

NIH Public Access

Author Manuscript

Arthritis Care Res (Hoboken). Author manuscript; available in PMC 2013 July 19

Published in final edited form as:

Arthritis Care Res (Hoboken). 2011 November ; 63(0 11): S431–S437. doi:10.1002/acr.20639.

Measures of Juvenile Fibromyalgia:

Functional Disability Inventory (FDI), Modified Fibromyalgia Impact Questionnaire–Child Version (MFIQ-C), and Pediatric Quality of Life Inventory (PedsQL) 3.0 Rheumatology Module Pain and Hurt Scale

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INTRODUCTION

Juvenile fibromyalgia (FM) is a chronic noninflammatory musculoskeletal pain condition typically diagnosed in adolescence. Juvenile FM is characterized by diffuse widespread pain, multiple painful tender points, sleep difficulty, fatigue, and other associated symptoms (1). Juvenile FM is also associated with considerable difficulty in physical, social, and emotional functioning (2–9). At present, there are no specific medical tests or disease markers to diagnose this condition, and assessment of symptoms and their impact is primarily by patient report. As noted by the Outcome Measures in Rheumatology Clinical Trials Fibromyalgia Syndrome Workgroup (10), a multidimensional assessment of FM syndrome is essential. Such an assessment should include measures of pain, fatigue, sleep, overall functioning, and quality of life. In patients with juvenile FM, research studies have traditionally utilized more generic pediatric measures that are applicable for many pain conditions. Only one measure has been specifically modified for use in juvenile FM: the Modified Fibromyalgia Impact Questionnaire- child version. In the following sections, we discuss 3 measures that can be used for assessment in juvenile FM, i.e., the Functional Disability Inventory (FDI), the Modified Fibromyalgia Impact Questionnaire- child version, and the Pediatric Quality of Life 3.0 Rheumatology Module Pain and Hurt scale. Measures used to assess pain characteristics, fatigue, and sleep used in pediatric pain disorders, including juvenile FM, are discussed in detail in the Measures of Pathology and Symptoms section in this issue.

FUNCTIONAL DISABILITY INVENTORY (FDI)

Description

Purpose—To measure functional disability (impairment in physical and psychosocial functioning due to physical health status) in children and adolescents with chronic pain. The FDI was initially developed to assess functional disability in children and adolescents (ages 8-18 years) with chronic abdominal pain (11,12), but has subsequently been used with a wide variety of pediatric pain conditions, including juvenile fibromyalgia (FM). The original

AUTHOR CONTRIBUTIONS

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Both authors were involved in drafting the article or revising it critically for important intellectual content, and both authors approved the final version to be published.

self-report scale was developed in 1991 and it has no updates or revisions. A parent-report version of the FDI is also available.

Content—The FDI assesses difficulty completing daily activities in home, school, recreational, and social domains such as "completing chores," "being at school all day," "walking the length of a football field," and "doing something with a friend." Items are rated in terms of difficulty the child or adolescent has completing each activity.

Number of items—There are a total of 15 items on the measure with no subscales.

Response options/scale—The child or adolescent rates the amount of difficulty they have completing each activity on a 5-point Likert scale (where 0 = no trouble, 1 = a little trouble, 2 = some trouble, 3 = a lot of trouble, or 4 = impossible).

Recall period for items—Respondents are asked to report how much difficulty they had with completing a variety of activities "in the last few days."

Endorsements—The Pediatric Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials (PedIMMPACT) guidelines (13) recommend the FDI for the assessment of physical functioning outcomes in clinical trials of pediatric chronic pain.

Examples of use—The FDI has been widely used in clinical research, including studies assessing the relationship between functional disability and psychosocial functioning, as well as clinical trials with a variety of chronic pediatric pain conditions, including juvenile FM (2,6,7,14).

Practical Application

How to obtain—Dr. Lynn Walker, Professor of Pediatrics and Director of the Division of Adolescent Medicine and Behavioral Science in the Monroe Carell Jr. Children's Hospital at Vanderbilt, 719 Thompson Lane, Suite 36300, Nashville, TN 37204. Copies and permissions can be obtained directly from Dr. Walker and there is no charge for the FDI.

Method of administration—The FDI is a child/adolescent self-report instrument. It can also be administered in an interview format, if needed, for younger children. The scale can be completed in person, by mail, or by phone. The instrument was designed so that followup assessments to monitor patient progress can be conducted by phone interview (12).

Scoring—Item scores range from 0 - 4. The total FDI score is a sum of all of the items and can be easily hand scored. Computer scoring is not necessary.

Score interpretation—Scores range from 0 - 60, with higher scores indicating greater functional disability. Recently, clinical reference points were developed to identify 3 categories of disability in pediatric chronic pain, i.e., no/minimal disability (0 –12), moderate disability (13–29), and severe disability (30), and these can be used for children and adolescents with a variety of pain conditions, including widespread chronic pain (3).

Respondent burden—Completion of the measure generally takes <10 minutes, although the measure may take longer for younger children with reading difficulties who require interview format administration. It has a Flesch reading ease of 89.7 and a Flesch-Kincaid grade level of 3.2.

Administrative burden—Time to administer is ~5–10 minutes and time to score is <5 minutes. No special training is necessary to administer or score the measure.

Translations/adaptations—The FDI has been translated to the following languages for use: Spanish, French, German, Swedish, Dutch, Arabic, Bulgarian, Polish, Afrikaans, Estonian, Croatian, Slovenian, Macedonian, Romanian, Hungarian, Greek, Russian, Hebrew, Finnish, and East Indian languages, including Hindi, Tamil, Gujerati, Kannada, Malayalam, Marathi, and Telugu (Walker L: unpublished observations). To date, no revalidation studies addressing cultural differences have been conducted.

Psychometric Information

Method of development—Items were generated by reviewing and adapting items from existing adult measures of physical and psychosocial functioning, i.e., the Sickness Impact Profile (15) and the Duke–UNC Health Profile (16). Once the items were selected, pilot testing was conducted with children and their parents in a pediatric out-patient clinic and several items were removed and other items reworded (12) to arrive at the content of the final scale.

Acceptability—The FDI was developed for children as young as 8 years old. The language difficulty of the measure is adapted to the typical reading level of children and adolescents. Missing data are not common, as items are easily understood. There are no known floor or ceiling effects, as very few individuals actually score either 0 or 60. Clinic-based studies have shown that children and adolescents with chronic pain generally obtain scores in the moderate range of disability (total scores 13–29) (3), whereas community-based studies show that healthy school-age children report overall FDI scores in the range of 3-8 (17,18).

Reliability

Evidence for internal consistency: Cronbach's alpha reliability coefficients for the FDI are high (a = 0.85-0.92) (11,12). The mean interitem correlation is 0.38 (12), which is consistent with the broad domain of functioning covered by the items.

Evidence for stability: Test–retest correlations are high at 2-week (r = 0.80, P < 0.001), 6-week (r = 0.70, P < 0.001), and 6-month followup (r = 0.63, P < 0.001) (12).

Validity

Evidence of content validity: Concurrent validity was examined by calculating correlations on the FDI with school absences, which is a common proxy for child disability (15). There was a significant correlation between reported FDI scores and the number of school absences (r = 0.52, P < 0.001) in the 3 months prior to the clinic appointment. Discriminant validity was evaluated by examining whether the FDI could discriminate between 3 diagnostic groups (abdominal pain with organic etiology, recurrent abdominal pain, and healthy controls). The FDI was able to discriminate among the 3 groups (F[2,97] = 26.40, P < 0.001). Post hoc analyses revealed significantly higher FDI scores for adolescents with recurrent abdominal pain and organic abdominal pain in comparison to healthy controls (12).

Evidence of construct validity: Construct validity has been demonstrated by examining the association between the FDI and other measures of child well-being. A study of 15 children with juvenile FM found that measures of depression, anxiety, fatigue, and pain (Pearson's r = 0.42-0.58, P < 0.05) all had positive significant correlations with FDI scores (7). A more

recent study had similar results with significant positive correlations with measures of depression (r = 0.45, P < 0.01) and pain (r = 0.41, P < 0.01) (3).

Evidence of criterion validity: Predictive validity was examined in an abdominal pain population by correlating FDI scores and school absences due to illness during the 3 months following the clinic appointment (r = 0.44, P < 0.001). The initial FDI scores were also highly correlated with medication use (r = 0.26, P < 0.05) and somatic symptoms (r = 0.45, P < 0.001) at 3-month followup (12). There are no studies examining criterion validity specifically in juvenile FM.

Ability to detect change—Studies have reported FDI results as a sensitive indicator of clinical improvement in juvenile FM. Two treatment studies examining the efficacy of cognitive– behavioral therapy in juvenile FM found significant decreases on the FDI posttreatment (2,14).

Critical Appraisal of Overall Value to the Rheumatology Community

Strengths—The FDI is a widely used measure to evaluate functional impairment in adolescents diagnosed with chronic pain. The measure is recommended for use in pediatric pain clinical trials by the PedIMMPACT guidelines (13). It has strong psychometric properties and has been used as a primary outcome measure in several clinical trials for pediatric chronic pain disorders, including juvenile FM (2,14,19).

Caveats and cautions—Until recently, there were no published clinical reference points for direct interpretation of scores based on clinical norms, which presented a challenge for research and clinical use (20,21). However, Kashikar-Zuck and colleagues (3) recently developed clinical reference points for no/minimal, moderate, and severe disability to allow for clinical interpretation of FDI scores.

Clinical usability—The FDI is a reliable and valid measure of functional impairment in children/adolescents diagnosed with juvenile FM in the clinic setting. It has been found to be an efficient and user-friendly tool for routinely tracking patient outcomes throughout the course of treatment, and has been successfully integrated into busy out-patient clinic settings (22). The FDI can be useful in the development of concrete treatment goals for disability reduction in collaboration with patients and their parents. The instrument poses minimal administrative/respondent burden and has not been found to limit clinical use.

Research usability—The FDI has been successfully used in clinical research in juvenile FM (2,6,7,14). The measure is easy to administer, requires minimal administrative/ respondent burden, and is a sensitive indicator of treatment efficacy in clinical trials.

MODIFIED FIBROMYALGIA IMPACT QUESTIONNAIRE-CHILD VERSION (MFIQ-C)

Description

Purpose—The MFIQ-C was developed as a brief measure to assess the spectrum of juvenile fibromyalgia (FM) symptoms and the impact of juvenile FM on the physical and emotional functioning of children/adolescents with juvenile FM. It has been used with patients ages 10–20 years (5,8,9,23). The measure is based on the original FIQ (24) and the MFIQ for adults (25), and was adapted for use in children and adolescents by making minor wording changes (i.e., substituting "work" with "school") (8). At this time, there is limited information about the MFIQ-C as it has been used in a very small number of pediatric

studies. For a more thorough description of the original adult FIQ measures, please see the fibromyalgia article in the Measures of Pathology and Symptoms section in this issue.

Content—The MFIQ-C measures physical functioning ("Were you able to do your chores around the house?"), how well the patient feels generally ("During the past week, how many days did you feel good?"), and participation in daily activities ("How many days last week did you miss usual daily activities because you were not feeling well?"). The measure also assesses participation in school activities, pain, fatigue, sleep quality, stiffness, anxiety, and depression using visual analog scales (VAS) that measure the degree to which symptoms interfere with daily activities.

Number of items—The MFIQ-C contains 19 items and 9 subscales. The subscales are: physical functioning (items 1–10), overall well-being (item 11), daily activities (item 12), school (items 13), pain (item 14), fatigue (item 15), sleep quality (item 16), stiffness (item 17), anxiety (item 18), and depression (item 19).

Response options/scale—For the physical functioning subscale (first 10 items), respondents are asked how often they were able to complete a variety of daily activities on a 4-point Likert scale with the response options of "always," "most times," "occasionally," or "never." The overall well-being and daily activities scales (2 items) ask respondents to rate the number of days in the week they felt good and how many days they missed daily activities, respectively (response option range 0 –7 days). For the remaining 7 items, patients rate the difficulty they have with each symptom on a 0 –10-cm VAS ranging from none to most severe.

Recall period for items—Respondents are asked to report the impact of their symptoms over the past 1 week.

Endorsements—There are no endorsements for the use of the MFIQ-C at present.

Examples of use—The MFIQ-C has been used to examine how physical functioning in juvenile FM is affected by coping strategies (8) and social context such as parental pain history and family environment (9). A more recent study found that adolescents with juvenile FM scored significantly higher on the MFIQ-C than matched healthy controls and that family factors and emotional functioning were related to physical functioning as measured by the MFIQ-C (26). A study conducted in an inpatient adolescent psychiatric setting found that patients who had been diagnosed with juvenile FM scored significantly higher on the measure than those without juvenile FM (23).

Practical Application

How to obtain—The original FIQ and MFIQ were developed and validated by Robert Bennett, MD, who can be contacted by e-mail at bennetrob1@comcast.net. The child version (MFIQ-C) was modified from the adult measures by Laura Schanberg, MD, Division of Pediatric Rheumatology, Duke University School of Medicine, Durham, NC 27710; e-mail: schan001@mc.duke.edu. There is no copyright on the measure.

Method of administration—The MFIQ-C is a brief patient self-report questionnaire.

Scoring—Scoring can be done by individual scale or by composite score; however, the composite score format is recommended by the authors of the adult FIQ measure. As in the FIQ, each scale on the MFIQ-C is transformed to a 0-10 scale score using a normalization procedure so that all scores are expressed in similar units (see the fibromyalgia article in the

Pathology and Symptoms section in this issue for detailed scoring procedures). A composite score can be calculated by adding the scores on each of the 10 scales to arrive at a score between 0 and 100, where 0 = no impairment and 100 = severe impairment. Computer scoring for the MFIQ-C is not available. Directions for missing values for items 1–10 are to prorate the items by dividing the score by the number of items endorsed.

Score interpretation—A higher score on the MFIQ-C indicates greater impact of juvenile FM symptoms in each domain assessed. Final scores for each scale range from 0 – 10 and total scores can range from 0 –100. There are no published norms available for the MFIQ-C. Two studies of patients with juvenile FM recruited from pediatric outpatient rheumatology settings reported similar mean \pm SD scores of 42.0 \pm 22.0 (8) and 40.11 \pm 14.07 (26). In contrast, healthy comparison controls reported a mean \pm SD score of 27.27 \pm 14.10 (26).

Respondent burden—The MFIQ-C takes ~5–10 minutes to complete; however, the format and language may be more difficult for younger children (ages <10 years) as the measure was originally developed for adults. It has a Flesch reading ease of 73.9 and a Flesch-Kincaid grade level of 5.6.

Administrative burden—Administration typically takes 5-10 minutes and scoring takes $\sim 10-15$ minutes. Some training and familiarity with the measure is required due to the somewhat complicated hand scoring.

Translations/adaptations—It is unknown whether the MFIQ-C has been translated into languages other than English or if other cultural adaptations have been made.

Psychometric Information

Method of development—Items for the MFIQ-C were modified from the adult version of the FIQ and the MFIQ, with the only modification being replacing items referring to "work" with "school." Children and adolescents were not involved in the development of the measure.

Acceptability—Because the MFIQ-C was modified from an adult measure, the readability of the MFIQ-C may be more difficult for children and adolescents. It is unknown whether missing data are common among children and adolescents.

Reliability—There are no known publications on the reliability of the MFIQ-C. Some studies have demonstrated good internal consistency and test–retest reliability in the adult version of the measure.

Validity—The MFIQ has been validated in adults and has been used clinically in a modified form with children and adolescents; however, no validation has been done specifically in the child and adolescent population. In a study by Schanberg et al (8), the MFIQ-C was found to be a better measure of daily functioning for juvenile FM than the physical function scale of the Arthritis Impact Measurement Scales 2. Additionally, the MFIQ-C has been shown to significantly distinguish juvenile FM patients from healthy controls (26).

Ability to detect change—The MFIQ-C has not been used in longitudinal studies or clinical trials; therefore, no information about sensitivity to change is available.

Critical Appraisal of Overall Value to the Rheumatology Community

Strengths—The MFIQ-C measures important juvenile FM–specific elements that other more generic measures do not incorporate. It appears to be a good measure of the impact of FM, including the core domains of pain, sleep, and fatigue. It is unknown whether the measure is appropriate for evaluating interventions or tracking patient progress over time.

Caveats and cautions—The primary weakness of the MFIQ-C is that there is minimal information about its psychometric properties for use in pediatric populations. It has been used in a small number of research studies, but not much is known about the clinical utility of the measure. Moreover, the hand-scoring algorithm for the measure is somewhat cumbersome and no computer scoring is available.

Clinical usability—The MFIQ-C is a brief measure that can be used to assess the impact of symptoms specific to juvenile FM. It can be easily administered in a clinical setting. However, the lack of information about clinical norms or reference points for interpretation of scores limits its clinical utility at this time.

Research usability—The original adult version of the measure was found to have adequate psychometric properties, but there is very little research on the MFIQ-C. There is currently limited information about whether the measure is reliable, valid, or sensitive to change over time in children and adolescents with juvenile FM.

PEDIATRIC QUALITY OF LIFE INVENTORY (PEDSQL) 3.0 RHEUMATOLOGY MODULE PAIN AND HURT SCALE

Description

Purpose—The disease-specific Rheumatology Module of the PedsQL was designed to assess health-related quality of life among children and adolescents with rheumatic conditions such as juvenile idiopathic arthritis, systemic lupus erythematosus, and juvenile fibromyalgia (FM), and is discussed in detail elsewhere in the juvenile idiopathic arthritis article in the Health Status and Quality of Life section in this issue. The pain and hurt scale of the PedsQL 3.0 Rheumatology Module is relevant to assessing juvenile FM symptoms of muscle and joint pain, stiffness, and sleep difficulties. The current measure was developed in 2002 (27) and it has not undergone any revisions or updates. There are different versions for children and adolescents, and a parent-proxy version of the PedsQL 3.0 Rheumatology Module is also available.

Content—The pain and hurt subscale assesses pain, stiffness, and disrupted sleep due to pain.

Number of items—The PedsQL 3.0 Rheumatology Module pain and hurt scale is composed of 4 items. Items are rated in terms of how much of a problem each symptom has been for the child or adolescent in the past month.

Response options/scale—A 5-point Likert scale is used to assess how often each of the items has been a problem (where 0 = never, 1 = almost never, 2 = sometimes, 3 = often, or 4 = almost always).

Recall period for items—The instructions ask how much of a problem each item has been in the past month.

Endorsements—There are no endorsements for this measure at the present time.

Examples of use—Other than published studies on the development of the measure, there are no studies of clinical or research use of the instrument.

Practical Application

How to obtain—James W. Varni, PhD, Professor of Architecture and Medicine, Department of Landscape Architecture and Urban Planning, College of Architecture, Texas A&M University, 3137 TAMU, College Station, TX 77843-3137; e-mail: jvarni@archone.tamu.edu. Copies can be ordered by going to the following web site: http:// www.pedsql.org.

The cost of the PedsQL varies based on the type of funding. For nonfunded academic research, the PedsQL may be used with permission from the author at no charge. For funded research, the rates vary depending on the sponsor (government, foundation, or industry-sponsored research) that includes a royalty fee to Dr. James Varni and a distribution fee to MAPI Research Trust. Users may purchase an annual license or pay a license fee per study. A full list of fees can be obtained online at http://pedsql.org/PedsQL-CostStructure.doc.

Method of administration—The instrument is a self-report measure for children (ages 8 -12 years) and adolescents (ages 13–18 years). The assessment is patient reported, but younger children may need to have a clinician administer it. Administration is typically completed in person but may also be completed by phone (28).

Scoring—Items are reverse scored and transformed to a 0-100 scale (where 0 = 100, 1 = 75, 2 = 50, 3 = 25, and 4 = 0) so that higher scores indicate better functioning (or less problems in an area). Scale scores are computed by summing the items and dividing by the number of items answered to account for missing data. If >50% of items in a scale are missing, that scale should not be computed. It is acceptable to impute values based on mean scores when there are missing data (27).

Score interpretation—Scores can range from 0-100, and higher scores on the pain and hurt scale reflect fewer problems with pain and other symptoms. Normative values are available for juvenile FM patients from 2 studies that included the Rheumatology Module pain and hurt scales, one comparing juvenile FM with other rheumatic diseases and another comparing the pain and hurt scale for juvenile FM patients to patients with cancer, patients with rheumatic diseases, and healthy controls (27,29). In each of the studies, the juvenile FM patients had significantly greater problems than the comparison groups on the pain and hurt scale.

Respondent burden—The measure takes <10 minutes for children and adolescents to complete. It has a Flesch reading ease of 84.6 and a Flesch-Kincaid grade level of 3.5.

Administrative burden—Time to administer the entire Rheumatology Module is <10 minutes. Scoring takes ~10 minutes and is simple with minimal training necessary.

Translations/adaptations—The PedsQL 3.0 Rheumatology Module is available in English, Spanish, French, German, Italian, Russian, and Slovenian. Cultural adaptations have been made for English for the US and Spanish for the US.

Psychometric Information

Method of development—The PedsQL 3.0 Rheumatology Module was developed based on the authors' research and clinical experiences with patients with rheumatic diseases. Development included a review of the literature, item generation, cognitive interviews, and pretesting and subsequent field testing of the measure in the target population (27). Patients were involved in the development of the measure by patient and parent focus groups and individual focus interviews.

Acceptability—Items were generated based on developmental level and understanding of concepts. The language difficulty of the measure is adapted to the typical reading level of children and adolescents. In a study specifically examining just the pain and hurt scale, the percentage of missing data among children and adolescents with juvenile FM was <1% (29).

Reliability

Internal consistency: A study of 231 children and adolescents with rheumatic diseases found high internal consistency reliability for each of the scales on the Rheumatology Module, with Cronbach's α ranging from 0.87–0.90 for the pain and hurt scale (27). A more recent study focused only on juvenile FM patients found somewhat lower internal consistency of the scale (Cronbach's $\alpha = 0.68$) (29).

Validity

Evidence of content validity: The inclusion of medical experts, patients, and patient families as part of the development of the PedsQL along with field testing of the measure warrants sufficient evidence for content validity.

Evidence of construct validity: The known groups method was used to determine construct validity of the Rheumatology Module. Two studies showed significant group differences between those diagnosed with juvenile FM and those with other rheumatic diseases on the pain and hurt scale, with juvenile FM patients reporting more pain and hurt (27,29).

Ability to detect change—One study on a small sample (n = 34) of children with rheumatic diseases, including juvenile FM, showed changes in mean scores on the pain and hurt scale over time across 3 treatment sessions. Mean scores for the initial session were 51.47 and steadily increased to 86.11, indicating lower symptom severity, by the third treatment session (27).

Critical Appraisal of Overall Value to the Rheumatology Community

Strengths—The PedsQL 3.0 Rheumatology Module is a brief and easy to administer self-report questionnaire. The pain and hurt scale consists of 4 items that are potentially a good indicator of symptom severity in juvenile FM patients. Initial evidence suggests that the pain and hurt scale has adequate psychometric properties and is sensitive to change. The measure allows for comparison between children and adolescents diagnosed with juvenile FM and other rheumatic diseases (i.e., juvenile idiopathic arthritis, systemic lupus erythematosus) as well as other chronic illnesses (e.g., cancer) and healthy children and adolescents.

Caveats and cautions—Other than the initial validation study published by the authors (27,29), there is limited information about the clinical or research utility of the measure. The module has no established clinical cutoffs and it has not been used as an outcome measure in clinical trials.

Clinical usability—The measure is brief, easy to administer and score, and developmentally appropriate for respondents. Unfortunately, its clinical utility has not been tested.

Research usability—The psychometric properties of this measure are strong and have been tested in multiple populations (children, adolescents, parents) with a variety of rheumatic diseases. The data support research use of this measure, but as of yet, few studies have published research related to the PedsQL Rheumatology Module pain and hurt scale in juvenile FM.

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Validity evidence	Excellent evidence for concurrent, construct, and criterion validity		Some evidence of content and construct validity
Reliability evidence	Excellent		None
Score interpretation	Scores range from 0–60, with higher scores indicating greater functional disability		Scores range from 0–100 with higher scores indicating greater impact of juventle FM symptoms
Administrative burden	Time to administer is ~5–10 minutes and <5 minutes to score		Time to administer is ~5–10 minutes Hand scored and requires knowledge of the scoring algorithm
Respondent burden	Minimal burden; <10 minutes to complete. May take longer for younger children (ages 8–10 years)		Minimal burden; <10 minutes to complete Response format and language may be difficult for children ages <10 years
Method of administration	Patient self-report; can be administered in interview form or by phone		Patient self-report
Purpose/content	To measure functional disability, i.e., difficulty completing daily activities in home, school, recreational, and social domains in pediatric pain conditions, including juvenile FM		To assess the spectrum of juvenile FM symptoms and impact on physical and emotional functioning
Scale	FDI		MFIQ-C

FDI = Functional Disability Inventory; FM = fibromyalgia; PedIMMPACT = Pediatric Initiative on Methods, Measurement, and Pain Assessment in Clinical Trials; MFIQ-C = Modified Fibromyalgia Impact Questionnaire-child version; PedsQL = Pediatric Quality of Life Inventory.

Table 1

Summary Table for Juvenile Fibromyalgia Measures *