

# Assessment and management of pain in juvenile idiopathic arthritis

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Juvenile idiopathic arthritis (JIA) is a common chronic childhood illness. Pain is the most common and distressing symptom of JIA. Pain has been found to negatively impact all aspects of functioning, including physical, social, emotional and role functions. Children with arthritis continue to experience clinically significant pain despite adequate doses of disease-modifying antirheumatic drugs and anti-inflammatory agents. The present article reviews the prevalence and nature of pain in JIA, the biopsychosocial factors that contribute to the pain experience, current approaches to assessing pain in this population, and ways of managing both acute and persistent pain using pharmacological, physical and psychological therapies. Finally, new approaches to delivering disease self-management treatment for youth with JIA using the Internet will be outlined.

**Key Words:** *Assessment; Internet; Juvenile idiopathic arthritis; Management; Pain*

Juvenile idiopathic arthritis (JIA) is the most common chronic rheumatic disease in children and adolescents, affecting approximately one in 1000 children in North America (1). It is diagnosed in children younger than 16 years of age with arthritis in one or more joints for at least six weeks after other causes have been excluded (2). Arthritis in JIA is characterized by stiffness, pain and swelling of affected joints. The disease course of JIA may involve flares of increased disease activity or chronic persistent joint inflammation, even into adulthood (3,4). Various complications may arise secondary to ongoing disease activity or treatment, including joint damage and deformity, growth abnormalities and osteoporosis with fragility fractures (5-7).

Pain is the most common and distressing symptom of JIA (8,9) and appears to be more frequent and intense in JIA compared with other rheumatic diseases (10). In a study of children with polyarticular arthritis, 76% of children reported pain on >60% of days despite being treated with methotrexate, tumour necrosis factor-alpha inhibitors or both (11). This is corroborated by a survey of North American pediatric rheumatologists, 77% of whom acknowledged that children with arthritis continue to experience clinically significant pain despite adequate doses of disease-modifying antirheumatic drugs and anti-inflammatory agents (12). Studies of health-related quality of life (HRQL) in children with JIA show that higher levels of pain are associated with poor physical, emotional and social functioning (13,14). Increased pain is also correlated with poor sleep and fatigue in patients with JIA (15).

## PREDICTORS OF PAIN IN JIA

The pathogenesis of pain in children with JIA is multifactorial. Multiple factors may affect the onset and persistence of musculoskeletal pain in JIA, including biological influences such as genetic (16), anatomical (16) and disease-related factors (17), psychosocial factors (eg, coping and cognitive health beliefs) (18-20) and environmental/social

## L'évaluation et la prise en charge de la douleur en cas d'arthrite juvénile idiopathique

L'arthrite juvénile idiopathique (AJI) est une maladie infantile chronique courante. La douleur en est le principal symptôme, le plus perturbateur. Elle nuit à tous les aspects du fonctionnement, y compris les fonctions physiques, sociales, affectives et de rôle. Les enfants atteints d'arthrite continuent de ressentir une importante douleur sur le plan clinique, malgré des doses suffisantes d'antirhumatismeux modificateurs de la maladie et d'anti-inflammatoires. Le présent article contient une analyse de la prévalence et de la nature de la douleur en cas d'AJI, des facteurs biopsychosociaux qui contribuent à l'expérience de la douleur, des démarches actuelles pour évaluer la douleur au sein de cette population et des manières de prendre en charge à la fois la douleur aiguë et persistante au moyen de traitements pharmacologiques, physiques et psychologiques. Enfin, de nouvelles démarches seront exposées pour offrir une prise en charge autonome du traitement par Internet aux jeunes atteints d'AJI.

cultural context such as parental history of pain (21,22). However, the precise mechanisms through which these factors influence pain are not fully understood (23). These factors need to be considered within a developmental framework, and their assessment is important to optimally treat pain in this population.

Results of research regarding the effects of age and sex on pain in children with JIA have been inconsistent (24-31). Disease status variables have also been found to have limited predictive value. Across studies, disease status variables predict a small to medium proportion of the variance in pain ratings (19,26,32-35). Further research is required to explore how child-specific (age, sex) and illness-related factors influence pain in children with JIA.

The role of negative emotions in the experience of pain in JIA is receiving more attention. Emotions can influence the perception of pain and the extent of functional impairment. Pain in JIA is exacerbated by changes in variables such as stress, coping and mood. Individual differences in anxiety levels have been found to predict greater daily pain and reduced participation in social and school activities in children with JIA (11). Children with JIA coping with higher levels of pain tend to use less positive self-statements and more catastrophizing (ie, engaging in overly negative thinking about pain) (9,18-20). In a study using a paper and pencil pain diary, pain and daily functional limitations were demonstrated to be higher during times of more intense negative emotions in children with JIA (36). Garnefski et al (37) examined emotional regulation in 53 youth with JIA who completed cross-sectional measures of emotion regulation strategies, internalizing problems and quality of life. They found that adolescents who used maladaptive emotion regulation strategies (eg, rumination) were more likely to experience internalizing problems and poorer quality of life. In a more recent study, an electronic diary was used three times per day for 28 days to evaluate whether components of emotional regulation predicted daily pain and function in 43 children

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with JIA (38). The results indicated that attenuation of high levels of negative emotion predicted reduced activity limitations and, to a lesser extent, reduced pain. Children with greater daily instability/variability of negative emotions also reliably experienced greater pain and more functional limitation. In addition, upregulation of positive emotion following a time of low positive emotion predicted reduced pain; children with greater instability/variability of daily positive emotion reliably experienced higher overall pain. These studies highlight the importance of exploring emotional factors in the assessment and treatment of pain in this population.

Parent and family environmental variables have also been shown to be related to pain reports in children with JIA. For example, the nature of family relationships, including family harmony and conflict (24), increased parental psychological distress (39), and parent and family history of pain, predicted pain in children with JIA (22). Parent responses to a child's pain also explain the extent to which pain affects the child's physical, emotional and social well-being. Connelly et al (40) conducted a prospective study to explore how parent responses to their child's pain predicted daily adjustment in nine children with JIA, in which subjects completed an electronic diary comprised of pain-related variables, activity participation and mood three times per day for 14 days, while parents rated their own mood and their behavioural responses to their child's pain at the same three timepoints as their child. Multilevel modelling demonstrated that the use of 'protective' pain responses (eg, high level of attention or vigilance to their child's pain, responses that convey permission to the child to avoid daily responsibilities) by parents significantly predicted decreases in child activity and positive mood; this was especially true for children with higher disease severity. Distracting responses by parents were significantly predictive of lower child activity restrictions, but only in children with higher disease severity. These studies emphasize the importance of parents in influencing adjustment in JIA, and the need to incorporate parents in comprehensive approaches to pain management by teaching parents more effective responses to their child's pain.

### ASSESSMENT OF PAIN IN JIA

To provide the best possible care for children and adolescents with JIA, timely and thorough pain assessment is crucial. Proper pain assessment in children and adolescents with arthritis has historically been hindered by a lack of valid and reliable tools, which is suspected to have led to a general underestimation and resultant undertreatment of pain in these individuals (41). However, the importance of this domain has been highlighted recently with the inclusion of pain assessment as an indicator of the quality of pediatric arthritis care (32). Formal recommendations that frequent pain assessments be performed on all patients with JIA, assessing all types of pain (ie, acute and persistent), have been made. Moreover, it has been recommended that pain be assessed using age-appropriate, reliable and valid tools (32). Additionally, as the multidimensional aspect of pain in children and adolescents with JIA is appreciated (41,42), the need for assessment tools to attend to these different dimensions becomes increasingly important. While there are several validated paper tools to assess chronic pain in children, they are not routinely used in everyday clinical practice, nor do they allow clinicians and researchers to track pain over time. To this end, novel electronic multidimensional pain assessment tools have been developed and tested in this population, three of which will be described in more detail below.

#### e-Ouch multidimensional pain diary for adolescents with arthritis

The e-Ouch multidimensional pain diary is an electronic pain diary accessible via a portable handheld device and is designed to obtain pain ratings from adolescents with JIA three times per day (43). As a multidimensional diary, the e-Ouch not only collects data related to pain intensity, but also pain unpleasantness, pain interference (ie, impact of pain on mood, sleep, walking, relationships and enjoyment of life) and perceived control over pain. The tool also consists of a body map (on which pain locations can be selected), word descriptors

based on the Adolescent Pediatric Pain Tool (44), and questions related to medications and other physical and psychological treatments used and the effectiveness of these strategies. The e-Ouch diary has been shown to be a valid and responsive assessment modality (45) and, by virtue of its electronic data-capture method, is not subject to recall biases or 'back-filling' of assessments as can be the case with paper diaries (46). However, to date, this tool has only been used in clinical research and has not been used to track musculoskeletal pain in routine clinical practice.

#### Standardized Universal Pain Evaluation for Pediatric Rheumatology Providers (SUPER-KIDZ) pain assessment tool

The SUPER-KIDZ pain assessment tool was recently developed for children and adolescents with rheumatic conditions. This multidimensional tool responds to the current dearth of musculoskeletal pain assessment methods available for use by pediatric rheumatology care providers during routine clinic visits. The SUPER-KIDZ tool was developed using a Delphi survey and a two-day consensus conference with members of the Childhood Arthritis and Rheumatology Research Alliance and pediatric pain experts. SUPER-KIDZ consists of developmentally appropriate self-report measures for children and adolescents eight to 18 years of age (pain intensity, location, pain impact on physical and emotional functioning) and a truncated version developed for use by children four to seven years of age (pain intensity and location). Coinciding with the truncated version is a parent/caregiver proxy report.

The feasibility of implementing the SUPER-KIDZ tool using three mediums (paper-and-pencil, laptop computer and handheld device) in routine practice was recently examined in a sample of 101 children with JIA (47). Overall, the tool was simple and quick to complete and considered acceptable to children, adolescents, parents and rheumatology care providers. Validity trials are currently underway and, once validated, the SUPER-KIDZ assessment tool will be made available for use in routine practice across North America.

#### Iconic Pain Assessment Tool (IPAT)

The IPAT is a multidimensional tool, which is currently being adapted for use by adolescents with JIA (48). The IPAT is a computer-based assessment that measures pain intensity and uses body maps to collect data regarding pain location. Again, as a computer-based assessment tool, the IPAT is not subject to 'back-filling' and data can be securely stored for future reference. In addition, it provides information regarding the quality of pain through the use of graphic selectable icons (49). Qualitative interviews with adolescents with JIA have revealed that the IPAT is perceived as being easy to use, easy to understand and valuable in terms of communicating pain information with clinicians (50).

### MANAGEMENT OF PAIN IN JIA

There are currently no established guidelines for the management of acute and persistent pain in JIA; however, pain control has recently been identified as a quality measure in the care of children with JIA (32). Following the biopsychosocial model of pain control, a multidisciplinary team including physicians, nurses, physiotherapists, occupational therapists and psychologists is the most effective approach for successful pain control in children with arthritis. Management includes early and aggressive treatment of the underlying joint inflammation, combined with pharmacological and nonpharmacological approaches to target pain and enhance pain coping and physical function.

#### Pharmacological management

There are no clinical trials that specifically examine pain management in patients with JIA. The standard pharmacological approach for treatment of active arthritis includes the use of nonsteroidal anti-inflammatory drugs (NSAIDs), disease-modifying antirheumatic drugs such as methotrexate (51) and, in more advanced cases, biological therapies such as anti-tumour necrosis factor-alpha agents (52-54) (eg,

etanercept) or inhibitors of T cell costimulation (55) (eg, abatacept). In addition, treatment of acute disease flares may include short-course systemic corticosteroids or intra-articular corticosteroid injections (56).

Studies examining the outcomes of children with JIA have shown that many of the medical therapies for JIA result in reductions in pain and improvement of HRQL. An evaluation of 521 children treated with methotrexate for six months reported dramatic improvements in pain, physical function and ability to participate in activities (57). Similar improvements have been demonstrated after treatment with etanercept (58) and abatacept (59).

Aside from controlling the underlying disease, additional pharmacological therapies may be used to specifically target acute pain in patients with JIA. NSAIDs, such as naproxen, have both analgesic and anti-inflammatory effects and have been the mainstay of pain treatment in pediatric patients with rheumatic disease (60). In addition, acetaminophen may be used in combination with NSAIDs and can provide good analgesia for mild pain (41,61). For more severe or refractory pain (eg, related to avascular necrosis), the use of opioids is an option. Opioid analgesics are gaining acceptance for use in chronic nonmalignant pain as an effective and safe therapy (62), and are included in the recent Canadian practice guidelines for chronic pain (63). However, there are limited data on the use of opioids in children with arthritis; a survey of pediatric rheumatologists revealed discomfort regarding the use of opioids to treat residual pain in their patients due to concern about side effects and dependence (12). Many of these concerns are unfounded (61,64). The benefits and risks of each therapeutic option must be weighed, including the consequences of ongoing untreated pain, and opioid analgesia may be used judiciously as part of a comprehensive pain management approach. Consultation with a specialized chronic pain team may be warranted in these cases. For acute pain, short-acting agents, such as oxycodone or hydrocodone, may be most beneficial, whereas longer-acting agents such as methadone are useful for persistent pain (41,61,64).

#### Physical therapy and sleep interventions

Physical and occupational therapy are key components of the management of JIA. Interventions such as splinting and foot orthoses can correct deformities and malalignments and decrease pain (65). Several studies have shown that children with polyarticular JIA are less active than their healthy counterparts and exhibit reduced aerobic and anaerobic exercise capacity (66,67). There is evidence that regular physical conditioning improves joint pain and range of motion in patients with JIA (68,69). A number of reports have suggested that engagement in both low- and high-intensity exercise programs results in improved physical function and decreased pain in patients with JIA (70,71), although a Cochrane meta-analysis of existing randomized controlled trials did not show statistically significant benefits (72). All studies confirm that exercise does not appear to have a detrimental effect on JIA. Guidelines from the Canadian Paediatric Society support the suggestion that children with JIA should participate in moderate fitness, flexibility and strengthening exercises as tolerated and with appropriate precautions (eg, mouth guards for jaw disease) (73). An Internet-based health promotion approach to increasing physical activity has been developed by Lelieveld et al (74). The site incorporates education regarding JIA and physical activity and helps children with goal-setting. In a randomized trial, the Internet program was found to be feasible and was associated with significant improvement in aerobic exercise capacity.

Children with JIA appear to experience an increased incidence of poor sleep quality and sleep disruption compared with healthy controls (75,76). Disordered sleep is found to be significantly correlated with increased morning stiffness (77), joint pain, fatigue and decreased HRQL (15). It is difficult to ascertain whether disturbed sleep causes increased pain and poorer HRQL, or whether pain and increased disease activity lead to poor sleep. Nonetheless, it is likely that sleep disturbance in children with JIA contributes to increased pain experience.

Thus, it is important to assess for and address disordered sleep as part of the comprehensive management of pain in JIA and to educate patients and their families about sleep hygiene.

#### Psychological interventions

Psychological strategies focus on the regulation of pain perceptions by self-regulation strategies that facilitate pain coping, modify the patient's subjective experience of pain and/or modulate pain behaviours (ie, maximizing adaptive and minimizing pain-related behaviours) as well as addressing contextual factors. The most successful psychological interventions for improving pain and associated impairments are based on cognitive-behavioural therapy (CBT) (78,79). CBTs incorporate normalization of the patient's experience through education regarding the condition and its impact, training in specific strategies, managing disease-related and other stressors, and providing guidance on developing and implementing a long-term plan for self-managing the condition (41). In a recent systematic review of psychological therapies in children and adolescents with chronic pain (79), psychological therapies reduced pain intensity by at least 50% in significantly more youth, compared with control conditions at post-treatment. Two studies have demonstrated improvements in self-reported pain in children with chronic arthritis following CBT immediately after treatment and at six-month follow-ups (80,81). While these psychological therapies have been found to be effective, the vast majority of children and youth with JIA do not have access to these therapies. Therefore, innovative approaches to deliver these therapies in this population have recently been developed and evaluated.

### INNOVATIVE APPROACHES TO DISEASE SELF-MANAGEMENT IN JIA

With emerging interactive and communication technologies (e-health), especially the Internet, new media for the delivery of psychological interventions are now available (82). The Internet has emerged as one of the top health information resources and modes of social communication for young people and continues to be increasingly integrated into the provision of health care services (83). The Internet provides patients, families and health care professionals with unparalleled opportunities to learn, inform and communicate with one another, receive meaningful social support, fulfill the rising demand for expedient access to evidence-based health information and achieve greater involvement in health care decisionmaking (84,85). Using the Internet to deliver health interventions dramatically reduces geographical constraints, provides opportunities for access regardless of language spoken and travel constraints (financial constraints or those due to physical disability), and provides 24 h access to information that can help patients feel less isolated and more in control of managing their chronic condition (86).

Therapeutic Internet interventions are treatments based on effective face-to-face interventions (eg, psychoeducational and CBT) that are transformed for delivery via the Internet with the goal of improved health outcomes (symptom reduction [pain and pain-related disability; anxiety and depression] and improved HRQL). Usually, they are highly structured, self-guided or partly self-guided (ie, minimal therapist support through regular brief telephone and or e-mail contact), tailored to the user's needs and interactive (84). Our group conducted a systematic review of online self-management programs in youth with chronic health conditions. Only nine of 29 published articles on Internet interventions met the inclusion criteria and were included in the analysis. Health conditions included asthma, obesity, traumatic brain injury, recurrent pain and encopresis. All interventions were psychoeducational in nature, targeting improved health outcomes. However, they varied greatly in content, procedural aspects of interventions (self-guided versus guided self-help with minimal therapist involvement) and duration and number of sessions. Parents were included in five studies as active participants; only one study had specific modules for parents, and two studies asked children and parents to complete

sessions together. While outcomes varied greatly among studies, overall, health outcomes (reduced pain, improved disease control in terms of number of asthma attacks and weight loss) improved in Internet interventions compared with control conditions in seven of nine studies. There was conflicting evidence regarding disease knowledge and HRQL, and evidence regarding decreases in health care utilization was limited. Conflicting evidence regarding HRQL outcomes may have resulted from limited post-treatment follow-up (less than six months) and using nonspecific disease measures. The article concluded there was preliminary evidence that self-management interventions delivered via the Internet improved selected outcomes in certain chronic childhood illnesses (87).

Stinson et al (88-90) developed an online psychoeducational program for youth with JIA using a sequential phased approach. In Phase 1 (88), a needs assessment was conducted using individual and focus group interviews with English- and French-speaking adolescents with arthritis (n=36) and their parents (n=34). Adolescents articulated a universal need for more disease-specific knowledge, self-management strategies and meaningful social support to better manage their arthritis. Parents believed that they required strategies to help them 'let go' and promote healthy behaviours in their adolescents with JIA. In Phase 2 (89), a usability testing study was conducted with English- (n=11) and French-speaking (n=8) adolescents with JIA and their parents to evaluate the user interface and refine the prototype using iterative cycles. Minor changes were made to the prototype and participants responded positively to the content, use, appearance, and theme of the website and believed that it was easy to navigate, use and understand. In Phase 3 (90), a pilot randomized controlled trial was conducted to determine the feasibility of the online self-management program. Adolescents with JIA and one of their parents were randomly assigned to either the experimental (Internet self-management program; n=22) or the attention control (n=24) groups. After completing the intervention, participants in the experimental group had significantly higher disease knowledge ( $P<0.001$ , with a large effect size of 1.32) and lower average weekly pain intensity ratings ( $P=0.03$ ,

with a moderate effect size of 0.78) compared with individuals in the attention control group. Program usage patterns indicated that users completed the program as instructed (high compliance [91%]), using communication features, and were actively engaged in the intervention through goal-setting and completing personalized information. In Phase 4, Stinson et al are conducting a multicentre randomized controlled trial across 10 pediatric rheumatology centres in Canada to determine the effectiveness of this program in improving health outcomes. These novel interventions may be a first step in a stepped approach to provide education and psychological therapies to help children and their families learn to better manage pain and ultimately improve HRQL.

## CONCLUSION

Frequent pain is common in JIA and appears to be largely responsible for the quality of life and functional impairments in children with this disease. Pain in JIA needs to be considered within a developmental biopsychosocial context. International efforts are underway to generate valid, useful, clinically friendly tools for routine assessment of pain in pediatric rheumatology practice. To prevent morbidity associated with acute and ongoing pain in children with JIA, pain should be treated aggressively using a multidisciplinary approach that encompasses pharmacological, physical and psychological strategies. Finally, there is a need to empower children and adolescents with accessible pain coping strategies that can augment the efficacy of medical care on reducing pain and disability, using novel approaches such as the Internet and smartphones.

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