Disablement Model and Health-Related Quality of Life Classification for Patient-Reported Outcomes Measurement Information System (PROMIS) Instruments

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Context: The National Institutes of Health created a medical research road map that included the development of the Patient-Reported Outcomes Measurement Information System (PROMIS). A key feature of PROMIS was the development of patient-reported outcome measures (PROs) addressing various aspects of health. Understanding disablement dimensions and health-related quality-of-life (HRQOL) domains captured through PROMIS measures will help with instrument selection.

Objective: To evaluate the pediatric PROMIS PROs and determine the areas of disablement and HRQOL captured within each instrument.

Design: Descriptive laboratory study.

Setting: Laboratory.

Patients or Other Participants: Twenty-two pediatric PROMIS instruments (19 short forms and 3 profiles).

Main Outcome Measure(s): Three raters independently reviewed the PROMIS instruments and categorized each question on each instrument according to the World Health Organization’s International Classification of Functioning, Disability, and Health disablement model domains (body functions and structures, activity, participation, environmental factors, personal factors) and HRQOL (psychological, physical, social, spiritual, economic) dimensions. A consensus process determined the final question category. The frequencies of disablement model domains and HRQOL dimensions captured by questions on PROMIS instruments were reported.

Results: The most frequently reported disablement model domain was body function and structure, which was captured by questions in 16/22 (73%) pediatric PROMIS instruments, followed by activity (13/22 [59%] pediatric PROMIS instruments) and participation (9/22 [41%] pediatric PROMIS instruments). The most frequently captured HRQOL dimensions were physical and psychological health, both evaluated in 13/22 (59%) of the pediatric PROMIS instruments. The social dimension of HRQOL was assessed in 9/22 (41%) of the pediatric PROMIS instruments.

Conclusions: Pediatric PROMIS fixed-length instruments captured a variety of disablement domains and health dimensions, but, like most PRO instruments, no single PROMIS instrument captured them all. Clinicians and researchers must consider their goals when selecting PRO instruments, which may require implementing multiple instruments and those beyond PROMIS.

Key Words: International Classification of Functioning, Disability, and Health, whole person, patient outcome assessment, health care surveys

Key Points

- The pediatric Patient-Reported Outcomes Measurement Information System (PROMIS) family of instruments consists of 22 instruments that evaluate various aspects of health and are not specific to a particular health condition.
- The pediatric PROMIS instruments captured a variety of disablement domains and health dimensions, but no single instrument captured them all.
- About half of the PROMIS patient-reported outcome measures focused on only 1 disablement level or health-related quality-of-life dimension, suggesting that multiple patient-reported outcome measures would be needed to capture a whole-person perspective when using these instruments.

Recent attention has been given to whole-person, patient-centered health care and the importance and value of the patient’s voice within the care process. One outcome of this attention has been a focus on creating better ways of obtaining the patient’s voice through the use of patient-rated outcome (PRO) instruments. A leader in this effort is the National Institutes of Health (NIH). In 2002, the NIH created a road map for 21st-century medical research that included 3 key areas: (1) new pathways to discovery, (2) research teams of the future, and (3) reengineering the clinical research enterprise. Although the entire road map is integral to progress in health care, the third key area, reengineering the clinical research enterprise, is of particular interest due to its emphasis on the patient’s voice within the care process. Reengineering the clinical research enterprise addresses investing in multidisciplinary training, developing networking and diagnostic tools, and creating academic homes for clinical and...
As part of this mission, the Patient-Reported Outcomes Measurement Information System (PROMIS) project was launched as a large-scale, collaborative effort aimed at developing PRO instruments to measure important symptoms and aspects of health domains that are applicable to various populations, including pediatric patients.3,4

Since the start of the PROMIS project in 2004, a variety of pediatric PRO item banks and instruments have been created for use in clinical practice and research, with ongoing development.3,5,6 The PROMIS family of pediatric PROs is intended to be generic in nature and not specific to any single disease, injury, or condition. The PROMIS instruments were developed to be health construct specific as opposed to disease specific,7 which is different than many of the commonly available instruments. As such, PROMIS instruments address distinct areas of health—such as fatigue, physical functioning, and anxiety—that apply to all people, regardless of their health conditions.7,8 In athletic health care, the focus is often on a specific injury or body region, and the PROMIS family of instruments does have questionnaires to address upper and lower extremity function. A potential benefit of these instruments is that a particular health construct can be further evaluated should it be of concern. For example, a long recovery time may increase concern that an athlete is experiencing depression or anxiety, and the PROMIS family of instruments allows those health constructs to be assessed in greater depth than by a region-specific instrument. Because of the variety of instruments available in the PROMIS system,5 careful thought should be given to selecting a PRO instrument, so that the items within a selected instrument align with the intended use of the instrument.9–11 In general, PRO instruments are valuable because they provide patients a chance to evaluate their health from their own perspective as well as in relation to the health concerns that matter most to them.

Understanding a health condition from the patient’s perspective and including the patient’s voice in the care process is necessary for delivering patient-centered, whole-person health care. To acquire this broader view of health, it is helpful to consider disablement models. Disablement models are conceptual frameworks that allow a clinician to view a patient from a variety of lenses spanning the origin of the health condition to the effect of the condition on the patient’s social roles.12–14 The broad, comprehensive view of disablement-model frameworks ensures that all areas of health are considered and that the functional limitations and disabilities that matter to patients are not overlooked. Further, using a disablement-model framework highlights the value of important health care outcomes, such as health-related quality of life (HRQOL). This multidimensional health construct is evaluated by the patient and encompasses a variety of health areas, such as psychological, physical, and social health.15–19 Additionally, HRQOL can be influenced by events, such as injury.20–32 thus, it should be a focus of patient care, especially when evaluating and managing the condition. Recently, the National Athletic Trainers’ Association adopted the World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) disablement model for the profession.33 A better understanding of the application of PRO instruments to disablement models and HRQOL will help ensure that a whole-person approach is a central focus of the patient care experience.

The PROMIS family of instruments offers an opportunity to incorporate the patient’s voice in the care process, and the variety of available instruments is appealing due to the unique and varied needs of patients. Selecting the right outcome tool for the intended purpose is challenging.9,10 especially given the large number of instruments available. One reason to consider the PROMIS family of instruments for use in athletic health care is the advanced, robust development process undertaken to create a standardized set of instruments that are useful across clinical practice and research and that address specific health constructs applicable to many health conditions.3,4 Development consisted of several steps, including item generation through literature searches,34 focus groups,35,36 and expert opinion,37 as well as construct calibration using item response theory.38,39 However, one limitation is that the development process did not include an evaluation of the instruments across frameworks for whole-person care, such as disablement models and HRQOL.

To our knowledge, no one has reported on the specific disablement-model domains and HRQOL dimensions that are captured by the pediatric PROMIS fixed-length instruments. A better understanding of the areas of disablement and HRQOL that pediatric PROMIS instruments capture will help clinicians select PROs to meet their intended purpose. Therefore, the goal of our study was to evaluate the pediatric PROMIS fixed-length PROs to determine the areas of disablement and HRQOL captured within each instrument.

METHODS

Procedures and Data Management

We retrieved 22 pediatric PROMIS instruments (19 short forms and 3 profiles) from the PROMIS Web site.40 The instruments included items (ie, questions) that assessed the following areas: anger, anxiety, asthma effect, depressive symptoms, fatigue, mobility, pain behavior, pain interference, peer relationships, physical activity, physical stress experiences, positive affect, psychological stress experiences, strength effect, upper extremity, pediatric profile (3 forms with 49, 37, and 25 items), global health, cognitive function, life satisfaction, meaning, and purpose. All pediatric PROMIS measures were included so the instrument family would be comprehensive. Some pediatric PROMIS short forms have different versions with various numbers of fixed items, typically ranging from 4 to 10. Additionally, the instruments can be administered using computerized adaptive testing (CAT), which draws from a larger item bank and limits the number of items a person is exposed to during the assessment. We chose to evaluate and report on the highest number of items possible from fixed-length PROMIS instruments to ensure that all potential questions could be rated according to disablement-model domain and HRQOL dimension. Therefore, we evaluated items outside the context of the CAT format. Pediatric PROMIS instruments are designed for patients aged 8 through 17 years old.39

Initially, 3 raters with expertise in clinical outcomes assessment independently reviewed and scored the instruments to the level of the primary category for disablement-model domains. Expertise was defined as postdoctoral
training in clinical outcomes assessment and teaching experience related to disablement models and HRQOL concepts. Raters were able to consult the ICF Web site\(^{41}\) when matching an item to a specific disablement-model domain. Each rater selected only 1 disablement-model domain for each question within an instrument. After completing the independent review, all raters convened to compare the disablement-model ratings. Differences in disablement-model ratings were discussed, and final ratings were made by group consensus.

When all disablement-model ratings were confirmed, the raters independently reviewed and scored the pediatric PROMIS instruments according to the dimensions of HRQOL. Each rater selected only 1 HRQOL dimension for each item within a short form or profile. After completing the independent review of questions, all raters convened to compare their HRQOL ratings. Differences in HRQOL dimension ratings were discussed, and final ratings were made by group consensus. Only 1 final rating was provided for each disablement-model domain and each HRQOL dimension.

**International Classification of Functioning, Disability, and Health**

The World Health Organization’s ICF disablement model is a framework that provides a standard language for disability and functioning and depicts the interactive relationship between a health condition and associated contextual factors. (Figure).\(^{13}\) According to the ICF, health domains (body functions and structures, activities, and participation) and health-related domains (environmental factors and personal factors) are part of the disablement framework. Functioning and disability, according to the ICF model, occur at the level of the body (body functions and structures), the person (activities), the person in society (participation), or a combination of these and can be referred to as impairments, functional limitations, and disability, respectively. Body functions and structures have been defined as the physiological and psychological functioning of body systems and the anatomical parts of the body, with examples of measures including pain, range of motion, strength, and swelling. Activities are best described as tasks or actions (eg, functions) conducted in a standard or usual environment with no social reference. Examples of activities are washing hair, kicking a ball, ascending and descending stairs, running, and jumping. Participation takes the general functional tasks and translates them to the person’s ability to engage in life situations, such as roles as an athlete, employee, friend, parent, or student. The health-related domains include the environmental and personal factors that provide context to each person’s unique situation. Environmental factors can be broad and address outside influences, including the attitudes of friends and family and relationships. Like environmental factors, personal factors, such as age, previous history of injury, fitness level, education, or experiences, are also broad in scope. The environmental and personal factors serve as facilitators or barriers to a person’s perception of or experience with disability.

The ICF Web site\(^{41}\) provides chapters related to several domains of the model, including body structures, body functions, activities and participation, and environmental factors. Further, the chapters are organized according to a variety of health areas, including mental functions, sensory functions and pain, neuromusculoskeletal and movement-related functions, and functions of the skin and related structures.\(^{41}\) In these chapters, examples are provided for each health domain at different levels.

**Health-Related Quality of Life**

Health-related quality of life is a global, multidimensional concept that refers to how a person’s unique life experiences and values interact with various health dimensions, including those related to physical, social, psychological, economic, and spiritual health.\(^{15–19}\) The physical dimension of health is characterized by a person’s ability to engage in activities that are important to him or her and include attributes of mobility, endurance, self-care, and performance.\(^{16}\) Social health covers a range of attributes that address relationships and interactions with family and friends as well as leisure and recreational activities.\(^{12,43}\) The psychological dimension of health relates to perceptions of well-being, emotional behavior,
depression, anxiety, and moods (eg, happiness and sadness).\textsuperscript{42,43} Economic health addresses personal financial status and financial burdens, insurance stability, and health care costs.\textsuperscript{18} Finally, spiritual health is conceptualized by the value of religion in a person’s life, including his or her religious beliefs and practices.\textsuperscript{18}

### Statistical Analysis

Frequencies are reported for the number of questions on the PROMIS questionnaires that corresponded to a disablement-model domain and HRQOL dimension. All questions were categorized into a single category of disablement or HRQOL.

### RESULTS

A total of 22 pediatric PROMIS instruments (ie, 18 short forms, 3 profiles, and 1 global health form) were included in our analysis. Tables 1 and 2 identify the disablement model domains and HRQOL dimensions that were addressed by questions within the 22 pediatric PROMIS

<table>
<thead>
<tr>
<th>Table 1. Pediatric Patient-Reported Outcomes Measurement Information System Instruments Organized According to International Classification of Functioning, Disability, and Health Disablement-Model Domain</th>
<th>Factors</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Instrument</strong></td>
<td><strong>Body Function and Structure</strong></td>
</tr>
<tr>
<td>Pediatric Anger – Short Form 5a</td>
<td>3</td>
</tr>
<tr>
<td>Pediatric Anxiety – Short Form 8a</td>
<td>8</td>
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<tr>
<td>Pediatric Asthma Impact – Short Form 8a</td>
<td>7</td>
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<tr>
<td>Pediatric Depressive Symptoms – Short Form 8a</td>
<td>7</td>
</tr>
<tr>
<td>Pediatric Fatigue – Short Form 10a</td>
<td>5</td>
</tr>
<tr>
<td>Pediatric Mobility – Short Form 8a</td>
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</tr>
<tr>
<td>Pain Behavior – Short Form 8a</td>
<td>0</td>
</tr>
<tr>
<td>Pediatric Pain Interference – Short Form 8a</td>
<td>2</td>
</tr>
<tr>
<td>Pediatric Peer Relationships – Short Form 8a</td>
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</tr>
<tr>
<td>Physical Activity – Short Form 8a</td>
<td>0</td>
</tr>
<tr>
<td>Physical Stress Experiences – Short Form 8a</td>
<td>8</td>
</tr>
<tr>
<td>Positive Affect – Short Form 8a</td>
<td>8</td>
</tr>
<tr>
<td>Psychological Stress Experiences – Short Form 8a</td>
<td>8</td>
</tr>
<tr>
<td>Pediatric Strength Impact – Short Form 8a</td>
<td>0</td>
</tr>
<tr>
<td>Pediatric Upper Extremity – Short Form 8a</td>
<td>0</td>
</tr>
<tr>
<td>Pediatric Profile – 49</td>
<td>22</td>
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<tr>
<td>Pediatric Profile – 37</td>
<td>16</td>
</tr>
<tr>
<td>Pediatric Profile – 25</td>
<td>11</td>
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<tr>
<td>Pediatric Global Health</td>
<td>4</td>
</tr>
<tr>
<td>Pediatric Cognitive Function – Short Form 7a</td>
<td>5</td>
</tr>
<tr>
<td>Life Satisfaction – Short Form 8a</td>
<td>8</td>
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<tr>
<td>Meaning and Purpose – Short Form 8a</td>
<td>8</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Table 2. Pediatric Patient-Reported Outcomes Measurement Information System Instruments Organized According to Health-Related Quality-of-Life Dimensions</th>
<th>Health-Related Quality-of-Life Dimension</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Instrument</strong></td>
<td>Psychological</td>
</tr>
<tr>
<td>Pediatric Anger – Short Form 5a</td>
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<td>Pediatric Anxiety – Short Form 8a</td>
<td>8</td>
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<tr>
<td>Pediatric Asthma Impact – Short Form 8a</td>
<td>0</td>
</tr>
<tr>
<td>Pediatric Depressive Symptoms – Short Form 8a</td>
<td>8</td>
</tr>
<tr>
<td>Pediatric Fatigue – Short Form 10a</td>
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<tr>
<td>Pediatric Function-Mobility – Short Form 8a</td>
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</tr>
<tr>
<td>Pain Behavior – Short Form 8a</td>
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<tr>
<td>Pediatric Pain Interference – Short Form 8a</td>
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<tr>
<td>Pediatric Peer Relationships – Short Form 8a</td>
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<td>Physical Activity – Short Form 8a</td>
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<td>Pediatric Strength Impact – Short Form 8a</td>
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</tr>
<tr>
<td>Pediatric Upper Extremity – Short Form 8a</td>
<td>0</td>
</tr>
<tr>
<td>Pediatric Profile – 49</td>
<td>16</td>
</tr>
<tr>
<td>Pediatric Profile – 37</td>
<td>12</td>
</tr>
<tr>
<td>Pediatric Profile – 25</td>
<td>8</td>
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<tr>
<td>Pediatric Global Health</td>
<td>2</td>
</tr>
<tr>
<td>Pediatric Cognitive Function – Short Form 7a</td>
<td>7</td>
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<td>Life Satisfaction – Short Form 8a</td>
<td>8</td>
</tr>
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<td>Meaning and Purpose – Short Form 8a</td>
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</tr>
</tbody>
</table>
instruments. The most frequently reported disablen-
tment-model domain was body function and structure, which was
captured by questions in 16 (73%) of the 22 pediatric
PROMIS instruments. Questions related to the activity
domain were captured in 13 (59%) of the pediatric
PROMIS instruments, whereas participation was captured in
9 (41%) of the pediatric PROMIS instruments. The
environmental domain was primarily assessed only in the
Pediatric Peer Relationships form. Questions pertaining to
the environmental domain that were included in the 3
Pediatric Profile instruments were from the same 6
questions included in the Pediatric Peer Relationships
form. No questions in the pediatric PROMIS instruments
captured the personal factors domain of disablenent. Two
questions on the Pediatric Global Health scale did not fit
any disablenent-model domain. Similarly, 1 question in the
Pediatric Profile 49-item, 37-item, and 25-item forms did not
fit any disablenent-model domain.

The most frequently captured HRQOL dimensions in the
pediatric PROMIS instruments were related to physical and
psychological health, which were each captured in 13
(59%) of the pediatric PROMIS instruments. Questions
related to the social dimension of HRQOL were assessed in
9 (41%) of the pediatric PROMIS instruments, with the
highest number of questions in the Pediatric Profile 49-item
form, followed by the Pediatric Peer Relationships form.
None of the 22 pediatric PROMIS instruments included
questions on the spiritual or economic dimensions of
HRQOL. Two questions on the Pediatric Global Health
scale did not fit any HRQOL dimension. Similarly, 1
question in the Pediatric Profile 49-item, 37-item, and 25-
item forms did not fit any HRQOL dimension.

DISCUSSION

To our knowledge, we are the first to review the pediatric
PROMIS instruments within the context of disablenent and
HRQOL. Our findings add value because although the
PROMIS instruments were created using a robust develop-
ment process,7,8,34,36,39 their development focused primarily
on evaluating single health constructs as opposed to
assessing how well the construct was captured across the
disablenent-model domains and HRQOL dimensions. Evaluating the domains of disablenent and dimensions of
HRQOL that are affected after injury is essential to
providing comprehensive athletic health care and helps to
ensure that attention to the health condition extends beyond
impairments. Authors investigating how musculoskele-
tal20–29 and head30–32 injuries affected patients found that
deficits were reported across a broad spectrum of health
categories and beyond impairments and physical function.
These results highlight the need for PRO instruments to
capture the whole-person perspective of health in order to
better guide patient care decisions.

Although incorporating the PRO instruments into clinical
practice and research is essential to the future of athletic
health care, it is important to note that no single instrument is
likely to capture all areas of disablenent or HRQOL. In
fact, a combination of generic and specific PRO instru-
ments may need to be used in patient care,9,10,44 partly due
to the limitations of a single instrument. The results of our
research align with this recommendation. We did not find a
single pediatric PROMIS instrument that included ques-
tions targeting all domains of disablenent or all dimensions
of HRQOL. However, the Pediatric Profile instruments and
the Pediatric Global Health instrument had at least 1
question in all ICF domains except for personal factors and
at least 2 questions in the psychological, physical, and
social dimensions of HRQOL. A few disablenent domains
and HRQOL dimensions were not captured by any of the
instruments. No pediatric PROMIS instruments captured
personal factors related to disablenent or spiritual or
economic factors related to HRQOL. Considering that these
instruments were designed for pediatric patients, questions
related to spirituality or financial health may be irrelevant.
Further, perspectives are mixed as to whether spiritual
health should be a component of athletic health care,45
which may make the fact that these instruments did not
capture the spiritual dimension of health less of a concern.
Of the 22 pediatric PROMIS instruments reviewed, 10
(45%) included questions from a single disablenent-model
domain, either body functions and structures or activities.
Fourteen of the 22 (64%) PROMIS instruments reviewed
included questions from a single HRQOL dimension, most
often psychological or physical. Taken together, these
findings suggest that in order to capture a whole-person
perspective that considers multiple areas of disablenent
and HRQOL, several instruments may be required.
Additionally, instruments outside of the PROMIS family
should be considered if areas of health not addressed with
PROMIS instruments are of interest. For example,
clinicians and researchers may need to include instruments
beyond those available through PROMIS if the spiritual and
economic aspects of HRQOL are important to the care of
a patient. During the PRO selection process, it is essential
that clinicians and researchers identify the primary goals of
their work to ensure that the instrument(s) selected
capture the information required to produce meaningful results for
their patient care or scientific needs.

Although selecting the appropriate instrument to fit the
need is important, it is also necessary to consider the
vehicle for implementing PROMIS instruments in patient
care and scientific investigations. Oftentimes, clinicians and
researchers are faced with the task of deciding whether to
implement a PRO instrument in paper or electronic form.
The PROMIS family of instruments can be delivered in
paper, computer, and application (ie, app) formats. The
pediatric short forms and profile instruments are available
in paper formats. Additionally, PROMIS short forms,
profiles, and CATs can be accessed through computer
formats, such as REDCap (Nashville, TN), Assessment
Center (Evanston, IL), Epic (Verona, WI), Assessment
Center Application Programming Interface (Evanston, IL),
and AO Patient Outcomes Center (Columbia, MO).40
Finally, PROMIS short forms, profiles, and CATs are
available in apps, including the PROMIS iPad app and the
NIH Toolbox iPad app (Bethesda, MD).40 Each format has
its benefits and limitations, making it important for
clinicians and researchers to weigh these aspects before
implementing PROMIS instruments.

Depending on the mode of administration, either paper or
electronic, different styles of pediatric PROMIS measures are
available: short forms, profiles, or CATs, all of which are
generated from item banks that were created for each of the
PROMIS content areas. Item banks contain the
information required to produce meaningful results for
their patient care or scientific needs.
created. For example, the Physical Function-Mobility instrument has an item bank of 24 questions (the short form includes 8) and the Cognitive Function instrument has an item bank of 43 questions (the short form includes 7). Further, some instruments have more than 1 short form, such as Physical Function-Mobility, which has short forms with 4 and 8 questions. The item banks are the sources of the most comprehensive assessment of the PROMIS construct of interest; however, these banks tend to include a larger number of questions and, therefore, may lack patient friendliness especially for young populations. Large numbers of questions may increase the time required to take and score the instruments for the patient and clinician, respectively, which is a noted burden associated with PRO instruments. Some PRO instruments have longer and shorter versions available for use. For example, the Short Form-36 and Short Form-12 and the Disabilities of the Arm, Shoulder and Hand and the QuickDash have both a longer, more comprehensive instrument and a shorter version that captures most of the variance of the longer instrument and is a valid alternative to the lengthier, potentially more burdensome questionnaire.

The PROMIS profiles include questions from several different PROMIS instruments, so more than 1 health construct is captured in the measure. Because the profiles are a combination of instruments, they typically include a greater number of questions than the short forms. For example, the pediatric profiles have 49, 37, and 25 questions. Further, the profiles tend to span more disablement-model domains and HRQOL dimensions than a single instrument. Therefore, these instruments can be helpful if a more comprehensive view of a health construct is desired. Use of a comprehensive instrument also streamlines the administration because only 1 instrument is needed instead of a collection of several shorter instruments.

When using the pediatric PROMIS instruments in electronic format, it is possible to administer them through CAT technology. The purpose of using a CAT is to generate a precise estimate of a construct for a patient, such as physical mobility, using the fewest possible number of questions. Thus, CAT technology is useful in reducing the patient burden and increasing the patient friendliness of instruments while producing a strong estimate of the construct of interest. The CAT technology works by using algorithms, or a form of artificial intelligence, to generate items and then modify subsequent items based on patient responses. The difficulty level of the questions is guided by how a patient responds to the first question, with a response related to good health leading to more difficult questions and a response related to poor health leading to less difficult questions. Essentially, the technology attempts to predict how patients will answer based on the initial response. Typically, a CAT can generate a precise instrument score with just 3 to 5 questions, which is even fewer than a short form, and these questions are generated from a very large item bank (eg, 95 questions). Due to the dynamic approach of CAT technology, this style of instrument is thought to assess the patient’s status more accurately and quickly than standard paper forms. However, with fewer questions, the chance of capturing multiple disablement-model domains or HRQOL dimensions is in question. Additionally, using CAT technology may limit exposure to the disablement-model domains and HRQOL dimensions captured by a fixed-length PROMIS instrument because, based on patient response, the questions are autopopulated without consideration of those domains and dimensions. Preselecting questions to capture a greater breadth of disablement or HRQOL is not possible. Further, questions delivered via the CAT may differ from patient to patient depending on their health status and answers. Lack of attention to multiple domains and dimensions of health seems to be a consideration regardless of the style of PROMIS administration and is also a consideration for the use of PROs in general.

Determining which pediatric PROMIS instruments to use is complex and requires the selection of an instrument that will fit the needs of the intended use. Because many of the PROMIS family of instruments were constructed to focus largely on single health constructs, they function slightly differently from region-specific measures, which focus on the body area affected by an injury or health condition. However, several measures are related to physical function, which is a common health concern of athlete-patients, as well as to global health, which combines several construct-specific measures to produce a more general assessment of overall health, both of which provide some flexibility within the family of instruments. Examples may help researchers better understand the application of PROMIS instruments to athletic health care.

Instruments such as the pediatric profiles and global health scale serve as general assessments of a patient’s health and function and are similar to other generic instruments, such as the Pediatric Quality of Life Inventory, which can be used for patients with any health condition or injury. The 3 versions of the pediatric profile all capture the same domains of disablement (body functions and structures, activity, participation, and environmental factors) and quality-of-life dimensions (psychological, physical, and social). The primary difference is the number of questions in each, which range from 25 to 49. Athletic trainers may wish to select the shorter version of the instrument to reduce the time burden. Another use of the PROMIS relates to concussed patients. The pediatric cognitive function and fatigue instruments may be useful in evaluating concussed patients because both constructs are of concern in recovery from this serious injury. The fatigue instrument evaluates impairments and some of the social effects of the condition on the patient, whereas the cognitive instrument evaluates impairments and functional limitations. Instruments related to anger, depression, stress, and affect may be used less frequently with specific patients. Although they are used less often, these instruments may be valuable when a particular patient concern requires deeper evaluation of one of these constructs. For example, after anterior cruciate ligament injury, athletes may experience emotional, mental, or fear responses that might benefit from greater evaluation of a specific health construct using the PROMIS instruments. Athletic trainers may find that the pediatric mobility, physical activity, strength, and upper extremity instruments apply to athlete-patients more commonly because they address movement and overall function, which are typical concerns of high-functioning people.

Our review should help facilitate the use of PROMIS instruments in athletic health care, but many questions must be addressed in future investigations. For example, in addition to the pediatric versions of the PROMIS instruments,
numerous adult versions are available. To gain a better understanding of the adult PROMIS instruments and their ability to measure health from a variety of disability domains and dimensions and HRQOL, future authors should evaluate the adult instruments within these frameworks. Further, although several funding agencies (eg, NIH, Patient-Centered Outcomes Research Institute [Washington, DC]) strongly encourage and often require use of the PROMIS instruments in clinical research studies, these instruments have rarely been used in investigations of athletic health care. Thus, we do not know how well the PROMIS instruments perform in a high-functioning athletic population, which is a frequent criticism of PRO instruments. One area in which the PROMIS tools are highlighted for athletes is the NIH Common Data Elements project related to neurologic disorders and stroke and the release of a common data element for sport-related concussion. The concussion data disorders and stroke (NIH, Patient-Centered Outcomes Research Institute [Washington, DC]) strongly encourage and often require use of the PROMIS instruments in clinical research studies, these instruments have rarely been used in investigations of athletic health care. Thus, we do not know how well the PROMIS instruments perform in a high-functioning athletic population, which is a frequent criticism of PRO instruments. One area in which the PROMIS tools are highlighted for athletes is the NIH Common Data Elements project related to neurologic disorders and stroke and the release of a common data element for sport-related concussion. The concussion data element includes a variety of PRO questionnaires, including PROMIS instruments. Athletic trainers should familiarize themselves with the common data element and the recommendations for PRO instruments to support clinical decisions with this important patient population. Although clinicians and researchers may wish to explore use of the pediatric PROMIS instruments, they should also continue using other established, appropriate PRO instruments to meet the needs of their clinical practice or research investigations.

LIMITATIONS

The current study had limitations. It is possible that each researcher’s content expertise in clinical outcomes assessment may have biased his or her rating of each PRO instrument item. To combat this limitation, we individually categorized each item and then met as a group to ensure consensus on every item. Additionally, we focused only on the PROMIS pediatric PRO instruments and profiles. Other pediatric PRO instruments are available that may more accurately capture the disablement domains and dimensions of HRQOL.

CONCLUSIONS

With the push for whole-person health care and patient-centered care, the use of PRO instruments is becoming an essential aspect of patient care. The PROMIS instruments provide an opportunity to incorporate PRO instruments and address the initiatives of the NIH, which are both important to the future of athletic health care. As with any new PRO instrument, it is important to understand the type of information the PROMIS instruments capture, particularly within the context of levels of disablement and aspects of HRQOL. The pediatric PROMIS instruments appear to capture a variety of disablement domains and health dimensions but, like most PRO instruments, no single PROMIS instrument captures them all. Thus, clinicians and researchers must consider their needs and goals when selecting PRO instruments, which may require the implementation of multiple instruments, including those beyond the PROMIS family. Athletic health care researchers should explore the PROMIS instruments when designing studies and should also be aware that few authors have used these instruments among high-functioning patient populations; thus, our understanding of how they function in athletic populations is largely unknown.

REFERENCES

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