activity, disability, pain, physical activity, exercise capacity, and self-efficacy), and whether fatigue is related to participation in physical education classes, school attendance, and sports frequency.	Yes- data collected on fatigue, assessed using the Pediatric-Quality-of-Life-Inventory (PedsQl)-Fatigue-scale and energy level assessed using a VAS scale. Other outcome measurements were disease activity (VAS Physician Global Assessment Scale), disability (Childhood Health Assessment Questionnaire), physical activity (accelerometer), exercise capacity (Bruce treadmill test), self-efficacy (Childhood Arthritis Self-Efficacy Scale), and participation (self-report).
Barthel, Ravens-Siberer et al., (2018).	Longitudinal	Yes- Identifying predictors of generic health-related quality of life (HRQoL) in chronically ill children and adolescents over time.	Yes- data collected on health related quality of life in children and adolescents with asthma, diabetes and juvenile arthritis

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Bartholomew, Koenning, Dahlquist & Barron., (1994).	Mixed Methods	Yes- To describe the use of the PRECEDE model (predisposing, reinforcing, and enabling causes in educational diagnosis and evaluation) to organize needs assessment data in order to define self-management behaviours and plan an educational intervention for children with juvenile rheumatoid arthritis (IRA) and their families.	Yes- data collected from several sources: 1) literature review, 2) survey of parents of 51 children with IRA, 3) group interview of seven parents of children with IRA, 4) results of pilot programs, and 5) clinical experience of an interdisciplinary paediatric rheumatology team.
Bessisso, Bener, Elsaid, Al-Khalaf & Huzaima., (2005)	Cross Sectional Survey	Yes- To determine the prevalence rate and impact of headache in schoolchildren on school attendance with particular attention to migraine.	Yes- data collected on prevalance of headache and impact on school performance/attendance via questionnaire.
Berrin, Malcarne et al., (2006)	Quant descriptive	Yes- To test a model of how pain and fatigue, independently or in combination, relate to school functioning in paediatric cerebral palsy (CP)	Yes- data collected on Pediatric Quality of Life Inventory™ (PedsQL™) 4.0 Generic Core Scales and the PedsQL™ 3.0 Cerebral Palsy Module.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Boey, Omar & Phillips (2003)	Cross Sectional Survey	Yes- To investigate the extent to which recurrent abdominal pain and other factors were associated with academic achievement among Year-6 schoolchildren.	Yes- data collected on academic acheivement, recurrent abdominal pain, socio-economic status, life events, demographic and other details.
Breuner, Smith & Womack (2004)	Retrospective	Yes- To examine possible risk and protective factors for school absenteeism among adolescents referred to a hospital-based behavioural treatment program.	Yes- data collected on school absenteeism, school performance, participation in extracurricular activty, anxiety, depression, headache type and frequency through interviews and screening questionnaires.
Castro, Rockett et al., (2013)	Cross Sectional	Yes- To evaluate the prevalence of headache in school-aged children and its relationship to anthropometric characteristics, lifestyle, and quality of life.	Yes- data collected on quality of life, sociodemographic characteristics (age, sex, socioeconomic status, educational system, and class schedule),clinical variables (presence of headache and menarche),anthropometric data, and lifestyle variables (alcohol consumption, smoking, and extracurricular activities.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Charuvanij & Chaiyadech (2018)	Cross Sectional	Yes- To measure the Health related quality of life (HRQOL) and identify factors influencing the HRQOL in Thai children with Juvenile Idiopathic Arthritis (JIA)	Yes- data collected on health related quality of life, age, sex, age at disease onset, age at diagnosis, JIA subtype, current clinical status, active joint count, limited joint count ,physician global assessment (PGA) of disease activity, patient/parent global assessment of well-being (PGW), medications and complications of JIA
Chomistek, & Johnson et al (2019)	Cross Sectional Observational	Yes- To identify patient-reported school barriers and their associated impact in juvenile idiopathic arthritis (JIA)	Yes- data collected on the barriers experienced by JIA patients at school, demographics, diagnosis, and disease course (obtained from health records).

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Claar, Kaczynski, Minster, McDonald, Nolan & LeBel (2012)	Quant descriptive	Yes- To examine whether school functioning and attendance improved after a multidisciplinary evaluation focusing on a return to functioning despite headaches.	Yes- data collected on the Paediatric Quality of Life School Functioning Scale, and semi-structured evaluation assessing patients' headaches, impact of headaches on functioning and activities (including school), patient's school attendance and performance, patient's current psychological functioning and psychosocial stressors, and family psychiatric history.
Clementi, Chang, Gambhir, Lebel & Logan (2019)	Retrospective cohort study	Yes- To examine the impact of sleep on functional outcomes and to explore pain-related fear as a mediator of the association between sleep problems and functioning	Yes- data collected on Functional disability, sleep and headache frequency.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Connelly (2003)	Descriptive Correlational study	Yes- Measuring how school-age children with Juvenile Rheumatoid Arthritis (JRA) live with this chronic pediatric disease and its impact on psychosocial development and family functioning, to examine the relationship between family functioning, hope, and quality of life in school-age children with JRA.	Yes- data collected on quality of life, childrens feelings of hope, and family functioning
Durmaz & Alayli et al (2013)	Cross Sectional	Yes- To determine the prevalence of JFMS in the urban population of Samsun and to determine the impact of JFMS on depression symptoms, school performance and quality of life (QOL).	Yes- data collected on qualty of life, school absence, depression and pain
Doležalová, Bohm et al., (2018)	Cross sectional (case-control)	Yes- Reports the results of the cross-cultural adaptation and validation of the parent and patient versions of the JAMAR in the Czech language.	Yes

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Subhadra & Taub et al (2010)	Observational	Yes- To describe sociodemographic, pain and health characteristics of a cohort of children presenting to an urban tertiary paediatric chronic pain clinic; and to document the role of sociodemographic factors, including child sex, age and the impact of minority status, on pain and health outcomes in patients.	Yes- data collected on functional disability, child health, demographic information, child somitisation and pain intensity
Fatoye (2008)	Cross Sectional	Yes- To identify the range of neuromuscular performance, functional range of motion (ROM) and QoL indices, and investigate the relationships between these features in children with Hypermobility Syndrome (HMS).	Yes- data collected on quality of life, pain intesnity, neuromuscular performance and range of motion.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Fischer & Barthel et al (2019)	Cross Sectional	Yes- examines HRQoL of children and adolescents with three different chronic conditions (i.e., diabetes mellitus, asthma, juvenile arthritis) using the computer-adaptive test Kids-CAT, comprising five HRQoL domains: physical well-being, psychological well-being, parent relations, social support and peers, and school well-being. Further, associations between HRQoL and distinct clinical data and medical assessments are investigated to explore how much variability of the five domains can be explained by these variables.	Yes- data collected on quality of life, functional disability, and paediatrician provided information on year of diagnosis, co-morbidity, disease control, and paediatricians' assessment of patients' overall health status.
Fichtel & Larsson (2002)	Quant descriptive	Yes-To examine the prevalence of headache, its comorbidity with other pains and psychosocial impact among adolescents	Yes- data collected on functional disability, school leave, illness behaviour, anxiety, medication use, frequency and severity of pain.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Fujita, Fujiwara,Maki, Shibasaki & Shigeta (2009)	Quant non randomised	Yes- To investigate the headache types, the clinical features, the treatments and the prognoses of chronic daily headache (CDH) associated with school phobia in our paediatric headache specialty clinic. To also examine whether CDH with school phobia is different in characteristics compared to CDH without school phobia.	Yes- data collected on headache type, clinical features, treatments, school attendance, psychiatric disorders.
Garmy, Hansson, Vilhjalmsson & Kristjansdottir (2019)	Cross sectional survey	Yes- The aim of this study was to examine the use of analgesics and its association with bullying among school-age children while considering regular bodily pain.	Yes- data collected on bullying, pain experienced and medication used.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Garralda & Rangel (2004)	Quant non randomised	Yes- To compare impairment, illness attitudes and coping mechanisms in childhood chronic fatigue syndrome CFS and in other paediatric disorders via interview and validated measures.	Yes- data collected on functional disability, degree of impairment, sociodemographic factors, illness attitude and school attendance.
Gibler, Beckmann, Lynch-Jordan, Kashikar-Zuck & Mano (2019)	Quant non randomised	Yes- To examine specific aspects of school anxiety in a paediatric chronic pain population.	Yes- data collected on school functioning and self perception.
Gil, Carson et al (2003)	Quant descriptive	Yes- To determine the extent to which daily stress and mood are associated with pain, health-care use, and school activity in adolescents with sickle cell disease (SCD)	Yes- data collected on self report diaries, psychological distress, daily hassles, mood, stress, school and other activities
Greco, Freeman & Dufton (2006)	Quant non randomised	Yes- This study compared children with frequent abdominal pain with a pain-free control group on measures of overt and relational victimization and examined the link between abdominal pain and school-related functioning.	Yes- data collected on pain, academic competence, social skills and use of medical services

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Groenewald, Giles & Palermo, (2019)	Quant descriptive	Yes- To estimate the national burden of school absenteeism associated with pain among 6 to17-year-old children in the United States.	Yes- data collected on school absenteeism, pain, sociodemographic variables and comorbid conditions
Haberfehlner & Visser et al (2011)	Quant non randomised	Yes- To describe handwriting difficulties of primary school children with juvenile idiopathic arthritis (JIA), and to investigate possible correlations with hand function and writing performance	Yes- data collected on pain, handwriting difficulty, disease activity and hand function.
Haraldstad, Sorum, Eide, Natvig & Helseth (2011)	Quant descriptive	Yes- to study the prevalence of pain, its association with age, gender, and socio-demographics, its frequency, duration, and type. A further aim is to describe the impact of pain on daily living, perceived triggers of pain, and correspondence between parents' and children's perceptions of pain.	Yes- data collected on demographics, pain frequency and intensity, and pain impact on daily life activities including school

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Haverman & Grootenhuis et al (2012)	Quant non randomised	Yes- To assess health-related quality of life (HRQOL) and its predictors in a group of children and adolescents with Juvenile Idiopathic Arthritis (JIA).	Yes- data collected on health related quality of life, functional ability, and sociodemographic information.
Ho, Bennett, Cox & Poole (2009)	Quant descriptive	Yes- To examine the patterns of cognitive functioning and academic achievement in children and adolescents with chronic pain attending a tertiary-care interdisciplinary pain service.	Yes- data collected on standardized psychoeducational testing results of children and adolescents with chronic pain.
Jones, Stratton, Reilly & Unnithan, (2004)	Quant descriptive	Yes- To provide evidence of the prevalence and consequences of recurrent low-back pain in children from Northwest England.	Yes- data collected on low back pain and impact on life and daily activities

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Kaczynski, Claar & LeBel (2012)	Quant non randomised	Yes-To assess for differences in headache characteristics and psychosocial factors based on headache diagnosis, and to evaluate whether headache diagnosis moderates relations between psychosocial factors and school difficulties.	Yes- data collected on anxiety, depression, headache characteristics, school functioning and parental protective behaviours
Kashikar-Zuck & Johnston et al (2010)	Quant descriptive	Yes- To describe school absences in adolescents with Juvenile Primary Fibromyalgia Syndrome (JPFS) and examine the relationship between school absenteeism, pain, psychiatric symptoms, and maternal pain history.	Yes- data collected on school absence, pain, psychiatric symptoms and maternal pain history.
Kashikar-Zuck & Zafar et al (2007)	Quant non randomised	Yes- To assess peer relationships of adolescents with juvenile primary fibromyalgia syndrome (JPFS) compared with matched classroom comparison peers (MCCPs) without a chronic illness.	Yes- data collected on social reputation and social acceptance.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Kashikar-Zuck & Zafar et al (2013)	Quant non randomised	Yes- To compare pain characteristics, quality of life, and emotional functioning among youth with paediatric chronic migraine (CM) and juvenile fibromyalgia (JFM)	Yes- data collected on quality of life, pain intensity, depression and anxiety symptoms
Kernick, Reinhold & Campbell (2009)	Quant descriptive	Yes- To quantify the impact of headache in a school population.	Yes- data collected on headache frequency, disease specific impact, and quality of life impact
Khan & Tran et al (2015)	Quant descriptive	Yes- To empirically test a model of associations between constructs predicting school functioning in youth with chronic pain to examine the direct effect of anxiety on school attendance and other indicators of school-related disability	Yes- data collected on school fucntioning and anxiety
Kuburovic, Pasic et al., (2014)	Cross Sectional (Case-control)	Yes- To evaluate levels of health-related quality of life (HRQOL) and the presence of anxiety and depressive symptoms in children with primary immunodeficiency disease (PID).	Yes- data collected on health related quality of life, anxiety and depressive symptoms.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Larsson, Melin, Lamminen & Ullstedt (1987)	Quant non randomised	Yes- To examine whether a self-help relaxation training (SHR) approach dealing with headache per se would more effectively reduce headache than a problem-discussion condition (PDC), focusing on common psychological stressors or headache elicitors.	Yes- data collected on school absence, medication consumption, social relationships, headache annoyance, frequency and intensity.
Logan, Gray, Iversen & Kim (2017)	Quant non randomised	Yes- To investigate school self-efficacy and sense of school membership (collectively “school self-concept”) as potential influences on impaired school function among adolescents with chronic pain, including comparison of adolescents with primary pain to those with disease-based pain and pain-free peers.	Yes- data collected on school efficacy, school membership, school absence, pain frequency and self efficacy.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Logan & Simons (2010)	Quant descriptive	Yes- To establish feasibility and preliminary efficacy of ‘‘Coping with Pain in School’’ (CPS), an intervention to improve school functioning in adolescents with chronic pain and depressive symptoms	Yes- data collected on pain, school absence, academic performance, pain interference, academic competence
Logan, Simons & Carpino (2011)	Quant descriptive	Yes- To test the hypothesis that parental pain catastrophizing and parental protective responses to child pain influence the extent of school impairment in children with chronic pain.	Yes- data collected on attendance, school functioning, parental catastrophizing and parental protectiveness.
Logan, Simons & Kaczynski (2009)	Quant descriptive	Yes- To explore associations between depressive symptoms and school functioning, including school attendance, academic performance, self-perceived academic competence, and teacher-rated school adjustment among adolescent chronic pain patients.	Yes- data collected on depressive symptoms, school functioning, attendance, academic performance, academic competence and school adjustment.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Logan, Simons, Stein & Chastain (2008)	Quant descriptive	Yes- To assess and describe school functioning among adolescents presenting for evaluation in a tertiary care paediatric chronic pain clinic	Yes- data collected on attendance, school performance, academic competence, and school acommodations made
Mandic, Baraban & Boranic (2003)	Quant non randomised	Yes- To assess basic personality traits and specific behaviour characteristics in adolescents with chronic tension type headache.	Yes- data collected on school acheivement, personality an behaviour triats, IQ
Mihaylova & Varbanova et al (2018)	Quant non randomised	Yes-To assess the results of the cross-cultural adaptation and validation of the parent and patient versions of the JAMAR in the Bulgarian language	Yes- data collected on school attendance and health related quality of life
Milatz & Klotsche et al (2019)	Quant descriptive	Yes- to (1) estimate the prevalence of participation in school sports among patients with JIA; (2) determine the correlates associated with school sports absenteeism; and(3) investigate whether attendance in school sports has changed in the era of biologics	Yes- data collected on sports attendance functional ability and disease activity

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Mohseni, Pei,Bagheri-Nesami, & Shayesteh-Azar (2007)	Cross Sectional Survey	Yes- To determine the prevalence of nonspecific LBP and associated risk factors in school-age children	Yes- data collected on point, last month, last 6-month period, and annual prevalence of LBP. Questions regarding -Lifestyle data -Prevalence of LBP -Characteristics of LBP
Neder, & Van Weelden et al (2015)	Quant non randomised	Yes- To evaluate the health-related quality of life (HRQL) in paediatric leprosy patients.	Yes- data collected on health related quality of life
Nijhof, Van de Putte, Wulffraat & Nijhof (2016)	Quant non randomised	Yes- To determine the prevalence of severe fatigue and fatigue-related limitations among adolescents with juvenile idiopathic arthritis (JIA) and other paediatric rheumatic diseases (PRDs). In addition, to assess the effect of disease activity and pain on the severity of fatigue.	Yes- data collected on school absence, physical functioning and fatigue

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Norgaard & Herlin (2019)	Quant non randomised	Yes- To investigate the habits of patients with JIA regarding participation in club sports, leisure-time physical activity, and school-educational physical activity and relate this to objectively measured physical activity using accelerometry and to compare the findings with those in healthy controls.	Yes- data collected on leisure time physical acitivity, school physical acitivity and participation in club sports
Nyame & Ambrosy et al (2010)	Quant Descriptive	Yes- To longitudinally evaluate the epidemiological characteristics of headaches in a school-based, community setting and to determine the impact of headache symptoms on the health of children	Yes- data collected on quality of life, headache severity and prevalance, somatic symptoms, anxiety and functional disability
Offenbächer & Kohls et al (2016)	Quant descriptive	Yes- To translate the Functional Disability Inventory (FDI) into German, to evaluate its validity and to assess functional limitation in a large cohort of children and adolescents with juvenile	Yes- data collected on school absence, school related issues, depressive symptoms, functional limitations and pain

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
		fibromyalgia syndrome (jFMS).	
Palermo,Witherspoon, Valenzuela & Drotar (2004)	Quant non randomised	Yes- To develop and validate a new measure, the Child Activity Limitations Interview (CALI), to improve the assessment of functional impairment due to recurrent pain in school-age children and adolescents, and to compare this measure to the Functional Disability Inventory.	Yes- data collected on functional disability, school absence, anxiety and depressive symptoms, activity limitations and pain.
Powers, Patton, Hommel & Hershey (2003)	Quant non randomised	Yes- To examine quality of life (QOL) in a clinical sample of children with headaches and compared with children with other chronic diseases.	Yes- data collected on headache pain and duration, and quality of life measures.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Pratsidou-Gertsi & Trachana et al (2018)	Quant non randomised	Yes- To cross-culturally adapt and validate the Greek parent, child/adult version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) in patients with juvenile idiopathic arthritis (JIA).	Yes- data collected on health related quality of life, physical function, medication, school problems and pain.
Ragnarsson, Johansson, Bergstrom, Sjoberg, Hurtig & Petersen (2019)	Quant descriptive	Yes- To explore the relationship between recurrent pain and perceived problems with academic achievement among boys and girls in middle and late elementary school.	Yes- data collected on pain, and percieved problems with academic acheivement.
Rousseau-Salvador, Amouroux,Annequin, Salvador, Tourniaire& Rusinek (2014)	Quant non randomised	Yes- To examine anxiety and depression, associated risk factors and school outcomes in a clinical population of youth with chronic daily headache CDH compared with youth with episodic headache (EH)	Yes- data collected on depression, anxiety and school attendance

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Rusoniene,& Panaviene et al (2017)	Quant non randomised	Yes- To cross-culturally adapt and validate the Lithuanian parent, child/adult version of the Juvenile Arthritis Multidimensional Assessment Report (JAMAR) in patients with juvenile idiopathic arthritis (JIA)	Yes- data collected on health related quality of life, physical function, medication, school problems and pain.
Salathe, Kalin, Zilse & Elfering (2019)	Quant descriptive	Yes- To investigate the effects of juvenile musculoskeletal (MSK) pain and psychosocial risk factors on future pain.	Yes- data collected on pain, media consumption, sleep, psychosocial strain, school variables and school pressure
Schanberg, Anthony,Gil & Maurin (2003)	Quant descriptive	Yes- To analyse patterns of daily pain, stiff-ness, and fatigue related to juvenile arthritis; to examine the relationships of demographics, disease severity, and psychological adjustment to daily disease symptoms; and to examine daily disease symptoms as predictors of reduced	Yes- data collected on pain, stiffness and fatigue, disease severity, psychological adjustment and school/social activity

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
		participation in school and social activity	
Schanberg, & Gil et al (2005)	Quant descriptive	Yes- To analyse patterns of stress, mood, disease symptoms, and activity reduction in children with polyarticular arthritis, using a prospective daily diary method.	Yes- data collected on stress, mood, disease symptoms and acitivty reduction.
Simons, Logan, Chastain & Stein (2010)	Quant non randomised	Yes- To further understanding of social functioning in children with chronic pain, and particularly how social functioning relates to school impairment in this population.	Yes- data collected on social functioning, school impairment and attendance

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Shapiro & Dinges et al (1995)	Quant descriptive	Yes- To gain information about the natural history of pain associated with sickle cell disease and its impact on sleep and school attendance	Yes- data collected on pain, impact on sleep and school attendance
Sherry, McGuire, Mellins, Salmonson, Wallace & Nepom (1991)	Mixed methods (Also uses individual case reports)	Yes- To report the clinical and psychological findings for children with psychosomatic musculoskeletal pain.	Yes- data collected on school acheivement, family environment, distress, depression, IQ, wellbeing and parental enmeshment using psychological scales and interviews to analyse.
Sole & Castarlenas et al (2017)	Quant descriptive	Yes-To (1) examine the reactions of teachers and student teachers to children experiencing pain, (2) identify the most common challenges and potential resources that are associated to dealing with them, and (3) examine whether their responses differed as a function of their experience or sex	Yes-data collected on teacher response to pain, problems dealing with pain in school and resources deemed helpful

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Stoff, Bacon & White (1989)	Quant descriptive	Yes-To investigate the relationship between the effects of a rheumatic disease (RD) and school functioning in children with RD.	Yes- data collected on school participation, absence, reading and maths acheivement scores and impulsivity/concentration
Sturge, Garralda,Boissin, Doré & Woo (1997)	Quant descriptive	Yes-To examine school attendance in children with chronic arthritis in relation to illness severity or type of illness as well as in relation to a child's psychiatric adjustment and compliance with treatment.	Yes- data collected on school attendance, illness severity and treatment compliance
Vervoort, Logan, Goubert, De Clercq & Hublet (2014)	Quant descriptive	Yes- To examine child and adolescent pain severity in relation to various domains of school functioning and, in line with self-determination theory, the potentially protective role of perceived teacher support of child/adolescent autonomy and competence	Yes- data collected on school functioning, attendance, pressure, academic performance, satisfaction, bullying, teacher support and pain characteristics

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Whitehouse, Shope, Sullivan, Kulik & Chen-lin (1989)	Quant descriptive	Yes-To explore parent reported problems at school for children with juvenile rheumatoid arthritis (JRA). To determine parent knowledge of the PL94-142 law.	Yes- data collected on parents knowledge of the PL94-142 law and school problems
Ungerer, Horgan, Chaitow & Champion (1987)	Quant descriptive	Yes- To assess the relations among disease severity, psychosocial functioning, and adjustment in three age groups—primary school, high school, and young adults with juvenile arthritis.	Yes- data collected on self concept, the number, frequency, and intimacy of social contacts, problems with social relationships, type of leisure activities, employment experience, ratings of physical health, illness related concerns, and the consequences of having JIA. Via multiple choice and open ended questions.

Reference	Design of study	Screening (All types) Are there clear qualitative and quantitative research questions (or objectives), or a clear mixed methods question (or objective)?	Screening (All types) Do the collected data allow address the research question (objective)?
Yadav & Yadav (2013)	Quant non randomised	Yes- To assess school adjustment, self-concept, self-esteem, general wellbeing and parent–child relationship in children with Juvenile Idiopathic Arthritis (JIA) and to study the correlation of these parameters with chronicity of disease, number of active joints, laboratory parameters of disease activity and JIA subtypes.	Yes- data collected on emotional, social and educational adjustment and general wellbeing.
Zhang & Deng et al (2015)	Quant descriptive	Yes- To investigate the prevalence of four types of chronic pain (headache, abdominal pain, neck and shoulder pain (NSP), and low back pain (LBP)) and to explore the relationship between the prevalence of chronic pain and self-reported academic pressure in high school students in Shanghai, China	Yes- data collected on academic pressure, type of chronic pain experienced and prevalance

C.3 Quality assessment using MMAT mixed methods qualitative components

Reference	Is the mixed methods research design relevant to address the qualitative and quantitative research questions (or objectives), or the qualitative and quantitative aspects of the mixed methods question (or objective)?	Is the integration of qualitative and quantitative data (or results*) relevant to address the research question (objective)?	Is appropriate consideration given to the limitations associated with this integration, e.g., the divergence of qualitative and quantitative data (or results*) in a triangulation design?	Are the sources of qualitative data (archives, documents, informants, observations) relevant to address the research question (objective)?	Is the process for analyzing qualitative data relevant to address the research question (objective)?	Is appropriate consideration given to how findings relate to the context, e.g., the setting, in which the data were collected?	Is appropriate consideration given to how findings relate to researchers' influence, e.g., through their interactions with participants?
Aasland & Diseth., (1999)	Yes- data collected on psychosocial outcome using established measures (the semi-structured Child Assessment Schedule (CAS) interview, the Youth Self Report (YSR) and Child Behaviour Checklist (CBCL) questionnaires). In order to explore the Harter Self-Perception Profile for Adolescents as an indicator of psychosocial outcomes	Yes	Yes	Yes	Yes	Can't tell- Not described	No- Not discussed

	in adolescents with chronic physical disorders.						
Bartholomew, Koenning, Dahlquist & Barron., (1994).	Yes- : Analysis of needs assessment data collected from several sources: 1) literature review, 2) survey of parents of 51 children with IRA, 3) group interview of seven parents of children with IRA, 4) results of pilot programs, and 5) clinical experience of an interdisciplinary paediatric rheumatology team.	Yes	Yes	Yes	Yes	Can't tell	Yes

C.4 Quality assessment using MMAT mixed methods quantitative non randomised

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Assa, Ish-Tov, Rinawi& Shamir.,(2015)	Yes- Same inclusion and exclusion criteria were applied to cases and controls	Yes- The variables are clearly defined and accurately measured; the measurements are appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- A table lists key demographic information comparing the groups	Yes
Aasland & Diseth., (1999)	Yes- sample is representative of the population	Yes- Well established measures of psychosocial outcomes were administered. Variables are clearly defined and accurately measured; the measurements are appropriate for answering the research question; and the measurements reflect what they are supposed to measure	Yes- The two diagnostic groups were compared according to demographic characteristics. No significant differences were found between the two groups.	Yes- one non participant in JCA group and 3 in the ARA group.

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Abdul-sattar, Abou El Magd & Negm,. (2014)	Yes- sample is representative of the population: 52 patients with JIA aged 7-17 years and with duration of disease ≥1year.	Yes-well established measures are used that are appropriate to answer the research question and reflect what they should be measuring.	Yes- A table of key demographic information is presented and socioeconomic and demographic factors are assessed.	Yes
Aggarwal,Khubchandani et al., (2018)	Yes- inclusion and exclusion criteria is described and participants were recruited as part of a wider study.	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Can't tell- Information is not provided regarding whether participant groups are comparable on key demographics.	Yes-99.2% of subjects had the parent version of the JAMAR completed by a parent. The child version of the JAMAR was completed by 69.4% of children.

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Cagliyan-Turk & Sahin., (2020)	Yes- cluster sampling used and participants were matched	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- sociodemographic data of the participants and parental information were collected using questionnaires, which also recorded information on the presence of chronic illness and drug use. A table of demographic data is presented for both groups.	Yes
Barthel, Ravens-Siberer et al., (2018).	Yes- sample are recruited from the same population	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups that may account for any differences in outcomes.	Yes

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Breuner, Smith & Womack (2004)	Yes- sample are recruited from the same population	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups that may account for any differences in outcomes.	Yes
Clementi, Chang, Gambhir, Lebel & Logan (2019)	Yes- sample is representative of the population (youth aged 7 to 17 years with persistent headache evaluated in a multidisciplinary paediatric tertiary headache program).	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic data was gathered	Yes

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Doležalová, Bohm et al., (2018)	Yes- Inclusion and exclusion criteria is the same for cases and control group. Recruitment was independent to the JAMAR (participants were enrolled at a paediatric rheumatology centre)	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Can't tell- Information is not provided regarding whether participant groups are comparable on key demographics.	Yes completed by 80.3% of children and 99.5% completed the parent version.
Durmaz & Alayli et al (2013)	Yes- sample is representative of the population (1109 children from middle schools and high schools in Turkey using a cluster sampling scheme)	Yes- The variables are clearly defined and accurately measured; the measurements are appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- Key demographic data was gathered	Yes

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Fatoye (2008)	Yes- sample is representative of the population (Twenty nine children with HMS and a healthy control group) and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- Key demographic data was gathered and considered	Yes
Fujita, Fujiwara,Maki, Shibasaki & Shigeta (2009)	Yes- sample is representative of the population (24 children with chronic daily headache CDH and school phobia, 26 children with CDH but without school phobia) and the sampling strategy (retrospective) is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Can't tell- Information is not provided regarding whether participant groups are comparable on key demographics.	Yes

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Garmy, Hansson, Vilhjalmsson & Kristjansdottir (2019)	Yes- Recruitment was independent- used the dataset from the WHO International Research Network HBSC (large-scale, cross-national study of 11-13- and 15-year-olds focusing on health behaviours and their determinants and consequences). The sample is representative (All students in Iceland in grades 6, 8 and 10 attending school on the day of administration were included. 161 schools with 11 018 students participated.	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- Age, gender and socioeconomic status were considered.	Yes- Response rate was 84%
Garralda & Rangel (2004)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups that may account for any differences in outcomes.	Yes

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Gibler, Beckmann, Lynch-Jordan, Kashikar-Zuck & Mano (2019)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups that may account for any differences in outcomes.	Yes
Greco, Freeman & Dufton (2006)	Yes- sample is representative of the population (60 children with frequent abdominal pain, age matched controls) and the sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups that may account for any differences in outcomes.	Yes
Haberfehlner & Visser et al (2011)	Yes- sample is representative of the population (15 children with JIA and reported handwriting difficulties, 15 matched healthy controls.) and the sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups that may account for any differences in outcomes.	Yes

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Haverman & Grootenhuis et al (2012)	Yes- sample is representative of the population (152 children with JIA, and a dutch norm population including children with other chronic health conditions) and the sampling strategy is explained.	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups that may account for any differences in outcomes.	Yes
Kaczynski, Claar & LeBel (2012)	Yes- sample is representative of the population (262 adolescents with chronic tension-type headache (CTTH) (n=153) and migraine (n=109) evaluated at a paediatric headache clinic) and the sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups that may account for any differences in outcomes.	Yes

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Kashikar-Zuck & Zafar et al (2007)	Yes- sample is representative of the population (55 adolescents with juvenile fibromyalgia and 55 peer matched controls) and the sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- the control group was matched on key demographic information and there were no obvious dissimilarities between groups that may account for differences in outcomes.	Yes
Kashikar-Zuck & Zafar et al (2013)	Yes- sample is representative of the population (Youth (ages 10-18) with Chronic migraine CM (N = 153) and juvenile fibromyalgia JFM (N = 151)) and the sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups that may account for any differences in outcomes.	Yes
Kuburovic, Pasic et al., (2014)	Yes-Sample representative of the population	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- Demographic information and differences between groups are taken into account.	Yes- complete outcome data.

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Larsson, Melin, Lamminen & Ullstedt (1987)	Yes- sample is representative of the population (34 students 16-18 years of age, recruited from three Swedish high schools.) diagnosed with headache. The sampling strategy is explained.	Can’t tell- The variables are clearly defined and accurately measured, however the social relationships measure is a measure developed for the purpose of this study and it's validity/reliability is not discussed.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups and this is discussed by the researchers	Yes (2 participants dropped out)
Logan, Gray, Iversen & Kim (2017)	Yes- sample is representative of the population and the sampling strategy is explained.	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups that may account for any differences in outcomes.	Yes
Mandic, Baraban & Boranic (2003)	Yes- sample is representative of the population and sampling strategy is explained	Yes- the variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups to account for differences in outcomes	Yes

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Mihaylova & Varbanova et al (2018)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups to account for differences in outcomes	Yes
Neder, & Van Weelden et al (2015)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities between groups to account for differences in outcomes	Yes
Nijhof, Van de Putte, Wulffraat & Nijhof (2016)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups, there are no obvious dissimilarities to account for differences in outcomes	Yes (86%)

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Norgaard & Herlin (2019)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each groups and is discussed, there are no obvious dissimilarities to account for differences in outcome	Yes
Palermo,Witherspoon, Valenzuela & Drotar (2004)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each groups and is discussed, there are no obvious dissimilarities to account for differences in outcome	Yes

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Powers, Patton, Hommel & Hershey (2003)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each groups and is discussed, there are no obvious dissimilarities to account for differences in outcome	Yes
Pratsidou-Gertsi & Trachana et al (2018)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Cant' tell- key demographic information was not presented but is described as being collected.	Yes
Rousseau-Salvador, Amouroux,Annequin, Salvador, Tourniaire& Rusinek (2014)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each groups and is discussed, there are no obvious dissimilarities to account for differences in outcome	Yes

Reference	Are participants (organizations) recruited in a way that minimizes selection bias?	Are measurements appropriate (clear origin, or validity known, or standard instrument; and absence of contamination between groups when appropriate) regarding the exposure/intervention and outcomes?	In the groups being compared (exposed vs. non-exposed; with intervention vs. without; cases vs. controls), are the participants comparable, or do researchers take into account (control for) the difference between these groups?	Are there complete outcome data (80% or above), and, when applicable, an acceptable response rate (60% or above), or an acceptable follow-up rate for cohort studies (depending on the duration of follow-up)?
Rusoniene,& Panaviene et al (2017)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups and is discussed, there are no obvious dissimilarities to account for differences in outcome	Yes
Simons, Logan, Chastain & Stein (2010)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups and is discussed, there are no obvious dissimilarities to account for differences in outcome	Yes
Yadav & Yadav (2013)	Yes- sample is representative of the population and sampling strategy is explained	Yes- The variables are clearly defined and accurately measured; the measurements are justified and appropriate for answering the research question; and the measurements reflect what they are supposed to measure.	Yes- key demographic information was gathered for each of the groups and healthy controls were age and sex matched	Yes

Table C4

Quality Assessment using MMAT Mixed methods Quantitative Descriptive

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Mohseni, Pei,Bagheri-Nesami, & Shayesteh-Azar (2007)	Yes- sample is relevant to population under study (5000 randomly recruited secondary schoolchildren aged 11-14 years in the north of Iran)	Yes- Effort was made to target homogenous subjects. 5000 state school children aged 11 to 14 years were randomly recruited. Inclusion and exclusion criteria are explained; Children were included if they were 11 to 14 years old and willing to take part. Reasons why some eligible individuals chose not to participate are not explained.	Yes- Structured questionnaire created by researchers. The reliability of the questionnaire was evaluated in a pilot study with repeated measures (with 1-week interval betweentest and retest). The questionnaire was found to be reliable with Cronbach a= 0.84.	Yes- 96.2%
Sherry, McGuire, Mellins, Salmonson, Wallace & Nepom (1991)	Yes- sample is relevant to population under study: 100 children with diagnosed psychosomatic musculoskeletal pain.	Yes- Inclusion and exclusion criteria are explained. Reasons why some eligible participants chose not to participate are not explained.	Yes- Variables are clearly defined and accurately measured using standard psychological scales	Yes
Abdul-Sattar, Elewa, Enass, El-Shahawy &Waly. (2013)	Yes- source of sample is relevant to the population under study, standard procedure for sampling.	Yes- inclusion and exclusion criteria are explained; and reasons why certain eligible individuals chose not to participate are not explained	Yes- well established and valid measures were used.	Yes

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Armbrust, Lelieveld et al., (2016).	Yes- source of sample is relevant to the population under study, standard procedure for sampling used,	Yes- inclusion and exclusion criteria are explained; reasons why certain eligible individuals chose not to participate are not explained.	Yes- Variables are clearly defined and accurately measured using well established valid measures	Yes
Berrin, Malcarne et al., (2006)	Yes- source of sample is relevant to the population under study, standard procedure for sampling.	Yes- Reasons why eligible particpants chose not to participate are explained. Inclusion and exclusion criteria is described	Yes- Variables are clearly defined and accurately measured using well established and valid measures- validity is discussed.	Yes
Bartholomew, Koenning, Dahlquist & Barron., (1994).	Yes- sample is relevant to the population under study.	Can't tell	Yes- variables are defined and measured using established measures.	Yes

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Bessisso, Bener, Elsaid, Al-Khalaf & Huzaima., (2005)	Yes- source of sample is relevant to the population under study, standard procedure for sampling (multistage stratified sampling procedure)	Yes- sample is representative of population studied (The sample size was determined with the prior knowledge that the prevalence rate of migraine and headache in Qatar is somewhat similar to Western countries) In order to secure arepresentative sample of the study population, thesampling plan was stratified with proportional allocation according to stratum size.	Can't tell- The information in the survey was based on a structured prospective questionnaire in Arabic by one of the researchers. (no additional description is given).	Yes
Boey, Omar & Phillips (2003)	Yes- source of sample is relevant to the population under study, procedure for sampling explained (random sampling from all primary schools in the district)	Yes- inclusion and exclusion criteria are explained; reasons why certain eligible individuals chose not to participate are not explained.	Yes- variables are defined and measured using established measures.	Yes
Castro, Rockett et al., (2013)	Yes- source of sample is relevant to population under study, procedure for sampling explained (random sampling from 6 schools in Brazil)	Yes- inclusion and exclusion criteria are explained; reasons why certain eligible individuals chose not to participate are not explained.	Yes- variables are defined and measured using established measures.	Yes

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Charuvanij & Chaiyadech (2018)	Yes- source of sample is relevant to population under study, procedure for sampling explained.	Yes- inclusion and exclusion criteria are explained, reasons why eligible participants chose not to participate are not explained	Yes- variables are defined and measured using established measures	Yes
Chomistek, & Johnson et al (2019)	Yes- source of sample is relevant, procedure for sampling is explained	Yes- inclusion and exclusion criteria are explained, reasons why eligible participants chose not to participate are not explained. Mentions that the JIA subtypes in this cohort reflected the normal JIA distribution.	Can't tell- variables are defined and measured using a questionnaire although the name of the questionnaire is not given- can't tell if this is an established measure	Yes
Claar, Kaczynski, Minster, McDonald, Nolan & LeBel (2012)	Yes- source of sample is relevant, procedure for sampling is explained	Yes- inclusion and exclusion criteria are explained, reasons why eligible participants chose not to participate are not explained	Yes- variables are defined and measured using established measures	Yes
Connelly (2003)	Yes- source of sample is relevant, procedure for sampling is explained	Yes- inclusion and exclusion criteria are explained, reasons why eligible participants chose not to participate are not explained	Yes- variables are defined and measured using established measures	Yes

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Subhadra & Taub et al (2010)	Yes- source of sample is relevant and procedure for sampling is explained (notes the sample is largely female however)	Yes- inclusion and exlusion criteria are explained reasons eligible participands chose not to participate are not explained	Yes- variables are defined and measured using established measures	Yes
Fischer & Barthel et al (2019)	Yes- source of sample is relevant (309 children and adolescents with three chronic pain conditions) and procedure for sampling is explained	Yes- inclusion and exclusion criteria are explained, reasons why eligible participants chose not to pariticipate are explained	Yes- variables are defined and measured using established measures	Yes
Fichtel & Larsson (2002)	Yes- source of sample is relevant (Seven hundred ninety-three adoles-cents from two cities in Sweden) and sampling procedure is explained	Yes- inclusion and exclusion criteria are explained, reasons why eligible participants chose not to participate are explained	Yes- variables are defined and measured using established measures	Yes
Gil, Carson et al (2003)	Yes- source of sample is relevant (Adolescents with SCD (n= 37) and sampling procedure is explained	Yes- inclusion and exclusion criteria are explained, reasons why eligible participants did not participate are not explained	Yes- variables are defined and measured using established measures	Yes

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Groenewald, Giles & Palermo, (2019)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion and exclusion criteria are explained, reasons why eligible participants did not participate are not explained	Yes- variables are defined and measured using established measures	Yes
Haraldstad, Sorum, Eide, Natvig & Helseth (2011)	Yes- source of sample is relevant and sampling procedure is explained (cluster sampling)	Yes- inclusion and exclusion criteria are explained and reasons why eligible participants dd not take part are given	Yes- variables are defined and measured using established measures	Yes (67%)
Ho, Bennett, Cox & Poole (2009)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion criteria are explained and reasons for drop out/ not taking part are given	Yes- variables are defined and measured using established measures	Yes
Jones, Stratton, Reilly & Unnithan, (2004)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion criteria are explained, reasons for not taking part are not explained	Can't tell- the questionnaire used is established as valid and reliable but is described as "a questionnaire to assess low back pain"	Yes
Kashikar-Zuck & Johnston et al (2010)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion criteria are explained, reasons for not taking part/ exclusion are explained	Yes- variables are defined and measured using established measures	Yes

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Kernick, Reinhold & Campbell (2009)	Yes- source of sample is relevant and sampling procedure is explained	Yes-inclusion and excluson criteria are explained, reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes
Khan & Tran et al (2015)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion criteria are explained, reasons for not taking part are not explained	Yes- variables are defined and measured using established measures	Yes
Logan & Simons (2010)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are explained and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes
Logan, Simons & Carpino (2011)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are explained and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes
Logan, Simons & Kaczynski (2009)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are explained and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Logan, Simons, Stein & Chastain (2008)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are explained and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes
Milatz & Klotsche et al (2019)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are explained and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes
Nyame & Ambrosy et al (2010)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are explained, those who did not take part are described but reasons for not taking part are not described	Yes- variables are defined and measured using established measures	Yes
Offenbächer & Kohls et al (2016)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are explained and reasons for not taking part are not given	Yes- variables are defined and measured using established measures	Yes

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Ragnarsson, Johansson, Bergstrom, Sjoberg, Hurtig & Petersen (2019)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are explained, reasons for not taking part are not given	Yes- variables are defined and measured using established measures	Yes
Salathe, Kalin, Zilse & Elfering (2019)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are explained, reasons for not taking part are given	Yes- variables are defined and measured using established measures	Yes
Schanberg, Anthony,Gil & Maurin (2003)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are given and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes
Schanberg, & Gil et al (2005)	Yes- source of sample is relevant and the sampling procedure is explained	Yes- inclusion/exclusion criteria are given and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Shapiro & Dinges et al (1995)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion/exclusion criteria are given and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes
Sole & Castarlenas et al (2017)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion/exclusion criteria are given and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes
Stoff, Bacon & White (1989)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion/exclusion criteria are given and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes
Sturge, Garralda,Boissin, Doré & Woo (1997)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion/exclusion criteria are given and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes
Vervoort, Logan, Goubert, De Clercq & Hublet (2014)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion/exclusion criteria are given and reasons for not taking part are explained	Yes- variables are defined and measured using established measures	Yes

Reference	Is the sampling strategy relevant to address the quantitative research question (quantitative aspect of the mixed methods question)?	Is the sample representative of the population understudy?	Are measurements appropriate (clear origin, or validity known, or standard instrument)?	Is there an acceptable response rate (60% or above)?
Whitehouse, Shope, Sullivan, Kulik & Chen-lin (1989)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion/exclusion criteria are given and reasons for not taking part are explained	Can't tell- a precoded questionnaire was used which seems to have been developed for the study, information is not given on reliability of the measure	Yes
Ungerer, Horgan, Chaitow & Champion (1987)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion/exclusion criteria are given and reasons for not taking part are given	Yes- variables are defined and measured using established measures	Yes
Zhang & Deng et al (2015)	Yes- source of sample is relevant and sampling procedure is explained	Yes- inclusion/exclusion criteria are given and reasons for not taking part are given	Yes- variables are defined and measured using established measures. Validity of the questionnaire was ensured	Yes

C.5 Quality assessment using MMAT mixed methods quantitative randomised controlled trials

Reference	Is there a clear description of the randomization (or an appropriate sequence generation)?	Is there a clear description of the allocation concealment (or blinding when applicable)?	Are there complete outcome data (80% or above)?	Is there low withdrawal/drop-out (below 20%)?
Armbrust, Bos et al., (2016)	Yes- Randomization was performed in SPSS software per center by investigators not involved in recruiting the children in a computer-generated way.	Yes- Patients received a letter informing them whetherthey could start right away or had to wait for 6 months.	Yes	Yes- Of the 28 participants in the intervention group, 22 were followed up and analyzed after 1 year.

Appendix D Outcome measures

Table D

School functioning outcome variables used in each study.

School functioning outcome variables

Outcome variable Measure [reference where applicable]	**[Study]**
School Attendance	
Juvenile Arthritis Multidimensional Assessment Report (JAMAR) [93] List of items including "problems attending school"	[1,12,65]
Pediatric Quality of Life Inventory (PedsQL) 4.0 Generic Core Scales [102] – Whole scale used Four subscales: physical functioning, emotional functioning, social functioning, and school functioning (addressing school performance and the ability to be in school). Each scale uses a Likert 5-point scale to ask the child or parent how much of a problem each item has been over the past month: (0=never a problem, 1=almost never a problem, 2=sometimes a problem, 3=often a problem, and 4=almost always a problem).	[10,11,26,32,47]
PedsQL School Functioning Scale (5-item child self-report subscale of the Paediatric Quality of Life Inventory) assessing school functioning in the past month. Modified to 3 months to assess school functioning during the current school term. ''In the past 3 months, how much of a problem have you had with....'' Items on the School Functioning Scale assess difficulty paying attention in class, forgetting things, keeping up with school, missing school because of not feeling well, and missing school because of medical appointments and hospitalizations. Responses are rated on a 5-point scale ranging from never (0) to almost always (4).	[28,40,50]
PedsQL [115]	[13,14,22,54]
Parent proxy Paediatric Quality of Life Inventory (PedsQL) School Functioning subscale [115]	[29]
3 point scale (A research assistant reviewed medical records and rated adolescents' school attendance for the past 3 months on a 3-point scale with 0 indicating not attending school (when patients missed greater than 75% of school days), 1 indicating partially attending school (when patients missed between 20% and 75% of school days), and 2 indicating attending school fully (when patients missed less than 20% of school days).	[28]
Numerical (Days missed)	[15, 24, 32,43,51,55,59,60, 72,76,82,86,88,90]
(Days missed, late arrivals and early dismissals due to pain)	[61, 63]

Percentage of classes attended in the past 6 months	[68]
Percentage (School attendance records used to indicate percentage of days on which the adolescent was absent, arrived late, and/or was dismissed early)	[62]
Hours absent Per week (Self report by adolescents. Absences were recorded in daily diaries as the number of hours absent per week)	[57]
Self-report by students about the number of school hours they had been absent due to pain in the past month. Responses were rated on the following scale: “0 hours,” “1 to 5 hours,” “6 to 10hours,” or “more than 10 hours.”	[37]
School Leave (Self-report by students- number of times students had left school in the previous month due to pain) Responses were recorded on the following scale: “never,” “1 to 3 times,” “4 to 6 times,” or “more than 6 times.”	[37]
Daily diary recording (students recorded whether they stayed home from school on each day)	[41,83]
Semi structured interview (children reported their school attendance)	[28]
Semi structured interview (parents and children reported separately their impairment in school attendance (current or during worst episode of illness). Scored as: none (none or only odd days off school); mild (attending at least 85% of the time); marked (attending between 50 and 85% of the time);severe (less than 50% attendance), and extreme (has not attended school at all for at least one academic term).	[39]
Bespoke questionnaire (days of school missed in the past school year, self-report and parent proxy report cross referenced with school annual report cards detailing days absent) 1.How many school days did your child/you miss during the last school year? 2.How many school days did your child/you miss because of abdominal symptoms? 3. How many days did your child/you miss because of hospitalizations? Clinic/ER visits?	[7]
Bespoke questionnaire regarding prevalence of lower back pain. Students were asked to report school absence.	[49]
Bespoke question item regarding school absenteeism in the past month (Child self-report. The question had five response alternatives from ‘never’ to ‘almost always’ during the last month.)	[75]
Home schooling status Bespoke demographic questionnaire (parents reported whether their child was attending school full time)	[33]
Parents reported on the type of schooling: regular school or home schooled (defined as full-time home schooling, home-bound, or internet-based home program) and reason for home schooling.	[51]
Pre-coded questionnaire asked parents to give a narrative response regarding whether their child was able to attend their regular public or private school.	[90]

Clinician rated school avoidance (Mental health providers reported whether the child demonstrated school avoidance based on their global clinical impression of the criteria (1) high rates of absenteeism; (2) unexpected treatment responses (including shifting symptoms, multi-“failed” medical interventions, and medical work-ups); (3) escalating symptom severity; (4) escalating functional disability; and (5) dramatic presentation (eg, cry, scream, or refuse to get out of bed or leave the house).	[55]
The KIDSCREEN-27 (110)	[71]
The Lubeck Pain-Screening Questionnaire [109] Question related to missed school days. Respondents were asked to rate the impact as never, sometimes, often, or always.	[46]
VAS (Parents and adolescents were asked “How much has pain interfered with your/your child’s attendance at school?” Responses were recorded on a 10-cm VAS with the anchors “Pain has not interfered at all” to “Pain has interfered extremely.”	[63, 82]
The Child Activity and Health Questionnaire for Teachers (Bespoke questionnaire) Teachers were asked to respond to questions about the child’s classroom participation, level of fatigue and mobility limitations in school and the teacher’s knowledge of disease. Absenteeism was also reported by teachers.	[85]
School attendance records	[63]
Social Impact	
Bullying (numerical scales). Self-report in response to the question ‘How often have you been bullied in school during the last months?’ Five response options ranging from ‘never’ to ‘several times a week’. Responses dichotomized: ‘two times or less’ = 0, and other options (ranging from ‘2-3 times a month’ to ‘several times a week’) = 1.	[2]
Bullying self-report. 5 point scale: Children and adolescents were requested to indicate how much they had been bullied at school during the past couple of months using a 5-point scale with the end points ‘I have not been bullied at school in the past couple of weeks’ to ‘several times a week.’	[88]
Children's Global Assessment Scale (CGAS) [98]	[8]
The PedsQL 4.0 Generic Core Scales [102]	[25,32]
Bespoke questionnaire (The questionnaire collected information about school attendance/performance, impact of JIA symptoms (e.g, pain and fatigue), physical challenges and accommodations, communication, participation and peers, and school support.)	[27]

The Kids- CAT school wellbeing [104]	[36]
Bespoke item (Diary recordings. Children were encouraged to record their headaches and life events e.g. troubles at school (including problems with peers and bullying) and/or home, in a headache diary.)	[38]
School Anxiety Inventory—Short Version (SAI) [108]	[40]
Children's Social Experiences Questionnaire-Peer Report [111]	[42]
The Lubeck Pain-Screening Questionnaire [109] Structured self-report questionnaire designed for epidemiological purposes. Evaluates the prevalence of pain during the preceding 3 months. The questionnaire addresses the prevalence and consequences of pain and describes self-perceived factors for evaluating the development and maintenance of pain and its impact on daily living. The questionnaire contains 13 questions about pain, the first ''Did you have pain within the past 3 months?'' If the answer was negative, no other question about pain needed to be answered. If the answer was ''yes'', the respondents were asked to describe where they had experienced pain during the preceding 3 months, and a list of choices was supplied (head, back, abdomen, arm, leg, ear, throat, chest, and tooth). In addition, the girls were asked about menstruation pain and pain in the pelvis. The children were asked about the duration of the type of pain that troubled them the most (answer categories: only once, <1, 1–3, ‡3, >6, and >12 months) and its frequency (answer categories: less than once a month, once a month, two to three times a month, once a week, two times a week to every day). The questionnaire also contained a visual analogue scale to assess pain intensity, questions about self-perceived triggers of pain, and requested an explanation for the first occurrence of pain. A list of possible causes was given (change of weather, lack of sleep, annoyance/conflicts, school tests, cold, common cold, school situation, sports/physical efforts, family situation, light, noise, computer use, consumption of sweets, nutrition, sadness, excitement, and nonspecific factors). The respondents were asked to tick all possible causes. There were also questions about the self-perceived impact of pain on daily living and a list of possible choices (disturbed sleep, problems with eating, missed school days, hobbies, social contacts, and health-care utilization). The respondents were asked to rate the impact of pain as never, sometimes, often, or always. The participants were also asked whether their pain had been medically diagnosed, whether a family member had experienced recurrent or chronic pain, and whether they had visited a doctor because of pain.	[46]
Revised Class Play [112] Three Best Friends [113] Likert rating of social acceptance (Adolescents were asked to rate all of their classmates on a 5-point scale (where 1=someone you do not like and 5=someone you like a lot).	[52]
The Social Relationship-Competence Questionnaire (Bespoke- developed for the study) comprising 53 items scored on a 0-8 scale.	[57]
The Psychological Sense of School Membership Questionnaire [114]	[59]

The Paediatric Quality of Life inventory [115] The Peds-QL social functioning subscale: A five-item rating scale assessing social functioning.	[59]
Youth-reported Functional Disability Inventory [106]	[72]
Bespoke questionnaire item (Questionnaires were developed for each age group and covered topics including the number, frequency, and intimacy of social contacts and problems with social relationships, illness related concerns and the consequences of having JIA. The questions varied from multiple choice to open ended format.)	[87]
Adjustment Inventory for School Students [116]	[91]
Emotional Impact	
Pediatric Quality of Life Inventory (PedsQL) [115]	[53,70]
The Kids- CAT school wellbeing [104]	[17,36]
The PedsQL 4.0 Generic Core Scales [102]	[32]
Bespoke item (Diary recordings. Children were encouraged to record their headaches and life events e.g. troubles at school and/or home, in a headache diary.)	[38]
School Anxiety Inventory—Short Version (SAI) [108]	[40]
Revised Children’s Manifest Anxiety Scale [117]	[50]
The Children’s Depression Inventory [118]	[50, 62]
SCARED anxiety scale [119]	[55]
Likert scale Participants evaluated the amount of pressure they felt to achieve good school grades (ranging from 1=no pressure to 5=very intense pressure.)	[78]
Bespoke item (school related pressure/satisfaction) Child/adolescent perceived school-related pressure was measured by means of 4 items (e.g., ‘I have too much school work,’ ‘I have more school work than I can handle’) rated on a 5-point scale with the endpoints ‘almost never’ to ‘very often.’ School related satisfaction: Children and adolescents were re-quested to indicate ‘how they felt about school at present’ using a 4-point scale with the endpoints ‘I don’t like it at all’ to ‘I like it a lot.’	[88]
Bespoke item (learning burden, academic pressure) A bespoke questionnaire asked questions about “extracurricular learning tasks,” “average daily sitting time” and “academic ranking”. Self-reported feelings of the adolescents, such as “very tired after every day learning” were also gathered.	[92]
School Performance Wide Range Achievement Test Revised [95]	[6,48]

Woodcock-Johnson Psychoeducational Battery [96]	[6]
Youth Self Report (YSR) and Child Behaviour checklist (CBCL) questionnaires. [99,100]	[8]
Child Assessment Schedule (CAS) [101]	[9]
The PedsQL 4.0 Generic Core Scales [102] – Whole scale used	[10,11,32]
PedsQL School functioning subscale	[28]
The PedsQL Generic Core Scales (Thai version) [128]	[26]
Pediatric Quality of Life Inventory (PedsQL) [115]- Whole scale used	[13,22,31,55,59]
School functioning subscale	[61]
Pediatric Quality of Life Inventory (PedsQL) [94]	[50, 70]
Bespoke item (derived from PedsQL Inventory) Perceived problems with academic achievement were measured by a question capturing whether the child had experienced ‘problems keeping up with schoolwork’ during the last month. The question had five response alternatives, ranging from ‘never’ to ‘almost always’.	[75]
Bespoke survey A survey was developed based on a structured prospective questionnaire in Arabic by one of the researchers. (No additional description is given).	[20]
Several measures were used to assess school-related functioning including academic performance. The majority of these measures were mandatory or optional questions in the cross-national 2009/2010 World Health Organization (WHO) collaborative Health Behaviour in School-Aged Children (HBSC) survey.	[88]
Numerical scale (Based on the Malaysian Primary School Achievement Examination) Grades: A (very good);B (good); C (moderate); D (weak); and E (extremely weak). Grade A was given a score of 4, Grade B a score of 3, Grade C a score of 2, Grade D a score of 1 and Grade E a score of 0.	[23]
Numerical scale (grades)	[24]
Interviewing parents and official school grades ranging from 1 (fail) and 5 (excellent).	[64]
Categorical scale (grades) Parent reports of adolescents’ average grades in the year prior to onset of the pain problem and average current grades (in 9-point multiple choice format from ‘‘Mostly A’s’’ to ‘‘Mostly F’s’’)	[82]
Parent reports of adolescents’ average grades in the year prior to onset of the pain problem and average current grades (in 9-point multiple choice format from ‘‘Mostly A’s’’ to ‘‘Mostly F’s’’)	[60]
Parents reported adolescents’ average grades before the onset of their pain problem and their current average grades in multiple choice format (“mostly A’s, “A’s and B’s,”	[63]

"mostly B's," "B's and C's," "mostly C's," "C's and D's," "mostly D's," "D's and F's," "mostly F's").	
Parent proxy Paediatric Quality of Life Inventory (PedsQL) School Functioning subscale [115] Items begin with the stem "In the past one month, how much of a problem has your child had with..." and are rated on a 5-point Likert-type scale ranging from 0 (never) to 4 (almost always).	[29]
Wechsler Intelligence Scale for Children-Third Edition [120] The Wechsler Adult Intelligence Scale-Third Edition [121] Gray Oral Reading Test-Third Edition [122] Test of Written Language-Third Edition [124] Wechsler Individual Achievement Test-Second Edition [125] Gray Oral Reading Test-Fourth Edition [123]	[48]
VAS Parents and adolescents responded to the question, ''How much has pain interfered with your/your child's performance (eg grades) at school?'' Responses were recorded on a 10 cm visual analog scale (VAS) with anchor points of ''Pain has not interfered at all'' to ''Pain has interfered extremely''.	[82]
The Child Activity and Health Questionnaire for Teachers (Bespoke measure designed for study) Teachers were asked to respond to questions about the child's classroom participation, level of fatigue and mobility limitations in school and the teacher's knowledge of disease.	[85]
Adjustment Inventory for School Students [116]	[91]
Limited school activities	
Bespoke question item: Structured questionnaire with items concerning; -Lifestyle data, Prevalence of lower back pain, characteristics of lower back pain.	[5]
Bespoke questionnaire Administered to the child to assess the barriers experienced by JIA patients at school. The questionnaire collected information about school attendance/performance, impact of JIA symptoms (e.g, pain and fatigue), physical challenges and accommodations, communication, participation and peers, and school support.	[27]
Bespoke questionnaire to assess low back pain history also asked questions relating to absence from school, medical treatment and limitation of activity.	
Psychological interview	[49] [6]
Daily diary recording: Adolescents were asked to note in a daily diary whether, on that day, they (1) stayed home from school, (2) participated in extracurricular or after-school activities, and (3) completed household chores.	[41]
Participation in physical education classes Measured during 3 months. Participation in physical education classes was rated as full when children did not miss any classes due to JIA. Partial participation was	[14]

defined as missing a class every now and then, or if the activities were adjusted because of the disease.
No participation was defined as no participation whatsoever due to JIA.

Participation in extracurricular activities:
Intake interview in the Headache and Stress Management Clinic included assessment of
participation in extracurricular activities. Involvement in extracurricular activities was [24]
also determined by review of the intake history. A yes score was recorded if the student
was involved in extracurricular activities. A no score was recorded for lack of
involvement. For each extracurricular activity noted in the chart, a separate yes score
was recorded

Bespoke handwriting activity [44]
A Dutch method for assessing children's handwriting ("Beknopte Beoordelings method Voor Kinderhandschriften = BHK) was applied.
The writing task consisted of copying a standard text that was printed on a card, within five minutes. 13 handwriting characteristics, such as insufficient word-spacing, acute turns in connecting letters, irregularities in connections, or their absence, and collisions of letters, were scored with the BHK.
The total BHK score was used to determine whether the child was 1) not dysgraphic (score 0-21), 2) at risk (score 22–28), or 3) dysgraphic (score 29 or higher).
Writing in print was also scored, Writing speed was determined by counting the number of letters produced in exactly five minutes.

The children were asked in a structured way about handwriting difficulties at school, and their use of handwriting aids. The questions were designed following the formulation used in the Dutch version of the Childhood Health Assessment Questionnaire (CHAQ). Children were asked to rate their answers on a 100 mm VAS, which is possible because from 8 years on, children are expected to understand the concept of rating a VAS. Questions concerned: 1) frequency of their handwriting difficulties, 2) severity of their handwriting difficulties 3) frequency of difficulties in finishing handwriting tasks on time, 4) severity of their difficulties in finishing handwriting tasks on time, 5) appearance of their handwriting, 6) frequency of pain during handwriting, 7) severity of pain during handwriting, and 8) frequency of their difficulties with sustaining handwriting throughout the day.

The Lubeck Pain-Screening Questionnaire [109] [46]

The PedsQL 4.0 Generic Core Scales [102] – Whole scale used [47]

Likert scale [66]
Participation in school sports was reported on a four-point Likert scale ranging from 'almost always' to 'sometimes not', 'often not' ,and 'exempt from school sports'.

In daily diaries, children were asked to indicate the amount they reduced school and
social activities each day. [79]
Ratings were on a 4-point Likert scale anchored by "not at all" and "a lot,"

In daily diaries, children were asked to indicate the amount they reduced school and
social activities each day.
Ratings were on a 4-point Likert scale anchored by "not at all" and "a lot," with higher [80]
values indicating greater reduction.

The Paediatric Quality of Life Inventory [115] – Whole scale used	[67]
The KIDSCREEN-27 [110]	[71]
Bespoke list of problem items. Eleven activities commonly performed in the school setting were listed. Parents indicated if their child currently, or in the past, had experienced problems with each of these activities.	[90]
Questionnaire (participation in school/after school activities) A questionnaire addressing the impact of gastrointestinal symptoms on the child's school absenteeism and participation in school and after-school activities. The questionnaire was composed of 9 questions: 1.How many school days did your child/you miss during the last school year? 2.How many school days did your child/you miss because of abdominal symptoms? 3. How many days did your child/you miss because of hospitalizations? Clinic/ER visits? 4.How often did your child/you participate in gym classes? 5. Did your child/you participate in school trips? 6. How often did your child/you participate in extracurricular school activities? 7. How often did your child/you participate in after-school (excluding sport) programs? 8. How often did your child/you participate in after-school sport activities? 9. How often did your child/you participate in after-school social activities?	[7]
Number of physical education classes missed	[15]
The PedsQL 3.0 Cerebral Palsy Module [105]	[22]
Youth-reported Functional Disability Inventory [106]	[29,72]
The Physical Activity and Sport Questionnaire [PASQ]: 31 questions on specific club sport habits and leisure-time and school-educational physical activities, including type of specific activity or sport, frequency, consistency, and intensity including type of specific activity of sport; frequency, consistency and intensity of participation; barriers to participation (e.g. disease related symptoms, adherence, competency, satisfaction with own effort); and strategy for those having difficulties during physical activity.	[69]
The Child Activity and Health Questionnaire for Teachers (Bespoke measure designed for study) Teachers were asked to respond to questions about the child's classroom participation, level of fatigue and mobility limitations in school and the teacher's knowledge of disease.	[85]

Academic self-efficacy Self-Perception Profile for Adolescents [97]	[8,63,82]
Varni-Thompson Pediatric Pain Questionnaire [31]	[2]
Academic competence scale (teacher report) Items on the Academic Competence Scale assess children's academic performance across multiple domains with a possible range in scores from 7 to 35. Higher scores = higher academic competence.	[42]
The Self-Efficacy Questionnaire for School Situations [126]	[59]
The Walker-McConnell Scale of Social Competence and School Adjustment [127]	[63]
Quality of life State-Trait Anxiety Inventory for Children [32]	[1, 2]
The PedsQL 4.0 Generic Core Scales [102] – Whole scale used	[47]
The Paediatric Quality of Life Inventory [115] – Whole scale used	[25, 73]
School functioning	[4,31,35,53]
The Paediatric Quality of Life Inventory (Varni, Seid & Kurtin, 2001) [94] – Whole scale used	
List of items including "problems at school" JAMAR [93]	[12,74,77]
Pediatric Quality of Life Inventory (PedsQL) [115] – Whole scale used	[13,54]
Kidcope [107]	[39]
Checklist of necessary accommodations in school. School personnel completed a checklist reporting all accommodations implemented for the student in response to their pain problem. Examples include extensions on assignment deadlines, modified schedule, and individual tutoring.	[63]
Teacher Response to Children's Pain Inventory [128]	[84]
Bespoke list of potential problems teachers might have when trying to help students experiencing chronic pain. Based on the results of a focus group made up of school personnel and the researchers clinical experience with young people with chronic pain, the researchers developed a list of 11 potential problems to assess the difficulties that teachers might have when trying to help students experiencing chronic pain: (1) students' absenteeism,(2) difficulties in helping students perform activities related to school work, (3) students demanding they be treated differently due to their pain condition, (4)a teacher's lack of knowledge about diseases that may cause chronic pain, (5) a teacher's lack of knowledge about the definition of chronic pain and its effect, (6) problems with making needed accommodations for students with chronic pain; for example, adapt certain gym	[84]

activities or exercises, (7) difficulties in facilitating interactions with peers; (8) difficulties in being able to provide suitable information to other students,(9) problems with balancing the needs of a student with chronic pain with the needs of the students without chronic pain, (10) difficulties associated with developing a shared understanding of the problem with parents, and (11) problems with promoting a school policy that facilitates the integration and adaptation of children with chronic pain.
Participants were asked to indicate which of these problems they had encountered; they could indicate as many problems as they thought might be present.

List of items (perceived teacher support) [88]
Indexed by 8 items reflecting competence and autonomy support. Participants were requested to rate each item on a 5-pointscale, with the endpoints 'strongly disagree' to 'strongly agree'(e.g., autonomy support: 'my teachers try to understand how I see things before suggesting a new way to do things; competence support: 'My teachers encourage me when I do school work').

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Studies 1-92 are included in the systematic review.

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Appendix E Study characteristics

Table E

Table of Study Characteristics.

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Assa, Ish-Tov, Rinawi& Shamir.,(2015)	Israel	43 children aged (10-17) with Chron disease 31 children (aged 10-17) with ulcerative colitis 42 children (aged 10-17) with Functional abdominal pain.	Self-report and proxy parent report.	MMAT Quant Non Randomised
Aasland & Diseth., (1999)	Norway	Adolescents (12-17 years old) with juvenile chronic arthritis (23) with good psychosocial adjustment. Mean age= 14 (2.0) Adolescents with anorectal anomalies (20) with a high level of psychosocial maladjustment. Mean age= 13.6 (1.7).	Self report by adolescents	MMAT Mixed Methods
Aasland, Flatö, & Vandvik. (1997)	Norway	23 children with Idiopathic Muskuloskeletal Pain and 52 children with juvenile chronic arthritis (JCA)	Self report by children via semi structured interview.	CASP

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Abdul-sattar, Abou El Magd & Negm,. (2014)	Egypt	52 patients with Juvenile Idiopathic Arthritis aged 7-17 years and with duration of disease ≥1year.	Self report by children and parent proxy report.	MMAT Quant Non Randomised
Abdul-Sattar, Elewa, Enass, El-Shahawy &Waly. (2013)	Egypt	58 patients with Juvenile Idiopathic Arthritis (aged 8-18)	Self-report by children.	MMAT Quant Descriptive
Aggarwal,Khubchandani et al., (2018)	India	275 Juvenile Idiopathic Arthritis patients	Self-report by child or proxy parent report.	MMAT Quant non randomised
Cagliyan-Turk & Sahin., (2020)	Turkey	juvenile fibromyalgia syndrome (JFMS)	Self report and parent proxy report.	MMAT Quant non randomised
Armbrust, Bos et al., (2016)	Netherlands	28 children diagnosed with Juvenile Idiopathic Arthritis.	Self-report children.	MMAT Quant RCT
Armbrust, Lelieveld et al., (2016).	Netherlands	80 patients with Juvenile Idiopathic Arthritis (age 8–13).	Self report children.	MMAT Quant Descriptive
Barlow, Shaw & Harrison,. (1999)	UK	Children designated as having ‘mild’ JCA (5) Children designated as having ‘severe’ JCA (5) Parents of the ‘mild’ children (6) Parents of the ‘severe’ children (7)	Focus group discussion (children, parents and health professionals).	CASP
Barthel, Ravens-Siberer et al., (2018).	Germany	248 Children and adolescents with Asthma, Diabetes and Juvenile arthritis. Aged 7-17 years.	Self-report (children and adolescents)	MMAT Quant Non Randomised

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Bartholomew, Koenning, Dahlquist & Barron., (1994).	USA	Children with juvenile rheumatoid arthritis. Pauciarticular: 10 Polyarticular: 16 Systemic: 9	Self report by parents where relevant (survey and group interview).	Mixed Methods
Batthish et al., (2005)	Finland	Fourteen patients with systemic onset form of juvenile idiopathic arthritis (SO-JIA)	Self-report by children and proxy report parents during interview.	CASP
Bessisso, Bener, Elsaid, Al-Khalaf & Huzaima., (2005)	Qatar	851 schoolchildren in Qatar	Self report (parent report if aged under 10)	Quant descriptive
Beresford & Sloper., (2003)	UK	63 adolescents with: Juvenile chronic arthritis (17), Cystic fibrosis (11) Diabetes (12), Epilepsy (10), Duchenne muscular dystrophy (13).	Self report through interview and discussion.	CASP
Berrin, Malcarne et al., (2006)	USA	73 children with a spastic CP diagnosis aged 5–18 (27 with hemiplegia, 34 with diplegia, 12 with quadriplegia)	Child self-report and parent proxy report	MMAT Quant descriptive
Boey, Omar & Phillips (2003)	Malaysia	1971 primary school children in year 6 (12 years old) randomly selected from all primary schools in Petaling Jaya, Malaysia.	Self-report	MMAT Quant Descriptive

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Breuner, Smith & Womack (2004)	USA	233 adolescents, aged 11 to 18 years, seen consecutively for behavioural treatment of recurrent headache in the Headache and Stress Management Clinic at Children's Hospital and Regional Medical Center.	Self-report	MMAT Quant Non Randomised
Castro, Rockett et al., (2013)	Brazil	750 students aged 7 to 14 years. Mean age was 10.4 ± 1.7 years ,and 56.1% were female.	Self-report	MMAT Quant Descriptive
Charuvanij & Chaiyadech (2018)	Thailand	Sixty-five children (33 girls and 32 boys) diagnosed with JIA.	Self-report and parent proxy report	MMAT Quant Descriptive
Chomistek, & Johnson et al (2019)	USA	98 children with JIA aged between 8-17	Self report	MMAT Quant Descriptive
Claar, Kaczynski, Minster, McDonald, Nolan & LeBel (2012)	USA	47 adolescents ages 12-17, diagnosed by their neurologist with chronic tension-type headache who underwent a multidisciplinary evaluation at a tertiary headache clinic.	Parent and child self-report	MMAT Quant Descriptive
Clementi, Chang, Gambhir, Lebel & Logan (2019)	USA	109 youth aged 7 to 17 years (Mean age= 14.01, SD= 2.36) with persistent headache evaluated in a multidisciplinary paediatric tertiary headache program	Self report and parent proxy report	MMAT Quant Non Randomised

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Condon, O'Regan, MacDermott & Killeen, (2017)	Ireland	Children with a confirmed diagnosis of JIA	Self report	CASP
Connelly (2003)	USA	Sixty-eight children, eight to twelve years of age, with a diagnosis of JRA and their parents	Child and parent self report	Quant descriptive
Doležalová, Bohm et al., (2018)	Czech Republic	103 children with juvenile idiopathic arthritis (JIA)	Self-report by either child or parent.	MMAT Quant Non Randomised
Durmaz & Alayli et al (2013)	Turkey	1109 children (mean age (14.8±2.0) years old). Age and sex matched non JFMS group.	Self report	Quant non randomised
Subhadra & Taub et al (2010)	USA	219 paediatric chronic pain patients (70.8% female (n=155) Mean age= 14.34	Self report and parent proxy report	Quant descriptive
Farre, Ryan, McNiven & McDonagh (2019)		39 young people who had been diagnosed with arthritis in childhood, adolescence or young adulthood.	Self report	CASP

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Fatoye (2008)	Scotland	Twenty nine children with HMS (aged 8-15 years) 8 boys and 21 girls diagnosed with HMS based on the Beighton scores Mean age= 11.9 Control group: 37 healthy children (aged 8 – 15 years) Mean age= 11.5	Self report	Quant non randomised
Fischer & Barthel et al (2019)	Germany	309 children and adolescents aged 7–17 years. Of these, 18.8% (n=58) were diagnosed with asthma, 65.4% (n=202) with diabetes mellitus (type 1),and 15.9% (n=49) with juvenile arthritis.	Self report	MMAT Quant descriptive
Fichtel & Larsson (2002)	Sweden	793 adolescents 13 to 19 years old (mean=15.8, SD=1.6) and the sample consisted of 49% girls (n=385) and 51% boys (n=407)	Self report	MMAT Quant descriptive

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Fujita, Fujiwara,Maki, Shibasaki & Shigeta (2009)	Japan	24 children with (Chronic daily headache) CDH and school phobia. 26 children with CDH but without school phobia.	Self- report	MMAT Quant Non Randomised
Garralda & Rangel (2004)	UK	28 children and adolescents with chronic fatigue syndrome CFS 30 with juvenile idiopathic arthritis (JIA) 27 with emotional disorders (ED).	Self-report and parent proxy report	MMAT Quant Non Randomised
Garmy, Hansson, Vilhjalmsson & Kristjansdottir (2019)	Iceland	Self reported pain: Headache, Stomach ache, backache, and neck and shoulder pain	Self report by children	MMAT Quant Non Randomised
Gibler, Beckmann, Lynch-Jordan, Kashikar-Zuck & Mano (2019)	USA	Adolescents with chronic pain (n=30) mean age= 14.5 and age-matched and sex-matched controls (n=30) mean age 14.5.	Self-report and parent proxy report	MMAT Quant Non Randomised
Gil, Carson et al (2003)	USA	Adolescents with sickle cell disease SCD (n= 37) (24 girls, 13 boys) in the age range of 13 to 17 (M= 14.8, SD= 1.4).	Self report	MMAT Quant Descriptive

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Greco, Freeman & Dufton (2006)	USA	60 children with frequent abdominal pain Mean age of 12.22 years (SD = 1.19) 60 gender- and age-matched peers. Mean age of 12.30 years (SD = 1.35)	Self report, peer and teacher report	MMAT Quant non randomised
Groenewald, Giles & Palermo, (2019)	USA	8641 school-aged children (6 to 17 y). In the overall sample 2698 children were identified with pain	Parent proxy report	MMAT Quant Descriptive
Guzman,Gómez-Ramírez et al.,(2014)	Canada	Youth with juvenile idiopathic arthritis. (Participants had different types of JIA, varied disease severity, and different disease duration)	Self report/ discussion by children and young people with JIA, parents, paediatric rheumatologists and allied health professionals through interview or focus group discussion	CASP
Haberfehlner & Visser et al (2011)	Netherlands	15 children with JIA and reported handwriting difficulties 15 matched healthy controls. Matched with regard to age, gender, writing left or right-handed, and school level.	Self report	MMAT Quant Non Randomised

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Hackett (2003)	UK	Twelve children between the ages of 7 years and 11 years. Mean age= 9 years. Attending a major children's hospital, who fulfilled the International League Against Rheumatism criteria for JIA.	Self-report	CASP
Haraldstad, Sorum, Eide, Natvig & Helseth (2011)	Norway	A cluster sample of children and adolescents (age 8–18 years N = 1238)	Self-report	MMAT Quant Descriptive
Haverman & Grootenhuis et al (2012)	Netherlands	152 JIA patients (ages 6–18 years)	Self-report	MMAT Quant Non Randomised
Ho, Bennett, Cox & Poole (2009)	USA	57 children and adolescents with chronic pain.	Retrospective review of cognitive scores	MMAT Quant Descriptive
Jones, Stratton, Reilly & Unnithan, (2004)	UK	A cross-sectional sample of 500 children and adolescents. Boys (n= 249) and girls (n= 251) Subjects were aged between 10 and 16 years [Mean age= 13.5 (2.0) years]	Self-report	MMAT Quant Descriptive
Kaczynski, Claar & LeBel (2012)	USA	262 adolescents with chronic tension-type headache (CTTH) (n=153) and migraine (n=109) evaluated at a paediatric headache clinic 11–17 years (mean= 14.7 years, SD= 1.6)	Self report and parent proxy report	MMAT Quant Non Randomised

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Kashikar-Zuck & Johnston et al (2010)	USA	Adolescents with JPFS (N=102; mean age 14.96 years)	Self-report and parent proxy report	MMAT Quant Descriptive
Kashikar-Zuck & Zafar et al (2007)	USA	55 adolescents with JPFS (ages 12–18 years) from a paediatric outpatient rheumatology clinic 55 matched classroom comparison peers (MCCPs) selected from the classroom of each target adolescent with JPFS.	Self-report (peer and teacher report)	MMAT Quant Non Randomised
Kashikar-Zuck & Zafar et al (2013)	USA	Youth (ages 10-18) with Chronic migraine CM (N = 153) and juvenile fibromyalgia JFM (N = 151)	Self report	MMAT Quant Non Randomised
Kernick, Reinhold & Campbell (2009)	UK	1037 school children aged between 12-15.	Self report	MMAT Quant Descriptive
Khan & Tran et al (2015)	USA	349 youth and their parents (311 mothers and 162 fathers) who attended a multi-disciplinary pain clinic.	Self report	MMAT Quant Descriptive
Konkol & Lineberry et al (1989)	USA	50 children with JA and their families.	Self report	CASP
Larsson, Melin, Lamminen & Ullstedt (1987)	Sweden	54 students 16-18 years of age, recruited from three Swedish high schools.	Self report	MMAT Quant Non Randomised

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Kuburovic, Pasic et al., (2014)	Serbia	50 children with juvenile idiopathic arthritis	Self and proxy parent rated data.	MMAT Quant Non Randomised
Logan & Curran (2004)	USA	Five groups, comprised of 38 schoolteachers, administrators, school nurses, and guidance/mental health staff.	Self-report	CASP
Logan, Gray, Iversen & Kim (2017)	USA	264 adolescents (12–17 years old) with primary pain conditions, juvenile idiopathic arthritis, or no pain.	Self report parent proxy report	MMAT Quant Non Randomised
Logan & Simons (2010)	USA	40 adolescents aged 12–17 years who presented for evaluation at an outpatient paediatric chronic pain clinic.	Self report and parent/teacher proxy report	MMAT Quant Descriptive
Logan, Simons & Carpino (2011)	USA	A clinical sample of 350 children ages 8–17 years with chronic pain and their parents.	Self report, parent proxy report	MMAT Quant Descriptive
Logan, Simons & Kaczynski (2009)	USA	217 clinically referred adolescents (aged 12–17 years).	Self report, parent proxy report	MMAT Quant Descriptive
Logan, Simons, Stein & Chastain (2008)	USA	Adolescents aged 12 to 17 presenting for evaluation at a tertiary care chronic pain clinic	Self-report, parent proxy report	MMAT Quant Descriptive
Mandic, Baraban & Boranic (2003)	Croatia	39 children 12-15 years old with chronic tension type headache and age matched healthy controls	Self-report	MMAT Quant Non Randomised

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Mihaylova & Varbanova et al (2018)	Bulgaria	83 JIA patients	Self-report	MMAT Quant Non Randomised
Milatz & Klotsche et al (2019)	Germany	Schoolchildren with JIA (n=5879)	Self-report, parent proxy report	MMAT Quant Descriptive
Mohseni, Pei,Bagheri-Nesami, & Shayesteh-Azar (2007)	Iran	Low back pain in 4813 randomly recruited secondary school children	Self-report by children.	MMAT Quant Descriptive
Neder, & Van Weelden et al (2015)	Brazil	47 leprosy patients and 45 healthy subjects.	Self report	MMAT Quant Non Randomised
Nijhof, Van de Putte, Wulffraat & Nijhof (2016)	Netherlands	175 patients (ages 10–18years) mean age= 14.5 who visited the paediatric rheumatology and immunology outpatient clinic at Wilhelmina Children's Hospital. Healthy control group. (n= 144) with a mean age of 15.3	Self report	MMAT Quant Non Randomised

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Norgaard & Herlin (2019)	Denmark	Children ages 10–16 years who met the 2001 revised International League of Associations for Rheumatology classification of juvenile idiopathic criteria. Mean age 12.7 118 healthy controls ages 10–16 years were recruited from a public school. Mean age 12.4	Self report	MMAT Quant Non Randomised
Nyame & Ambrosy et al (2010)	USA	237 3rd- 8th grade students at two Chicago Public Schools.	Self report	MMAT Quant Descriptive
Offenbächer & Kohls et al (2016)	Germany	329 patients with juvenile fibromyalgia Mean age= 13.9 years	Self report	MMAT Quant Descriptive
Palermo,Witherspoon, Valenzuela & Drotar (2004)	USA	89 children, aged 8 – 16 years (Mean age = 12:4; SD 2.5), 60% female, who were part of a longitudinal study of recurrent pain in children with headaches, juvenile idiopathic arthritis, and sickle cell disease.	Self report	MMAT Quant Non Randomised

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Powers, Patton, Hommel & Hershey (2003)	USA	572 consecutive patients (mean age, 11.4 + 3.6 years) who presented with headaches to a children's headache centre.	Self-report	MMAT Quant Non Randomised
Pratsidou-Gertsi & Trachana et al (2018)	Greece	272 JIA patients and 100 healthy controls	Self-report and parent proxy report	MMAT Quant Non Randomised
Ragnarsson, Johansson, Bergstrom, Sjoberg, Hurtig & Petersen (2019)	Sweden	1524 children attending elementary school in Sweden.	Self-report	MMAT Quant Descriptive
Rousseau-Salvador, Amouroux,Annequin, Salvador, Tourniaire& Rusinek (2014)	France	368 consecutive patients presenting with primary headache at a paediatric headache centre. Aged 8-17 years.	Self-report and parent proxy report	MMAT Quant non randomised
Rusoniene,& Panaviene et al (2017)	Lithuania	100 patients with JIA Median age= 12 100 healthy children Median age= 15.8	Self report and parent proxy report	MMAT Quant non randomised
Salathe, Kalin, Zilse & Elfering (2019)	Switzerland	The baseline sample comprised 189 adolescents, and 5-year follow-up resulted in 107 15- to 18-year-old adolescents	Self-report	MMAT Quant Descriptive

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Schanberg, Anthony,Gil & Maurin (2003)	USA	41 children with polyarticular arthritis, Mean age= 12.3 years	Self report	MMAT Quant Descriptive
Schanberg, & Gil et al (2005)	USA	51 children with polyarticular arthritis (mean age 12.4 years, 65% female)	Self report	MMAT Quant Descriptive
Sen & Morgan et al (2017)	UK	10 children and young people aged between 6 and 18 years with uveitis.	Self report	CASP
Simons, Logan, Chastain & Stein (2010)	USA	126 patients with chronic pain between the ages of 12-17.	Self report and parent proxy report	MMAT Quant Non Randomised
Shapiro & Dinges et al (1995)	USA	18 children and adolescents with a diagnosis of sickle cell disease 8-17 years of age (average: 13 years).	Self report	MMAT Quant Descriptive
Sherry, McGuire, Mellins, Salmonson, Wallace & Nepom (1991)	USA	100 children with diagnosed psychosomatic musculoskeletal pain.	Self-report by children	MMAT Quant Descriptive
Sole & Castarlenas et al (2017)	Spain	40 teachers and 318 student teachers teaching in secondary schools in Spain.	Self report	MMAT Quant Descriptive
Stoff, Bacon & White (1989)	USA	46 children with rheumatic disease aged 5-18 years. Mean age= 12 years	Self report	MMAT Quant Descriptive

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Sturge, Garralda,Boissin, Doré & Woo (1997)	UK	13 children and adolescents (mean age 11 years) with juvenile chronic arthritis (73 with pauci-arthritis and 40 with polyarthritis).	Self report	MMAT Quant Descriptive
Ungerer, Horgan, Chaitow & Champion (1987)	Australia	363 children, adolescents and young adults with juvenile arthritis. Primary aged= 109 mean age= 10.6 High school aged= 163 mean age= 15.3 Young adult= 91 mean age= 21.7	Self report, parent proxy report	MMAT Quant Descriptive
Vervoort, Logan, Goubert, De Clercq & Hublet (2014)	Belgium	10650 children and adolescents. Mean age= 14.33 years	Self report, parent proxy report	MMAT Quant Descriptive
Waite-Jones & Swallow (2018)	UK	8 young people diagnosed with JA aged 10-18 years old.	Self report	CASP
Whitehouse, Shope, Sullivan, Kulik & Chen-lin (1989)	USA	135 children and adolescents with JRA (mean = 11.5 years.)	Parent proxy report	MMAT Quant Descriptive
Yadav & Yadav (2013)	India	64 children (32 children with juvenile idiopathic arthritis 32 age and sex matched control healthy children) Mean age for cases= 12.75 Controls= 12.73	Self report	MMAT Quant Non Randomised

Reference	Country	Chronic Pain Condition	Person Completing the School Functioning Variable	Risk of Bias Assessment Used
Zhang & Deng et al (2015)	China	3000 high school students aged 16-18.	Self report	MMAT Quant Descriptive

Appendix F Topic Guide

Topic Guide

[Version 1 08/04/2020] [ERGO ID: 55569]

Ask about other staffs roles in supporting when mentioned e.g ELSA's school nurses etc

1. Could you tell me about your experience of supporting a child/young person with chronic pain in school?

Did you find these children had co morbidities/ other issues too?

2. Did you/ do you feel prepared and competent to do so? (if yes; why, if no, why?)

3. Did you/ do you encounter any difficulties/issues?

4. Is there anything you felt was effective/ worked well?

5. Is there anything you would have liked to do differently?

Do you feel there are social aspects of school that are difficult for children with chronic pain? How does your school support with this?

6. What (if anything) would you have liked/ what would have made your experience of supporting a child/young person with chronic pain different?

7. In light of the COVID-19 school closures, could you tell me about your experience of supporting children remotely?

- Supporting children without chronic pain conditions who would usually not require work to be set online

-Supporting children with chronic pain conditions remotely

8. Have you encountered any difficulties/ issues?

9. Has any aspect of remote working worked better than you expected?

10. How do you feel the children have responded to remote working?

11. What do you feel you have learned, if anything since working with children remotely?

12. Has the necessity for remote working due to COVID- 19 changed your thinking regarding how work is set remotely for children and young people who cannot attend school as usual?

13. Thinking about the experiences you have discussed, what would you keep the same and what would you change/improve if you were able to?

14. As a result of COVID 19, do you think you will make any changes to your work with children/young people with chronic pain when schools reopen?

- Are you likely to continue using some of the systems developed during the school closure time (if yes/no why/why not)

15. (If yes in answer to question 14) what, if anything would help you make these changes/keep using these systems?

16. Is there anything else you would like to add about your experiences that my questions have not covered?

Appendix G Participant consent form

Study title: **How can schools support the education of children and young people experiencing chronic pain: Perspectives of teachers and other school staff.**

Researcher name: Lauren Baggley

ERGO number: 55569

Participant Identification Number (if applicable*):*

Please initial the box(es) if you agree with the statement(s):

I have read and understood the information sheet [Version 1 08/04/20] and have had the opportunity to ask questions about the study.	
I agree to take part in this research project and agree for my data to be used for the purpose of this study.	
I understand my participation is voluntary and I may withdraw up to one month after the interview for any reason without my participation rights being affected.	
I understand that my personal information collected about me such as my name or contact details will not be shared beyond the study team and will be stored separately to my transcript data.	
I understand that I may be quoted directly in reports of the research but that I will not be directly identified (e.g. that my name will not be used).	
I agree to take part in the interview for the purposes set out in the participation information sheet and understand that this will be audio-recorded.	

Name of participant (print name)……………………………………………………………………………

Signature of participant…………………………………………………………………………………….

Date……………………………………………………………………………….. ………………….

Name of researcher (print name)……………………………………………………………………

Signature of researcher …………………………………………………………………………………….

Date………………………………………………………………………………………………………..

Appendix H Participant information sheet

Study Title: **How can schools support the education of children and young people experiencing chronic pain: Perspectives of teachers and other school staff.**

Researcher: Lauren Baggley

ERGO number: 55569

You are being invited to take part in the above research study. To help you decide whether you would like to take part or not, it is important that you understand why the research is being done and what it will involve. Please read the information below carefully and ask questions if anything is not clear or you would like more information before you decide to take part in this research. You may like to discuss it with others but it is up to you to decide whether or not to take part. If you are happy to participate you will be asked to sign a consent form.

What is the research about?

This research is for a doctoral thesis carried out by a trainee Educational Psychologist as part of their professional training at the University of Southampton. The researcher is interested in understanding the experiences of school staff who are currently working with or have worked with children and young people experiencing chronic pain. It is expected that this study will improve the understanding of the experiences of school staff working with children and young people experiencing chronic pain in an education context.

Why have I been asked to participate?

You have been asked to participate because the researcher is interested in the experiences of school staff who are working with/have worked with children and young people experiencing chronic pain. You have been asked to participate because you work in this professional role and have worked with/are working with children and young people experiencing chronic pain. A total of 20 participants will be recruited.

What will happen to me if I take part?

You will take part in a single semi-structured interview with the researcher about the topic via Microsoft Teams. Interviews will be conducted between April 2020 and May 2021. This interview will take approximately 40 minutes and will be arranged at a time that is convenient for you. The interview will be audio-recorded and transcribed. This is so that we have an accurate record of what you say to inform the research described above. The audio recording will be deleted from the recording software once the interview has been transcribed and the transcript will then be analysed by the researcher. After the interview, you will be given a debrief sheet re-iterating the aims of the study via email.

Are there any benefits in my taking part?

There are no direct benefits. However the study may help to improve current understanding of school staff's experiences of working with children and young people with chronic pain, and may inform supportive recommendations that are made to schools in future.

Are there any risks involved?

While unlikely, there could be a possibility of distress when recalling experiences working with children and young people with chronic pain. During interviews, you will be able to pause or stop the interview at any time.

What data will be collected?

The researcher will collect an audio-recording of your interview which will be stored on the University of Southampton's secure system. The recording will subsequently be transcribed and personal identifiable information will be removed from this transcript. The audio-recording will be deleted from the recording software immediately following transcription. Transcripts will be stored on the University of Southampton's secure system and pseudonyms will be applied to facilitate confidentiality. Consent forms will be stored electronically on the University of Southampton's secure system, separate to the transcripts. Your name and the email address that you provide will be stored in a password-protected file on the University's secure system along with your allocated pseudonym; this will be stored separately to your transcript data. Research data will be stored for 10 years and personal identifiable information will be stored for 1 year after the study has finished in the University of Southampton's repository (ePrints Soton).

Will my participation be confidential?

Measures will be taken to maintain confidentiality through the following means. The audio recording will be transcribed and personal identifiable information will be removed from this transcript. The audio-recording will be deleted from the recording software immediately following transcription. As stated above, transcripts, consent forms, contact details and allocated pseudonyms will be stored on the University of Southampton's secure system. Pseudonyms will be applied to the transcripts in order to reduce risk of identification. It is recognised that it may be possible for participants to be identified, as they might be known to one another in their working practice. Therefore participants' involvement in the study cannot be maintained as anonymous but these procedures will maintain confidentiality as much as possible.

Only members of the research team and responsible members of the University of Southampton may be given access to data about you for monitoring purposes and/or to carry out an audit of the study to ensure that the research is complying with applicable regulations. Individuals from regulatory authorities (people who check that we are carrying out the study correctly) may require access to your data. All of these people have a duty to keep your information, as a research participant, strictly confidential.

Do I have to take part?

No, it is entirely up to you to decide whether or not to take part. If you decide you want to take part, you will need to sign a consent form to show you have agreed to take part. The relationship between your school and the researcher as well as the Educational Psychology Service will not be affected in any way by your decision to take part/not take part.

What happens if I change my mind?

You have the right to change your mind and withdraw at any time without giving a reason and without your participant rights being affected. You can withdraw by contacting the researcher by email (see below). Due to the nature of the research, you can withdraw up to one month after your interview. In this instance, your transcript and personal data will be destroyed and removed from the database.

What will happen to the results of the research?

Your personal details will remain strictly confidential. Research findings made available in any reports or publications will not include information that can directly identify you without your specific consent. Verbatim quotations might be used in the research write-up, which means you might be able to identify yourself, but will be non-identifiable to others. You will receive a summary of findings when the research project is complete. The researcher will seek publication in peer-reviewed academic journals.

Where can I get more information?

For more information about this research, please contact the researcher via the email address below:

l.baggley@soton.ac.uk

What happens if there is a problem?

If you have a concern about any aspect of this study, you should speak to the researchers who will do their best to answer your questions.

If you remain unhappy or have a complaint about any aspect of this study, please contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Data Protection Privacy Notice

The University of Southampton conducts research to the highest standards of research integrity. As a publicly-funded organisation, the University has to ensure that it is in the public interest when we use personally-identifiable information about people who have agreed to take part in research. This means that when you agree to take part in a research study, we will use information about you in the ways needed, and for the purposes specified, to conduct and complete the research project. Under data protection law, 'Personal data' means any information that relates to and is capable of identifying a living individual. The University's data protection policy governing the use of personal data by the University can be found on its website (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page).

This Participant Information Sheet tells you what data will be collected for this project and whether this includes any personal data. Please ask the research team if you have any questions or are unclear what data is being collected about you.

Our privacy notice for research participants provides more information on how the University of Southampton collects and uses your personal data when you take part in one of our research projects and can be found at http://www.southampton.ac.uk/assets/sharepoint/intranet/ls/Public/Research%20and%20Integrity%20Privacy%20Notice/Privacy%20Notice%20for%20Research%20Participants.pdf

Any personal data we collect in this study will be used only for the purposes of carrying out our research and will be handled according to the University's policies in line with data protection law. If any personal data is used from which you can be identified directly, it will not be disclosed to anyone else without your consent unless the University of Southampton is required by law to disclose it.

Data protection law requires us to have a valid legal reason ('lawful basis') to process and use your Personal data. The lawful basis for processing personal information in this research study is for the performance of a task carried out in the public interest. Personal data collected for research will not be used for any other purpose.

For the purposes of data protection law, the University of Southampton is the 'Data Controller' for this study, which means that we are responsible for looking after your information and using it properly. The University of Southampton will keep identifiable information about you for 12 months after the study has finished after which time any link between you and your information will be removed.

To safeguard your rights, we will use the minimum personal data necessary to achieve our research study objectives. Your data protection rights – such as to access, change, or transfer such information - may be limited, however, in order for the research output to be reliable and accurate. The University will not do anything with your personal data that you would not reasonably expect.

If you have any questions about how your personal data is used, or wish to exercise any of your rights, please consult the University's data protection webpage (https://www.southampton.ac.uk/legalservices/what-we-do/data-protection-and-foi.page) where you can make a request using our online form. If you need further assistance, please contact the University's Data Protection Officer (data.protection@soton.ac.uk).

Thank you for taking time to read this information sheet and considering taking part in the research.

Appendix I Participant debriefing information

UNIVERSITY OF
Southampton

How can schools support the education of children and young people experiencing chronic pain: Perspectives of teachers and other school staff.

Debriefing Statement *(written)* (Version 1, 08/04/2020)

ERGO ID: 55569

The aim of this research was to understand the experiences of school staff working with/ who have worked with children and young people experiencing chronic pain in an education context. It is expected that this study will improve the understanding of school staffs experiences working with children and young people experiencing chronic pain. Your data will help our understanding of school staffs experiences. Once again results of this study will not include your name or any other identifying characteristics. The research did not use deception. You will receive a summary of research findings once this project is completed.

If you have any further questions please contact Lauren Baggley at l.baggley@soton.ac.uk

Thank you for your participation in this research.

Signature Date 28/05/20

Name Lauren Baggley

If you have questions about your rights as a participant in this research, or if you feel that you have been placed at risk, you may contact the University of Southampton Research Integrity and Governance Manager (023 8059 5058, rgoinfo@soton.ac.uk).

Appendix J Interview field notes

Interview number	Observations
1	The participant was clearly emotional at being in lockdown and away from her job- she lives alone and mentioned that she has been finding it difficult during the pandemic and has been feeling isolated. I wondered if this impacted her enthusiasm about virtual learning- she appeared to get a lot out of her virtual connections with the students. The participant mentioned how the pandemic had brought to her attention how important it is to connect with people and this greatly improved her understanding/empathy for students who are not always able to attend school. Perhaps an unexpected benefit of doing the interviews during the pandemic is that all of the participants were experiencing the frustrations of students with chronic pain who are regularly unable to attend school and feel isolated at home. This participant explained she feels emotions deeply, she is a worrier and sometimes makes herself unwell because she feels such high levels of empathy for the students she works with. It was important to check in with this participant more often throughout the interview to ensure she felt comfortable and supported emotionally. The participant said she had enjoyed the interview and found it therapeutic to discuss her feelings, particularly about the emotional impact of working with students with chronic pain, she explained the interview gave her a new found sense of motivation for her job which was an unexpected positive aspect of taking part.

2	Participant was forthcoming that their school is not doing enough to support chronic pain and this seemed to be a source of great frustration to the participant- perhaps because they mentioned they had experience with a chronic pain condition themselves and therefore felt strongly about supporting students with chronic pain.
3	Participant seemed glad of the opportunity to discuss the pressures they felt (particularly managing their time and trying to make adaptations in school) Very honest about their perceived lack of knowledge about chronic pain but then went on to show they did have a good knowledge of the different ways chronic pain affects a student.
4	Sometimes the participant appeared frustrated about working with students with chronic pain and they seemed not to understand the wide ranging impact e.g. the participant referenced times that they have had a migraine but still had to go to work, and they felt it should be the same for students with chronic pain attending school. The participant mentioned that they were stressed in their role, and I wondered if this was impacting their capacity to be empathetic towards the students.
5	Participant seemed reluctant to address issues of bullying and perhaps a little defensive- said that bullying is addressed immediately at their school and is not an issue for students with chronic pain.
6	This participant seemed less inclined to give desirable answers and was very honest about shortcomings in their setting. They were honest about their lack of knowledge and lack of feelings of competence when working with chronic pain. They felt lucky to have many resources at their disposal and

	flexibility in their setting to make adaptations however they still felt ill informed regarding the correct adaptations to put in place. The participant clearly felt comfortable discussing their experiences supporting students with chronic pain and they mentioned that they had enjoyed the opportunity to reflect, which probably helped facilitate their open approach to the interview. Again this participant was preoccupied with trying to unpick the cause of chronic pain conditions and this was present in much of their thinking.
7	This participant felt very reflective and the answers were well thought about. The participant reflected on her time in various school roles and also on her own personal experience with a chronic health condition. Like many other participants, this participant felt she did not have a good understanding of chronic pain and was working beyond her remit, however as she discussed her experiences working with students with chronic pain it was apparent she did have a good understanding of the impact of chronic pain but seemed unaware about how much she knew.
8	The participant mentioned they had a chronic condition. It was interesting that they felt this improved their understanding of chronic pain, they did not seem to acknowledge that the experience of chronic pain may be different for adults/ children and can vary between individuals generally. The participant seemed to be applying their experience of chronic pain to the students experiences with good intentions, however not realising that their experience may be different and it may be harmful to tell students "I know how you feel"

9	It was clear throughout this interview that many years of experience working with chronic pain leads to a good understanding of the wide ranging impact and importance is placed on different things e.g. many participants were concerned with "unpicking" the cause of chronic pain but this participants explained that with experience she has come to realise the cause doesn't matter, nor does a lack of knowledge about chronic pain conditions specifically- the most important thing is to listen to the child/parent about their experiences and learn in this way.
10	Participant felt unsure about admitting to their personal stigmas regarding chronic pain perhaps due to wishing to give desirable answers, however it was implied in some of the answers e.g. references to other staff perhaps feeling the condition was made up.
11	This participant also seemed reluctant to discuss issues of bullying and areas that their school did not do so well to support students with chronic pain. The participant seemed conflicted in that they wanted to be honest about their lack of knowledge/training/feelings of competence working with chronic pain, however they also wanted to give desirable answers e.g. they were keen to show how they tried their best to do the right thing by the students. They regularly empathised with the student's position and how difficult it must be to have chronic pain, however they also suggested they did not feel it was within the remit of their role to support with chronic pain.
12	Being a more senior member of staff seemed to influence this participants approach, they were concerned about policies and frameworks that should be in place for students with chronic pain and spoke more about this than personal experiences like the other participants- this is perhaps because

	their role is largely implementing and ensuring the smooth running of policies. Again the participant felt they didn't have a good understanding of chronic pain but went on to show that through their work with students they in fact did have a good understanding of the wide ranging impact of chronic pain. This participant seemed to feel frustrated regarding other members of staff's reactions and stigmatising beliefs towards chronic pain.

Appendix K Coding manual

Theme: ***sub-theme***	**Description**	**Example**	**Elaboration, exclusion and / or inclusion criteria**
Theme One: Theme 1: Perceived misunderstanding of chronic pain as a biopsychosocial phenomenon: ***Chronic pain is misunderstood***	Participants describe various ways in which chronic pain is not fully understood and the result of misunderstandings.	*"Staff still find those, those types of conditions like chronic fatigue, like chronic pain, fibromyalgia, those sort of things really difficult to get their head around."* *"It's almost is that kid making this up?"* *"But as adults, we've had a migraine and we've gone into work. So, yeah, it does seem that we don't really understand."*	This could include participants' descriptions of their own or other staff's misunderstandings of chronic pain conditions, and the responses they observed when chronic pain was misunderstood e.g. stigma towards chronic pain.
Theme One: Perceived misunderstanding of chronic pain as a biopsychosocial phenomenon: ***Feelings of lack of competence when working with chronic pain.***	Participants describe how confident/competent or incompetent they felt working with children with chronic pain in school.	*"I think I'm competent enough because I'm experienced teacher. Yeah, I think I'm competent enough because my degrees in psychology."* *"Not very [competent] at all, to be honest with you. And even by the end of that year, I don't think*	Including participant's descriptions of their own feelings of competence/confidence or incompetence/ feeling under confident or unprepared to work with children with chronic pain. Descriptions could be explicit or implicit e.g. "I don't feel competent at all" (explicit) "I'm just the teacher, I don't know what to do"

		I felt that competent at all."	
Theme One: Perceived misunderstanding of chronic pain as a biopsychosocial phenomenon: ***Training Needs***	Participants comment on the value of training and their want/need for further training in relation to chronic pain.	*"I don't have the training, to kind of know what else to kind of bring in."* *"I think it would be definitely useful for every member of staff in a school to have [training], you know, like I've said, See, if there's been no training for any of this."*	This could include participants commenting on their training needs or the lack of training received in relation to chronic pain.
Theme One: Perceived misunderstanding of chronic pain as a biopsychosocial phenomenon: ***The emotional impact of working with children with chronic pain***	Participants express a view that working with children with chronic pain impacts their emotional wellbeing.	*"I get upset and you know…I worry worry worrying"* *"Your first instinct is to soothe them. But if it's something that you can't soothe them because of, because it's something that it's just there, there's nothing that you can do to fix it.*	This includes participants' descriptions of how they felt when working with children with chronic pain and the impact this had on their wellbeing.

		That's really hard." *"He would literally roll around the floor holding his head, it was so distressing."*	
Theme Two: The wide ranging impact of chronic pain: ***The fluctuating nature of chronic pain***	Participants describe how the presentation of chronic pain changes day to day and the sense they make of the changing nature of chronic pain.	"S*ome of our students who have chronic pain. It really is a mixed bag as to which end it tends to burn for them. But it can be anything."* *"I think the problem with chronic pain when you've got pain all the time, the ebbs and flows…are harder to explain."* *"They couldn't comprehend that his writing would go from being quite good when he when he was on doing well, to being bad…Almost illegible on a bad day"*	Examples include reference to any changes participants noticed in the presentation of chronic pain, the way in which this fluctuation impacts the support they put in place and how they make sense of the changing nature of chronic pain. This also includes references when participants/others have not understood the fluctuating nature of chronic pain.

Theme Two: The wide ranging impact of chronic pain: ***Attendance***	Participants discuss the impact of chronic pain on student's ability to attend school and the consequences of gaps in attendance.	*"She was off school for a long period of time. And then that gap, that challenge she had going forwards like she was she was about two years behind, behind her peers."*	Including references to students attendance both positive and negative, and the consequences of non-attendance that school staff observe.
Theme Two: The wide ranging impact of chronic pain: ***Learning Impact***	Participants discuss the impact of chronic pain on student's learning.	*"They've missed out on so much learning because of being at home because because they've not been well enough to come in. There are gaps."* *"I would say because in a normal classroom, you can just sit them down and do your lesson with this- concentration is reduced."*	Including references to students learning ability both positive and negative, and the wide ranging impact of chronic pain on learning such as concentration, general ability, achieving grades and readiness to learn.

Theme Two: The wide ranging impact of chronic pain: ***Social Impact***	Participants discuss the impact of chronic pain on student's social lives and social skills.	*"You have the chronic pain, then you can't go to school, then you become socially isolated from your peers"* *"When he was unwell, he would disappear for weeks. And it could be months, and he would come back and almost the entire social landscape of where he of the year group have changed for him"*	Including references to student's social skills and experiences both positive and negative, and the wide ranging impact of chronic pain on a student's social life such as friendships, bullying, belonging to a peer group, peer understanding and acceptance and feeling different to peers.
Theme Two: The wide ranging impact of chronic pain: ***Impact on parents/family***	Participants discuss the wider impact chronic pain can have on a child's parents and wider family network.	*"So it's recognising the tensions in the relationship between the parent and the child, the stress the parent is under not knowing what is wrong with their child."* *"Children who might be experiencing these things are possibly kept away from school quite a lot. Because parents think I can manage the pain, I can manage the bad days better at home, than school can."*	Including references to the ways in which chronic pain impacts the emotions and day to day life of a child's parents and wider family.

Theme Three: Lessons learned from lockdown: ***Benefits of virtual learning***	Participants discuss the positive aspects that they noticed as a result of implementing virtual learning during the global pandemic.	*"I think going forward, we will definitely make sure we put these things in place…going forward, I think if we had that situation again, if any of our children were in a similar situation, we would rethink how we support them. Because of we've had this opportunity to learn how to advance- to access people."* *"Any child that's in pain if they were in a hospital or say, they could communicate with their teachers or their class friends…It's just a fabulous way to erm, keep, keep them, keep them going and keep*	Including any positive reference to aspects of virtual learning e.g. maintaining relationships, improved attendance from those not usually able to attend, ease of use etc.

		them you know, well make them feel better."	
Theme Three: Lessons learned from lockdown: ***Barriers to virtual learning***	Participants discuss the barriers to virtual learning that will need to be overcome in order to use this method more often in the future.	*"I think it's always being isn't it, really sensitive to the fact that families might not have access to the technology."* *"That's a barrier at the minute I think that I hope would be removed once we're out of this pandemic (L: yeah) because we can't actually have those face to face meetings with parents at this point in time we show them how to work these things. And you show them what the expectation is and how to submit work and things like that."*	Including references to barriers the participants have experienced whilst using virtual methods during the pandemic, and those they foresee arising on the return to school. Including discussion of aspects that will need to be addressed in future or that participants feel worried about e.g. students having difficulty accessing technology.

Theme Three: Lessons learned from lockdown: ***Continuing a blended learning approach***	Participants discuss continuing to use the virtual learning methods used during lockdown upon the return to school, not to replace face to face learning but a blended approach of in person learning and use of virtual methods when it is more difficult for students to attend.	*"When we come back in the perfect world, if I'm notified that child x is going to be off for two weeks, within, there is no reason why I can't upload my lessons on to teams, and then child it has access to them."* *"I think more online working is definitely the way forward. I think, especially with tutoring. It'd be quite nice if we could get a system where we're doing tutoring from home. And with groups of kids online."*	Including references to participant's wishes to continue using virtual learning upon the return to school, references to using virtual learning alongside face to face learning and participants ideas regarding implementing a blended learning approach.
Theme Four: Managing chronic pain in a school setting: ***Chronic pain is a hidden problem in schools***	Participants discuss feeling as though chronic pain is not commonly known about within school settings	*"I've never even really had this kind of experience of or a conversation about kind of chronic pain. It's not really something that in my experience is really talked about."* *"Because he finds it so painful, he tends to hide that."* *"Hello, I've never met this child, but I understand they're in my*	Including references to school staff not being explicitly aware of students with chronic pain conditions and students with chronic pain not being present in the school setting either due to absence, being supported in alternate provisions, spending time out of the classroom etc.

		class. Can I teach them please?"	
Theme Four: Managing chronic pain in a school setting: ***Lack of information sharing***	Participants discuss the lack of information shared in relation to students with chronic pain within the school setting	*"There was no, hey, what are we doing for (name)...There's nothing there's no sort of flow of information from anywhere in the school, pastoral or senior level. It's literally parents and teachers."* *"When he is in lesson he never comes to tell me about anything. So…"* *"Just more information would be nice. Across the board. Because I've worked for a couple of different schools, and it's been the same thing."*	Including references to students themselves not sharing information about their chronic pain, a lack of information sharing amongst staff and from healthcare professionals, and a lack of information sharing from parents with school.

Theme Four: Managing chronic pain in a school setting: ***Adaptations made by trial and error***	Participants discuss the adaptations they make to their classrooms/teaching in order to accommodate students with chronic pain. Largely, participants use their common sense and a trial and error approach to implementing adaptations.	*"A lot of it for me was just trial and error. And should we try- should we have a go with this tomorrow?"* *"There's no textbook, or there's no handbook that tells you exactly what to do. To start off with, there's a lot of trial and error about different approaches, and different ways of working."*	Including references to participants using their common sense and trial and error methods to implement adaptations rather than specifically recommended adaptations, and their feelings about doing so. Also including references to participants making changes to suggested adaptations based upon their thoughts and feelings about what is best for the student.
Theme Four: Managing chronic pain in a school setting: ***Barriers to making adaptations*** ***-Time*** ***-Comorbid needs***	Participants discuss the barriers they are presented with when trying to implement adaptations for students with chronic pain in school, which complicate implementing the necessary support.	*"But it really is that there's no central resource out there, and it's something that needs to be there."* *"The speech language communication challenges are the biggest challenge we have, because of those children not being able to sort of like… to express themselves."* *"The logistics of that take time set up, which then you think of some of these individuals that have chronic pain*	Including references to any aspect of the school setting that participants feel prevent them from successfully implementing adaptations such as time restrictions, comorbid needs, managing other students in the class, lack of resources etc.

		challenges. They need that support straightaway."	
Theme Four: Managing chronic pain in a school setting: ***Improved communication with healthcare professionals***	Participants discuss the value that improved communication and opportunities to liaise with healthcare professionals could bring to their practice and support of students with chronic pain.	*"I can't ever possibly become an expert…any, you know, if we could have had a discussion with a nurse that had or an, you know, an expert in that field, who could say here's a bank of ideas."* *"In terms of like medical profession, yeah, kind of the parents are the go between for us. They will tell us the information and then we will then kind of go Okay, this is what it is. And then we never we don't actually speak to that professional."*	Including references to current communication with healthcare professionals, wishes and hopes for future communication with healthcare professionals and the benefits of improving this communication in order to work collaboratively.

Theme Four: Managing chronic pain in a school setting: ***Multiagency working***	Participants discuss the value of multiagency working, which is working collaboratively with each professional involved in supporting the child with chronic pain.	*"I would have liked more access to is almost more of that more multidisciplinary meetings more. More possibility for having those really open discussions."* *"A directory of people that we can go to that and the appropriate people to go to for that child would be really good."*	Including any references to the benefits of collaborative working and liaising with the various agencies and professionals involved in supporting a child with chronic pain.
Theme Four: Managing chronic pain in a school setting: ***Parent/child centred working***	Participants discuss the importance of placing the parent and child experiencing the chronic pain condition at the centre of the support planning process.	*"Whenever we have any meetings, make sure that the young person and their parent is the focus point in that meeting."* *"I always think that the best thing that we can do is listen, listen to the child, listen to the parent, about what the impact of their condition is."*	Including references to the importance of listening to the views of the parent/child, including them in the process of developing support and believing in their experiences. Also including any reference to working in collaboration with the parent/child.

Appendix L PARAMOUNT project materials (under development)

L.1 Information sheet for school staff

What is Chronic Pain?

Chronic pain is defined as pain that persists beyond the expected period of healing and recovery. Sometimes the pain develops following an injury or illness, sometimes there is no identifiable cause. However, the pain experienced is genuine and troubling. Chronic pain can be as the result of a condition or illness (e.g. Fibromyalgia, Juvenile arthritis) or pain can be the condition itself (e.g. Headache, musculoskeletal pain) sometimes the pain remains unspecified or undiagnosed.

Chronic pain is described as a biopsychosocial phenomenon, meaning pain is influenced by an interaction between physiological, psychological and social factors that interact with one another and vary for different individuals. This means that chronic pain impacts many aspects of a young person's life to varying degrees at different times and in different ways.

Chronic pain is very common and it is very likely that multiple students at your school have experienced it at some time. Prevalence statistics vary however, it is thought to be experienced by between one quarter to one third of children worldwide (World Health Organisation). Roughly one in ten children will experience chronic pain at one time or another.

School is very important for young people with chronic pain

It is clear that school provides vital developmental opportunities, learning skills, qualifications, social skills and life skills that prepare young people for the world. The school setting is also vitally important for young people with chronic pain.

The structure and routine provided by school is important in helping young people maintain consistency when many things may feel beyond their control, attending school seeing friends and engaging with different activities can help young people focus on things other than their pain and provides a welcome distraction, which has been directly linked to experiencing less pain.

Consistent routine and staying engaged throughout the day is also linked to better sleep cycles, with better sleep again linked to less pain. The supportive relationships young people build with adults in school can boost self-esteem and importantly in young people with chronic pain, positive relationships with school staff are considered a protective factor.

> *"It's not just about the learning, because school it's so much more than the physical learning. It's social, understanding the social engagement, those opportunities to connect with people. And also just opportunities to have downtime"*

How can I support a young person with chronic pain in school?

- ***Start the conversation.*** Many students feel embarrassed and unsure about approaching staff to talk about their condition and many wish staff would raise the topic with them. Let the student know privately that you want to understand and support with their condition, and that you will always be available if they want to talk. The student may prefer not to discuss it, and that is fine too. You can ask the student how they like to be approached. Opening the conversation positively can be helpful e.g. "You did a brilliant job in our games lesson, I know it isn't always easy for you and if there is anything I can do to help/if you ever want to talk please let me know" for younger children " If I had a magic wand and I could make things the best way they could be, what would be the same and what would be different?"

  "The best thing that we can do is listen, listen to the child, listen to the parent, about what the impact of their condition is."

- ***Know that symptoms can fluctuate.*** By its nature, chronic pain and its impact will fluctuate. Students may experience very few difficulties for some time and suddenly become debilitated. They may be able to take part in a PE lesson one day and will struggle the next. In a bid to fit in with their peers students may over exert themselves e.g. running around on the playground and they may feel the after effects of doing so. This can appear as though students are "picking and choosing" and it is important to understand this is not the case. Children worry that they are not believed, and that if they are able to do something once they will be expected to do it all the time without issue. Understanding that students support needs will change regularly and will need to be flexible to take this fluctuation into account will help in this respect.

  "They said, if they were able to do something one day, people think they can do it all the time."

- ***Consider other stressors***. Stress, tiredness, diet and general health all affect pain levels. Pain is harder to cope with when a person is tired, anxious or having problems at school or home. It is important to check in with children about how they are feeling in general, and to understand that they may want to discuss issues other than their chronic pain condition (friendship issues, bullying, learning difficulties, worries about appearance and home life arise most commonly as they do for other students). Reiterating to students that it is normal to have worries, whether they are related to chronic pain or not is helpful to normalise their feelings.

- ***Have high aspirations***. Having high aspirations for these students and believing they can achieve the same standards as their peers boosts their self-esteem and motivation. Research has found that teacher's perceptions of students with chronic pain as academically competent are a protective factor against the impact of chronic pain.

- ***Help students keep up to date with schoolwork***. When students have extended periods of absence and miss chunks of learning, it can be difficult to catch up and students may become avoidant because they know they will find it more difficult when they return. Speak with the student and parents about the best way to set work for them during absences- they may feel too unwell to complete the work and this is ok, but equally schoolwork can provide a good distraction and maintains an important sense of normality.

- ***Validate the feelings.*** Accepting that a student's feelings are genuine and valid makes a big difference to how well supported they feel. Students may say that they feel silly, or that other people have it worse- if something is upsetting them then it is valid regardless of how big or small it seems. Sometimes adults with good intentions make comparisons to try to empathise, or point out the positives to cheer a student up. Try not to do so, as everyone's experience of pain is different, and sometimes pointing out the positives minimises the difficult feelings.
  It can be uncomfortable but necessary to acknowledge difficult feelings. Useful empathetic statements that validate difficult feelings include "I can hear how hard that is for you, It seems like that is really difficult, I'm sorry to hear things are hard at the moment, can I do anything to help you?"

- ***Maintain a sense of belonging***. When students are frequently absent from school due to pain, hospital visits and treatments it is important that they still feel a part of the class. Cards and messages from the class during periods of extended absence and opportunities to join the class/speak with friends virtually will help maintain this important sense of connection and keep the student up to date with class events. It will also make students more likely to look forward to returning to school, rather than feeling anxious about being left behind.

"In their views, they told me I feel lonely, I feel isolated. I feel I can't talk to my friends. So they, for them, that's a big concern."

- ***rovide alternative choices***. There will inevitably be times that a student's pain prevents them from joining in with activities such as PE. Discussing alternatives in advance with CYP with be helpful. Appointments such as physiotherapy, counselling etc. can be planned to coincide with activities students may find more difficult, and this will mean they are not removed from lessons they are able to take part in. It may also be helpful to minimise unnecessary changing into PE kit in order to reserve energy.

- ***Minimise focus on the pain***. Of course there will be occasions when a student wishes to talk about their pain or they are having a particularly bad day and this must be acknowledged sympathetically. However, it is generally best not to focus on the pain as this is not helpful. Instead of asking how a child is feeling regularly and drawing attention to the pain, it may be useful to agree a discrete signal or way of checking in so that the student can let you know when things are getting too much for them. A check in system could be beneficial for the whole class and will help students who feel sensitive about being different to their peers.

- ***Acknowledge strengths and defining qualities.*** All children have strengths, talents, and positive qualities. Regularly acknowledging these helps a child feel that they are not defined by their chronic pain and they have an identity outside of their condition.

How can I work with parents?

- Many parents of a child with chronic pain can understandably feel very anxious about how their child will cope in school. It is important to recognise that parents may have been through a long arduous process to get to the bottom of their child's pain experience which has been stressful and frightening. Parents may feel it is best to keep their child at home where the pain can be managed, and they may be facing challenges from their child who feels worried about going to school and asks to stay home because they are in pain.

"Your child is unwell…that is terrifying…And you cannot help as a parent, your anxiety is transferring to your child."

- Parents may have experienced not being believed in the past, they may have worries arising from their own experiences of school, they may not realise the help that can be offered in school or how to go about asking for this help, legislation, procedures and acronyms that are commonplace in schools can be confusing and overwhelming and so being patient and to providing a listening space for parents, with opportunities to ask questions and clarify information are key.
- It is helpful to reassure parents, both about the support that can be offered in school and reassuring that their concerns have been heard- their child will not be pushed beyond their capacity for example, and the school will seek guidance from healthcare professionals to ensure adaptations made are appropriate.
- It will be helpful to reassure parents that you will keep in touch and update them on how their child's day at school has been (for younger children this could be in the form of a home school communication book, for older students this may be parent mails or phone calls).
- Parents are the experts of their children and can provide valuable insight about what works well to support them- it is helpful to work collaboratively with parents and to keep reviewing the suggested strategies to ensure they are as up to date as possible.

"The key thing really is all working together to move things forward."

"Often the most top tip came from the parent…So respecting them as being experts in their child's care."

Who can I ask for further advice?

It may be helpful to get in touch with the child's health care team (after receiving permission from parents) in order to ask further questions and clarify any information you may feel unsure about.

You could also speak with your school SENCo about seeking advice from an Educational Psychologist. They may be able to help with suggestions and resources for individual children, providing staff training and advising the school about appropriate adaptations.

"My philosophy is, is ignore the root cause of the pain, the child has got chronic pain, how can we devise a learning programme to enable them to access education?"

Working with children and young people with chronic pain can be challenging due to the heterogeneity of the needs of children with different conditions, and the fluctuating nature of chronic pain symptoms. It is common for staff to feel worried that they do not have the necessary knowledge about chronic pain to support these children effectively, however with experience school staff quickly get to know the child and draw on their wide range of experiences working with children and young people to support with their chronic pain in the same way that they would approach any other need in the classroom. Things do become easier with time, experience and collaboration.

Moreover, school staff have a wealth of experience in the aspects that mean the most to children and young people with chronic pain- listening to the child's views, caring, supporting, wanting to help, believing in the child's abilities and holding the child in unconditional positive regard, all of which make a lasting difference in the life of a child with chronic pain.

"We find ourselves in the thick of it, and we respond with our hearts"

L.2 School adaptations check list

Managing pain at school

Why is school so important?

Regularly attending school is important to give children and young people the best opportunities in life and to help prepare them to achieve their goals. School provides the opportunity to develop learning skills, to discover individual strengths, talents and hobbies. Children and young people can become involved in activities they may not experience otherwise, as well as opportunities for play and outdoor time that are key to positive mental wellbeing.

School is also vital in helping children develop social skills and an understanding of others, membership of a class group at school develops a sense of belonging which is important for children's self-esteem and happiness. Children and young people learn to build and manage relationships and interactions with peers and key adults alike.

Finally, school provides much needed routine in the lives of children and young people which brings a sense of comfort and consistency. Regular routines lessen anxiety, help children set their body clocks thus improving sleep cycles, provide regular mealtimes, offer stability during times of change or stress and encourages the development of independence skills.

What if I feel worried about school?

While there are so many clear benefits to regularly attending school, it is completely normal for all young people to have some problems at school now and again for all different reasons. It is common for young people to feel worried about getting good grades, keeping up with schoolwork, managing friendships and fitting in- it can feel as though there are many demands to balance all at once and this can be overwhelming.

Feeling worried about certain aspects of school is normal, and learning to manage these worries is all part of growing up. However, if you feel so worried that you don’t want to go to school, or feel you don’t enjoy school at all, it is important to get support and it is best to do this early on, before the problems feel too big to manage.

Having a medical condition and managing this at school can be particularly hard for many young people. School can be stressful at times and it is common to feel a bit lost and unsupported- particularly if your school setting is large. It can be difficult to know how to approach staff to let them know what you need, especially if there are lots of different teachers and you might feel worried that they will not fully understand. You do not have to sort these problems on your own, and you will certainly not be the only student to have support with a problem- that is why there are so many staff at school to support the students, we all need a little help from time to time and we cannot always manage on our own.

When things feel hard, it is tempting to avoid worries by staying at home, however this makes things harder in the long run. Missing lessons means the learning can be harder to catch up with when you are at school, and time away from friends makes keeping friendships harder too. These problems can be avoided, and that is why it is so important to get support. School staff are there to help you, and they will want to do so- they may just need some help understanding your worries and what works best for you so that they can make sure the right support is in place.

What can school do to help me?

It is important that you, your parents and your school work together to help you attend and feel happy. There are lots of staff at your school who are there to listen to you and help you manage, and there are many things they can do to help you feel happier and more confident. The best way to organize the support that works best for you is to talk all together about exactly what you need and what you find helpful. This way everyone is working together, arranging the agreed support and keeping up to date with what is working and what might need adjusting.

A good starting point is to think about the things you would like the school to know about your condition, the things you feel worried about at school and what might help you feel better. It might help to think about particular times/lessons in school that cause you difficulty or that you worry about a lot. You can also think about the things that already work well to see if they could also be useful at school.

Completing a checklist like the one below, with ideas that other children and young people have found helpful, can be a useful starting point- bringing this along to meetings with your school can help to guide the conversation. It is common for children and young people to worry that their school won’t be able to do the things they would find helpful, but once the school understands why certain adaptations are needed, lots of people are surprised at how much can be done. You might also want to think about asking your healthcare professional to write to the school to explain your needs and the type of support that has helped others.

School accommodations checklist

Please tick anything here that you feel would help you attend school/college more comfortably:

- ☐ Information session with all staff at school about pain and how it affects young people in general and me in particular
  - ☐ An information sheet that explains my needs to all staff
  - ☐ A note on the register so that cover teachers will also know what I need
  - ☐ A key adult to meet/check in with me when I arrive at school
  - ☐ A "one page profile" that tells all staff at school the strategies that work best for me, my likes and dislikes, and how I want to be supported
  - ☐ Leave class early/ late to avoid the rush in the corridor
  - ☐ Move around in class when I need to (approximately every ……minutes)
  - ☐ Have homework / teaching materials provided for me when I am absent from class or need to leave class early
  - ☐ Plan events e.g. school trips with me in advance
  - ☐ An exit pass/ time out card I can discreetly show to the teacher
  - ☐ An agreed visual/signal so that I can discreetly tell my teacher how I am feeling e.g. a red pen/highlighter placed on the desk.
- ☐ Have help regarding stairs, e.g. access to a lift key or move all of my classes downstairs
  - ☐ Have somewhere to leave heavier things, e.g. a locker
  - ☐ Nominate a friend to help me carry materials between lessons
  - ☐ Support with note taking and/or breaks from writing

☐ Reduce my subjects to core subjects so that I can manage my work-load better

☐ Have a mentor/buddy/someone that I can talk to in school

☐ Nominate a friend to join me for alternate activities

☐ Support to talk to my class about my condition (Perhaps in PSHE Lessons)

☐ Help with friends / issues with bullying

☐ Have a place in school where I know I can rest/lie down in lessons or breaks

☐ Have access to an alternative activity or classroom / allowed to do my personalized physiotherapy during PE

☐ Have classes changed so that I don't have to walk very far

☐ Special arrangements for exams

☐ Access to medication at school

☐ Have special arrangements for using the toilet

☐ Seating that I am comfortable with in all classrooms

☐ Use an Ipad/ laptop for extended writing tasks

☐ Wear a nonstandard school uniform (e.g. wear shoes with ankle support)

Anything else? …………………………………………………………………………………………….

………

L.3 Pain management at school and nursery information sheet

The importance of nursery and school

Children and young people benefit from regularly attending nursery and school. Attendance helps them to achieve their goals, develop new skills, discover their strengths and talents, try out new activities and hobbies, play and spend time outdoors. All these things are key to positive mental wellbeing (Nijhof et al., 2018; Storli & Hansen Sandseter, 2019).

Going to school or nursery also helps children to develop socially. School is beneficial for developing social skills and an understanding of others (Osher, Kendziora, Spier, & Garibaldi, 2014). School helps children develop a sense of belonging within a class, which increases their self-esteem, happiness and school success (Korpershoek, Canrinus, Fokkens-Bruinsma, & de Boer, 2020). Children also learn to build friendships and manage interactions with peers and adults (Teodoro et al., 2005;Gulay & Akman, 2009).

School and nursery provides a routine for children, which gives them a sense of comfort and consistency (Arlinghaus & Johnston, 2019) and is linked to school success (Spagnola & Fiese, 2007). Regular routines can lessen anxiety, offer stability during times of change or stress, and encourage children to become more independent. They also provide regular mealtimes and help encourage good sleep cycles (see Section 6), which can improve pain and encourage daytime activity (Mindell & Williamson, 2018; Tang & Sanborn, 2014). School routines reduce the time children have to think about their pain and condition and children experience less pain overall (Evans, Tsao, & Zeltzer, 2008).

> *“It’s not just about the learning, because school it's so much more than the physical learning. It's social, understanding the social engagement, those opportunities to connect with*

The stresses of school

Many children can find school stressful and challenging, particularly if they are going through periods of developmental change. Common school stressors include difficulties with friendships, pressure to fit in and feeling different to peers. Children may also worry about their appearance, including worries about getting changed for PE lessons. They may also experience pressure to achieve good grades and anxiety about exams and managing teachers’ expectations. Being in large school environments that can be noisy and overwhelming and children may also find it hard to organise and manage their time and workload.

Difficulties children with chronic pain face at school

Managing the stresses of school can be particularly hard for children with pain. Children may have to miss school regularly due to appointments, procedures, pain, or other symptoms. Poor sleep, tiredness, poor health, medication side-effects, and symptoms including pain can make it harder to concentrate and complete school activities. Children can feel lost and unsupported. They may worry about discussing their needs with teachers, especially in secondary school where they may be taught by many different members of staff.

These problems can lead to children attending school less, or not at all. Unfortunately, this can become a vicious cycle, which can make problems worse. The longer children avoid school, the more learning they missed. It can be hard for them to catch up when they return, and they may lose confidence in their abilities, creating extra stress. Friendships can be difficult to maintain when children are often absent, which can cause loneliness and a sense of isolation. For some children, even thinking about how they will get through the school day can be overwhelming.

> *"When he was unwell, he would disappear for weeks. And it could be months, and he would come back and almost the entire social landscape of the year group have changed for*

It is important to address these worries early on before children becomes 'stuck' in a vicious cycle of worry and school avoidance.

> *"Whatever cause- you have the chronic pain, then you can't go to school, then you become socially isolated from your peers, and everybody else, and then you get anxious because*

Concerns about increasing your child's attendance at school

You may have concerns about how your child will cope in school. Some parents worry that their child may overexert themselves or may not follow their treatment plan properly.

Action:

- Remind yourself that if your child goes to school regularly, this can reduce their pain and improve their wellbeing. Attending school can give children joy and a sense of normality
- Adapt goals for school. In most cases, the goal should be for forward progress, even if the progress is small

> *"They do messy play with them. There's a sensory room there, lots of things - they keep them occupied all day long. He has stimulation, comes home, then just chills"* Parent of a child

What can you do to support your child in going to school?

Action:

Develop a plan: To help your child get back on track at school, it is a good idea to develop a plan with their school to find strategies that can support your child. This can take time, energy, and persistence. As your child's condition develops, their plan will need to be reviewed and updated. Involve your child in the plan (see below).

Establish and maintain a positive relationship with school:

- Maintain regular contact with the school - it can be useful to identify a key contact.
- Written communication is important to keep a record of discussions and decisions. Tip: save draft emails for you or a friend to look over before sending. It can be easy to send a frustrated email in the moment and many parents regret doing so later.
- Communicating in-person or over the phone is helpful to build positive relationships and problem solve complex issues.
- Collaborative working with your child's school is key. Listening and sharing expertise will ensure that you are working in partnership which will ensure your child is well supported. Be flexible in trying solutions suggested by the school and make your own suggestions (see Appendix F: Managing pain at school information sheet).
- Try to avoid talking negatively about school staff in front of your child. If they pick up on your frustrations, they may want to avoid going to school.
- Remember that school staff may have limited knowledge about your child's condition and pain. There may also be limits on how the adjustments they can make for your child.
- Ensure staff have the necessary information about your child's needs and ask your child's healthcare team to provide information or liaise directly with the school as needed (see Appendix E: Information sheet for school staff)

> *"To know she's at school now, and enjoying school, is respite for me, but it's also quality*

Involve children and young people in plans

- Ask your child what support they would like
- Speak to your child about what any worries they have about school. Some of these may be unrelated to pain or your child's condition e.g. learning difficulties, sensory issues, friendship problems.
- Note down your child's concerns or questions about their support to discuss with the school (for example, adaptations that make children appear different to their peers is a common concern)
- Work with your child and their school to develop **a one-page profile** (see Appendix G: All about Alex example):
    - Profiles include everything that the child would like school staff to know, for example, how they want to talk about their condition, the support they want, their hopes and goals.
    - Profiles are brief and given to every member of staff working with your child
    - Your child may want to design theirs in their favourite colour, decorate it with pictures of characters, pets and other things that are important to them. Older children may want their profile to look more like a CV or fact sheet.

Set SMART Goals

Goals that are **S**pecific, **M**easurable, **A**ttainable, **R**elevant and **T**ime bound (SMART) are useful to review and measure your child's progress. SMART goals:

- Are useful for breaking larger goals down into more manageable chunks.
- Ensure that everyone (your child, you, school staff) will work towards the same goal
- Show who is responsible for each aspect of the goal.

SMART goals should be set collaboratively between school staff, parents, and children. They should be attainable but not too easy.

Don't worry if a goal is not achieved within the planned time frame. Instead, think collaboratively about why this happened. The goal or the support given to your child may need to be changed in future.

Example SMART goal for Owen (16) who is preparing to sit his GCSEs shortly:

I will revise my biology topic by attending the three after-school supervised study periods (Specific, Relevant). By the half term holiday (Time bound) I will have: completed at least one practice past paper and made flashcards for each section of the topic (Measurable and Attainable).

Be positive and enthusiastic about education and school

Share positive stories from your time in education with your child. You can also talk about how you overcame difficulties but avoid talking about overly negative experiences. Children's attitudes towards school are influenced by their parents' modelling and views. By sharing your experiences, you can encourage your child to develop a 'growth' mind set. Using this mind set, mistakes and challenges are seen as positives that are needed to learn and better ourselves.

Give praise and encouragement to your child for 'having a go' rather than getting things exactly right, especially if tasks seems difficult and overwhelming.

Request an Education, Health and Care plan (EHC plan) where appropriate.

If, after discussion with the school setting it is felt that your child requires support beyond that which an educational setting can provide at the level of special educational needs support, it may be felt necessary to request an EHC plan.

An Education, Health and Care plan (EHC plan) is a legal document created collaboratively between the Local Education Authority, Health and Social Care and parents (young people aged 16- 25 will also be included where appropriate).

Information about EHC plans:

- An EHC plan identifies a child's strengths, hopes, and needs and includes the provisions needed to meet these.
- Parents' and children's views and wishes are central in developing the plan.
- The local authority funds the support identified in the plan.
- The process can take time, so it is useful to explore other forms of support in the meantime.
- Children with an EHC plan are given priority when applying to their chosen school.
- An EHC plan is regularly reviewed - usually annually. The support given is monitored and changed as children mature.

The process:

Requesting a needs assessment: The process usually begins with a request for an EHC needs assessment (EHCNA). Your school special educational needs coordinator (SENCo) can request this, so it is helpful to arrange a meeting to discuss this with them. Alternatively, parents or young people aged 16-25 can contact the special educational needs department of their local authority to request one.

Next steps: When a needs assessment request is accepted, the local authority will gather information from the parents and all professionals working with the child. A draft plan is agreed on at a collaborative meeting involving the parent(s) and young person if appropriate. Once this has been accepted, it will be published and used at school.

Seek Specialist Support (where appropriate)

Several school professionals can help to support children, young people and their families to manage pain in the school setting:

Special educational needs coordinator (SENCo): SENCos identify any special educational needs a child may have. They develop strategies to help children make progress at school. The SENCo will liaise with teaching staff to ensure these are in place and may arrange staff training courses to improve understanding.

If you are concerned about your child, speak to the SENCo to discuss this. Children do not have to have a diagnosed special need to receive support from them.

Educational Psychologist (EP): In some cases, the school in discussion with parents, may wish to involve an Educational Psychologist. EP's work with schools to help children to fully participate in school and community life. They provide advice to school staff about adaptations and resources to support children. They can train staff to develop skills to support children with specific needs. They also help schools to involve parents in developing school support for their child. An EP will also have local knowledge and can signpost to agencies and services in your area.

EPs work with children, school staff and families to gain a clear picture of a child's strengths and needs. They will usually hold a consultation meeting and may write a formal report suggesting support and adaptations for the child in school. Usually, requests to involve an EP are made through the school SENCo.

School counsellor: Some school settings may be able to offer sessions with a school counsellor. The school counsellor can provide a safe space for your child to discuss and work through their concerns about school and other areas of their life. School counsellors are not teaching staff, and it can be helpful for children to be aware that they can speak freely to them. The school counsellor can support children with their emotional wellbeing, help with adaptive coping strategies for managing school-based stress and ask children about the type of support they would find most helpful.

Pastoral care staff: The school SENCo may involve pastoral care staff to help support your child. This could include extra learning support in the classroom, mentoring or a point of contact for your child to talk to about any worries. Pastoral care staff work closely with your child and can monitor the types of support that work well and those that may need changing.

Further resources

- Council for disabled children https://councilfordisabledchildren.org.uk/help-resources/resources/understanding-needs-disabled-children-complex-needs-or-life-limiting-conditions
- A family guide to the special educational needs and disability (SEND) system in England A Family Guide to the SEND System in England | Council For Disabled Children

- Advisory centre for education (ACE) http://www.ace-ed.org.uk/ ACE provides independent advice and information on state education in England

- Child law advice https://childlawadvice.org.uk/ provide specialist advice and information on child, family and education law to parents, carers and young people in England

- IPSEA: https://www.ipsea.org.uk/ offers free and independent legally based information, advice and support to help parents get the right education for children and young people with special educational needs and disabilities. They host an information service, advice line and tribunal helpline and provide training for parents, schools and local authorities.

- CONTACT https://contact.org.uk/ provide direct advice and support services to parents/carers. They host a free national helpline which is open Monday to Friday between 9.30am and 5.00pm: 0808 808 3555