

# Disclosure and Self-Report of Emotional, Social, and Physical Health in Children and Adolescents With Chronic Pain—A Qualitative Study of PROMIS Pediatric Measures

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**Objectives** To examine the content validity of the Patient-Reported Outcomes Measurement Information System pediatric measures, including the pain interference scale, among children and adolescents (aged 8–18 years) who experience chronic pain. To describe children's understandings of the health domain constructs and elucidate verbal and conceptual aspects of self-reported pain-related functioning, which shape disclosure and reporting. **Methods** 34 children and youth with diagnoses of juvenile idiopathic arthritis or noninflammatory chronic pain completed semistructured and cognitive interviews exploring the meaning, experience, and expression of up to 4 of the Patient-Reported Outcomes Measurement Information System pediatric domains: anger, anxiety, depressive symptoms, fatigue, pain interference, and peer relationships. Team-based thematic and content analyses were conducted. **Results** Clear verbal and social-cognitive differences were observed in representations and accounts of the domain-experiences across age-groups, but we noted little, if any, evidence of problems with content validity. **Conclusions** Findings suggest the importance of a rigorous developmental approach for understanding the verbal and cognitive dimensions of pediatric self-reports and patient-reported outcomes.

**Key words** adolescents; children; chronic and recurrent pain; developmental perspectives; qualitative methods.

## Introduction

Chronic pain in children is a highly prevalent problem and estimated to affect between 11 and 38% of children and adolescents (Huguet & Miro, 2008; Hunfeld et al., 2001; King, 2011). Chronic pain in children can be associated with substantial functional impairments (e.g., school absences), emotional distress, and reduced quality of life (Cohen, Vowles, & Eccleston, 2010; Gold, Mahrer, Yee, & Palermo, 2009; Hunfeld et al., 2001; Kashikar-Zuck,

Goldschneider, Powers, Vaught, & Hershey, 2001). Because pain is largely subjective and invisible to others, assessment of the pain experience depends chiefly on patient self-reports of the intensity, quality, and functional impact of pain. An extensive literature describes the development and validation of self-report measures to assess both acute and chronic pain and the impact of pain on children's functioning (Stinson, Kavanagh, Yamada, Gill, & Stevens, 2006; Varni et al., 2010; von Baeyer, 2009).

Easily administered and scored and incorporating the child or youth's subjective pain perceptions, self-report outcome measures have become key assessment tools in pain-related pediatric clinical trials and translational research studies.

As indicated in the Pediatric Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (PedIMMPACT) consensus guidelines (McGrath et al., 2008), comprehensive assessment of the core domains of the pain experiences of children and adolescents should include measurement of pain intensity, physical and emotional functioning, and role functioning. Recognizing that children differ across the developmental span in their ability to provide self-reports in each of these domains, the recommendations included the development of appropriate measures for different age-groups. The PedIMMPACT statement also encouraged streamlining the wide variety of available tools for pain assessment used in clinical trials, many of which are condition-specific (e.g., for headache, abdominal pain, fibromyalgia) and difficult to compare across studies.

In an effort to improve the efficiency and precision of patient-reported outcomes (PRO) assessment, the NIH has created a cooperative network of researchers to develop new PRO scales using modern measurement theory, PROMIS (Patient-Reported Outcomes Measurement Information System; Reeve et al., 2007). This initiative aims to create "generic" assessment tools that can be used across medical conditions, including chronic pain conditions, rather than a multiplicity of disease-specific scales. The PROMIS system spans pediatric (8–17 years old) and adult (18+ years) groups, and measurement tools are systematically developed using both qualitative and state-of-the-art psychometric methodologies, including item response theory to create either static short forms or computerized adaptive versions that can be administered in an array of clinical and research settings (DeWalt, Rothrock, Yount, & Stone, 2007, available at [www.nihpromis.org](http://www.nihpromis.org)). Because the emphasis is on "patient-reported," it is essential that extensive input be provided by the patients themselves as to the most appropriate and meaningful ways to assess their health experience, recognizing that expert opinion is influential in setting the scope, content, and selection of PRO measures (Magasi et al., 2012).

During the development of the PROMIS pediatric version 1.0 item banks, focus groups were conducted with diverse, age-stratified sets of healthy children and asthma patients to qualitatively explore how well the content of items represented or captured respondents' own experiences and perceptions of social, emotional, and physical functioning (Walsh, Irwin, Meier, Varni, & DeWalt, 2008).

In children with chronic pain for which there is often no objective means of confirmation of disease status, however, it remains unclear how well generic measures capture or allow for the communication of pain-related impairment.

Many factors are known to shape the interpretation, expression, and communication of pain and pain-related functioning. In adults, fear of embarrassment or of negative medical consequences, desire to save face, or the perception of clinician skepticism can all affect the self-report of pain in the clinical encounter (Schiavenato & Craig, 2010); however, communication factors affecting self-report of pain in children and adolescents are not as well understood. Although a number of studies have reported on factors affecting the comprehension and self-report of pain and—to a lesser extent—pain-related functioning among children and adolescents (Bevans, Riley, Moon, & Forrest, 2010; Chambers & Johnston, 2002; Huguet, Stinson, & McGrath, 2010; Lavigne, Schulein, & Hahn, 1986; Stanford, Chambers, & Craig, 2005; Von Baeyer, 2009), these studies have tended to focus on the self-report competencies of young children using visual analogue scales and/or rely on primarily quantitative psychometric approaches (Brod, Tesler, & Christensen, 2009; Huguet, et al., 2009; Walsh et al., 2008).

Qualitative interview studies conducted with school-aged children (aged 10+ years) with chronic pain illustrate how threats to normalcy and developing relationships can also result in ambivalence about the expression and disclosure of pain symptoms and related functioning. Carter's (2002) examination of the impact of chronic pain in the lives of three 12–13-year-old subjects and their families in England illustrates these issues through the identification of three common themes. "Referral fatigue" refers to the repeated cycles of hope and disappointment associated with consulting different "experts" who are unable to explain why a child is experiencing pain and what is causing it. "Professional disbelief" is signaled by the clinician's emphasis on searching for psychogenic sources of the pain, and "professional ventriloquism" refers to the clinician's reinterpretation and mistranslation of the patient's words into a medically oriented paradigm that effectively silences the patient's voice. More recent studies also suggest that a child's growing sense of isolation and differentiation from peers (owing to pain interference) is often accompanied by ambivalence about disclosure of the pain (Meldrum, Tsao, & Zeltzer, 2009; Nutkiewicz, 2008; Sallfors, Fasth, & Hallberg, 2002). There is evidence for the influence of social desirability bias in pain-related PROs among 11–14-year-old children, specifically the disinclination to report emotional distress when pain is

medically unexplained or understood to be “psychogenic” (Logan, Claar, & Scharff, 2008).

In light of the inherent potential for qualified reporting of pain and pain-related impact as suggested in the qualitative literature, we endeavored to examine the performance and content validity of PROMIS pediatric version 1.0 short forms among children and adolescents with chronic pain conditions (8–18 years old). Specifically, we sought to examine (1) whether there were limitations in children’s understanding of each of the domains, (2) whether there were age, gender, and diagnostic group differences in understanding, and (3) whether the children felt the PROMIS version 1.0 short form items were reflective of and applicable to their experiences. Our motivation was to incorporate children’s voices and perspectives into the evaluation of the items with attention to their use in clinical, as well as research, contexts.

## Methods

Children and youth with diagnoses of either juvenile idiopathic arthritis (JIA) or noninflammatory chronic pain were recruited from outpatient pediatric rheumatology, behavioral medicine/clinical psychology, and pain management clinics at a large Midwest children’s hospital between July 2010 and February 2011. Patient referrals to these clinics typically originate from both primary care and subspecialty pediatric clinics. Eligible patients were between the ages of 8 and 18 years, had a diagnosis of a painful chronic condition (JIA or noninflammatory chronic pain), and could speak and read English. Children with any concurrent medical, psychiatric, or cognitive condition(s) that would interfere with participation in the study were excluded. The primary treating clinician introduced the study to eligible patients, and those who were interested were contacted by a research coordinator who explained the study to them and addressed any questions or concerns. Participants were assured that their clinical care would not in any way be affected, regardless of whether they chose to participate. Written assent and consent were obtained from the participant and legal guardian before each interview.

Designed to last between 30 and 60 min, semistructured, one-on-one interviews explored up to four of the PROMIS pediatric domains: *anger*, *anxiety*, *depressive symptoms*, *fatigue*, *pain interference*, *peer relationships*, *physical functioning* (overall mobility and upper extremity). The domains explored and their ordering were rotated in interviews according to a purposeful stratified sample strategy aimed at representing perspectives across gender,

diagnosis, and age-group. Because of time constraints and concerns about respondent burden, each participant interview generally assessed only 3 or 4 domains. Sample sizes of 10–15 per diagnostic group (JIA and chronic pain) were planned with the expectation that these might be adjusted based on ongoing assessment of domain relevant data saturation and team analysis of transcribed interviews. Interviews were audio-recorded, unless refused by the participant, in which case detailed notes were recorded. After each interview, the child or youth was given a cash incentive for time and participation in the study. All procedures were approved by the hospital’s institutional review board.

Two female master’s-level research coordinators were trained in the administration of open-ended, domain experience/concept-focused probes and in more structured, item-focused cognitive interviewing techniques. Guided by an experienced PhD-level qualitative researcher, these training activities involved practice sessions in paired or research group contexts, pilot interviews with children and youth in the target age-groups, and research team review of transcripts from pilot and early participant interviews.

For each of the PROMIS domains assessed (anger, anxiety, and so forth), interviewers first elicited the subjective meaning of the domain construct from the respondent (e.g., “What kinds of things come to mind when I say the word \_\_\_\_\_?” or “What does \_\_\_\_\_ mean to you?”). Additional probes elicited recent examples of domain experiences and explored their sensory and affective qualities (e.g., “What does it feel like to experience \_\_\_\_\_?”), as well as perceived expression and responses in social contexts (“Can others tell? Do you let others know?”). Finally and in accordance with recommended PROMIS cognitive interview procedures, participants completed a paper version of the corresponding PROMIS Short Form (6–10 items) and were then queried about any comprehension or wording problems and asked to suggest possible alternatives.

## Analysis

Digital audio recordings were transcribed verbatim. After removal of any personal identifiers, transcript documents were formatted to indicate domain section (anger, anxiety...) and subsection (open ended vs. item focused) transitions and then entered into a qualitative text management software program (NVIVO8) to facilitate analysis. To facilitate comparison and interpretation, interview content associated with each domain was consolidated into a single document consisting of domain-related excerpts ordered by increasing age and separated by diagnosis. For each consolidated domain document, all team members

(consisting of the two MA-level interviewers, one physician, two PhD–psychologists, and one PhD–anthropologist) first individually read and “open-coded” the report documents to: (1) identify and label content related to respondents’ conceptual-verbal understandings of the domain; and (2) identify and interpret communication factors affecting the expression and self-report of pain and pain-related symptoms under different conditions. At this point in our analysis, we decided to limit our focus to the six PROMIS domains that, like pain, involved a primarily subjective experience and form (anxiety, anger, depressive symptoms, fatigue, pain interference, and peer relations) and to exclude the more objectively visible domains of physical mobility and upper extremity mobility. Over the course of several meetings, team members reviewed and further refined our coding and interpretations, paying particular attention to and discussing observed differences in conceptual scope and comprehension of domain constructs across age, gender, and diagnostic groups.

## Results

### Participants

The sample consisted of 34 children and youth aged 8–18 years, 81% of whom were female, with a mean age of 13.8 years. Participants had a diagnosis of JIA ( $n = 18$ ; 53%) or a chronic pain condition ( $n = 16$ ; 47%) (Table I). Chronic pain conditions included the following: migraines (25%), chronic headaches (19%), abdominal pain (13%), and musculoskeletal pain (25%, one patient each with fibromyalgia, complex regional pain syndrome, chronic foot pain, progressive pseudorheumatoid chondrodysplasia, and chronic lower back pain). In seven interviews (21%), children were accompanied by a parent during the interview based on child preference. With the exception of one 14-year-old girl who declined to be audio-recorded but was comfortable with note-taking, all the interviews were audio-recorded.

### Descriptions, Expression, and Disclosure of Domain Constructs

Our analyses across age, gender, and diagnostic groups revealed no evidence of differences in comprehension, meaning, or disclosure of domain experiences across diagnostic groups, and only one apparent difference across gender groups, as discussed later in the text. However, differences across age-groups were clear, and they were first signaled and perhaps most obvious in younger respondents’ common inability to understand, define, or use the domain label (as opposed to the generally simpler language in the items). Presentation of the results is thus

Table I. Participant Characteristics

Group characteristic	JIA group N (%)	Chronic pain group N (%)	All N (%)
All participants	18 (53%)	16 (47%)	34 (100%)
Gender (female)	15 (82.4%)	13 (78.6%)	28 (82.4%)
Age, years			
Mean	13.1	14.6	13.8
Median	13.1	14.8	14.4
Range	8.0–18.6	8.4–18.0	8.0–18.6
8–10	5 (28%)	1 (6%)	6 (18%)
11–12	4 (22%)	3 (19%)	7 (21%)
13–15	6 (33%)	7 (44%)	13 (38%)
16–18	3 (17%)	5 (31%)	8 (23%)
Ethnicity			
Non-Hispanic	17 (94.4%)	16 (100%)	30 (96.8%)
Hispanic	1 (5.6%)	0 (0%)	1 (3.2%)
Race			
White	16 (88.9%)	14 (87.5%)	30 (88.2%)
Black	1 (5.6%)	0 (0%)	1 (2.9%)
Biracial	1 (5.6%)	2 (12.5%)	3 (8.8%)

Note. JIA = juvenile idiopathic arthritis.

organized around content and thematic findings across subsets of PROMIS domains and across age-groups (8–12 years, 13–18 years.) First, we examined the emotional distress domains of *anger*, *anxiety*, and *depressive symptoms*, then the domains of *fatigue* and *pain interference*, followed by *peer relationships*. As we show, notable differences across developmental age-groups provide an internal standard for judging verbal-conceptual comprehension of the domain concepts.

### Anger, Anxiety, and Depressed Affect Among 8–12-Year-Old Children

Interviews began with probes concerning the perceived meaning of the domain construct label. As with the wording in the individual PROMIS items assessing these domains, interviewers used the simpler terms *mad*, *nervous/scared*, and *sad* to elicit and assess the child’s understanding of the construct, as needed. Most children under the age of 12 years could neither define nor appropriately use the more abstract domain labels *anger*, *anxiety*, or *depression*. Children in this age-group reported feeling *mad*, *sad*, *excited*, or *upset* as a result of specific short-lived situations involving triggers such as name calling, getting injections or other medical procedures, receiving a bad grade, or missing a social event. For instance, one 10-year-old girl diagnosed with JIA reported feeling angry when “my cousin called me names, like ‘chicken butt’ . . .” Their attempts to define one affective domain often involved reference to another, and

Table II. *Anger, Anxiety, and Depression: Participants' Understandings and Experiences (Examples)*

Age (years)	Sex	Diagnosis	Quote
Anger			
10	M	JIA	Mad and nervous. That I cannot play football and all the sports I want to play.
13	F	Pain	It's not like angry, like ANGRY. It's like a low anger. I don't think... ANGRY.
14	F	JIA	(When she is not in pain) Thinks back and wonders why she ever got mad about things (no audio).
15	M	JIA	I yell a lot, get a little more violent (yelling make you feel less angry?) Yes, but it's not always the best thing I've found out recently.
17	M	Pain	I normally don't let other people know that I'm angry.
Anxiety			
8	F	Pain	(Does not understand word anxiety, <i>nervous</i> ?) Like if you were in a choir from your school or church, and they told you, "you have a solo."
9	F	JIA	Excited? Getting a shot, needles. Roller coaster ride.
12	F	JIA	Emotions, what you feel, how you are feeling.
15	M	JIA	I don't really get nervous that much... I'm pretty laidback, I don't get nervous really. I don't stress that much.
16	M	Pain	Um, fidgety, kind of can't sit still. (Let others know you're anxious?) I don't really say anything.
16	F	JIA	In a rush to get things done. Can't sleep when anxious, I can't stop thinking about what's going to happen. Not really as attentive, sitting still might be harder.
18	F	JIA	For me it's like failure, feeling like you're going to fail or upset something, or if you say the wrong thing, it might make somebody upset.
Depression			
10	F	JIA	(Does not understand word depression, feeling down or blue?) Makes me think... feeling sad. I was sad on my birthday. I thought one of my friends were coming over but they weren't.
10	M	JIA	Sad, nervous. When I first got arthritis... (and) when someone died.
11	F	Pain	Sad about something, and you get a little upset about it or you get mad and maybe a little angry or like quiet. I got an F. I got sad and mad, but after teacher told us that we could redo the test, I got a little more happy; (or) when my grandpa died.
13	F	Pain	Sometimes I'll ask my siblings to go away and just let me be alone... or ask my mom to watch a movie with me to distract myself from the pain so I'm not as sad.
14	F	JIA	Friends can tell because she becomes quiet and stays to herself. Doesn't tell others to avoid being "bugged" about it. Listens to hard rock music to feel better (no audio).
15	F	Pain	I'll tell my mom, or just let it go, and do something I like to do (such as) play in the backyard or cut the grass.

Note. JIA = juvenile idiopathic arthritis.

they demonstrated little appreciation for more persistent or lingering forms of these affects/constructs (see Table II).

As noted, all respondents were also asked to describe sensations associated with the domains and to envision whether and how others could notice their experience. Younger children's experiential accounts of distressed affect emphasized somatic or physiological sensations like nausea, racing heart, tight chest, shaking and sweating, as well as behaviors such as yelling and crying. However, despite probing, their responses rarely incorporated the perspectives of others and presented instead a more naïve egocentric viewpoint relatively free of concerns about how they were seen by others whether among family and friends or in the interview context.

A notable exception to these patterns among the younger children can be seen in the comments of a 9-year-old girl with JIA. Defining depression as a situation

in which "you really don't want to interact with other kids because you think that they're going to think you're different," and "when I'm sad, I'm not active and I don't talk a whole lot, so maybe they don't see me as my usual self," she displays an unusual and precocious understanding of depressed affect along with a notable sense of social and self-awareness. Consideration below of the descriptions and understandings of distressing affect by older respondents (aged 13–18 years) further illustrates these conceptual-verbal and social-cognitive differences across age-groups.

### **Anger, Anxiety, and Depressed Affect Among 13–18-Year-Old Adolescents**

At the level of cognitive representation and verbalization of distressing affect, older children more clearly differentiated between anger/anxiety/depression and showed greater

comprehension and awareness of these affects in self and others. Teens also demonstrated an appreciation for the more persistent or recurrent forms of these emotions using expressions such as *down mood*, *forever tired*, *anxiety issues*, and *anger issues*. Although older respondents' attempts to define and characterize distressing affect referred to many of the same physiological sensations mentioned by younger children (*short of breath*, *stomach turning*, *yelling*, *crying*, *fidgety*), they more commonly used metaphors ("stuckness," *lion's roar*, *heart jumping out of chest*, *a black and white world*), and they provided much more cognitively elaborated affect accounts, invoking expressions such as (*my mind goes crazy*, *not as attentive*, *anxiety goes straight to your head*, *can't pay attention*, *distracted*, *feeling like you're going to fail*) (Table II).

Teenagers also exhibited considerably greater social-cognitive and interpersonal awareness in relation to the expression and disclosure of distressing affect. Their accounts of experiencing anger, for example, are presented less as an affective experience than as a reflection on the social proscriptions against expressions of anger (e.g., "it's not always the best thing," or "it's like a low anger, not ANGRY"). Anxiety appeared to be more readily acknowledged and verbally elaborated among female respondents—one of the only gender-related differences we observed; depressed affect, although sometimes disclosed to mothers, was often suppressed or concealed among peers (Table II).

### **Fatigue**

We found *fatigue* similar to the triad of distressing affects both in terms of age-related differences in the verbal-conceptual comprehension of the domain construct and in terms of the respondents' self- and social-cognitive awareness of the display or expression of being fatigued or tired. Few respondents under the age of 13 years (1/6) showed any comprehension of the term *fatigue*, and their examples of *being tired* or *tiredness* were limited to the immediate effects of tiring activities such as playing with friends or siblings, doing sports, running out in the sun, jump-roping, or watching TV. Only three respondents under the age of 10 years completed the fatigue domain interview, but each provided the kinds of physiological, egocentric, and socially naïve experiential accounts that also characterized the description of distressing affects among younger children (Table III).

The mother's input in the example involving the 9-year-old girl draws attention to the social aspects of affect recognition and management insofar as her daughter's "grumpy and aggravated" state has to be pointed out or made aware to her. The focus on irritability also

anticipates a major theme of teen respondents' accounts of fatigue and its effects, examined next.

Respondents aged 13–18 years defined fatigue using expressions such as *feeling poorly*, *groggy*, *sleepy*, *worn out*, *ready to pass out*, *not wanting to do anything*, *not getting enough sleep*, *general tiredness*, (*susceptible to*) *pick up bugs*, and *physical and mental tiredness*. Their examples of being fatigued emphasized the effects of busy school and after-school schedules involving getting up early (or not being able to "sleep in") and staying up late for sports practice or events, and/or doing homework. One respondent associated fatigue with not eating. Older children's accounts of the causes and effects of fatigue also referred to pain and to feeling irritable or asocial and used such terms as *aggravated*, *cranky*, *whiny*, *grumpy*, *snappy*, *irritable*, or *having an attitude*. Increasing self-awareness of the socially recognized irritability associated with fatigue—along with a tendency to withdrawal—is echoed in the comments presented in Table III.

These excerpts also suggest how pain and fatigue enter into a feedback loop in which pain at night interferes with sleep, and daytime fatigue exacerbates pain, often forcing social withdrawal and napping, which further disrupts sleep at night. This vicious cycle is further considered in the next section.

### **Pain Interference**

As part of the effort to understand how pain interferes with child and adolescent functioning, respondents were asked to describe what the word "pain" meant to them and how they acted or behaved differently when in pain. In defining and conceptualizing pain, children and youth at all ages pointed to and gave examples of their diagnosed pain condition. In their descriptions of what they do or how they act when in pain, that is, its social presentation, there were notable differences between younger and older children. The youngest children aged 8–10 years were again concrete in their accounts. This is exemplified by a 9-year-old girl diagnosed with JIA when she reports, "if I play outside and the pain is causing me, you know, if I can't move my hand as much as I was before, then I have to stop playing for awhile and it usually just takes about a minute for the pain to go away" (additional examples in Table IV).

Among teenagers, reports of the effects, expression, and display of pain symptoms or behaviors highlighted sleep disruption and irritable mood while also revealing a growing preoccupation with the management of social impressions. The excerpts presented in Table IV depict how fatigue, pain, and irritability interact, but they also show an emerging sense of self-identity and concern with shaping the display and influencing the social interpretation of

Table III. *Fatigue: Participants' Understandings and Experiences (Examples)*

Age (years)	Sex	Diagnosis	Quote
Fatigue			
8	F	JIA	My eyes feel like they want to close. I will wanna lay down.
8	F	Pain	I probably just start yawning, really nothing else.
9	F	JIA	My eyes start to get tired. My eyes get real droozy, real dizzy (mother adds: she's grumpy and aggravated easily).
12	F	JIA	Well, sometimes I do get aggravated easier which I kind of do have to work on because I shouldn't get mad just 'cause I am tired. But sometimes I do get aggravated easier.
14	F	Pain	I probably act different, like I don't talk and I am kind of not participating as much as I can in whatever I'm doing. If I have a really bad headache, I'll like lay down and try to take a nap and try to get rid of it . . . or just lay down and take a break.
15	F	Pain	I think when I'm tired I can feel it (lower back pain) more and I get crankier and I feel like my back hurts "just leave me alone." When my back injury was really bad I'd only get like a couple hours of sleep and then I'd be tired throughout the day.
18	F	JIA	(My) Sister gets very grumpy when she gets tired. She will walk in the house and announce that she's tired. She gets very grumpy. I might get fatigued but I still operate. It's just normal.

Note. JIA = juvenile idiopathic arthritis.

Table IV. *Pain Interference: Participants' Understandings and Experiences (Examples)*

Age (years)	Sex	Diagnosis	Quote
Pain interference			
8	F	Pain	(Headaches affect your activities?) No, but normally I would just sit at my desk instead of working.
9	F	JIA	If I play outside and the pain is causing me, you know, if I can't move my hand as much as I was before, then I have to stop playing for a while and it usually just takes about a minute for the pain to go away . . .
10	F	JIA	You know the scales to one through ten, how their faces look? I'll look like one of those when I start hurting . . . but I'll still be in pain, I'll just start leaving it alone and not trying to do anything. Sometimes I'll take pills like Tylenol . . . to get it to stop hurting.
12	F	JIA	(Disclose your pain?) I might tell peers what I have gone through, just to give them a sense that it wasn't a walk in the park. Of course it wasn't a walk in the park . . . I couldn't walk in a park! But I wouldn't make them feel sorry for me. That's one of the least things I want people to do.
12	F	Pain	I don't get as much sleep. Because it's hurting at night and then it's hard to get to sleep, and then it's hard to wake up in the morning. So it's caused me to be more tired. I try not to (act differently) unless it's really, really bad. Then I have to stop what I'm doing and . . . take a break.
12	F	Pain	Sometimes I just don't act like myself and stuff. I wouldn't be as talkative to (mother) and stuff. Or when I'm in pain I get more irritable and stuff and sometimes I get snappy and stuff.
15	M	JIA	It makes me a little more tired. Which I think probably makes me a little more irritable, easy to snap. Get upset with something. But I try not to make it too obvious. I'd have to say something normally.
16	F	JIA	Not all my friends know that I have arthritis. I guess I would just say that my hand hurts, but I mean at school, that could just mean I'm writing too much. I just don't want people judging that I'm 16 with arthritis.

Note. JIA = juvenile idiopathic arthritis.

being in pain. Sentiments or actions such as wanting not to be pitied or judged as arthritic at age 16 years, trying not to make it (pain) too obvious, trying not to act differently, and reflecting on how one is harder to be around—all suggest the complexity and ambivalence associated with interpersonal disclosure at a time when peer relationships are becoming increasingly important.

### **Peer Relationships**

Only two participants under the age of 12 years (vs. 14 participants aged 12–18 years) were interviewed about the nature and quality of their peer relationships, and they characterized their relationships in terms of "friends" or "friendships" and as individuals or groups with whom they shared activities and interests (sports, playground

Table V. Peer Relationships: Participants' Understandings and Experiences (Examples)

Age (years)	Sex	Diagnosis	Quote
Peer relationships			
12	F	JIA	Friends, or if you sat out in gym class... like what they would think of you...
13	F	JIA	People that make you nervous, I guess... feel funny or something.
14	F	Pain	Friends, how others view you.
15	F	Pain	I really care what people think. I'm always like "oh, what are they thinking about me?"
16	F	JIA	Friendship and how other people see you.
16	F	Pain	I kind of keep to myself, 'cause I think everyone else is just too much drama for me.
16	F	JIA	I'm quiet, but I don't have trouble making friends.
16	M	Pain	I'm not exactly the social butterfly. I don't have a lot of friends.
18	F	JIA	I tend to like people who are a little older than me... I'm a bit more introverted than my usual peers.

Note. JIA = juvenile idiopathic arthritis.

cliques) or who were generally "nice" as opposed to "mean" to them.

Among teenagers ( $n=9$ ), relationships with peers were characterized as "getting along" with others, being "nice" and not "mean," and having lots of friends was valued. There was also a notable self-conscious emphasis on "how others view you," both in general and as a person with a chronic pain condition (Table V).

Younger teenagers (aged 13–15 years) also commonly expressed concerns about peers' perceptions of, or reactions to, being associated or "friends" with a person suffering from chronic pain. They noted that owing to their pain condition, peers and others can "get nervous," "go overboard" in their sympathy or support, "might not wanna be around you cause you've got arthritis," might "think bad of me" for missing school, or "thought I was boring."

The five respondents aged  $\geq 16$  years downplayed the importance of having a lot of friends, and they more commonly described themselves as "introverted" or "(not) social butterflies" and as not being able to deal with all the "drama" associated with, as one respondent put it, "stereotypical teenage social situations" (Table V).

Comments made by some older respondents regarding who can be trusted and to what extent (e.g., "will they take a bullet for you?") also suggest greater wariness and, perhaps, increasingly rigorous standards for peers to be considered friends.

### Item Level Review

Our analyses of respondents' global comprehension of the domain constructs combined with findings from item-level cognitive debriefing on the PROMIS version 1.0 short forms revealed minor problems in content relevance, specificity, or time frame with a few items across the domains. For example, school-related items were deemed

inappropriate during summer months or among the homeschooled; within the Pain Interference domain, physical function-related items were found too general, and with respect to assessment of peer relationships, the response period of 7 days was perceived as too brief. We have listed the items that were identified as problematic by two or more respondents (Table VI). As a consequence of the analyses, we developed a single new pain interference item for testing: "it was hard for me to play sports when I had pain." Issues identified with particular items may be handled at the discretion of the end-user, as the PROMIS system offers the flexibility to customize item content of short forms or adaptive testing ([www.nihpromis.org](http://www.nihpromis.org)). Overall, we did not identify any significant content gaps or absence of typical language used to express the health domain constructs by our study populations.

### Discussion

We examined how children and adolescents with JIA and noninflammatory chronic pain conditions describe, conceptualize, express, and disclose experiences targeted by PROMIS version 1.0 pediatric outcome measures. At the item level, the minor problems found with the outcome domains resulted in the development of a single additional Pain Interference item with greater specificity related to sports participation. Otherwise, we found little qualitative evidence to distrust or doubt overall content validity across the measures for our respondent groups.

As noted earlier, an unintended consequence of efforts to elicit respondents' understandings of the relatively abstract domain labels (vs. the simpler language used in the items) was greater insight into the conceptual limitations of younger respondents, as the cognitive-linguistic ability to define or depict the more abstract domain state (anger, anxiety, and so forth) was rare among children



Table VI. *PROMIS Pediatric Version 1.0 Short Form Item Issues*

Domain	PROMIS item(s) (in the past 7 days...)	Issue/problem (noted by two or more respondents)
Anger	I felt fed up.	The term “fed up” was not well understood by younger participants.
Depression	I felt everything in my life went wrong.	The term “everything” was described as too broad. However, the item may serve to assess more severe depressive symptoms.
Depression	I felt like I couldn’t do anything right.	The term “anything” was described as too broad. However, the item may serve to assess more severe depressive symptoms.
Fatigue	Being tired made it hard for me to keep up with my schoolwork.	In most cases, this item is not relevant during summer months.
Fatigue	I was too tired to do things outside.	Depending on geographic location, outside play may not be normative during period of reference.
Pain interference	It was hard for me to walk one block when I had pain. It was hard to stay standing when I had pain. It was hard for me to run when I had pain.	Stand, walk, and run are very nonspecific and not sensitive to relevant areas of youth functioning. Sports and play items needed. Note: To address these comments, a new item developed for future testing “It was hard for me to play sports when I had pain.”
Peer relations	I was able to talk about everything with my friends.	This item considered too broad. (“everyone’s got secrets”).
Peer relations	I was good at making friends.	Time period of reference (past 7 days) considered not appropriate for making friends.
Peer relations	Other kids wanted to be my friend. Other kids wanted to be with me. Other kids wanted to talk to me.	Items seeking the perspective of “what other kids wanted” were considered too difficult to assess.

<12 years and common by age 14 years. This relative limitation among younger children did not appear to affect their comprehension of specific items. Overall, younger children had relatively egocentric awareness of and limited ability to verbalize the different ways they felt upset; however, with the exception of the minor concerns mentioned in Table VI, the PROMIS item language and content were unproblematic from a patient response perspective. In light of this, it might be helpful to use simpler language (and avoid using the more abstract domain labels) while discussing test results with children and families to ensure the child’s comprehension.

Among adolescents, representations of the targeted experiences displayed greater cognitive abstraction, verbal complexity, and discrimination. These advances in cognitive linguistic competency were, nevertheless, invariably accompanied by advances in the ability to consider and incorporate other’s viewpoints toward symptom states that, themselves, were also increasingly understood as nonnormative and thus socially undesirable. Adolescents’ heightened self-consciousness and awareness of others’ emotions, intentions, and beliefs clearly complicated the reported expression and disclosure of distress. Sentiments

like not wanting to be seen as a 16-year-old with arthritis, preferring to avoid the drama of disclosing, or trying not to make it obvious all reflect how the reporting or expression (or not) of symptoms is increasingly understood to have implications for the kind of person one is taken to be. Particularly among peers, disclosure of pain or related symptoms represents a threat to an emergent sense of identity and appears increasingly dependent on a feeling of interpersonal trust and security.

We did not explore respondents’ communication or disclosure of pain or pain-related symptoms in the clinical context, but qualitative research discussed earlier highlights health care experiential themes, such as “professional disbelief” and “referral fatigue” with the potential to undermine basic assumptions motivating the communicative interaction between the patient and clinician. Schiavenato and Craig’s 2010 model of pain assessment as a transaction is helpful for thinking about the communicative nature of the patient–clinician interaction and factors that may threaten the appropriate expression and assessment of pain. According to this model, which assumes the patient is speaking the truth and the clinician is attentive and competent (p. 668), various

communicative threats nevertheless do exist reflecting distinct developmental, socio-cultural, and clinical contexts, and at different stages of the illness experience and health care referral process.

This model helps us understand, for example, how patients experiencing referral fatigue and disbelief lose trust in the clinician. Once trust is damaged by perceptions of clinician incompetence, the reporting of symptoms becomes problematic. Other examples of communicative threats or “interference” factors include fear, stress, personal and cultural views on pain, socioeconomic status, clinical status, addiction, and so forth on the part of the patient, and empathy, training, communication skills, workload, resources, and so forth on the part of the clinician.

Our study has helped clarify the role of age and developmental factors in the meaning, experience, and expression of chronic pain and related symptoms. Given our exploration of the broader, that is, nonclinical, experience and expression of pain, distressed affect, and fatigue, we can only speculate on the role of the observed cognitive-linguistic and social-cognitive developments on reports in the clinical setting, or during the completion of a self-report measure. However, our findings suggest that while limitations in the ability to differentiate distressing affects were seen in younger respondents (aged <12 years) and in some adolescent boys, youth at all ages (ages 8–18 years) had the linguistic skills necessary to provide a coherent expression of pain and related symptoms, particularly in the form of a verbal self-report.

Findings related to the reported expression and disclosure of the domain content in social settings and among peers indicate how developments in self- and social awareness complicate the disclosure of nonnormative states and conditions. Of course, the peer relationship differs greatly from the patient–clinician relationship, and the threats to identity that complicate peer disclosure may not be relevant in the clinical setting. Nevertheless, for children in early adolescence, the increasing complexity of the meaning of pain symptoms combined with not yet adequate verbal expressive abilities, the report or account of pain may be more susceptible to errors or distortion than for younger children, who show much less regard to social perspectives, norms, and meanings. Indeed, considered within a communicative framework, there are good reasons to think that, with their use and purpose adequately understood, self-report and self-administered measures like the PROMIS scales may provide a *more* trustworthy venue or environment in which to express and assess such symptoms, as self-report can diminish concerns about how one is being perceived.

Limitations of our study include the following: the disproportionate number of girls (vs. boys), thus limiting our ability to discern gender differences; the potential influence of parental presence in some of the interviews with younger children; the absence of the voices and participation of nonwhite children. Some of these limitations are a consequence of the local epidemiological predominance of white girls among those receiving care for chronic pain.

## Conclusions

Using a combination of semistructured and cognitive interviews and a team-based, immersive, and constant-comparative qualitative analysis approach, we explored the conceptual and linguistic scope and comprehension of PROMIS outcome domains among children and adolescents with experience of chronic or recurrent pain. Our findings were supportive of overall content validity across the measures for our study groups diagnosed with JIA or chronic pain. Overall, however, we found clear age and developmental status differences, and more provisional gender and diagnostic differences in the experience, understanding, and expression of health constructs. Findings of the study have implications for interpretation of self-report and interactions with patients in both research and clinical settings and reinforce the need to better understand the role of psychosocial developmental changes in accurate self-reports, and importance of rigorous developmentally sensitive approaches to pediatric patient-reported outcome measure development.

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