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# Impact of Musculoskeletal Pain on Functioning and Disability in Children with Juvenile Idiopathic Arthritis in Iceland

Bjorg Gudjonsdottir<sup>a</sup>, Svanhildur Arna Oskarsdottir<sup>a</sup>, Audur Kristjansdottir<sup>a</sup>, Judith Amalia Gudmundsdottir<sup>b</sup>, Solrun W. Kamban<sup>b</sup>, Zinajda Alomerovic Licina<sup>b</sup>, and Drifa Bjork Gudmundsdottir<sup>b</sup>

<sup>a</sup>Department of Physical Therapy, School of Health Sciences, University of Iceland, Reykjavik, Iceland;

<sup>b</sup>Landspítali – The National University Hospital of Iceland, Children's Medical Center, Reykjavik, Iceland

## ABSTRACT

**Aims:** 1) to map questions of pain from a survey to the International Classification of Functioning, Disability and Health (ICF) 2) to compare the impact of musculoskeletal pain on functioning based on the different components of the ICF in children with juvenile idiopathic arthritis (JIA) and age-matched peers.

**Method:** A cross-sectional case-control survey. A total of 28 children with JIA and 36 age-matched children participated. The survey included questions on the child's sex and age, about pain experienced, number of painful body areas, pain frequency and three short forms of Patient-Reported Outcome Measurement Information System (PROMIS) pain questionnaires. Sixteen children with JIA (57%) and 10 peers (28%) reported pain during past seven days. Their responses were used in the description of impact of pain.

**Results:** After the mapping of the questions to ICF, a comparison between the two groups indicated that a higher number of children with JIA described effects of pain on mental function, mobility, general tasks and demands, than their peers. More children with JIA expressed to others that they had pain, non-verbally and verbally.

**Conclusion:** The findings provide important information about the impacts of pain on daily life in children with JIA and about their intervention needs.

## ARTICLE HISTORY



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## KEYWORDS

[MeSH] Children; disability and health; international classification of functioning; juvenile idiopathic arthritis (JIA); pain; patient-reported outcome measures

Juvenile idiopathic arthritis (JIA) is an umbrella term for chronic childhood arthritis with various clinical pattern that begins before 16 years of age, persists for longer than 6 wk and are of an unknown cause (Petty et al., 2004). The primary clinical symptoms of JIA are recurring episodes of acute inflammation with swelling in one or more joints, joint pain, stiffness, and muscle weakness and atrophy. When the disease is inactive the symptoms are less prominent. Other symptoms can follow such as a limited joint range of motion, fatigue, decreased aerobic capacity and osteopenia (Net et al., 2017; Petty

**CONTACT** Bjorg Gudjonsdottir  [thbjorg@hi.is](mailto:thbjorg@hi.is)  Department of Physical Therapy, School of Health Sciences, University of Iceland, Reykjavik, Iceland

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et al., 2003; 2004; Ravelli & Martini, 2007). Previous research has demonstrated that pain in children with JIA occurs frequently and is associated with difficulties in performance of routine physical activities and participation in social or school activities (Bromberg et al., 2014; Kimura & Walco, 2007).

The treatment of JIA includes pharmacologic management and nonpharmacologic interventions by various health professionals including physical therapists (Net et al., 2017). Pharmacologic management is needed to induce remission of the disease and control the arthritis (Berntson et al., 2019; Beukelman et al., 2011). Studies indicate that the effects of specific pain medications are not straightforward (Bromberg et al., 2014). Pain perception in children with JIA is complex. Inflammation and joint damage “prime” peripheral nociceptors and central pain circuits, (Cornelissen et al., 2014; De Lalouvière et al., 2014) but the perceived pain doesn’t appear to reflect the disease activity. Research findings have demonstrated that children with JIA had a substantially lower pain threshold compared to healthy children, even in body areas usually unaffected by arthritis, (Cornelissen et al., 2014; Leegaard et al., 2013) which supports the theory of a pain sensitization, suggesting that the JIA alters the pain perception and causes decreased pain threshold. Studies have demonstrated no correlation between disease duration and pain threshold, indicating that the sensitization may occur relatively soon after the disease develops (De Lalouvière et al., 2014; Leegaard et al., 2013). Sensitization may not explain all the pain experienced in JIA. A study from 2004 demonstrated that a small amount of pain variance or 22% can be explained by demographic- or disease related variables (Malleeson et al., 2004). The amount of pain experienced may be modulated by both psychological and environmental factors independent of the inflammatory disease activity. Findings from Thastum et al. (2005) showed that children with JIA and a high level of pain report more catastrophizing pain coping strategies and more pain belief of disability and harm, than children with JIA and a low pain report. More catastrophizing pain coping strategies include magnifying the pain and feeling helpless. More pain belief of disability and harm mean that the children may perceive themselves as more disabled and are likely to believe that pain signifies damage. Psychological factors may therefore be strongly influential (Thastum et al., 2005). Parent and family factors may influence the pain experience of children with chronic pain. Parent emotions, behaviors, and health status play a role in children’s pain experiences, where protective parent behaviors, increased distress, and history of chronic pain are important parent level influences (Palermo et al., 2014).

Studies have shown that children with JIA experience more impact of pain on daily life than peers (Cavallo et al., 2015; Limenis et al., 2014; Schanberg et al., 2003). It is of interest for physical therapists and other health professionals to get a better understanding of the impact of pain on different aspects of functioning in this population. In this study, different measures of pain were taken. Three questions on the presence of pain, its frequency and the number of painful body areas were included. In addition, three Patient-Reported Outcome Measurement Information System (PROMIS) questionnaires (Health Measures, 2019) about pain were used.

The PROMIS is a patient-reported system, that includes a self-report measure for adults and children as well as a parent proxy version in which the parents rate the impact of pain on the child’s function. The International Classification of Functioning, Disability

and Health (ICF) (World Health Organization, 2001) is the most comprehensive framework to describe and classify functioning and disability in relation to a health condition. It is based on an integrative biopsychosocial model of health, functioning and disability. ICF has become an international standard for describing health and functioning. Linking concepts on one system to another framework that uses common meaningful terms can be of benefit. Many health measures have been compared and mapped to the ICF by using the ICF Linking Rules developed specially to provide a common language for researchers and clinicians. The ICF Linking Rules were published to provide a method to link health-related outcomes to the ICF's universal codes (Cieza et al., 2002; 2005; 2019).

The aims of the current study were 1) to map questions of pain from a survey to the ICF, 2) compare the impact of musculoskeletal pain on functioning in children with JIA and age matched peers by looking at each question.

## **Materials and Methods**

### ***Design***

This was a quantitative case-control study with a cross-sectional design.

### ***Participants and Procedure***

Children with all subtypes of JIA (except systematic arthritis), treated at The National University Hospital of Iceland, between 2016-2019 were participants in the study. The control group was a random sample of children from Registers Iceland. The inclusion criteria were age 8-18 years, residence within 100 km of the capital area, children, or parents able to understand the Icelandic language, and lack of disabilities. There were 48 eligible children with JIA. A list of 500 children was obtained from Registers Iceland and 249 who met the criteria were invited to participate in the control group. The children in the control group were paired with the group with JIA regarding age and sex.

### ***Data Collection***

Data collection took place at The National University Hospital of Iceland, from October 2019 to March 2020. Information on the JIA subtypes and age was obtained from the hospital medical record system and age of the control group from Registers Iceland. The legal guardians of eligible children were contacted by telephone and invited to participate. A reminder notice was sent to non-respondents, one week later. A few days later a researcher called the parents, encouraging them to participate. Snowball sampling was used at the end of data collection to obtain a large enough control group.

The children came to the hospital and answered a survey on the SurveyMonkey online survey tool. The height and weight of the children were measured. The children with JIA underwent a medical examination by a pediatric rheumatologist, including an evaluation of the disease status with Juvenile Arthritis Disease Activity Score-27 (JADAS27), a commonly used tool to evaluate the disease activity in standard clinical care. The JADAS-27 (scores range 0-57) includes the following four measures: 1) physician's global assessment of disease activity on a 0-10 visual analog scale (VAS) where 0 = no activity and

10 = maximum activity 2) parent global assessment of well-being on 0-10 VAS where 0 = very well and 10 = very poor, 3) the erythrocyte sedimentation rate (ESR), normalized to 0 to 10 scale and 4) a count of joints with active disease, assessed in 27 joints. A higher JADAS-27 indicates higher disease activity (Consolaro et al., 2009).

### **The Survey- Outcome Measures**

The survey included demographic questions on the child's sex, three questions about pain (presence of pain, frequency, and number of painful body areas) during the last seven days, and three fixed-length short forms of PROMIS questionnaires consisting of questions on pain in the past seven days (Health Measures, 2019). They were the PROMIS Pediatric Numeric Rating Scale v1.0—Pain Intensity 1a including one question; the PROMIS Pediatric Short Form v2.0—Pain Interference 8a; and the PROMIS Pediatric Short Form v1.0—Pain Behavior 8a. The latter two both consisted of eight questions. (Health Measures, 2019) The three PROMIS questionnaires are standardized with established psychometric properties (Brandon et al., 2017; Cunningham et al., 2017; Jacobson et al., 2013; Luijten et al., 2020).

### **Ethics**

The children and parents received verbal and written information. Informed written consent was obtained from one or both parents, and the child, depending on the child's age (over 12 years). Participation was voluntary and anonymous. The National Bioethics Committee (VSN-19-141) granted ethical approval for the study.

### **Linking Process**

The ICF focuses on four components: 1) Body Functions and Structures, 2) Activities and Participation, 3) Personal Factors, and 4) Environmental Factors. Each component is divided into a hierarchy which is reflected in the coding of the classification system. The hierarchy is as follows: 1) Component e.g. Activities and participation, 2) Chapter e.g. Mobility (Chapter 4 (d4), 3) Two-level Category e.g. Walking (d450) and 4) Three-level Category e.g. Walking short distances (d4500). The component of Body structure and Body function include eight chapters each and nine are within the Activity and participation component. The Environmental component consists of five chapters but the Personal factors component is not classified (World Health Organization, 2013).

Concepts of all the adult PROMIS versions have been linked to the ICF by Tucker et al. (Tucker et al., 2014) who used the item-level content analysis mapping methods described by Cieza et al. (Cieza et al., 2002; 2005; 2019). They identified the ICF chapters (ICF one-level classification) for each PROMIS item and then found the category (ICF two-level classification) within the ICF chapters which the PROMIS question could be linked to.

For each PROMIS item Tucker et al. found a primary ICF mapping. Many of the PROMIS items contain more than one ICF concept since they assess the impact of one concept (pain) on other ICF concepts (e.g. behavior, mobility). Subsequently, a

secondary ICF category was found for another concept included in the same PROMIS item. That means that within the ICF two-level classification, one PROMIS item can either have one primary category or one primary category and a secondary category (Tucker et al., 2014).

As many items in the adult versions of PROMIS are the same as in the pediatric versions, the mapping from Tucker et al. for comparable pediatric items was used in this current study. The item-level content analysis mapping methods described by Cieza et al. (Cieza et al., 2002; 2005; 2019) were used to map the three items of pain and items that are not in the adult PROMIS questionnaires (and had not been mapped before), to the best fitting category of ICF. The ICF online browser on the WHO-website (<https://apps.who.int/classifications/icfbrowser/>) was used to find an appropriate code and a detailed description for each variable.

Items with meaningful concepts but not enough information to select an ICF category were labeled not definable as described in the mapping methods by Cieza et al. (Cieza et al., 2019).

## Data Analysis

After the item-level content analysis mapping, a descriptive analysis of children in both groups who reported pain in the past seven days was performed. The data that were used were the frequency of pain, pain intensity, the number of children that reported one or more painful body areas and the number of children in each group who rated the questions on the PROMIS pain interference and pain behavior scales with scale scores  $\geq 3$  ('sometimes', 'often' or 'almost/nearly always')

The item "it was hard for me to run when I had pain" in the pain interference questionnaire was deleted from the online survey, by mistake. The PROMIS pain interference and behavior questionnaires are based on item response theory (IRT), often called "modern psychometric theory." (Health Measures, 2021). IRT is a family of mathematical models that estimates how individuals will respond to items with specific characteristics (called parameters). Examples of parameters include item difficulty (e.g. high vs. low) and item discrimination. The item response theory arranges the items in the questionnaires by level of difficulty/severity from low to high. The difficulty level of the item "running" is higher than the item "walking one block" in the item series within the pain interference scale. Thus, it was decided that the number of children with difficulties in running was the same as in walking. That way at least, the number of those who could run would not be overestimated.

## Results

### Participants

A total of 28 children with JIA participated in the research (58% response rate) and 36 matched controls in terms age and sex. In a few age groups of the controls there were two children who matched to one child in the group with JIA, willing to participate. They were included in the study. In other age groups of the controls, no child was willing to participate and snowball sampling was used at the end of data collection to

**Table 1.** Characteristics of children with juvenile idiopathic arthritis (JIA) and controls, and subgroup diagnoses of the children in the research group according to the diagnostic criteria of the International league of association for rheumatology. There was not a significant difference between the groups in terms of sex, age, height, weight, and body mass index.

	Children with JIA (n = 28)	Control group (n = 36)	p-value
Age in years, mean $\pm$ SD	12.9 $\pm$ 3	13.1 $\pm$ 3.1	0.56
Female, %	57	56	0.16
Height in cm, mean $\pm$ SD	156 $\pm$ 13.8	159 $\pm$ 15.2	0.41
Weight in kg, mean $\pm$ SD	51.2 $\pm$ 19.5	52.3 $\pm$ 13.3	0.80
BMI in kg/m <sup>2</sup> , mean $\pm$ SD	20.2 $\pm$ 4.6	20.3 $\pm$ 2.7	0.92
JADAS from 0-57	2.9 $\pm$ 3.1		
Children with joint inflammation, n	6		
Children with oligoarthritis n(%)	13 (46.4)		
Children with rheumatoid factor positive polyarthritis n(%)	1 (3.6)		
Children with rheumatoid factor negative polyarthritis n(%)	2 (7.1)		
Enthesitis related arthritis n(%)	5 (17.9)		
Children with psoriatic arthritis n(%)	2 (7.1)		
Children with undifferentiated arthritis n(%)	5 (17.9)		

recruit children in these age groups. The number of children in the two groups was therefore unequal.

Characteristics of both groups, subtypes of JIA and JADAS27 scores are shown in Table 1. There was no difference between the groups in terms of sex, age, height, weight, and body mass index.

Results of comparison of the two groups have been published previously in which significantly more children with juvenile idiopathic arthritis had pain compared with the control group. And children with JIA also had a greater number of painful body areas, more pain intensity, and showed more pain behavior, and pain interference (Oskarsdottir et al., 2022).

Results from the children who reported pain in the past seven days are presented in this current study. Sixteen children with JIA (57%) and ten controls (28%) reported pain in the past seven days.

### **Results of the Mapping of the ICF Components**

The majority of the PROMIS items could be mapped to a two-level classification (Tables 2–5).

### **Body Structure and Body Function Component**

The focus of PROMIS is on person-centered health measurement, so concepts in body structures have minimal coverage in PROMIS. However, some body functions were covered. The items on the presence of pain, number of painful body areas and frequency of pain include only one concept that is within the chapter *Sensory function and pain* and have the primary ICF category *Sensation of pain*.

All the remaining PROMIS items could also be linked to the primary ICF category *Sensation of pain*. The PROMIS pain intensity scale includes only one concept and two items from the pain behavior questionnaire (when I had pain, I protected the part of



**Table 2.** Mapping the contents of pain experience, pain frequency and painful body areas, using the International Classification System of functioning, disability and health (ICF).

QUESTIONS	Response	ICF domains/chapters ICF one-level classification	ICF categories ICF two-level Classification	
			Primary ICF Category	Secondary ICF Categories
Did you experience pain in the past 7 days?	Yes/no	Sensory functions and pain	B280 Sensation of pain	Not definable
How was the frequency of PAIN in the past 7 days?	No pain/once/ recurrent/constant		B280 Sensation of pain	Not definable
Where was the pain ... mark each body area where you had pain in the past 7 days?	Head, neck, shoulders, arms, hands, back, both hips, one hip, both knees, one knee, both legs, one leg, both ankles, one ankle, both feet, one foot		B280 Sensation of pain	Not definable

**Table 3.** Mapping the contents of the pain intensity questionnaire from the Patient-Reported Outcomes Measurement information system (PROMIS®), using the international classification system of functioning, disability and health (ICF).

PROMIS PEDIATRIC PAIN INTENSITY				
QUESTION	Response	ICF domains/chapters ICF one-level classification	ICF categories ICF two-level classification	
			Primary ICF Category	Secondary ICF Categories
In the past 7 days: How bad was your pain on average?	From 0-10	Sensory functions and pain	b280 Sensation of pain	Not definable

my body that hurt, I asked for help) do not have a secondary category. However as stated earlier, many of the PROMIS items also include secondary ICF categories which are classified within the chapters of the *Body structure and body function component* or the chapters of *Activities and Participation component*.

The pain interference questionnaire includes items that link to the chapter *Mental functions* and the secondary categories *Temperament and personality functions*, *Sleep functions* and *Attention functions* (feeling angry, hard to have fun, having trouble sleeping, hard to pay attention).

### **Activities and Participation Component**

In addition to the primary ICF category *Sensation of pain*, the pain interference questionnaire includes secondary items in the chapter of *Mobility* within the categories: *Changing and maintaining body positions* and *Walking and moving* (it was hard to walk one block, run and stay standing, when I had pain).

Running can also be included in the chapter *Community, social and civic life* because it often includes engaging in informal or organized programs for leisure activity. The



**Table 4.** Mapping the contents of the pain interference questionnaire from the patient-reported outcomes measurement information system (PROMIS®), using the international classification system of functioning, disability and health (ICF).

PROMIS PEDIATRIC PAIN INTERFERENCE – SHORT FORM				
QUESTIONS In the past 7 days ...	Responses:	ICF domains/chapters ICF one-level classification	ICF categories ICF two-level classification	
			Primary ICF Category	Secondary ICF Categories
I felt angry when I had pain	Never/almost never/ sometimes/often/ almost always	Sensory functions and pain Mental functions	b280 Sensation of pain	b126 Temperament and personality functions
I had trouble doing schoolwork when I had pain	Never/almost never/ sometimes/often/ almost always	Sensory functions and pain Major life areas	b280 Sensation of pain	d820 School education
I had trouble sleeping when I had pain	Never/almost never/ sometimes/often/ almost always	Sensory functions and pain Mental functions	b280 Sensation of pain	b134 Sleep functions
It was hard for me to pay attention when I had pain	Never/almost never/ sometimes/often/ almost always	Sensory functions and pain Mental functions	b280 Sensation of pain	b140 Attention functions
It was hard for me to run when I had pain	Never/almost never/ sometimes/often/ almost always	Sensory functions and pain Mobility Community, social and civic life	b280 Sensation of pain	d455 Moving around d920 Recreation and Leisure
It was hard for me to walk one block when I had pain	Never/almost never/ sometimes/often/ almost always	Sensory functions and pain Mobility	b280 Sensation of pain	d450 Walking
It was hard to have fun when I had pain	Never/almost never/ sometimes/often/ almost always	Sensory functions and pain Mental functions	b280 Sensation of pain	b126 Temperament and personality functions
It was hard to stay standing when I had pain	Never/almost never/ sometimes/often/ almost always	Sensory functions and pain Mobility	b280 Sensation of pain	d415 Maintaining body position

item engaging in schoolwork is linked to the secondary category *School education* in the chapter *Major life areas*.

The pain behavior questionnaire also includes items that can be linked to the secondary level categories within the chapters *Mobility*, that is *Changing and maintaining body positions* and *Walking and moving* (I had to lie down, moving slower), and the category *Communicating—producing* (when I had pain it showed on my face, I talked about the pain, I asked for medications) in the *Communication* chapter. All the items in the *Communication* chapter can be seen as an expression of the intensity and impact of pain.

The item from the pain behavior questionnaire, “When I had pain, I stopped what I was doing” can be mapped to many secondary categories within various ICF chapters (*General tasks and demands*, *Mobility*, *Self-care and Community, social and civic life*), depending on which activity the child had to stop doing.

### **Environmental Component**

Given that the focus of PROMIS is on measurement of a person’s health outcomes, concepts in ICF environmental factor have minimal coverage in PROMIS. One item in the pain behavior questionnaire “when I had pain, I asked for medication” could yet be

**Table 5.** Mapping the contents of the pain behavior questionnaire from the patient-reported outcomes measurement information system (PROMIS®), using the international classification system of functioning, disability and health (ICF).

PROMIS PEDIATRIC PAIN BEHAVIOR – SHORT FORM		ICF categories ICF two-level classification	
QUESTIONS In the past 7 days, when I was in pain ...	Responses:	ICF domains/chapters ICF one-level classification	Primary ICF Category
It showed on my face	Had no pain/never/almost never/sometimes/often/almost always	Sensory functions and pain Communication	b280 Sensation of pain
I moved slower	Had no pain/never/almost never/sometimes/often/almost always	Sensory functions and pain Mobility	b280 Sensation of pain
I protected the part of my body that hurt	Had no pain/never/almost never/sometimes/often/almost always	Sensory functions and pain	b280 Sensation of pain
I had to stop what I was doing	Had no pain/never/almost never/sometimes/often/almost always	Sensory functions and pain General task and demands. Mobility Self-care Community, social and civic life	b280 Sensation of pain
I asked for someone to help me	Had no pain/never/almost never/sometimes/often/almost always	Sensory functions and pain	b280 Sensation of pain
I lay down	Had no pain/never/almost never/sometimes/often/almost always	Sensory functions and pain Mobility	b280 Sensation of pain
I asked for medicine	Had no pain/never/almost never/sometimes/often/almost always	Sensory functions and pain Communication Products and technology	b280 Sensation of pain

*Secondary ICF Categories*  
 d335 Producing nonverbal message  
 d4 d410-d429 Changing and maintaining body position. d430-d449 Carrying, moving, and handling objects. d450-d469 Walking and moving.  
 Not definable  
 Can include many categories within these chapters d2, d4, d5, d6, d9  
 Not definable  
 d410-d429 Changing and maintaining body position.  
 d330 Speaking e110 Products or substances for personal consumption

linked to the secondary category *Products or substance for personal consumption* in the chapter *Products and technology*. Therefore, this item does not only refer to an expression of the presence of pain (*Communication*) since medications and access to them are categorized as environmental factors.

### The Children's Responses

Tables 6–8 demonstrate the number of children who reported pain and difficulties in relation to pain in each item.

A higher number of children with JIA than controls described effects of pain on sleep (*Mental function: Sleep functions*), and attention (*Mental function: Attention functions*). On the contrary, a higher percentage of children in the control group described more effects of the pain in the item “It was hard to have fun when I had pain” within the *Mental function category: Temperament and personality functions*. The control group

**Table 6.** Pain intensity, number of children reporting pain, frequency of pain and number of painful body areas in both groups. The combined number of children who replied “sometimes”, “often”, or “almost always” to items that had only one primary category: sensation of pain (within *body structure and body function component*), of the International Classification System of Functioning, Disability, and health (ICF) are demonstrated. JIA: Juvenile idiopathic arthritis, Nd: not definable.

Items of pain experience, frequency, intensity, location and one item from the PROMIS Pediatric Short Form – Pain Behavior: protection of a body part

ICF categories	Question	Children with JIA	Age-matched peers
Sensory functions and pain Secondary categories not definable	<b>I experienced pain during the past 7 days (Y/N)</b>		
	Yes	16/28 (57.1%)	10/36 (27.8%)
	<b>Question</b>	<b>Combined number (%) of children who replied sometimes, often, or almost always</b>	
	<b>The frequency of pain during the past 7 days</b>	<b>Children with JIA</b>	<b>Age-matched peers\</b>
	Pain was constant the whole week	1/16 (6.25%)	0/10 (0%)
	Pain came and left	1/16 (6.25%)	1/10 (10%)
	Repeated occurrence of pain	14/16 (87.5%)	9/10 (90%)
	<b>Pain intensity (0-10)</b>	<b>Children with JIA</b>	<b>Age-matched peers</b>
	Mean ± SD	3 ± 2.89	1.17 ± 2.04
	<b>Questions</b>	<b>Combined number (%) of children who replied sometimes, often, or almost always</b>	
	<b>Number of painful body areas during the past 7 days</b>	<b>Children with JIA</b>	<b>Age-matched peers</b>
	One painful body area	6/16 (37.5%)	8/10 (80%)
	More than one painful body area	10/16 (62.5%)	2/10 (20%)
	<b>Question</b>	<b>Combined number (%) of children who replied sometimes, often, or almost always.</b>	
	<b>In the past 7 days, when I was in pain ...</b>	<b>Children with JIA</b>	<b>Age-matched peers</b>
	I protected the part of my body that hurt	7/16 (43.75 %)	4/10 (40%)

#### Summary:

More children with JIA reported pain. Of those who reported pain, the pain intensity, number of painful body areas and the frequency of pain was higher in the group with JIA. Similar percentage of each group protected their body part that hurt.

**Table 7.** The combined number of children who replied “sometimes”, “often”, or “almost always” to items that had one primary category: sensation of pain within *body structure and body function component*, and secondary category also within *body structure and body function component*, of the International Classification System of Functioning, Disability, and health (ICF) are demonstrated. JIA: Juvenile idiopathic arthritis.

Items from the PROMIS Pediatric Short Form – Pain Interference			
ICF categories	Question	Combined number (%) of children who replied sometimes, often, or almost always	
Sensory functions and pain Mental functions	During the last 7 days/ during the past 7 days ...	Children with JIA	Age-matched peers
	I felt angry when I had pain	3/16 (18.75%)	2/10 (20%)
	I had trouble sleeping when I had pain	5/16 (31.25%)	2/10 (20%)
	It was hard for me to pay attention when I had pain	6/16 (37.5%)	1/10 (10%)
	It was hard to have fun when I had pain	2/16 (12.5%)	2/10 (20%)

**Summary:**

A higher number of children with JIA than the controls, described effects of pain on sleep and attention

also described more effects of pain in the items “I had to stop what I was doing” and “I asked for someone to help me” within the category *General tasks and demands*.

Children with JIA also reported having greater difficulty with schoolwork (*Major life areas: School education*) and all mobility items in the PROMIS scales due to pain (ICF categories *Changing and maintaining body positions* and *Walking and moving*) than age-matched controls who also had pain. Additionally, more children with JIA expressed their pain both non-verbally and verbally (*Communication: communicating—producing*) with the exception than more children in the control group talked about the pain.

## Discussion

In this study, the ICF was used to organize the complex pattern of functioning and disability of children with JIA and an age-matched control group. The children with JIA and controls who had had pain in the past week were compared.

### Mental Function

Children in both groups described effects of pain on sleep but a higher percentage of the children with JIA did so. A systematic review from Stinson et.al. 2014 supports an association between poor sleep and increased symptoms related to JIA, most often the experience of pain. However, the researchers suggested that there might be a complex bidirectional interplay between pain and sleep disturbance, but available evidence is limited and of low methodological quality (Stinson et al., 2014) and more research is needed in order to establish the nature of this association. Sleep disturbance has been associated with poor health outcomes such as a poor quality of life (Stinson et al., 2014).

**Table 8.** The combined number of children who replied “sometimes”, “often”, or “almost always” to items that had one primary category: sensation of pain within *body structure and body function component*, and secondary category within *Activities and participation* of the International Classification System of Functioning, Disability, and health (ICF) are demonstrated. JIA: Juvenile idiopathic arthritis.

A. Items from the PROMIS Pediatric Short Form – Pain Interference and one item from the PROMIS Pediatric Short Form – Pain Behavior (I moved slower.)

ICF categories	Question	Combined number (%) of children who replied sometimes, often, or almost always.	
		Children with JIA	Age-matched peers
<i>Sensory functions and pain</i>	<b><i>During the last 7 days/ in the past 7 days ...</i></b>		
<i>Mobility</i>	I had trouble doing schoolwork when I had pain	5/16 (31.25%)	1/10 (10%)
	It was hard for me to run when I had pain*	7/16 (43.8%) *	0/10 (0%)*
	It was hard for me to walk one block when I had pain.	7/16 (43.8%)	0/10 (0%)*
	It was hard to stay standing when I had pain	5/16 (31.3%)	0/10 (0%)
	I moved slower	8/16 (50%)	2/10 (20%)

B. Items the PROMIS Pediatric Short Form – Pain Behavior.

ICF categories	Question	Combined number (%) of children who replied sometimes, often, or almost always.	
		Children with JIA	Age-matched peers
<i>Sensory functions and pain</i>	<b><i>In the past 7 days, when I was in pain ...</i></b>		
<i>General tasks and demands</i>	I lay down	9/16 (56.25%)	2/10 (20%)
	I had to stop what I was doing	3/16 (18.75%)	4/10 (40%)
	I asked someone to help me	2/16 (12.5%)	2/10 (20%)
<i>Sensory functions and pain</i>	It showed on my face	4/16 (25%)	1/10 (10%)
<i>Communication</i>	I asked for medicine**	6/16 (37.5%)	0/10 (0%)
	I talked about the pain	6/16 (37.5%)	6/10 (60%)

\*The number of children with difficulties in running was estimated from the number of children who had trouble walking one block.

\*\*The item “I asked for medicine” has the primary category Sensory functions and pain AND can have a secondary category within Environmental factors; chapter: Products and technology as well as within Activities and participation: Communication.

More children with JIA than peers described difficulties with attention due to pain. To our knowledge no study of the effects of pain on attention has been performed on children with JIA. However, a systematic review from 2016 demonstrated a relationship between attention problems and chronic pain in children and adolescents although the strength and direction of these relationships are unclear (Kamper et al., 2016).

### Major Life Areas

More children with JIA had trouble doing schoolwork than the control group. Difficulties in carrying out schoolwork may be because of negative effects of pain on attention, or due to joint pain and stiffness that make manual tasks or sitting for a long period of time hard. Whatever the reason is, physical therapists should inform parents and school personnel of the potential impact of JIA on school performance and suggest

modifications to the educational program, e.g. adaptive writing tools or changes in the child's schedule.

### **Mobility**

A higher number of the children with JIA described difficulties in all the mobility items compared to peers. This is not surprising and is consistent with other studies on mobility (Gueddari et al., 2014; Nordal et al., 2019). The primary symptoms of JIA are inflammation, with swelling in one or more joints, joint pain and stiffness causing difficulties in mobility.

### **General Tasks and Demands**

To lie down, stop doing things or ask for help can all be regarded as short-term pain-relieving strategies for all who experience pain. Children in both groups used these strategies but a higher percentage of children with JIA stated that they laid down when they had pain. This may be a useful strategy when the pain is widespread.

### **Communication**

Members of both groups expressed their pain to others, either verbally or non-verbally. More children in the control group talked about the pain. Their experience of pain may be more sporadic than the for the group with JIA and they may therefore talk more of their pain than the group with JIA which may have slight sense of pain most of the time.

Five children with JIA asked for medication to reduce pain compared to none in the control group. Children with JIA have been prescribed medications to alleviate the symptoms of their disease, so it is not surprising that they ask for medications.

### **Therapeutic Intervention**

Even though the questions in the survey did not cover all chapters of the ICF and the groups were small, the results demonstrated that the presence of pain has extensive negative effects on the functioning of children with JIA. Given the broad impact of pain, multidisciplinary intervention should account for the complex interplay of the biological, psychological, and environmental factors that contribute to and maintain pain symptoms. The intervention should be tailored to each individual child based on his/her unique profile and preferences. Physical and occupational therapists are a part of the pediatric rheumatology team, and conduct an examination of impairments in body structure, body function, and potential activity limitations and participation restrictions. Based on the examination they get a comprehensive overview of the child's clinical symptoms and functioning in order to develop an intervention plan (Ginter & Vogel, 2022; Net et al., 2017).

Therapeutic intervention is always individualized. At the level of body structure and body function, the intervention includes pain relief and management of joint health,

increase of muscle strength, endurance, and agility. Research has demonstrated that active aquatic and land-based exercises can decrease pain and increase strength in children with JIA (Klepper et al., 2019; Kuntze et al., 2018).

Intervention to reduce activity limitations and participation restrictions involves maintaining functional mobility and encouraging independence in self-care activities within the home, school, and community. Exercises can increase daily activities (Kuntze et al., 2018) and a recent study has demonstrated that video games-based task-oriented activity training can also be effective for children/adolescents with JIA (Arman et al., 2019).

Educating the children and families on pain and giving advice for supporting effective self-management also have impact on pain and daily activities. Recent studies have shown potential benefits of online and smart phone programs, both in terms of providing information to the users and using interactive functions. These programs can give health care professionals a better understanding of each user's condition facilitating improved health care and a better outcome for this age group (Armbrust et al., 2015; Cai et al., 2017).

### ***Strengths and Limitations***

The study had several limitations. This was a cross-sectional observational study; therefore, no causal inferences can be made and there may have been unmeasured confounding factors. The data were based on self-reports, which are inherently subjective and rooted in individual personality and background. The study may have been prone to non-response bias with participants potentially having more interest in health and JIA than nonparticipants. Generalization to other groups, therefore, must be handled carefully. The main limitation in this analysis is the small number of children with pain in both groups. Even though pain is one of the primary clinical symptoms in all children with JIA, few studies have demonstrated a difference in pain intensity between subtypes and sex (with girls experiencing more pain). The difference in pain intensity between boys and girls may however be due to different prevalence in JIA subtypes between sexes (Malleon et al., 2004; Tupper et al., 2013). Variations in pain intensity can have different impacts on daily activities. In this study the sample of children with JIA is too small to compare the impact of musculoskeletal pain on functioning in children with different subtypes of JIA. A much bigger sample is needed in which the impacts of psychological and environmental factors would also be considered.

The strengths of the study include the use of the three standardized PROMIS questionnaires with established psychometric properties. The PROMIS include short, clear, and user-friendly questions. The use of the questionnaires had the benefit of being time- and cost-efficient and easy to administer. All the questions were on pain and the impact of pain during the past seven days. When children experience episodes of joint inflammation and pain it is of value to ask about pain experienced over a period. It is more valuable to ask them about pain experienced over a week, rather than on one day. It might have been better to use a questionnaire including questions of pain over a longer period. However, recall bias can be a problem, increasing the possibility of inaccuracy if they are asked to recall pain for several weeks.



## Conclusion

The questions used in this study do not cover all chapters within the ICF. It was expected since PROMIS is a measurement of a person's health outcomes. However, the results give us some indications of the extensive impact of pain on functioning in children with JIA. The study included small samples of children, but by presenting a content mapping of questions on pain to the ICF it suggests how researchers in other studies can achieve detailed information on the impact of pain.

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## Notes on contributors

*Bjorg Gudjonsdottir* is a specialist in pediatric physical therapy and a assistant professor at the Department of Physical Therapy, School of Health Sciences, University of Iceland.

*Svanhildur Arna Oskarsdottir* is MSc student at the time of the study. She now works at a physical therapy clinic in Iceland.

*Audur Kristjansdottir* is MSc student at the time of the study. She now works at a physical therapy clinic in Iceland.

*Judith Amalia Gudmundsdottir*, PhD, is a specialist in pediatric rheumatology. She is a member of the pediatric rheumatology team at the Children's Medical Center, University Hospital of Iceland.

*Solrun W. Kamban* is a specialist in family nursing. She is a member of the pediatric rheumatology team at the Children's Medical Center, University Hospital of Iceland.

*Zinajda Alomerovic Licina* is a social worker. She is a member of the pediatric rheumatology team at the Children's Medical Center, University Hospital of Iceland.

*Drifa Bjork Gudmundsdottir*, PhD, is a specialist in clinical psychology. She is a member of the pediatric rheumatology team at the Children's Medical Center, University Hospital of Iceland.

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## Abbreviations

JIA	Juvenile idiopathic arthritis
ICF	The International Classification of Functioning, Disability and Health
PROMIS	Patient-Reported Outcome Measurement Information System.