Assessment and treatment of pain in children and adolescents

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Keywords:
Pain
Children
Adolescents
Assessment
Management
Technology

Abstract

Pain is one of the most common and distressing symptoms experienced by children and adolescents with juvenile idiopathic arthritis. Pain is known to negatively affect all aspects of health-related quality of life, including physical, emotional, social, and role functioning. The valid and reliable assessment of pain is the first critical step to developing an effective plan for pain management. This chapter will address the following key questions:

(1) What is the prevalence and impact of pain in children and adolescents with arthritis?
(2) Why is it important for clinicians to assess the multidimensional nature of pain and what are the practical issues that should be considered?
(3) What tools are available to help clinicians to assess pain?
(4) How can Internet and mobile technologies be used to improve the assessment of pain?
(5) What are the recommended strategies for clinically managing pain, including pharmacological, physical, and psychological approaches?

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Prevalence and impact of pain in children and adolescents with arthritis

How common is pain in juvenile idiopathic arthritis?

Pain is the most common and distressing symptom experienced by children and adolescents with juvenile idiopathic arthritis (JIA). In a longitudinal study of polyarticular arthritis, $N = 41$ patients (aged 8–18 years) completed daily paper diaries over an 8-week period to report daily symptoms and function [1]. On average, patients reported the presence of pain on 73% of days, with most patients reporting pain on more than 60% of days. The average number of painful joints reported on pain days was $8.1 \pm 12.6$. A significant proportion of patients (39%) reported the experience of pain on all diary days, while a minority (5%) reported no pain over the study period. The average pain intensity was in the mild range ($36.6 \pm 24.5$ on a 100-point scale), although a sub-group of participants (31%) reported average pain intensity greater than 40 [1]. More recently, a sample of $N = 76$ patients with JIA (aged 9–17 years) completed electronic pain diaries three times per day over a 2-week period [2]. On average, participants reported pain intensity ($21.7 \pm 20.1$), unpleasantness ($19.8 \pm 19.5$), and interference ($13.4 \pm 15.2$) in the mild range on a 100-point scale. Pain was found to interfere most with walking ability, and was also associated with symptoms of stiffness ($24.4 \pm 23.2$) and mild to moderate fatigue ($36.6 \pm 24.1$) [2]. Recently, Kimura and colleagues surveyed North American pediatric rheumatologists to assess current practices regarding treatment of chronic arthritis pain [3]. The sample included $N = 53$ pediatric rheumatologists with an average of $14.0 \pm 7.7$ years in practice. Overall, 77% of respondents agreed that there are pediatric patients who continue to experience moderate to severe pain despite adequate treatment with disease-modifying therapy and non-steroidal anti-inflammatory drugs [3]. These findings are supported by a recent electronic diary study by Bromberg and colleagues where a sample of 59 JIA patients aged 8–18 years completed an e-diary three times per day for one month [4]. Although most participants were under treatment with a disease-modifying anti-rheumatic drug (79%) or a biologic agent (47%), patients continued to report pain in 66% of all e-diary entries. Across the entire study period, not one participant was completely pain-free, and 86% of participants reported at least one high pain level [4]. Several studies have also reported reduced pain thresholds and reduced pain tolerance in patients with JIA, including those with active and quiescent disease [5–7]. These lowered pain thresholds and tolerance have been correlated with increased reported pain, suggesting a role for central sensitization and nociceptive pathway plasticity in JIA [8].

How does pain affect health-related quality of life?

Pain is known to negatively impact all aspects of health-related quality of life (HRQL). In a study involving $N = 59$ patients (aged 8–18 years) and their parents, Sawyer and colleagues found that children and adolescents with JIA experienced significantly more problems with physical, emotional, social, and school functioning than healthy individuals [9]. Furthermore, reports from parents and children showed that higher pain levels were associated with more impairment in physical, emotional, and social functioning. In a larger study involving $N = 308$ adolescents with JIA aged 11, 14, and 17 years, Shaw and colleagues found that HRQL scores were less than optimal, particularly related to gross motor functioning (e.g. kneeling, standing, running) and systemic functioning (e.g. stiffness, joint tenderness, tiring easily, joint swelling) [10]. Lower scores for HRQL were consistently related to greater levels of disability, worse pain, and greater joint involvement. Furthermore, adolescents who were most likely to rate frustration or depression as one of their biggest problems were those with worse pain [10]. In the survey of pediatric rheumatologists conducted by Kimura and colleagues, 98.1% of respondents agreed that there is a strong relationship between pain and perceived quality of life for children and adolescents with arthritis [3].

How does pain affect sleep?

Poor sleep and fatigue are other important consequences associated with arthritis pain. In a cross-sectional study involving $N = 155$ patients (aged 8–16 years) with JIA or juvenile dermatomyositis, all
participants experienced moderately severe fatigue, and 44% reported sleep disturbances [11]. Increased pain was associated with more sleep disturbance, more fatigue, and decreased quality of life. A recent systematic review of sleep in pediatric pain populations identified 9 JIA studies with a total of \(N = 310\) patients [12]. Overall, findings from behavioural measures and polysomnography demonstrated that children with persistent pain have significantly more sleep disturbances, including lower sleep efficiency, than healthy individuals. Sleep problems were also linked with impaired executive functioning. Specifically, more night awakenings predicted poorer rapid visual processing and higher apnea severity scores predicted longer reaction times. The authors of this systematic review concluded that, “... children with persistent pain commonly suffer from disturbed sleep, which puts them at risk for poor functional outcomes” (p. 126) [12].

**What is the patient experience of living with arthritis pain?**

It is important to consider the perspective of patients to better understand the impact of living with JIA. Tong and colleagues recently completed a systematic review of qualitative studies, which included 27 studies of \(N = 542\) patients with JIA (aged 6–30 years) [13]. One of the major themes identified across all studies was an aversion to being different. Specifically, patients described the presence of unrelenting and unpredictable pain as a major disruptor to their sense of normalcy compared with healthy peers. They also described the experience of disablement due to restrictions on their physical, social, and school activities. These impairments had a negative impact on emotional functioning, such as feelings of powerlessness and sadness. Another major theme discussed by patients was the stigma and misunderstanding associated with JIA, including frustration at the ‘invisible’ nature of arthritis pain and the unpredictability of symptom flares. The authors of this systematic review concluded, “JIA can have a debilitating impact on children and adolescents. Patients must contend with unpredictable phases of incapacitating pain, stigmatization, and physical limitations” (p. 1403) [13].

**What are the long-term consequences of arthritis pain?**

In terms of long-term impact, Packham and Hall followed-up on functional outcomes of adults with long-standing JIA (average disease duration of 28.3 years ± 10.8) [14]. A total of \(N = 246\) adults took part in an interview, clinical examination, and notes review, while \(N = 231\) of these individuals completed a comprehensive functional and psychosocial questionnaire. The mean patient age was 35.4 years ± 11.1 at the time of the study, and average age at disease onset was 7.1 years ± 4.5. Overall, 24.5% of study participants had moderate clinical inflammation, while 18.8% had severe inflammation. Similarly, 54.4% had active arthritis according to laboratory tests (elevated C-reactive protein). A total of 42.9% of patients were characterized by severe disability across all disease subtypes. Severe disability was most common among individuals with systemic onset JIA (62.5%) and seronegative polyarticular JIA (50%), while oligoarticular (0%) and enthesitis-related JIA (16.1%) were associated with less functional impairment. In terms of emotional impact, a significant proportion of participants had high anxiety levels (31.6%) or had suffered from significant depression in the past (21.1%). Most participants continued to experience persistent pain from their arthritis, with 25% reporting pain intensity between 26 and 50 (100-point scale) and 32.9% reporting severe pain scores greater than 50. Only 7% of participants were pain-free at the time of assessment. The mean reported pain score across all participants was 37. Perceived level of control over pain was ‘poor or very poor’ in 22.8% of participants and ‘moderate’ in 45.2% of the sample. The authors of this study concluded, “adults with JIA often have significant levels of disability, usually related to severe continuing active disease over a prolonged period” (p. 1435) [14].

**Section summary**

- Pain is the most frequent and distressing symptom associated with JIA.
- Intensity is typically reported in the mild to moderate range, although severe pain is experienced in a smaller sub-group during disease flares [1].
Many patients continue to experience moderate to severe pain despite adequate treatment with disease-modifying therapy, biologics, and non-steroidal anti-inflammatory drugs [3,4].

Pain patterns can be unpredictable, with fluctuations within and between days [1,2,15].

Pain is associated with impairment of physical, emotional, social, and role functioning as well as sleep disturbances and fatigue [9–12].

About half of pediatric patients will continue to have active disease into adulthood, including symptoms of pain [14].

Why is it important for clinicians to assess the multidimensional nature of pain and what are the practical issues that should be considered?

Pain as a multidimensional experience within a biopsychosocial model

Clinical rheumatologists are frequently challenged to assess and manage the pain of children and adolescents with rheumatic disease [16]. In the context of assessment, it is critical to consider pain as a multidimensional experience that is comprised of sensory, affective, and evaluative components [17]. The sensory dimension of pain is related to quality (what pain feels like), intensity (how much pain hurts), location (spatial distribution of pain), and duration (how long pain lasts). The affective dimension is related to the emotional impact of pain, such as the extent to which pain is perceived as unpleasant or distressing. The evaluative dimension describes the degree to which pain is perceived to interfere with physical, psychological, role, and social functioning.

The multidimensional nature of pain is best considered within the context of a biopsychosocial model, which encompasses biological, environmental, and cognitive-behavioural mechanisms. As described by Anthony and Schanberg (2005), the development and maintenance of a child's arthritis pain experience is influenced by an interaction of: (1) biological factors such as genetics, disease activity, abnormal pain processing, and medications; (2) environmental factors such as parent pain history, parent coping and adjustment, family relationships, as well as school and social relationships; (3) cognitive-behavioural factors such as stress, mood, psychological adjustment, pain coping skills, and self-efficacy [18]. Importantly, several studies have demonstrated that disease activity (e.g. physician global assessment scores) typically accounts for only a small proportion (6.5–28%) of variance in reported pain [19,20]. Other factors that influence pain perception include patient age, developmental status, coping ability, mood, stress levels, as well as family and environmental factors [21]. Thus, an understanding of the many interconnected factors that may contribute to a patient's pain experience can enhance the ability of clinicians to manage pain using multimodal approaches, including pharmacological, physical, and psychological strategies [18]. Importantly, the failure to recognize and manage potential contributing factors to pain, such as poor sleep, anxiety, social isolation, and inactivity can lead to a cycle of pain and maintenance of symptoms [18].

Pain assessment as a cornerstone of pain management

It is well recognized that pain assessment is the first step in the effective management of pain. To treat pain effectively, an ongoing assessment of the severity and impact of pain and the patient's response to treatment is essential for disease management. Pain measurement typically refers to a quantification of pain intensity (for example, ‘how much does it hurt?’) [22]. In contrast, pain assessment involves a comprehensive characterization of the pain experience by using clinical judgement to consider the nature, significance, and context of a patient's pain [22]. The importance of pain assessment as a cornerstone of disease management has been recognized by a working group of representatives from the American College of Rheumatology, American Academy of Pediatrics, American Board of Pediatrics, and Association of Rheumatology Health Professionals [23]. This working group established a set of quality measures for the assessment of the process of care in JIA. Specifically, this group recommended that, “pain should be assessed in all patients at the first visit [to a pediatric rheumatologist after a diagnosis has been made] and at each subsequent visit that occurs at least 7 days apart” (p. 13) [23]. The group also emphasized that pain must be assessed using valid and reliable tools that are developmentally appropriate for the individual patient.
Sources of pain assessment data

Patient self-report is a key source of data for the assessment of pain in pediatric patients who are cognitively able to describe their pain experience. Research suggests that chronological age is the best predictor of whether an individual patient is able to accurately self-report their pain [24]. As described by von Baeyer (2006), most children aged 5 years and older are able to self-report their current pain when provided with a developmentally appropriate tool [25]. For children younger than 5 years and/or patients with cognitive impairment or communication difficulties, an observational pain measure should be utilized [26]. In all cases, patient self-report of pain should be considered alongside knowledge of the clinical context, the patient’s current state, as well as behavioural observation [27–29]. The same pain scale should also be used for individual patients over time in order to generate consistent data for longitudinal comparison across the trajectory of disease management.

Practical issues to consider when assessing pain using self-report scales

The issues are discussed in Table 1.

Section summary

- The assessment of pain is a cornerstone of disease management for children and adolescents with arthritis [23].
- Pain is a multidimensional experience that should be considered in the context of a biopsychosocial model [18].
- Pain should be assessed frequently and consistently by clinical rheumatologists throughout the disease management process using valid and reliable measures [23].
- Patient self-report is a key source of pain information and should be considered alongside knowledge of clinical context, patient narrative, and behavioural observation [25,27–29].
- Most children aged 5 years and older are able to self-report their current pain when provided with a developmentally appropriate tool [25].
- For children younger than 5 years and/or patients with cognitive impairment or communication difficulties, an observational pain tool should be used [26].

What tools are available to help clinicians to assess pain?

There are numerous options available to aid the assessment of arthritis pain in children and adolescents. The recommended characteristics for a pain scale are provided in Table 2. This section will describe traditional paper-based scales that meet these criteria, while the next section will provide details on more recently developed electronic tools.

Table 1
Issues to consider when assessing pediatric pain in clinical practice.

| 1. Choose an age-appropriate and culturally appropriate pain assessment tool. |
| 2. If possible, explain how to use the tool when the patient is not in pain. |
| 3. Choose an observational pain tool for patients who are: very young (under 5 years), cognitively impaired, and/or highly distressed at the time of assessment. |
| 4. Use simple vignettes to help the patient gain experience with the pain rating task and establish parameters. For example, “imagine that you just touched a hot stove. Show me how much hurt you would have”. |
| 5. Collect numerous pain ratings for individual patients over time (using the same tool) and keep track of how the scores correspond with clinical context. For example, how do pain scores change after administering a treatment of known efficacy versus a painful procedure? |
| 6. Always consider the narrative of patients and parents to provide context for individual pain scores. |
| 7. Track pain scores throughout the disease management process, from treatment planning to long-term follow-up. |
| 8. Be cognizant of potential discrepancies in the pain scores provided by patients, parents, and clinicians and use discussion to resolve. |

Adapted from Ref. [25]. See also: [28,30–34].
Self-report measures

Uni-dimensional pain tools (intensity only)

There is a high availability of self-report pain scales that assess the magnitude of pain intensity. Based on the desired features described in Table 2, the recommended tools for use in clinical practice are:

Verbal rating scales (VRS): use numbers and simple phrases to describe different intensities of pain. Patients are asked to choose the phrase that best represents their pain level, and their score is recorded as the corresponding number. For example, a commonly used VRS is: not at all = 0, a little bit = 1, quite a lot = 2, and most hurt possible = 3 [37].

Numerical rating scales (NRS): consist of a range of sequential numbers, usually 0—10 or 0—100, which are presented either verbally or in a graphical format. The scale is anchored by word descriptors such that a zero rating corresponds with ‘no pain’ and the highest number corresponds with ‘most pain possible’. The patient is asked to select the one number on the scale that best represents the magnitude or level of their pain intensity. The NRS can be administered either verbally (patient states their pain rating) or on paper (patient circles their pain rating). While the NRS has been extensively validated in adult populations, studies examining validity and reliability in pediatric populations are more recent [38—42]. The NRS requires numeracy skills to complete, and is recommended for children and adolescents aged 8 years and older.

Faces pain scales: consist of sequential drawings or photographs of facial expressions that show different degrees of pain [43]. Patients are shown the series of faces and asked to choose the one face that best represents how they feel inside. Each face has an associated numerical score. Research has shown that scales with a smiling face for the ‘no pain’ anchor, or a face with tears for the ‘most pain’ anchor can influence patient scores. For example, scales with a ‘smiling’ lower anchor may produce higher pain ratings than ‘neutral-faced’ anchors [44]. Thus, it is recommended that the ‘no pain’ anchor should have a neutral facial expression. Commonly used tools include the Oucher photographic scale [45], the Faces Pain Scale-Revised [46], and the Wong-Baker FACES Pain scale [47]. Faces scales have been well validated in children and adolescents aged 5—17 years across several different ethnic and cultural groups [43,48,49]. The Faces Pain Scale-Revised [46] is available at: http://www.webcitation.org/6OsqVjTP6.

Visual analogue scales (VAS): consist of a single vertical or horizontal line with anchors such as ‘no pain’ and ‘worst pain imaginable’. The patient is asked to place a mark on the line to show their level of pain. A score is generated by measuring the relative position of the patient’s mark along the length of the line with a ruler. The VAS is well validated in children and adolescents and is recommended for patients aged 8 years and older [49]. One commonly used and well-validated variation of the VAS is the coloured analogue scale (CAS) [50—52]. The CAS consists of a 100 mm long triangle that increases in width (from 10 to 30 mm) and colour (from white to dark red) and is mounted in plastic with a sliding marker.
The lower anchor of the scale is labeled ‘no pain’ and the top anchor is labeled ‘most pain’. The back of the scale has a ruler ranging from 0 to 10 in 0.25 increments. Patients are asked to slide the marker along the scale until it reaches the level that depicts their level of pain. Patients do not see the number that corresponds to the marker, but this score is recorded by the clinician [50–52].

**Graphic rating scales**: the most common concrete graphic rating scale is called the Pieces of Hurt tool [53]. It consists of four tokens (e.g. poker chips), which each represent a different amount of pain, ranging from ‘a little hurt’ to ‘the most hurt you could ever have’. The child is asked to choose the token that represents their level of pain. It is recommended for use in pre-school age children. It is easy to use and score, and the instructions have been translated from English into several languages and validated for use in Jordanian and Thai children [54,55].

**Multidimensional pain tools**

There are a limited number of self-report pain scales that assess multiple dimensions of pain (i.e. beyond intensity).

**Pediatric Pain Questionnaire (PPQ).** The design of this tool was modeled after the McGill Pain Questionnaire, which is one of the most common multidimensional pain scales for adults [17]. The PPQ uses a 10 cm horizontal VAS anchored with happy and sad faces to assess present pain intensity and worst pain intensity in the past week [56]. Patients are also asked to choose from a list of 46 word descriptors to express sensory (e.g. cutting), affective (e.g. horrible), and evaluative (e.g. sad) qualities of their pain. Pain location is recorded by asking the patient to colour in painful regions on anterior and posterior aspects of a gender-neutral outline of the body. The PPQ is intended for use in children and adolescents aged 5–18 years and takes 10–15 min to complete. There are different versions of the PPQ for children, adolescents, and parents. The PPQ-parent form contains items similar to the patient version with the aim of allowing cross-validation of child reports. The PPQ has been translated from English into multiple languages, including Danish, French, Norwegian, Portuguese, Spanish, and Swedish. According to the Cohen criteria, the PPQ has ‘well established’ evidence of validity [56].

**Abu-Saad Pediatric Pain Assessment Tool (PPAT).** Originally developed for Dutch-speaking children, the PPAT includes a 10 cm VAS to assess present and worst pain intensity [57,58]. It also asks patients to select from among 32 word descriptors to express sensory (e.g. burning), affective (e.g. fearful), and evaluative (e.g. horrible) dimensions of their pain. The PPAT is intended for use in children and adolescents aged 5–16 years, and takes 5–10 min to complete. According to the Cohen criteria, the PPAT is ‘approaching well established’ in terms of validity.

**Adolescent Pediatric Pain Tool (APPT).** This questionnaire was originally developed for children and adolescents with post-operative pain and has subsequently been used in patients with acute and chronic disease-related pain, including arthritis [59,60]. Pain intensity is measured using a 0–100 mm word graphic rating scale anchored by the phrases, ‘no pain’, ‘little pain’, ‘medium pain’, ‘large pain’, and ‘worst possible pain’. Patients are asked to indicate the location of their pain by colouring painful areas on a gender-neutral body outline showing anterior and posterior aspects. A list of 67 word descriptors is used for patients to express sensory, evaluative, and affective qualities of their pain. The APPT is available in English and Spanish. It is intended for use in patients aged 5–17 years and takes 3–6 min to complete. Jacob and colleagues recently conducted a critical review of the psychometric properties of the APPT across multiple studies, and concluded that it has good evidence of construct validity in a variety of painful conditions [61].

**Observational (behavioural) measures**

As described by von Baeyer and colleagues, observational (behavioural) pain tools should be used with children and adolescents who are: (a) too young to understand and use self-report measures (e.g. less than 4 years), (b) too highly distressed to self-report their pain, (c) impaired in their
communicative or cognitive skills, (d) physically restricted by medical treatment (e.g. bandages, mechanical ventilation, paralyzing drugs), or (e) providing self-report ratings that are considered to be exaggerated, minimized, or unrealistic due to cognitive, emotional, or situational factors according to clinical judgement [26].

Revised FLACC (r-FLACC) behavioural scale

This scale uses the indicators of facial expression, leg movement, activity, cry, and consolability (FLACC) to assess pain [33,34]. Each indicator is rated as 0, 1, or 2 based on the observed behaviour in the patient. The r-FLACC includes pain behaviours that are commonly seen in children with cognitive impairments. It is intended for use in children aged 2 months to 8 years, and is simple for clinicians to use, score, and interpret (see Fig. 1).

Non-Communicating Children’s Pain Checklist-Revised (NCCPC-R)

This checklist was designed to assess pain in children aged 3–18 years who are unable to speak due to cognitive impairments or disabilities [30,31]. The observer is asked to indicate how often the child has exhibited specific behaviours over the past 2 h. The checklist is divided into vocal, social, facial,
activity, body and limbs, physiological, and eating/sleeping categories. Each item is rated as 0 (not at all), 1 (just a little), 2 (fairly often), 3 (very often), or ‘not applicable’. The NCCPC-R has been translated from English into French, German, and Swedish. The checklist was designed to be usable by parents and caregivers without training, as well as other adults who are unfamiliar with a particular child.

Section summary

- There are numerous validated uni-dimensional tools for the self-report of pain intensity. Based on recent reviews [49,62,63]:
  - For children aged 3–4 years, the Pieces of Hurt tool is recommended.
  - For children and adolescents aged 8 years and older, a 0–10 numerical rating scale should be considered.
  - For children aged ≥5 years who do not understand the NRS, the faces pain scale-revised is recommended.
- There are a limited number of validated multidimensional self-report tools that assess pain intensity, quality, and location:
  - For children and adolescents aged 5 years and older, the pediatric pain questionnaire, pediatric pain assessment tool, or adolescent pediatric pain tool can be used.
  - For children and adolescents who are unable to self-report pain, a behavioural (observational) measure should be selected:
    - For cognitively impaired patients aged 4–21 years, the revised FLACC can be used to assess pain in the moment.
    - For cognitively impaired patients aged 3–18 years, the non-communicating children’s pain checklist-revised can be used with observation of the patient over a 2 h period.
- The same pain assessment tool should be used consistently over time with individual patients in order to allow for longitudinal score comparison.

Use of Internet and mobile technologies to improve pain assessment

Real time data collection (RTDC) to improve pain assessment

Children and adolescents with arthritis often experience changes in their pain over the course of a single day, such as exacerbated pain during the morning due to joint stiffness [2,15]. It is important for clinicians to be able to capture these daily fluctuations in arthritis pain in order to evaluate effectiveness of their disease management plan, and make adjustments as needed [64]. The multidimensional pain assessment tools described in the previous section (PPQ, PPAT, APPT) are not suitable for capturing prospective longitudinal data because they: (a) rely on the patient’s ability to recall past pain, and (b) do not capture ‘in the moment’ pain reports in the patient’s natural environment (e.g. home, school). The use of retrospective pain ratings, such as asking patients to recall their pain from the past week, can introduce significant error and distortion into pain assessment data [65,66]. These recall biases can be influenced by the frequency of painful events within a specified time period, the length of time between painful event and recollection, and the child’s psychological state, among other factors [65,67]. Furthermore, the act of reducing pain intensity to a single static number fails to account for the dynamic, fluctuating nature of arthritis pain over relatively short time periods.

These documented shortcomings of static, retrospective pain ratings can be minimized through the use of real time data collection (RTDC) methods [68]. This family of techniques is used to “collect data about experience as it naturally unfolds in a person’s life” (p. S85), and includes ambulatory monitoring,
experience sampling method and ecological momentary assessment [69]. The use of RTDC minimizes the risk of recall bias by asking patients to describe their pain ‘right now’ on multiple occasions and also facilitates the monitoring of within-person changes in pain. By providing multiple snapshots of pain over a given time period, these longitudinal data can be examined to identify patterns in pain as well as responsiveness to treatment [65].

While the earliest pediatric RTDC studies used pencil-and-paper pain diaries [70], recent advances in information and communication technology (e.g. Internet, smartphones) have permitted the development of electronic methods such as e-diaries. Advantages of this electronic approach over paper-based techniques include: minimizing errors in data transfer and transcription, ability to capture time-stamped data, ease of data sharing, increased compliance, and heightened patient satisfaction [65,71,72].

Electronic pain diaries for use in children and adolescents

There are a limited number of multidimensional electronic pain assessment tools for use in children and adolescents with arthritis. In 2004, Palermo and colleagues developed the first e-diary to record pain and functional limitations in children and adolescents with chronic arthritis pain. In a study involving 60 participants aged 8–16 years, this research group compared the e-diary format with a traditional paper diary in terms of patient compliance, accuracy, and acceptability [73]. Results indicated that the e-diary method was associated with significantly greater compliance and accuracy in pain reporting. These authors also noted that, “an unparalleled advantage of e-diaries...[is] an objective determination of adherence to the diary protocol through the time- and date-stamped feature, which cannot be achieved via the p-diary format” (p. 218) [73].

From 2006 to 2008, Stinson and colleagues iteratively developed and evaluated a multidimensional electronic pain diary called e-Ouch©. This tool was designed to obtain three daily pain ratings (upon waking, after school, and before bed). In phase 1, the prototype tool underwent usability testing in adolescents with arthritis [74]. All participants indicated that the tool was easy to learn, use, and understand, and was also satisfying to complete. In the next phase, the e-Ouch© was pilot tested in terms of acceptability and compliance [75]. Participants rated the tool as highly acceptable and easy to use, and average compliance rates of 71.7% were achieved. Subsequent studies provided evidence of construct validity and feasibility in adolescents with arthritis aged 9–18 years [2].

More recently, Stinson and colleagues developed and evaluated feasibility of the Standardized Universal Pain Evaluation for Rheumatology providers (SUPER-KIDZ) using a two-phased approach [76]. In phase 1, consensus was established across rheumatologists and pediatric pain experts regarding the most important pain domains that should be assessed in routine clinical rheumatology practice. This iterative consensus process was used to generate self- and proxy-report pain measures. The final SUPER-KIDZ measure consisted of four domains: (i) pain intensity and location, (ii) fatigue, (iii) pain interference/evaluative, and (iv) affective/emotional dimension. There is a self-report version for children (aged 4–7 years) and youth (aged 8–18 years), as well as a proxy-report version for the parents of children aged 4–7 years. In the next phase, a prospective study of 100 children and adolescents aged 4–18 years was completed to determine the feasibility and acceptability of three mediums of tool administration (paper, computer, and iPod Touch). Children, parents, and healthcare providers found the tool very acceptable and easy to use. Most children (65%) preferred the computer-based version, while youth reported no preference between different media. The majority of physicians (60%) indicated that they would recommend the computer summary over the paper questionnaire to a colleague [76]. Validity trials are currently underway. Once validated, the SUPER-KIDZ tools will be included in CARRAnet, an online battery of measures that are used with all pediatric rheumatology patients during routine clinic visits across North America.

Pain-QuILT™ (previously called the iconic pain assessment tool) is a web- and mobile-based tool for the visual self-report and electronic tracking of sensory pain [77–79,102]. Patients can choose from a library of pain quality ‘icons’ to express different types of pain, such as a ‘matchstick’ for ‘burning pain’. Descriptive icons can be assigned a rating of intensity (0–10 NRS) and then dragged-and-dropped onto a detailed virtual body map to show pain location. All pain parameters are electronically captured and
can be used to track changes in pain over time. Studies to date in adolescents aged 12–18 years with chronic pain, including arthritis, indicate that Pain-QuILT™ is easy to use and understand, preferred by a majority of patients, and perceived to improve the communication of pain symptoms with healthcare providers. A free version of the tool is available at: http://painquilt.mcmaster.ca.

Section summary

- Information and communication technologies offer great opportunities for innovation in the field of pain assessment by capturing:
  - real time data of pain ‘right now’ without memory bias,
  - longitudinal pain reports that account for the dynamic fluctuations in arthritis pain.

Strategies for clinical management of pain

The consideration of pain within the biopsychosocial model means that clinicians should use multimodal approaches for the management of pain. This section will provide a brief overview of currently recommended pain management strategies, including pharmacological, physical, and psychological approaches.

Pharmacological treatment of pain

To date, there have been no clinical trials that directly address pain management in JIA [18]. The standard approach for treating active arthritis often includes non-steroidal anti-inflammatories (NSAIDs) such as naproxen, disease-modifying anti-rheumatic drugs such as methotrexate, and biological therapies such as anti-tumour necrosis factor-alpha agents [80–83]. Additionally, acute disease flares may be treated with short-course systemic corticosteroids and/or intra-articular corticosteroid injections [84]. Many of these pharmacological therapies result in improved pain and HRQL. Clinical studies have demonstrated that many pharmacological therapies for JIA are associated with reduced pain and improved function. For example, in a study involving 521 patients with polyarticular JIA, Céspedes-Cruz et al. report that treatment with methotrexate over a six-month period was associated with significant improvements across all HRQL areas, particularly in physical domains [85]. In addition, the total number of painful joints and parents’ scores of child pain intensity (measured on a 0–10 cm VAS) was significantly reduced from baseline to six-months [85]. Similarly, Prince and colleagues followed a cohort of 53 patients with refractory JIA over a 27-month period of treatment with etanercept [86]. These investigators assessed HRQL and pain at baseline and after 3 months, 15 months, and 27 months of treatment. There were significant improvements observed in HRQL and pain after 3 months of etanercept treatment, and these improvements were sustained over the study period.

In addition to pharmacological therapies that aim to reduce arthritis disease activity, acute pain flares can be treated with NSAIDs such as naproxen [87]. The combination of acetaminophen and naproxen can also be used for the effective treatment of mild pain [18,21]. For patients with more severe pain, the use of opioids can be considered [88]. The recent Canadian best practice guidelines for the treatment of chronic pain include recommendations regarding use of opioids [89]. However, there is limited research on the use of opioids in children and adolescents with arthritis. According to a survey of North American pediatric rheumatologists, only 51% of respondents indicated that they were comfortable in prescribing opioids and other potent analgesics to their patients [3]. However, as summarized by Kimura and colleagues, “… chronic opioid use to achieve pain control may be preferable to escalating therapy with potentially dangerous treatments such as DMARDs, steroids, and biologic response modifiers, especially when the opioids are prescribed based on a protocol structured to highlight safety and proper use” (p. 82) [3]. Lastly, consultation with a specialized pediatric chronic pain team should be considered for patients with refractory pain.
Physical strategies for treatment of pain

Many patients who are under treatment with pharmacological therapy still continue to experience significant pain [1,21]. In addition, a recent systematic review demonstrated that patients with JIA have moderate to severe impairment in physical fitness compared to healthy children [90]. Thus, it is important for clinicians to incorporate physical strategies into their management plan.

Participation in regular physical activity has been shown to improve symptoms of pain, fatigue, and disability over the long term for children and adolescents with arthritis. One of the biggest challenges associated with physical therapies is that an increase in exercise can initially exacerbate pain [91]. However, participation in a sustained exercise routine is associated with benefits such as improved strength and general health. There is also a growing body of research suggesting that regular physical activity can reduce pain. For example, Klepper and colleagues evaluated the effects of an 8-week weight-bearing physical condition program in 25 patients with JIA. Significant improvements were found in physical fitness, and mean pain intensity scores decreased 16% from baseline to study end [92]. In a randomized controlled trial involving 80 patients with JIA, Singh-Grewal et al. compared vigorous and gentle exercise regimens over an 8-week period [93]. These investigators found that both exercise regimens were well tolerated and led to improvements in physical function. However, while a Cochrane meta-analysis of existing randomized controlled trials found that exercise does not exacerbate arthritis, this analysis also failed to identify significant evidence of improvements in pain [94]. The Canadian Pediatric Society currently recommends that children with JIA should take part in moderate fitness, flexibility, and strengthening exercises [95]. However, as summarized by Tupper, “patients must continually strive for a level of exercise that stresses their systems sufficiently to improve function yet avoid a level that causes an excessive symptom reaction, signaling that the patient has exceeded a safe limit” (p. 7) [91].

Psychological strategies for treatment of pain

Studies in pediatric chronic illnesses have shown that comprehensive psycho-educational interventions are associated with symptom reduction and improved HRQL compared with care that is strictly medication focused, with a postulated mechanism of enhanced self-efficacy and empowerment over disease and symptom management [96,97]. Self-efficacy has been defined as the patient’s perceived ability to successfully produce a desired effect in a task or behaviour affecting their life [98].

Some of the most successful psychological strategies for improving pain and associated functional impairments are rooted in cognitive-behavioural therapy (CBT) [99]. CBT typically incorporates normalization of the patient’s experience through education, training in strategies for managing disease-related symptoms and other stressors, enhancing self-efficacy, and guidance on developing and implementing a long-term management plan [100,101]. A systematic review of 25 randomized controlled trials involving 1247 children and adolescents with chronic pain found that omnibus CBT, relaxation therapy, and biofeedback all produced significant positive effects on pain reduction [101].

Given the strong empirical foundation for psychological interventions in improving the coping skills necessary for reducing pain and improving HRQL in chronic pain, it is recommended that these therapies be considered for children and adolescents with persistent arthritis pain [100,101].

Section summary

- No clinical trials to date have directly addressed pain management in JIA.
- Pharmacological treatment is typically focused on controlling underlying disease activity with NSAIDs, disease-modifying anti-rheumatic drugs, and biological therapies.
- Acute pain flares can be managed with agents such as NSAIDs and acetaminophen, while for severe pain, opioids can be considered.
- Many patients continue to experience arthritis pain despite adequate pharmacological treatment.
- Physical therapies are a vital component of improving disease management, including pain and function. Clinicians should aim to help patients achieve an optimal level of physical activity in order to improve function within safe limits.
Psychological therapies, in particular cognitive-behavioural therapy, are an important part of pain management and have demonstrated efficacy in improving pain and HRQL.

Chapter summary

It is critically important for clinicians to recognize that pain is the most common and distressing symptom of JIA. Therefore, the frequent and consistent assessment of pain using valid, reliable, and age-appropriate tools should form a cornerstone of disease management. Given that many patients will continue to experience pain despite adequate pharmacological treatment, clinicians should incorporate other pain management modalities, such as physical and psychological therapies, into their practice.

While there has been great progress in the field, unanswered questions still remain and must be addressed in future research. Despite recent advances in pharmacotherapy, children and adolescents with arthritis continue to experience significant persistent pain. Thus, there is an urgent need to better understand the neurobiological pain processing mechanisms in the central nervous system that persist following the resolution of the inflammatory component of JIA. It is likely that current therapies do not address or target these changes. However, to date, there have been no clinical trials to directly evaluate the effectiveness of different pain medications for alleviating pain in JIA. In the context of the biopsychosocial model, future work is also needed to better understand the impact of factors such as mood, anxiety, and pain coping in the maintenance of JIA pain.

References


Practice points

- Pain is a common and distressing component of arthritis.
- Pain should be assessed frequently and consistently throughout the disease management process using valid and reliable tools.
- Pain management strategies, including pharmacological, physical, and psychological approaches, are an essential part of overall disease management.

Research agenda

- Information and communication technologies (e.g. Internet, smartphones) are a promising means of improving pain assessment. Further research is needed to rigorously evaluate these electronic tools and determine feasibility of incorporation into routine clinical practice.
- There is a need for clinical trials to evaluate different pain management strategies for JIA.


